



Interprofessional Workshop Series

Youth & Young Adults in Transition

Knowledge Translation and Consultation Workshop

Vancouver, BC

April 15 - 16, 2011

Executive Summary

On April 15th and 16th, 2011 a knowledge translation and consultation workshop was held in Vancouver, BC on Youth & Young Adults in Transition. The workshop was held in partnership with Child Health BC, and the BC Children's Hospital Division of Adolescent Medicine, and with the support of the British Columbia Medical Association (BCMA).

The workshop was designed to bring together representatives from the Ministries of Health, Children and Family Development and Education, decision makers and health care clinicians, researchers and educators to explore the multifaceted needs of youth and young adults with chronic health conditions and special needs as they transition from pediatric to adult sub-specialty and community services. The workshop provided an opportunity for dialogue on stakeholder issues, models of care, health care systems that impact the care and health outcomes of youth and young adults with chronic health conditions.

The main themes of discussion centered around identifying priorities to create an effective and sustainable transition system appropriate for BC, including infrastructure requirements, communication and medical records management, unique regional requirements, training and educational needs.

Speakers and participants collectively acknowledged the challenges associated with transitioning adolescents into adult care. Gaps in services were identified and solutions to best support youth and their families in the transition were highlighted.

Key challenges and opportunities that were raised include:

Key Challenges

- Youth are undergoing multiple transitions at this stage in life – not just

in their health care needs. Other key transitions including schooling, housing, employment and participation in the community need to be taken into account.

- Numerous systems are involved during the transitional stage (i.e. multiple ministries). With this comes the added challenge of cross-organization communication.
- The adolescent's chronological age may not match the developmental age. Therefore, more flexibility and individualized transitional care planning is required.
- Fragmented information systems are not providing a complete medical record for patients as they transition into adulthood. The limits information sharing and decision making capabilities.
- As youth are living longer into adulthood there is often a lack of adult services for specific chronic health conditions.
- Funding mechanisms are not in place to support transitional health care roles or the meet the complex health care needs of adults who are survivors of chronic illness originating in childhood.

Key Opportunities

- Extend the transitional age spectrum to 25.
- Look at collaborative models of care, \ including pediatric and adult care providers working together.
- Empower and engage youth and families to be leaders in their own care (using technology as a key resource).
- Better utilize technology to support information sharing across organizations and across the pediatric and adult 'gap'.
- Develop navigational roles across the health system to support patients and

families by coordinating care and providing access to resources.

- Build capacity across health care provider disciplines to better support patients and families during the transitional years and beyond.

Introduction

About Child Health BC

Child Health BC, an initiative of the BC Children's Hospital, is a network of health authorities and health care providers dedicated to excellence in the care of infants, children and youth in BC. BC Children's Hospital is an agency of the Provincial Health Services Authority.

Child Health BC's mandate is to bring together partners from BC's health authorities, The Ministry of Health, the Ministry of Children and Family Development, the Ministry of Education, and other provincial agencies and services to optimize the health of children and youth and to improve access to high quality clinical health services.

In partnership with BC's health delivery partners, Child Health BC is working to ensure children receive the right service at the right time, in the right place, by the right provider. Through cooperative partnerships, regional subspecialty programs, education and dissemination, research, monitoring quality and performance, and developing standards, protocols and guidelines, Child Health BC and its partners are creating an integrated, standardized and accessible system of care available to all children in BC.

About the Division of Adolescent Medicine

The mission of the Division of Adolescent Health is to improve the health of adolescents through clinical services, education and training, advocacy, health promotion and research. The Division seeks to define best practices for youth, educate and train health professionals in these best practices, facilitate youth involvement in program planning and evaluation, identify and address adolescent health issues, and develop

partnerships for clinical services, training and research.

Workshop Purpose & Objectives

The workshop was designed to facilitate discussions towards creating a sustainable, cross-jurisdictional provincial system for youth with chronic health conditions to transition from the pediatric to the adult health care system through the development of infrastructure, integration of health care services and knowledge transfer.

The objectives of the workshop were to:

- Understand the health and social consequences when there is a lack of effective transitional care planning, coordination and continuity of care for youth.
- Understand the core features of transition planning: developmentally appropriate care, transition readiness planning, planned transfer and appropriate integration with excellent clinical care in the adult health care system.
- Understand the major features of an effective and sustainable transition system including system requirements, communication and medical records management, unique regional requirements, training and educational needs.
- Understand the roles of health care system leaders, pediatric and adult specialists, family medicine physicians, nurse and other health care providers in successful transition planning and effective inter-agency collaboration.
- Provide an opportunity for participants to network and determine avenues for best practice in the transitional care of youth with chronic health conditions throughout BC.

Workshop Highlights

Living the Experience of Transition: a Young Adult's Personal Journey

Lead: Jocelyn Tomkinson, Research Coordinator, Child and Family Research Institute

Jocelyn provided an account of her personal experiences as an adult with Spina Bifida and spoke of what it's like to transition from pediatric to adult care and the impact this had on her need for independence. Providing some history of her journey with Spina Bifida, Jocelyn commented on the valuable support provided by the Spinal Cord Clinic at BC Children's from the time she was five up to eighteen years of age. Having been seen by a variety of health care providers and allied health professionals Jocelyn commented on the value she saw in them coming together to minimize the impact of her condition and, along with her parents support, to encourage her independence.

As Jocelyn recalled personal stories and spoke of the importance of fighting against labels and self advocating for independence, she described what it was like to graduate from the Spinal Cord Clinic at BC Children's, "in my mind I was a healthy person and a normal part of everyday life. Graduation, with referrals to adult care providers felt like a report card". Recalling an incidence when Jocelyn required specialized care she spoke of how she felt she was stuck in the middle between pediatric and adult care and actually felt illiterate in her own condition. While her parents provided a bridge to her childhood history, Jocelyn ended up back in the care of BC Children's at 28 years of age. Jocelyn has struggled to find someone to take her case because her condition is very complicated: adult complications of a pediatric condition. "The most seminal event for me was having to sign my own discharge report. I'd never had to do that before, and as my parent watched me sign, I wished I could be a kid again".

Jocelyn challenged the care providers in the room she has such gratitude for by asking, "now that you've got us here, how do we thrive to be adults?" A clear next step was identified as needing to approach this challenge collaboratively with patients and doctors working together, empowering young people and doctors to be active and supportive champions. While health care providers may not know all the answers, Jocelyn concluded with a final comment, she emphasized that by working with patients health care providers will be able to find the answers.

Living the Experience of Transition: a Parent's Journey

Lead: Susan Murphy, Parent; Endocrine Clinic Nurse

Susan spoke in her role as a parent with a son, aged 25, with a complex chronic condition. Susan expressed her appreciation for the family centred care provided at BC Children's. Acknowledging that her family still has strong ties to BC Children's as they are still transitioning to an adult care system, she indicated this is, in part because there are no adult services available for her son's needs in BC. Susan commented that this gives a legitimate reason for still being at BC Children's and that while the neurologists have expressed their willingness to care for her son, she sometimes feels they are not as welcome anymore because of his age. Although he's 25 years of age, he is academically and cognitively still at four.

Susan commented on the impact transitioning a multitude of services at age 18 has on the family. It's important to recognize that adolescents are losing the support of the school system at the same time. As Susan recalled her

family's journey, she noted that it's better to work into the education system earlier to help with the transition to community programming. Through collaboration with the health and education systems, Susan's son now takes part in a day program in the community, with the assistance of a one-to-one care aide.

"We have an amazing trust relationship with the staff at the Children's Hospital. Staff trust us on understanding the child and we trust the staff on understanding the illness. It's a very collaborative relationship. They've been on the journey with us. To let go of this trust and the relationships is very difficult."

Susan commented on successes to date, including acquiring good community supports and developing good relationships with adult care providers. She noted the importance of developing relationships with adult care providers while still under the care of BC Children's, to ease the transition. Strong advocacy is required to find a primary care physician who will take on the case management for such a complex, chronic condition. Susan spoke of next steps including the need to set more goals for transitioning care, including finding primary care physician and continuing to connect with specialists in the community and the adult world. She also spoke of the importance to consider long term financial planning and long term housing.

An Overview of Transition: Defining the Issues for Consideration

Lead: Dr. Sandy Whitehouse MD, Division of Adolescent Medicine; Clinical Associate Professor of Pediatrics, BC Children's Hospital

Dr. Whitehouse spoke about the importance of viewing transition as an ongoing life process. Dr. Whitehouse spoke of the aim today being to create a framework for Transition based on the narratives of youth, families and providers while considering the literature of best practices in transitioning from pediatric care to adult care. Recalling the experiences shared by Jocelyn and

Susan, Dr. Whitehouse noted the impact of transition experienced by the first generation of young adults living into adulthood. She emphasised the importance of creating a sustainable framework for transitioning services into adulthood. Bob Blum was quoted with his definition of transition: *purposeful planned movement of adolescents with chronic medical conditions from child-oriented to adult-oriented care*. Dr. Whitehouse spoke about the importance of viewing transition as an ongoing life process.

Dr. Whitehouse discussed the health goals inherent in transitioning from pediatric to adult care as being:

- To provide optimum medical knowledge.
- To provide optimal medical control.
- To provide optimal engagement in self management.
- To enable trust openness and confidentiality.
- To enable self advocacy.
-

Dr Whitehouse presented best practice policy statements from the Canadian Pediatric Society, Society of Adolescent Medicine and UK Department of Health spoke to the need for continuous, comprehensive coordinated,, individualized, flexible, and developmentally appropriate care, with transition planning that starts early.

Dr Whitehouse reviewed challenges to the transition process. These included failures to connect with adult health care services, failures to stay with family physicians, increased use of emergency services, as well as increased morbidity and mortality. Internists' concerns around their medical competency (feeling they need better training), as well as their ability to address the psychosocial needs of the patient and their family and assist with coordination of care, is another issue to address.

There is an inherently different culture of health care provision for adults. While the pediatric system is multidisciplinary, family focused and developmentally oriented, the adult system is much more autonomous, less coordinated and can be frightening to young adults.

Dr. Whitehouse spoke about the need to address specific transition issues in the clinical setting namely: the shift of decision making from the parent to the patient, the possibility of incomplete cognitive and emotional maturation, the importance of considering concurrent multiple life transitions and an inevitable loss of connections. With respect to ensuring adolescents don't fall into the gap between pediatric and adult services it is important to understand how to attract young people to stay in system and to engage them to be partners in their own care.

Changing Populations: How many Youth in BC are We Talking About?

Lead: Dr. Elizabeth Saewyc MD, Professor & Public Health Chair, UBC School of Nursing & Division of Adolescent Medicine; Research Director, McCreary Centre Society

Through a population health perspective, Dr. Saewyc spoke of the impact of children with congenital and chronic health conditions living longer. In detailing what has changed over the years, Dr. Saewyc pointed to improvements in diagnosis, treatment and care – highlighting that 98% of children and youth with chronic health conditions are living to adulthood. What this fact illustrates is the urgent need for appropriate transitions into adulthood.

While it is challenging to understand the true impact of children and youth with chronic health conditions for several reasons, including varying definitions and inclusion criteria, the Adolescent Health Survey provides an indication. In 2008, BC's adolescents (grades 7-12) self reported: a chronic health condition (9%), a physical disability (1.5%), a long-term disability (4.5%) and a mental or emotional

health condition (2.8%). Dr. Saewyc also spoke of the importance of creating transitional supports into adulthood not just adult care. In reporting differences between adolescents with disabilities and chronic conditions and those without, Dr. Saewyc noted adolescents with disabilities and chronic conditions:

- Are three times at a higher risk for abuse.
- Have a lower sense of safety and connectedness to school.
- Are more likely to be involved in risky behaviours.
- Miss out on normative teen activities.

Dr. Saewyc commented on the fact that adolescents with disabilities and chronic health conditions may be seeing a great number of specialists, but often do not see a primary care physician to deal with normative adolescent issues. In closing Dr. Saewyc challenged care providers to prepare children and adolescents for adulthood, not just adult care.

Framing the Issues: Developmentally Appropriate Care from Diagnosis to Young Adulthood

Lead: Mary Paone MSN, Health Care Consultant, BC Children's Hospital

In reviewing how to best support adolescents in the transition to adult-oriented care, Mary spoke of several elements, such as government policies and legislation affecting health care, as well as availability and accessibility of appropriate care and new skills required by both youth and practitioners. Mary discussed the key clinical, personal and family issues associated with transitioning care. The driving clinical issues include:

- Changing populations with 98% living into adulthood.
- Increased complexity of conditions.
- New adult population of pediatric conditions.
- Need to focus on quality of life issues not just longevity.

- 50% of youth not accessing adult care.
- Increase in mortality and morbidity.
- Only 50% identifying a primary care physician.
- Limited adult sub-specialists for referral.
-

Mary challenged the group to question clinical knowledge and skills and whether confidence and beliefs are best supporting adolescents in their transition. Emphasizing that for youth this is a time of developing self-esteem, moving away from parentally-guided to self-managed health care, forming a sexual identity, developing meaningful social and peer relationships and planning for education, work and living. Mary reiterated that, as practitioners, the role is to help adolescents to define who they are.

With respect to the family, it is essential to create systems that understand an adolescent's development is not necessarily ready to be released from pediatric care. In reviewing the clinical transition framework Mary reiterated the need to consider self advocacy; independent health care behaviours; sexual health; education, vocation and financial planning; social supports; and, health and life style at all four stages (early, middle and late adolescence and early adulthood). In closing, Mary summarized the importance of viewing transition as a philosophy and acknowledged the multitude of community partnership supports available to support adolescents and young adults, along with care providers, in their journey.

Experience of Health Care Providers: Concerns, Issues, Barriers and Gaps in Services for Youth Moving into Adulthood.

Leads:

Sandra Sirrs, Clinical Associate Professor, UBC Division of Endocrinology; Medical Director, the Adult Metabolic Diseases Clinic

Allison Mounsey, Social Worker, Complex Developmental Behavioural Conditions Program, Sunny Hill Health Centre for Children

Dr. Steve Mathias, Child and Adolescent Psychiatrist; Medical Manager, Inner City Youth Mental Health Program

Dr. Bent Hougesen MD, MPH, CCFP(EM), FCFP, FRCPC

Dr. Daniel Metzger MD, FAAP, FRCPC, Endocrinology & Diabetes Unit, BC Children's Hospital, Provincial Health Services Authority

Panelists discussed key challenges focusing on five specific areas:

Issues faced after transition to adult care

- Patients often think of tertiary centres as being the point place to go, whereas it is often better for patients to go to local sites for urgent health care needs. This demonstrated the need to build trust in local health care providers. However local sites need information to care for complex patients and this may not be readily available .
- Hospital Procedures in adult and pediatric facilities are different. For example adult hospitals do not accommodate elective admission for adults while patients are used to this in pediatric care (this poses challenges for care givers travelling with patients).

Transition is not the same for all patients:

Cognitively challenged patients:

- there are often unrealistic expectations of the health care system (i.e. coordination of appointments, as well as understanding what is feasible from a developmental perspective). This emphasizes the need to enter into discussions at a young age of what's realistic in their adulthood (i.e. living independently).

Fetal Alcohol Spectrum Disorders (FASD) and Foster Care Placements

- There are no adult FASD clinics for youth to transition to.

- There is a cultural focus on independence, but in reality, interdependence is more realistic for those with FASD.
- There has been a reduction in community based services and funding with more short term funding and goal oriented programming (which is not in the best interest of FASD patients).
- FASD is 'invisible'.
- Patients often have a lack of awareness of their own diagnosis and often care givers do not have a great deal of understanding either, and/or may have tremendous guilt.
- When youth leave foster care, they often require ongoing supportive relationships.
- Often immediate situational needs take the focus off long term planning.

Mental Health

- Fewer than one on four children and youth with mental health needs receive specialist treatment when needed. The lack of adequate resources is compounded by barriers to accessing care.
- Services have seldom been designed in a way that engages youth.
- Youth are sometimes denied services as the problem is not deemed serious enough.
- Many transition-aged youth fall between the cracks created by the division of services between providers (Child and Youth Mental Health, Ministry of Health, Ministry of Education (as youth seek support from school counsellors), Ministry of Children and Family Development and Adult Mental Health services).
- Youth addictions are mostly delivered by independent organizations that straddle the youth/adult age range.
- The stigma is mental health continues to be a barrier to seeking help. Youth tend to be poorly informed about

mental health disorders and how to access available services.

- Evidence points to mental health issues accounting for 50% of disabilities experienced by youth. It is critical that mental health is at the core of solutions for transitions going forward.

Rural Communities

- Hazelton, BC was highlighted as a rural community where the average income is less than 17,000 and the practice is 90% first nations.
- As youth enter into adulthood, services are limited. The family physician becomes the primary point person for all services required (to deal with chronic condition, obstetrics, mental health, housing, education, etc.).
- These issues are systemic in nature and finding solutions can be very challenging.

Endocrinology

- There are 2000 children in BC with diabetes (1000 followed at BC Children's) and 100 children transitioned to adult care every year.
- Most endocrinologists are located in the lower mainland. There are no adult endocrinologists in the north and interior.
- When youth are transitioned they are provided with referrals and community supports. Several issues ensue:
- There are areas in BC without adult specialists.
- Youth tend to move a lot during this time in their lives.
- Not all youth have, or go to, their GP.
- While the pediatric endocrinologist writes a letter to the adult endocrinologist and initiates the referral it becomes an issue when adult specialists need re-referrals every 6 -12 months. Consequently, pediatric endocrinologists often make multiple referrals over the first few years

adolescents transition. Patients are 're-launched' multiple times.

- While it is excellent to have multiple referrals centres, this presents challenges in managing multiple contacts. This actually limits having an adolescent transition clinic.

Communication and Health Care Information Management

Lead: Dr. Ellen Balka Ph.D., Professor, Communications, Simon Fraser University; Michael Smith Foundation for Health Research Senior Scholar; Research Scientist, Clinical Epidemiology & Evaluation, Vancouver Coastal Health

Dr. Balka's presentation focused on how computer systems can play a role in supporting transitional care. Computer systems are used to support population health, determinants and causes, interventions, delivery systems and health policies (to support allocation of resources). Patient data (from multiple sources) may be combined via computer in order to assess population health, and to identify the causes and determinants of health problems. By analyzing data to develop interventions, computers may be used as part of the delivery of the intervention. Administrative data and data about health outcomes will increasingly be used in health policy making. Electronic records are essential in the use of data. Strategies for use of technology in transitions include: electronic records to improve informational continuity of care, computer support for transition capacity development, patient navigation, and improving health outcomes and self-efficacy through computer aided self-management and monitoring, consumption of health information and access to providers.

Dr. Balka stressed the importance of remembering that patients may have health literacy challenges with respect to understanding health information, even if they have access to it. Specifically, patients may not necessarily have the ability to read and comprehend health-related materials, the

capacity to obtain, process, and understand basic health information and services, or have the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health.

The good news, Dr. Balka relayed is that British Columbians have potential to access to health information though high internet usage and well as smart phones. As internet usage increases with income and decreases with age it is important to consider alternate strategies for targeting patients and their families. An example of an innovative technology was shared – My Health Passport, an online tool that allows patients to enter key information and prints a wallet size card that patients can show providers and emergency departments.

Dr. Balka reiterated that there are numerous changes during the transition period which presents challenges for informational continuity of care. For example, the location of care changes, relationships change, expectations of patients change, the availability of information changes, and the legal responsibility for patients changes. As transitions involve handovers and transfers it is important to remember that each time a handover or transfer occurs an opportunity for information loss can occur. Information loss threatens continuity of care and patient safety and hampers research. Without data to allow health care providers to see what happens when patients cross jurisdictions, the magnitude of problems cannot be defined, nor can it be determined whether interventions are having the desired effect.

There is a diverse environment of information systems across BC. With just a fraction being displayed, there are over 30 systems across BC. Challenges include information systems not communicating with each other, passing information back and forth and tracing patients as they move from one environment to another. Next steps include mapping patient movement across care providers and

information systems to identify constraints to conducting health outcomes research across the pediatric to adult transition and conducting interviews with providers about challenges they face in obtaining information about patients across jurisdictions and reviewing documents about BC's health information system environment.

Dr. Balka encouraged understanding the context from a pre-implementation (planning), implementation and post-implementation (sustainability) perspective, considering six domains: technical, professional, organizational, economic, ethical and legal.

Designing Health Care Communication Tools

Lead: **Robert Inkster**, Associate Vice-President Research & Industry Liaison, Emily Carr University of Art and Design

Robert spoke about the unique perspectives that designers lend to developing and creating health care communication tools. Aside from a multidisciplinary perspective designers are very focused on the end user and the usability and integration of communication tools. Two specific projects were highlighted:

An iPad application that acts as a pre-screening tool to help facilitate communicate between youth and physicians about the transition from BC Children's to adult health care. The electronic tool uses iconography for the youth end of the interaction, providing an interactive method of sharing information. Information is displayed in a more traditional spreadsheet style for the physicians side of the interaction.

Onward, branded as 'living in your moment' was highlighted as another example that facilitates connectivity and engagement. This application/mobile site looks to aid youth at BC Children's transitioning from youth to adult care.

Cross Ministry Transition Planning: Protocols for Youth with Special Needs

Leads:

Monica Flexhaug, MHSU (Mental Health & Substance Abuse), Ministry of Health

Lynne Bruce, Community Living BC

Shirley Meaning, Ministry of Children & Family Development

The Protocol for Youth with Special Needs was reviewed in detail. The protocol is a signed agreement between nine government organizations: six ministries (Advanced Education, Children and Family Development, Education, Health, Social Development and Public Safety and Solicitor General), two service delivery partners (BC Housing and Community Living British Columbia) and the Office of the Public Guardian and Trustee. The focus is to improve and enhance youth transition planning within and across organization and to explore access to existing services and supports. The protocol was developed to

- Address families' concerns around the need for better coordination across youth and adult service sectors (education, health, social).
- Focus on the need to plan and to begin planning early (by age 14).
- Provide information about transition planning and how to access services – making it easier to understand and navigate.

The purpose of the protocol is to improve access to existing resources and supports and ensure that a coordinated transition process occurs for youth with special needs and their families. The objectives of the protocol are to:

- Promote cross-government commitment to a collaborative transition planning process.
- Outline roles and responsibilities.
- Support information sharing to facilitate transitions for individual youth and their families and assist with service planning at a systems level.

The impetus for the protocol came about in June 2008 when the government announced responsibility for services for children with special needs provided by Community Living BC would move to the Ministry of Children and Family Development. Cross-ministry dialogue and preliminary work on the scope of the protocol began in October 2008 and a working group with government and community agency representatives was established in April 2009. Once stakeholder feedback was obtained the protocol was signed and came into effect in November 2009. This timeline coincided with the transfer of services to the Ministry of Children and Family Development.

The protocol is about supporting youth with special needs and their transition to adulthood – not just about transferring to adult services. The definition of youth with special needs was adapted from BC's cross ministry Children and Youth with Special Needs Framework for Action (*"Persons between the age of 14-25 years of age who require significant additional education, medical/health and social/environmental support – beyond that required by youth in general – to enhance or improve their health, development, learning, quality of life, participation and community inclusion".*) The fact that significant special needs is part of the definition limits youth with an isolated mental health issue or with chronic health conditions from being part of this protocol. Discussions are underway to consider these youth. The protocol includes: guiding principles of the protocol (the transition planning process for individual youth is to support his/her lifetime opportunities and community participation), government funded supports and services, and a draft transition timeline of roles and tasks.

To support implementation, a Youth Transition Joint Management Committee was established to provide overall direction. The Executive Sponsors are from the Ministry of Social Development and the Ministry of Children and Family Development. A Youth Transition Protocol Implementation Working Group was also established with representation from

signatory bodies as well and community agencies.

Current work was reviewed, which includes:

- A scan of tools (policies, guidelines, processes) used by signatory organizations completed.
- Reviewing the findings from the scan to determine next steps (using common transition language).
- Finalizing an evaluation framework.
- Finalizing the roles and tasks timeline document.

Challenges and lessons learned were shared:

- Provide sufficient time to coordinate and collaborate in a meaningful way (need to acknowledge and factor into planning the time required to collaborate on complex issues that involve multiple parties).
- Learn each other's language. This requires patience and repetition to become familiar with one another's lingo.
- Recognize that some organizations do not serve the full range of youth with special needs due to their mandate. There is a need to accept that the level of participation will vary over time and is influenced to a certain degree by organizational mandates.
- Coordinate across multiple organizations. This requires ongoing project management to support communication and administrative activities.
- Adapt to changes in government structure. This requires flexibility to maintain membership on working group and have a common / ongoing understanding of the protocol and the youth with special needs population it is intended to support.
- Sustain momentum. This requires ongoing shared commitment at all levels and formalized structures.

- In closing, the benefits of the process used to develop and implement the protocol were acknowledged, including the greater understanding of the array of services and the complexity of the systems used to support youth transitions to adulthood as well as having a forum to explore systemic issues.

Models of Transitional Care from a Clinical Perspective

Leads:

Dr. Lori Tucker MD, Clinical Associate Professor in Pediatrics, Division of Rheumatology, BC Children's Hospital, University of BC

Dr. Duncan Etches MD, General Practitioner, Family Practice Centre, BC Women's and Children's Hospital

Dr. Jacqueline Purtzki MD, Clinical Assistant Professor, Division of developmental Paediatrics, BC Children's Hospital; Clinical Assistant Professor, Physical Medicine and Rehabilitation, UBC; Adolescent and Young Adult Rehabilitation, GF Strong Rehabilitation Centre; Sunny Hill and BC Children's Hospitals

Dr. David Wensley M.D., Clinical Professor of Paediatrics, UBC, School of Medicine; Staff Physician, Critical Care and Respiratory Medicine, BC's Children's Hospital

The four panelists spoke of their individual practices and challenges. Each is summarized below.

Dr. Lori Tucker

Dr. Tucker's focus is on juvenile arthritis (noting that 1/1000 children get affected by arthritis and continue to have problems into adulthood). Dr. Tucker spoke of the Young Adult Rheumatology Disease (YARD) clinic, a transition clinic. Youth are between 18-22 years with rheumatic disease diagnosis. Rheumatologists, nurses and allied health professionals provide services to youth at the YARD clinic, at the Mary Pack Arthritis Clinic and purposely treat patients as new patients without their parents not in the room. This may be the first time the youth has been asked to give their whole history. There is a nurse available to support parents as the transition is challenging for them as well. Issues ensue when adolescents move (they need to develop new relationships with new specialists).

Dr. Duncan Etches

Dr. Etches focused on six main points:

- Patient registries would be helpful in providing good information as patient transition (i.e. contact information, substitute decision makers, surgeries, and complications).
- Physician involvement early on is critical (initiating discussion around age 12), so the transition isn't sudden, but, rather over time.
- Specialized clinics are extremely helpful. Would like to see these be provided outside the lower mainland to rural providers. Specialized clinics provide a good basis for research as well as patient registries.
- A list of consultants interested in caring for complex patients would be beneficial.
- Access to specific education to support adults care providers in caring for youth with pediatric issues would be valuable (i.e. literature resources and numbers to call for answers to specific questions).
- Important to recognize the value in initiating discussions on self management earlier on.

Dr. Jacqueline Purtzki

Dr. Purtzki spoke of her work with patients with severe muscular skeletal injuries and neuromuscular dystrophies. Recognizing the value of an interdisciplinary team, with a focus on function (participation and functioning in the community), Dr. Purtzki discussed the value in working with adult care providers to help ease the transition for providers as well as patients. The importance of asking patients what they want to accomplish in terms of a variety of goals, includes school, community, living arrangements and financial considerations. With respect to challenges, geography is an issue. It can take hours for patients to travel in a wheel chair. Dr. Purtzki communicates with patient via email when possible but would like to see more clinics to enable more access for patients. In closing, Dr. Purtzki recognized the

stress on care givers and pointed to the need to help care givers negotiate the system.

Dr. David Wensley

Dr. Wensley spoke of his work with BC Children's home tracheostomy and ventilation program. A significant success is that there are 140 children out in community with home support. However, this is new. As children are living longer, it is challenging to find other facilities that can support youth when they transition from BC Children's. The coordination of clinics needs allied health and social workers. A key challenge is to understand whose responsibility it is to support these programs. Children have been managed at BC Children's for years. In this patient population the burden of their care increases over time so that by adulthood they are extremely dependent. This puts added strain on parents while resources for care are diminished. This group needs to have more care in the community, but who will manage this has not been identified. Questions to be answered include: who is going to care for the children, and who is going to care for care givers? Respite and as end of life care is needed. The end of life care is being shifted into the adult world as children are living longer.

A Regional Transition Model using Patient Navigation

Lead: Lynne Brodie, ACI Transition Care Manager, New South Wales (ACI) Agency for Clinical Innovation

Lynne provided an overview of an established state/province based Transition Model, which sits under the Agency for Clinical Innovation's Clinical Networks in New South Wales, Australia. The Transition Network (one of 22 networks) was profiled as a bottom-up initiative with designated network coordinators. For youth, coordinators:

- Help to find adult services and provide support by attending the first clinic.
- Provide information about adult health care services.
- Assist in the adjustment to a new adult team and adult service.

- Follow up to ensure they are engaged in adult services.

For health care providers, coordinators:

- Link with appropriate adult services.
- Provide resources to help prepare youth.
- Follow through and provide feedback.

Lynne described the priorities of the Transition Network:

- Transition service delivery models.
- Workforce needs and planning around system capacity.
- Resource development.
- Information management and data collection.
- Education and research.

The main objective for children's services is to prepare children well and for adult services, to aim for long term retention, so youth don't fall through the gap. In holding a forum for youth on what they feel about the transition, Lynne reported that youth asked for:

- Continuity of care by a provider they trust.
- Care provided locally (as much as possible).
- Youth friendly staff.
- Confidentiality, privacy and safety.
- Expert knowledge.
- Someone to help them through the process.
- A one stop shop.

Key outcomes achieved include:

- Models of care developed for the top 10 conditions.
- State wide data collection and referral system.
- Policies and guidelines.
- Resources.
- Formal partnerships through MOUs.
- Education and research.

The biggest challenges include:

- Getting key players interested in the adult world when that is not their core line of business.
- Obtaining data from busy clinicians.
- Incorporating transition into health care provider education.
- Taking time to evaluate.
- Engaging youth.

The key lessons learned shared by Lynne are to:

- Set realistic timeframes.
- Start with data.
- Be persistent.
- Make time to evaluate.
- Involve clinicians and patients in all aspects.
- Value early adopters and passionate individuals to guide the rest.

Youth Friendly Care: What Does it Look and Feel Like?

Leads:

Sabrina Gill RN, Nurse Clinician, Division of Adolescent Health and Medicine, BC Children's Hospital

Sachpreet Srah, Third Year Nursing Student; Transitioned from Hematology Clinic at Children's Hospital to St. Paul's

Justin Gloanec, Student, about to transition (Crone's Disease)

Lauren Jackie, Student, Chronic Kidney Disease, transitioned from Children's Hospital to Vancouver General Hospital

Amol Gill, Health Sciences Student, SFU, Type 1 Diabetes, transitioned from BC Children's Hospital Endocrinology when transitioned to University

Panellists discussed their health care experiences and transitions and provided their insights into what youth friendly care looks like:

- Focus on making connections with youth: "it's not the tasks you complete but the relationships you build".
- Be present – youth are very in tune to emotions.
- Treat youth as individual people, not conditions.
- Be a partner with the youth.

- Be a listener and listen to what youth have to offer.
- Don't use confusing medical terms.
- Be non-judgemental and respectful of different cultures and backgrounds.
- Be aware of resilience – bring our youths' strengths rather than focusing on what they didn't do.
- Recognize the stages of child/youth development.
- Create a comfortable environment.
- Provide emotional support.
- Ask youth for their feedback.
- Be passionate and be an advocate.
- Be friendly and have an open atmosphere.
- Build on personal experiences where it's relevant and appropriate.
- Be attentive and caring.
- Be aware of other non health care issues going on.
- Streamline patient visits to minimize lost school time.
- Collaborate with other specialists.
- Embrace technology (social media and apps).
- Incorporate peers to help support youth.
- Recognize youths' need for independence.
- Involve youth in decision making (shift the focus from the parent to the youth and don't disclude/discredit youth).
- Have pediatric and adult care providers collaborate.
- Provide a summary of issues in childhood/adolescence for youth to give to adult care providers.
- Host transition nights at adult facilities where youth can tour the adult facility and familiarize themselves with the new environment.
- Provide youth with information and knowledge to make the right choices/decisions.
- Acknowledge stress and emotions.

Moving Forward: Opportunities & Emerging Vision Solutions & Strategies

During a breakout session, workshop participants were asked to identify opportunities for moving forward. The following ideas were brought forward that focus on creating supports for health care providers, developing funding models that support transitional care, engaging youth, considering an individualized age of transition and developing infrastructure for system navigation and coordination of multidisciplinary care.

Supports for Health Care Providers

- Develop a directory of resources so physicians know how to access support (i.e. who to call).
- Identify GPs and specialists who are interested and available for transition care.
- Develop a patient registry.
- Need to consider the practitioners side of the transition process. Reluctance from providers' perspective to give up the care of youth; haven't addressed what it means to providers.
- Develop a shared care model involving GPs right from the start.
- Integrate more transition education in training of health care providers.
- Develop flexible models of physician care (i.e. GP involved but not necessarily responsible for the transition).
- Need health care providers from the adult environment to be involved in transitional planning, not just pediatric care providers.
- Utilize telehealth as a mechanism for specialty consultation and GP care.
- Elevate the issues and understanding with administrative and policy makers with research and partnership.

- Identify all stakeholders at the executive level to be involved in the planning.
- Consider the role of the BC Children's brand. There are the same specialists working in other areas, but families think they can only go to BC Children's.

Funding models that support transitional care

- Integrate primary care and funding (i.e. billing codes for transfer of care).
- Develop a funding process specifically for complex pediatric primary care.
- Change fee structure to support multidisciplinary care and transitional care.

Engage Youth

- Develop strategies to maintain relationships with youth.
- Involve youth in planning transitional care services.
- Enable youth to find/choose their own GP.

Flexible and Individualized Transition Age

- Need a flexible transition age range that meets the child's needs, both in community and acute sectors. A flexible discharge age from BC Children's would enable this.
- Recognition that the same education plan is not applicable for each youth.
- Acknowledge that some youth may need to come back to BC Children's (therefore, need to understand readmission protocols).

System Navigation/Coordination of Multidisciplinary Care

- Develop a children's transition summary record which gets passed to parents, caregivers, available to the young adult.
- Need a navigation coordinator/case manager to be assigned to each youth (not necessarily a GP)

- Transition coordinator should have a holistic approach to address other needs such housing, social work, in addition to medical needs.
- Need mechanisms to improve communication between GPs and specialists.
- Need better communication and collaboration between ministries, community care, and health care system (i.e. clarifying various government ministry policies and roles).
- Need youth centered, multi-disciplinary clinics.
- Consider a holistic perspective. Primary care physician has an overview of the person as the whole, as opposed to specialty care looking at different “parts” of the person.
- Multi-disciplinary team needed to provide care and interface with GP.
- Improve access to mental health services – psychiatrist, group sessions, etc.
- Include community based care as one of the partners in pediatric care.
- Need for more and more awareness if community and grassroots initiatives.

Determining Priorities & Developing Strategies

Workshop participants were asked to consider the following key questions in discussing eight specific topics (a detailed report back follows for each):

- What can you do now?
- What are long term goals?
- How can they be reached?
- Who will do the work?
- Who will be the champions?

Navigational support for youth

What can be accomplished now?

- Community Health and Resource Directory (CHARD) is being developed by the GP Services Committee (GPSC).

- This could be expanded to make it accessible for youth and families.
- This could incorporate information about GPs and specialists interested in transitional care.
- Could begin to build pediatric/adult services relationships right away.
- Need adult and youth services to be involved in youth transitional clinics.
- Need to focus on individualized models of transitional care.
- Develop pilot drop-in programs for adolescents
- Identify point people within pediatric services, then start discussions with adult services about a similar model.
- Consider sessional funding for GPs.
- Involved Nurse Practitioners or other health care professionals.
- Look to the social pediatric model as a frame of reference.

What can be accomplished within 5 years?

- Develop a 1-800 resource number.
- Make use of online services and social media such as Facebook and Inspirenet.
- Develop navigational tools for families including resources and roadmaps (can be web-based).
- Develop a transitional care interest group that could meet on an ongoing basis.
- Include schools and education system in planning.

Who would be involved?

- “Everyone” - it would be an inter-professional and collaborative model
- However Infrastructure Leadership required

Strategies for engaging youth in planning

- Map the youth transition/developmental process.
- Start the transition process and empower the youth early. Start relationship building early (grade 8).

- Take a multi-disciplinary approach including the patient, family, teachers and the health care team.
- Proactive approach: Discuss future aspirations and meet annually with the entire team to address issues before they become problems.
- Develop a model for the 18-30 population.
- Consider an Alumni model.
- Utilize peer mentors who have experienced the transition.
- Recruit youth to be involved in the program. Have youth speak about their experiences.
- Host a social transition night where the disease isn't talked about. Rather, it's a comfortable environment where youth can interact with peers going through a similar processes.
- Involve health care providers and staff and the Ministries of Health and Children and Family Development, GPs and a transition coordinator.
- Consider how to engage youth that don't want to be involved.
- In everyday interactions with children/youth, look for informal opportunities to chat. Conversations don't always have to take place in an interview room.
- Recognize the need for a philosophical/cultural shift when approaching a teenager.
- Confidentiality, respect and acknowledgement of youth's independence and autonomy are critical (may need to set aside other objectives in order to develop relationships).

Resource support for providers (mechanisms not funding)

Gaps:

- Funding for multi-disciplinary clinics in the adult system.
- Education for care providers taking on care.

- Need to create avenues for sub-specialist to educate the new physician taking over the care.
- Communication between specialist team, GP, and community resources.
- Clarity of available resources (including what is available and how to access them).

Solutions:

- Education of family needs.
- Structuring time into providers schedules for transition services.
- Funding and support for all health care providers.
- Integrated models of primary health care.

Leads:

- BCMA (responsible for negotiating for physicians).
- Health authorities (responsible for allied health professions, funding infrastructure such as clinics).

Data collection and registries (including medical records)

- Need a registry of: GP providers with specialty interests and sub-specialist providers. (CHARD- see Navigational support)
- Need more comprehensive list for the Redbook. Redbook has resources with ministries, but need it in a usable form, e.g. subsidized housing options. Need to determine who is responsible for updating this resource.
- Need a reporting system where a program using patient identifiers is developed.
- Report the number of youth transitioning within the next 5 years to help with planning. Assess at level 1-5 depending on their needs. Report on April 1 each year. Projected number of resources needed could be looked at by ministries.
- Give the youth a USB with relevant history (detailed to be web-accessible)

as well to ensure integrity of data). Youth can choose to share their information. There is a danger that youth may lose medical records.

- Information needs to be standardized (this is 5 years down the road).
- Need policies on confidentiality and privacy to support cross-disciplinary and jurisdictional work.
- Need a primary transition coordinator.
- Remember the youth is a consumer of the health care (not just the parents).
- Utilize internet-based or Smartphone applications for the target population.
- When considering technology used to support transitional needs, remember that the most marginalized are the least likely to access services.
-

Regional models for transitioning

- Need to hire a project manager.
- There are models for transition in existence. Share and evaluate what's already working.
- Be explicit about roles and responsibilities.
- Over the long term need to understand the implications of implementation planning.
- Clearly identify provincial/regional partners.
- Need a feedback loop from the community to specialists.
- Consider parent champions. They are better at accessing resources. Let's learn from parents.
- Health authorities need data to inform planning (including financial data).
- Pilot initiatives to test, evaluate and learn from them before rolling out provincially.
- Prioritize who needs the navigator services first.
- Consider the impact on the adult system (challenging to anticipate demand and costs).
-

Youth friendly care in adult settings

- Important to recognize that needs are so different for those with complex problems
- Consider subset committees for complex issues
- Build communication bridges between inpatient and outpatient settings
- Liaise with local hospitals
- Look at ways to create units within existing services (and have visiting specialists)
- Need to create a registry of interested specialists (CHARD)
- Work with the Divisions of Family Practice. (BCMA)
- For long-term: increase training for adult care providers
- In the USA, there is a Fellowship in Youth Medicine.
- Look at multi-disciplinary training programs to give nurses and psychologists extra background in youth needs.
- Create multi-disciplinary youth clinics to be accessible when youth need help (drop in model).
- Utilize telehealth and other modes of communication to support GPs
- Need to develop champions (i.e. parent groups).
- Need to recognize there is no 'set' place a family can go to for advocacy for a specific condition.
- Need to respect parents and prior care providers.
- While a coordinator in the community is valuable, for some services GPs are best to refer to other medical specialists.

•

How to improve inter-ministerial dialogue

- A significant accomplishment has been achieved in bringing different ministries together. Ministries are committed to using information to inform Ministry plans

- Goal for the next year is to see the transitional protocol implemented. To help achieve this, a provincial steering committee is needed.
- Models already exist to build upon.
- Various ministries should be at the table, along with agency stakeholders, health authorities, providers, allied health specialists, consumers, youth, and family.
- Need to develop a mandate that addresses how the journey from adolescence to adulthood is successful. Mandate needs to reflect an administrative community of practice with deliverables, timelines and a budget.
- By 2013, would like to see a provincial attachment initiative.
- Goal is that every youth with chronic health needs will have a transition plan (that includes all sectors of service provision not just health).
- Would also like to see consumer and provider registries by 2013.
- Champions are needed to endorse the cause and engage in the cause (including youth, families, funders, and health care service delivery partners)

•
Expanding the transition age to 24 / should 18-24 be an 'added generation'

- Should be an individualized decision with flexibility to move between the pediatric and adult environments as needed to best support the youth.
- Recognition that some resources stop at 18 and others start at 19. What happens in between? Need to expand that part of pediatric service, so youth don't have to go to multiple agencies.
- Age 18-19 - first help youth with social issues then look at ongoing medical need.
- Adult and pediatric specialists are starting to come together to share knowledge.

- Anticipation this will continue to build from this workshop.
- Key stakeholders include: adult and children specialists, community workers (GPs, schools, social workers), families and children, policy makers and government.

Key leaders:

- Dr. Sandy Whitehouse, Dr. Maureen O'Donnell, Mary Paone and the cross-ministry group.

Moving Forward

The workshop wrapped up with the desire to move forward with creating a supportive environment for patients and families to transition from pediatric to adult care. With a consensus on many of the challenges (described in the Executive Summary), the workshop identified the following opportunities:

- Extend the transitional age spectrum to 25.
- Look at collaborative models of care, which includes pediatric and adult care providers working together.
- Empower and engage youth and families to be leaders in their own care (using technology as a key resource).
- Better utilize technology to support information sharing across organizations and across the pediatric and adult 'gap'.
- Develop navigational roles across the health system to support patients and families by coordinating care and providing access to resources.
- Build capacity across health care provider disciplines to better support patients and families during the transitional years.

Thank you to Craig Ross for creating the Mediasite and Webcast.

Acknowledgements

The workshop came together through the efforts of Child Health BC and Division of Adolescent Medicine. The BCMA is recognized for supporting the attendance of physicians from across the province. All speakers, presenters and participants are sincerely thanked for their valuable contributions.

**Child Health BC
2H2 – 4480 Oak Street
Vancouver, BC
Canada, V6H 3V4
Web www.childhealthbc.ca
Phone 604.875.2345 x5305
Fax 604.875.2074**