



Youth and Young Adults with Chronic Health Conditions in Transition: A Provincial Perspective with Regional Focus for Integration

Child Health BC

Co-sponsored with the Shared Care Committee
(Ministry of Health and BCMA)

Vancouver, BC

November 1, 2013



Executive Summary

On November 1, 2013, a second workshop on Youth and Young Adults in Transition was held in Vancouver, BC, to report on the ON TRAC initiatives arising from the 2011 workshop. The workshop was co-partnered by Child Health BC and the Shared Care Committee of the BC Medical Association (BCMA) and the Ministry of Health.

The workshop was designed to bring together the many professionals working with youth and young adults with chronic health conditions and disabilities (CHC/Ds) as they transition from pediatric to adult care within the provincial health care system.

Unique within the medical system, transition was identified as an area of special concern in the 2011 report, requiring standardization of protocols to manage the changeover between systems effectively, and ensure continuation of care.

The workshop followed an interactive format, with panels of experts presenting the progress made on previously identified areas of concern, followed by discussion and feedback from the audience.

The main themes centred around the transition process itself, identifying attachment to a family practitioner (FP) as the primary step that is key to success.

Other themes included development of the medical home, youth empowerment, revision of FP fee codes to incentivize uptake of complex cases, knowledge transfer, and patient-centred customization of the transition process.

Regional variations and the concerns unique to remote communities were specifically addressed by participants, who gave feedback on how these issues could be addressed.

Delegates also identified multidisciplinary delivery of services and the use of teamwork as essential during management of the transition process. These were seen as important to ensure clinical practice guidelines are attained for youth after they transition out of pediatric care.

In the final session, workshop attendees and speakers combined their ideas to propose key areas of action for the future, focusing on the overarching themes of youth empowerment, inter/multidisciplinary service, policy, and analysis.



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.

Meeting Goal & Objectives

The goal of the meeting was to facilitate discussion towards creating and integrating a sustainable, cross-jurisdictional provincial system for youth with chronic health conditions and/or disabilities (CHC/Ds) to transition from the pediatric to adult health care systems through development of infrastructure, integration of health care services, and knowledge transfer.

The objectives of the workshop were to:

- Understand the evolution of the ON TRAC Transition Initiative (2011 to present) in developing a multifocal transition process with clinical practice recommendations, policy and system components for all stakeholders.
- Within a provincial context, explore and discuss models of care for transition across the continuum that could be integrated into the health regions.
- Identify the challenges in implementing models of transitional care, both those that are common throughout the health regions and those that may be unique to particular health regions.
- Strengthen relationships with regional stakeholders to collaborate on integration and uptake of recommended practices and toolkits.

Workshop Highlights

Setting the Context for Discussion: Issues of Transition

Sandy Whitehouse, Pediatrician and Medical Lead on the ON TRAC projects

After welcoming delegates, and thanking the Shared Care community and organizing team, **Sandy Whitehouse** encouraged participants to engage in frank and honest discussion to facilitate moving the ON TRAC initiative forward.

ON TRAC is a province-wide multifocal initiative, aimed at ensuring successful planning and preparation for youth with chronic health conditions (CHC) to transition from pediatric to adult care systems. This is a unique instance in medicine, transitioning from one care system to another. The focus at this stage is on attachment to the family practitioner (FP) as primary caregiver.

Whitehouse highlighted differences between the two care systems: pediatric care is family centred with parental involvement, and mostly multidisciplinary; whereas the adult system is referral based, relying on appointments with many specialists. Users are more responsible for setting their own appointments, and the system is fee driven per specialty.

Explaining the need for discussion, Whitehouse cited statistics that show a steep decline in patients reaching clinical practice guidelines between age groups 10–14 and 20–24. Sadly, this decline is associated with an increase in mortality, whereas correctly managed transition avoids this, and can be a cost benefit to the health care system.

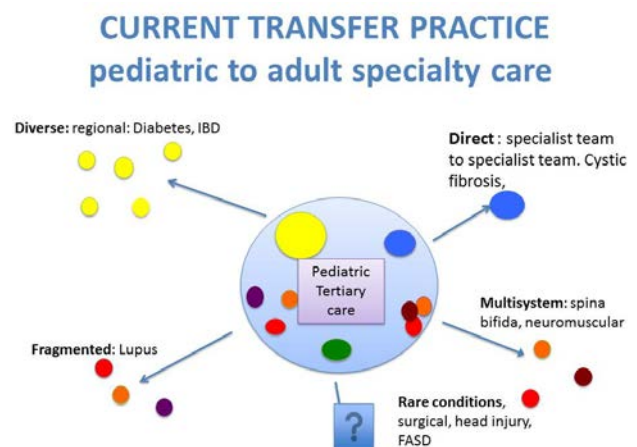
Currently, there are four programs in the ON TRAC initiative, all attempting to ensure continuity of care into adult specialties:

1. Clinical Practice Guidelines (CPGs; BC Children’s Hospital - BCCH)
2. Shared Care (BCMA)
3. Youth Voice (Vancouver Foundation)
4. Specialized Services (BCMA)

These initiatives were launched following the 2011 Child Health Workshop (*Youth and Young Adults in Transition: Vancouver, April 2011*) that created a mandate to work on issues surrounding responsible transition to adult care. This was to be accomplished by developing evaluation strategies for:

- Content (patient records for transition)—information, data, tools, and resources
- Process (patient transfer initiation) — system reviews, strategies, collaboration
- Structure (who does what and when) — role definition, scope of practice, work load
- Collaboration (on a provincial level) — engagement within regions/divisions, community organizations

All were developed in conjunction with the BCCH ON TRAC team, also noting how care is sent out into the province, and any correlation between specialty/disease condition and variation in team/specialist involvement.



Whitehouse noted that in some cases, care may be split between adult and child specialist. However, in some instances, an adult specialist simply doesn't exist and patients have no other option than to return to BCCH.

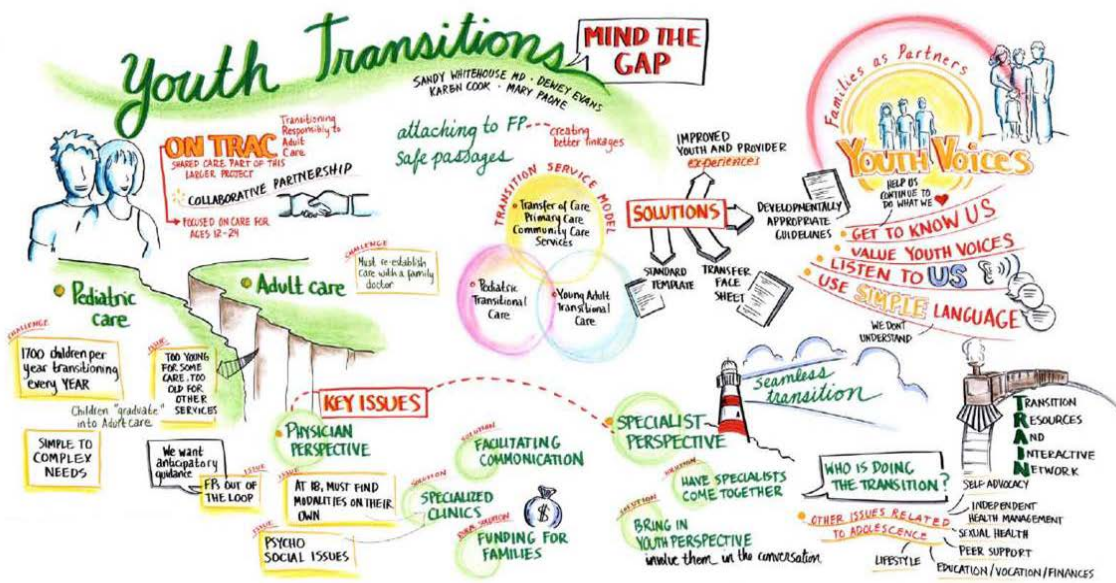
She also noted that multidisciplinary teams for complex conditions do not exist outside pediatric care.

Commenting on the steep decline in clinical practice guideline attainment, Whitehouse revealed that, although 98% of pediatric patients have an FP, the frequency of visits is low as care is managed predominantly by pediatricians. When children do visit the FP, it is rarely alone.

Currently, the ON TRAC projects are grouped into three sets:

- Clinical
- Community and youth engagement through family workshops and online resources
- Health systems function—for patients and practitioners

In summary, 1700 children leave BCCH every year. Transition needs to focus on engaging these patients with an FP, making sure that the practitioner receives education for rare conditions, and ensure that there is support in the community.



Success for Launch: A Parent Story

Margaret English, medical administrator and parent of a child with CHC

Parent and Executive Director of North Shore Family Practice Division, **Margaret English** shared her family's story of her son's ongoing transitions from pediatric to adult medical care.

First Launch

D was born one month premature by C-section. His cardiac condition became apparent at birth, so he was admitted to BCCH while his mother remained at St. Paul's Hospital. Over the next two days, Margaret was left in the dark, until on day three, D's pediatrician visited her to discuss his ongoing care. From then, the family developed many relationships with specialists and care teams, which was especially good with the primary care provider. "We felt supported by a knowledgeable and informed team."

Second Launch

Not expecting any problems, D entered the adult care system at age 16 and was lucky that his FP was willing to take responsibility. Unfortunately, the FP was underprepared for crisis when D developed chest pains that could not be diagnosed in practice. D's confidence dropped and he was referred back to BCCH. An advised echocardiogram was not ordered as no one knew who was responsible. Eventually, D went back to BCCH completely for ongoing care.

Third Launch

At age 18, D was transferred to the Pacific Adult Congenital Heart Clinic (PACH) clinic at St. Paul's for a care plan. In his words, the best thing to come out of this was a plasticized wallet card, giving medical information and care provider contact details.

But two years ago a heart valve deteriorated and there was no care plan in place for his FP to correctly diagnose the warning signs of this unstable condition. His follow-up was delayed and there was a gap in assessment by St. Paul's. Again, D was back at BCCH but this further

delayed adult assessments as appointments could not be repeated within a year.

Currently, D has an FP, but there are still problems with recognition for the support needed for his complex condition. Communication between specialties and caregivers is poor, and there appears to be little knowledge sharing. Furthermore, D does not meet the level on the frailty index that would reimburse his FP for ongoing care.

In Margaret's opinion, communication is important for success in transitioning. This means communication with the patient as well as among the medical care teams. What worked best was the direct communication between specialists, using the direct dial from the rolodex approach. As D's confusion in the system developed, his confidence in both his care and in his own abilities decreased.

Audience reactions included:

- Were you surprised at the lack of immediate contact between specialists?
- Is there now a procedure in place for transition?

Summary

Lack of knowledge is stressful—education is needed for patient and caregivers alike.

Evolution of Core Recommendations for Transition

Patti Byron, Senior Director—Inpatient and Ambulatory Patient Care Services, BCCH

The seven core recommendations for transition started as BCCH Clinical Practice Guidelines (CPGs) to ensure that transitioning youth have high-quality care after leaving the hospital. They have evolved into recommendations or potential guides for developing strategies to improve transition provincially.

These recommendations focus on planning for transition into the adult care system, preparation of youth and their families, and

initiation of transfer procedures for youth with CHC, ensuring attachment and quality in ongoing care.

Since 2011, the team has reviewed over 400 papers and 40 transition programs worldwide for best practice.

Outcomes proposed included:

- Standard of care continues to age 18 at BCCH
- Document preparation for transition
- Access to education, information, and resources
- Analysis and data monitoring for evaluation

BCCH is aiming for 70% adoption of guidelines by March 2016.

Currently, out of 180 stakeholders consulted, 60% responded with 95% positive in favour of core recommendations.

In collaboration with the Canadian Association of Pediatric Health Centres (CAPHC), the next steps in the process are:

- Continue support and development of national Community of Practice (COP) and CPGs
- Present findings to provincial health regions
- Seek opportunities to spread uptake of initiatives

Transition Landscape Through Data

Sandy Whitehouse, Pediatrician and Medical Lead on the ON TRAC projects

Dewey Evans, BCMA ON TRAC Evaluator/Shared Care Project Manager

Dewey Evans described the data collected and available so far. He noted limitations with the data sets:

- Ambulatory Clinic data does not have discharge data, so the team created an

algorithm to deal with transitions from pediatric to adult care.

- Classification of chronic conditions was not appropriate for data collection, so conditions may be missed.

The data did show that numbers of youth in transition have increased, since more survive into adulthood.

Using MSP data, the team followed a cohort of 18-year-old, heavy healthcare system users through the care system.

Evans noted that when attached to an FP, costs were reduced.

The data also show that a small number of very complex patients are presenting to FPs.

Sandy Whitehouse continued the complexity theme.

- “One size doesn’t fit all”—the definition of complexity varies with the patient; some rare disorders do not have a diagnosis.
- Understanding complexity is complex and there is variation in assessing it—FPs see all youth in transition as complex cases.
- Complexity scales—the Minnesota Complexity Scale is based on diagnosis and pathology in addition to personal and health care system issues.
- Different concepts of complexity and how it is defined affects service provision and availability.
- FP fee codes are limited and do not reflect the range of pediatric transitions for complex cases.
- Complexity measurements don’t always correctly define a patient’s needs.

Questions from the floor:

1. Why is there a one-year gap between pediatric services and adult care?

Healthcare is siloed, and since patient numbers for this population are small there has been no pressure to improve the situation. Collaboration with all stakeholders is key to move forward, as is the need to refocus on the needs of the patient rather than the needs of the program.

2. Does attachment to the FP vary with region? Does this reflect resources across the province?

Data are not available, although this does appear so in MSP data of heavy health care system users.

3. There is a shortage of FPs taking complex patients within BC—perhaps an overhaul of fee codes is needed?

Since all youth in transition, even those with only one CHC, are seen as complex, then yes, new fee codes to incentivize FPs are needed. The issues of complexity affect the system, the patient, and the environment.

Focusing on Patient-Centred Care & Documentation

Panel Presentation

Mary Paone, Nursing Lead for ON TRAC

Janet Murphy, Regional Clinical Planner for the Maternal Infant Child Youth Program, FHA

Anne Goodine, Director of Clinical Management for Bayshore Home Health Pediatric Services

Mary Paone introduced the speakers, commenting that ON TRAC is developing protocols through outreach from BCCH. These focus on transfer and attachment to a primary caregiver. Although guidelines and implementation are still in development, BC is further ahead than many other provinces.

The outreach comprises interviews with specialty teams; gleaned best practice from literature reviews; and focus groups with

families and patients—all focusing on streamlining patient-centred care for the 12–24 age group.

Note: adult literature advises 28 years as the age to fully transition into adult care systems.

Issues in the transition pathway that need to be addressed: e.g., skills, education/training and information, documentation standards, personnel time and availability, and clarity of roles will be managed by evaluating patient experience, care outcomes, and health system needs.

The ON TRAC team aims for transfer and appropriate attachment by age 18, though Paone noted that individualized care means that some transfers are delayed.

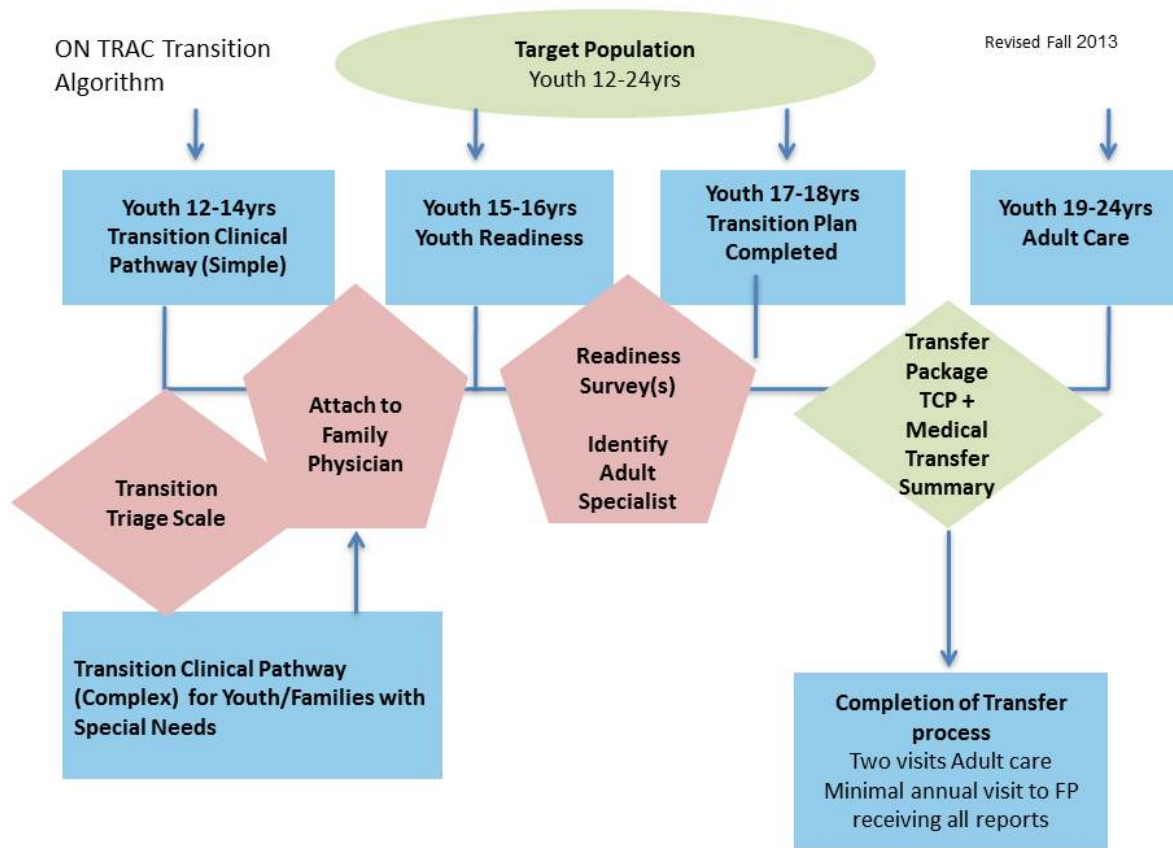
Guidelines/standards for practitioners must include:

- Preparation for transition from 12 years of age
- Help families prepare for transition through regular and progressive planning
- Enable youth to take responsibility

Feedback from the adult care system advises that a transition pathway be developed for the 18–24 age group. This pathway is started at BCCH clinic visits, with progressive completion of transfer progress forms at each visit.

1. At 12 years of age—ensure attachment to FP, to prevent fall-off at pediatric discharge
2. At 16 years of age—identify adult specialists for the next steps; prepare youth for discharge from pediatric services; prepare a youth readiness checklist
3. Ensure records return to the correct FP in a timely manner

Through collaboration with Shared Care and three FPs from the North Shore Family Practice Division, ON TRAC is working on:



- Developing reports and documentation for successful pediatric discharge
- Developing a triage scale for simple to complex patient assessments
- Fee code revision and definition of FP roles
- Identification of the 20% of complex cases that need extra care for transition

Anne Goodine works with Bayshore, providing in-home nursing care to clients including youth in transition. This includes super complex cases—airway management, artificial feeding, and pain management.

Goodine described the transition process as “horrid” for some families, noting that they needed to be very strong advocates in order to get the support needed from provincial health authorities.

Problems:

- Transition often not initiated until six months prior to 19th birthday in some health authorities
- Responsibility shifts from parents to patient for care organization—family relationships change
- Adult system requires patient to make decisions

Bayshore has instituted workshops for staff, implemented focus groups, and developed a triage scale to assess complexity and needs.

Goodine’s suggestions to “minimize confusion and chaos” include standardization, use of key worker transition support for families, and exploration of what longer-term care means.

Janet Murphy gave some insight into how Fraser Health Authority (FHA) explored the challenges facing families in transition.

- An external audit in 2009 advised a seamless transition to adult CHC care and a clearly defined pediatric age definition policy.
- Age definition was developed in collaboration with BCCH, defining pediatric as age 17 minus one day, and transition covering 17–19 years of age.
- Partnerships were developed with adult care providers and specialists.

Using the Abbotsford pediatric diabetes clinic as an example, Murphy described how the rising demand for subspecialty clinics could be developed in collaboration with adult specialists.

- Development of successful transition protocols
- Guiding development of adult clinics for onward care of transitioned youth

Family feedback has been: “this is reassuring.”

Discussion Points:

With these recommendations for standardized transition tools,

1. How do you see them integrated into your practice, your health authorities?
2. Do you have any questions/concerns we can learn from?

Audience feedback:

- Dealing with unplanned pregnancies, as an example of who takes responsibility for sexual health advice in transition, needs to be addressed.
- Funding needs and acquisition for such a small section of the population—how can this be managed? Where are the sources? Is it all through reallocation of existing budgets?
- Multisystem, complex patients often do not fit into the adult care “single system” adult patient tool kits—who

will initiate the transition pathway for children under various specialty teams? Is this where a transition navigator/key worker fits in?

- Where does mental health fit into transition? Where does cognitive ability fit into the transition process? Will substance abuse be evaluated or dealt with during the transition phase, and by whom?
- What are the ‘friendly’ adult specialties across the province? And how do rural FPs access this support?
- What is the role of the FP on discharge from BCCH—this needs defining? FPs need to access support for onward care in the community, and the local authority needs to be prepared for handover.

Continuity of Care Across Transition and Transfer: “Standardizing Care and Moving Forward on Initiatives.”

Susan Rabinovitz, *Specialist Services Project Manager—ON TRAC*

Stella Cockett, *Coordinator for BCCH Cardiology Partnership Program*

Mitchell Fagan, *Langley FP and Family Physician Content Expert with Care Youth Transitions*

Brian Sinclair, *Pediatric Cardiologist*

Lynn Straatman, *cardiologist at VGH*

Using cardiology and neurology cases to illustrate issues arising in current transition management, **Susan Rabinovitz** described the steps needed to improve delivery of specialist services and continuing care for youth with CHC/Ds.

The issues here are:

- Improving provision and continuity of care for youth in transition
- Identifying care requirements in the adult system, and defining roles for the specialist and FP
- Refining long-term care plans
- Delivery of training tools to medics

- Ensuring patient attachment
- Adjusting FP fee codes to encourage joint management of cases by both adult and pediatric systems during transition

Transition and Transfer: Cardiology

Brian Sinclair started by noting that there are more adult patients with congenital heart conditions than there are child cases currently in the system. This presents difficulties in care for adult cardiologists who may not have knowledge of care/training required for management of congenital conditions.

In transition of congenital patients:

- Who is responsible?
- How do we develop the knowledge transfers necessary for providers as well as for patients?
- Is this where a Medical Home should be established where the knowledge resides?

When transferring knowledge during the transition process:

- Consider the needs of all carers as well as the patient
- Consider age-specific delivery
- Flag key pieces of information for onward dissemination—no multipage reports to wade through
- Individualize process per patient—congenital conditions can start out as simple, but as the patient ages, they can become complex, so a long-term care plan (LTCP) is required.
- Define who is responsible for health surveillance, FP or specialist—break down complex issues into understandable components for ongoing monitoring

Challenge of Continuity of Specialist Care

Using the case study of a 19 year old youth with Duchenne muscular dystrophy (DMD) in

assisted living outside the Metro Vancouver area, **Lynn Straatman** outlined problems arising from the transition between pediatric and adult care.

At age 18, the patient transitioned from the single appointment DMD clinic at BCCH, to combined UBC and VGH appointments in a number of specialty clinics.

- Loss of financial support for travel to and accommodation in Vancouver
- Multiclinic visits require different appointments, with travel between institutions
- Lack of attachment to local FP for primary care

The patient dropped out of regular care and has since developed congestive heart failure. Ongoing monitoring is problematic even though a local cardiology clinic has been found and the FP is happy to oversee care.

Real world solutions require:

- Local medical caregivers and attachment to FP
- LTCPs that are condition specific and precise, given to patient, FP, and specialist
- LTCPs individualized to the patient and social environment
- Relationships between all caregivers, defining roles of providers for ongoing care and monitoring
- Defined responsibilities for sexual health and genetic counselling
- Established guidelines for care

Continuity of Care—Transitioning in the Community

Stella Cockett gave an overview of how a mobile cardiology team, comprising a nurse clinician, pediatric cardiologist, and pediatric echo technician, manages care for over 700 children in remote communities around the province. Their patient population is made up predominantly of open heart surgery cases.

The challenge in remote communities is that on transition, discharge to the care of an FP is difficult as the number of these clinicians is low.

Follow-up care is very efficient up until age 19. When youth enter into the adult system, many are lost to follow-up. This is especially true in cases of financial hardship, compounded by poor education, as patients cannot afford to travel to adult services and do not access funding.

Mitchell Fagan commented on the lack of FPs, advising a rethink of the solo practitioner and instead working as a team as the best way forward. In this way, patient-centred care plans could be formulated in collaboration with local providers, leading to better management. Teamwork would spread the management load and aid the timely flow of information between specialist and FP.

Brian Sinclair summarized the main points:

- Use basic principles to build patient-centred care plans, but realize the limitations of the surrounding medical system
- Check in with patients and families for their understanding of LTCP
- Reality check—re-evaluate changes regularly

Audience feedback:

- Change the system from disease-focused to a patient-centred care model—what works in the acute care model does not work for chronic care in the community
- Individualize the care plan and empower the patient
- Consider using technology, e.g., smartphone apps, teleconferencing—and deal with perceived privacy issues
- Team approach is good, but how does this work with more specialized care?

Will it fit in with broad health and wellness provision?

- Involve relevant adult care providers as early as possible in the transition process and care conferences
- Change needed for fee reimbursement schedules
- Access other support, e.g. Shriners for transport assistance

Strategies for Youth & Family Engagement – Youth Presentation

Leah Horlick, Youth Engagement Facilitator/Youth Voice Project—ON TRAC

Lewis Lai, Youth Advisory Council (YAC) member

Leah Horlick noted that only 50% of youth with CHC attend their first adult care visit.

To improve engagement and encourage youth to take ownership, she suggests:

- Shift access—empower youth with information to manage their own transitions
- Recognize youth as leaders
- Cater to youth daily routines—avoid school times and early morning appointments
- Accessibility = inclusivity; respect privacy
- Use technology—conference calls, texting, www.drugcocktail.ca for drug interaction information
- Acknowledge input—recognise volunteer activities and reimburse transit costs
- Awareness of mental health issues

Horlick described regular monthly ON TRAC YAC meetings, where participants gave feedback on initiatives in a safe social space. From input, the Youth Advisory Council has put together a website and handbook about drug interactions. This includes street drugs and hormonal birth control. The website has a parent mode, which switches the screen quickly to the Google

homepage to preserve user privacy. The team has also developed a youth-focused iPad questionnaire on health monitoring.

Peer-led transition readiness workshops have taken place, most recently with Hearts of Gold at Vancouver Aquarium:

- Preparation for the transition process and the transition clinical pathway
- Peer support for the transition process into the adult system
- Peer mentoring
- Feedback from youth in transition on their fears/concepts of going into the adult system

Horlick hopes that provincial YACs will develop outside Vancouver, and spread the word on empowering youth to manage their own transitions with confidence.

Lewis Lai, a YAC member, described a new initiative—the Just Trac It program—that encourages youth to make use of existing smartphone apps to gain control of their own medical care.

Using specific prompts, users are guided to enter caregiver contact details into the Contacts app, and make notes on their CHC in the Notes app. This way, youth can access all necessary information at the time of medical appointments, increasing their participation in care decisions, and increasing confidence in their own abilities to manage. The information-gathering activities are freely available and no special app purchases are necessary.

The Just Trac It initiative was presented at a recent CAPHC Dragon's Den workshop. YACs also use social media—the @ontracyouth Twitter account regularly tweets out relevant information to followers.

Regional Approaches to Provision of Community & Adult Services

Sandy Whitehouse, *Pediatrician and Medical Lead on the ON TRAC projects*

Georgia Bekiou, *Director of Integrated Primary and Community Care, FHA*

Dean Brown, *Chair of the NS Division of Family Practice*

Mitchell Fagan, *Langley FP and Family Physician Content Expert with Care Youth Transitions*

Annette McCall, *family practitioner*

Jacqueline Purtzki, *pediatrician at GF Strong*

Elizabeth Watt, *Abbotsford Youth Health Centre—Lead Physician and co-chair*

John Wu, *Director of Clinical Hematology, BCCH*

Georgia Bekiou discussed strengthening attachment with the primary caregiver, the FP, as being a cornerstone for successful transition. Although regional approaches are required, the situation revolves around the individual needs of the patient transferring back to the community. Even though there is variation in needs for the type of specialist, home support, etc. required, all patients must have access to primary care designed around the FP.

Work is needed to deliver services in a collaborative and integrative model within community services.

Strengthening the relationship with the primary caregiver should be initiated from early stages in the pediatric care system rather than waiting for the traditional transition phase. The medical home should be established with the FP.

At a regional level, possibilities for managing transition include specialized clinics, nurse practitioner clinics, pooled FP service, and fully distributed/solo practitioner models.

Jacqueline Purtzki, who works in the young adult transition clinic of GF Strong, described her typical case load as comprising neuromuscular skeletal conditions such as DMD, spina bifida, and cerebral palsy. Carers work as an interdisciplinary team to manage their pediatric patients, and try to identify

regional adult specialists for transition cases to support the primary FP.

Elizabeth Watt, working in primary care for 12–24 year old youth, described the transition phase in terms of the loss of provincial funding support, among other factors. Patients must be empowered to take charge in adult care.

A community collaborative project in Abbotsford has built a network of awareness and access, housing multiple disciplines under one roof.

The admission process to the unit is as follows:

1. Intake McCreary-style questionnaire
2. Youth advocate triage to identify service(s) required at visit
3. Anonymity maintained at front desk, where patients can point to a chart to request services
4. Youth advocate helps with forms, resources, access issues, etc.
5. Coordination and reminder system for clients
6. Referral to support organizations as required
7. Advocacy through Abbotsford Community Services for disability funding, etc.
8. Contact maintained via Twitter, e-mails, dedicated phone line

In summary, the centre offers youth-specific service provision and has community service providers on side.

Dean Brown described the provincial initiative for Family Practice Divisions as a way to collaborate together on issues surrounding transition.

Using this approach, it is possible to identify and address a high-needs population and form a high-needs clinic, with a multidisciplinary team for unattached patients.

Complexity scores that address **Attachment, Medical, Psychiatric/Psychological, and Social** needs (AMPS) are used to assess needs and indicate complexity.

Employing a hockey metaphor to describe how this approach would work, Brown likened the FP to the goalie—currently the only player on the ice—when in reality, to manage transition it takes a whole team. Primary care needs to have the whole team on the ice.

“We need to stop playing in silos and play as a team.”

Mitchell Fagan repeated support for developing a team approach for managing transition, saying that this is the best way to cope with complex cases. He described an alternative practice plan in development in Langley, where the community takes ownership of care.

Developing a care plan around a patient needs a cross-disciplinary approach and a team is needed to treat the patient as a whole person.

John Wu described close teamwork in his field of speciality, hematology, in management of transition for youth into the adult system, commenting that this was transferring from single team to single team. Close work with adult services aided transitions.

He also offered an insight to how centralization can also streamline service provision, save money, and fund other service provision within a specialty, citing unified storage and distribution of clotting factors as a success story.

Annette McCall advised using the best from the past with current good practice to develop for a future medical home supporting care during transition.

Table Discussion and Floor Feedback

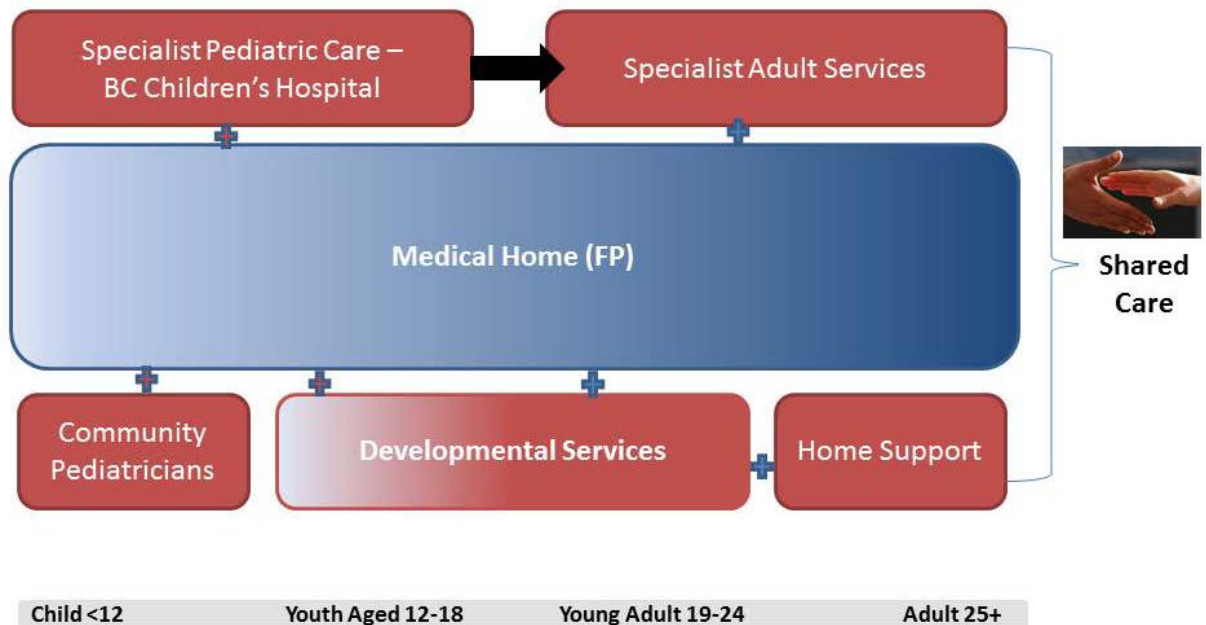
Q1: From what you have just heard, and in the context of youth-responsive care, what are the most important and/or relevant elements in these approaches to care?

Q2: What are the practical actions that could be considered feasible to implement these in the near future?

- Responses must be multidisciplinary, well-funded and youth-friendly, with community collaboration
- Require other agencies to recognize transition
- Medical home development is necessary
- Develop classification and recognition of complex needs
- Use IT to support care, either peer-to-peer or for medical personnel

- Family-centred care should not end at pediatrics
- Encourage youth to take control
- Share information among professionals
- Recognize strengths and weaknesses inherent in the system
- Teamwork and multidisciplinary approach
- Coordinator for transition as an active member of the team, to give knowledge of resources and ensure access
- Provide age- and stage-specific appropriate care plans
- Funding adequacy
- Use AMPS assessment as tool
- Concern over funding and fees to practitioner
- Appropriate use of technology to communicate with specialists and patients alike
- Use specific youth-appropriate methodology
- Recognize that the impact of CHC

**To...
Coordinated, Seamless Youth Transitions & Young Adult Service Support 'Networks'**



- during youth is profound in terms of years lost/cost of health care analyses
- Empower youth by focus on family or patient advocate during transition process—for booking appointments and accessing information
 - Team approach to managing transition
 - Continuity of care “cradle to grave” approach requires strong attachment to primary caregiver
 - Establish a youth-led practice support module
 - Provide peer mentoring for youth in transition
 - Identify youth needs so patients can be directed to the correct support on the team
 - Investigate unique funding models for multidisciplinary integration of services, and establish who controls the finances
 - Teamwork essential for strength and identifying resources
 - Break the silos and let information flow

In summary:

1. Use technology wisely for education.
2. Adopt a patient-centred, youth-empowered approach.
3. Ensure a flow of information, integration of services and team collaboration.

Supports to Enable Development of Transition Service Delivery Throughout the Province

Dewey Evans, BCMA ON TRAC Evaluator/Shared Care Project Manager

Dean Brown, Chair of the NS Division of Family Practice

Dan Horvat, family physician

Garey Mazowita, Clinical Professor—Faculty of Medicine, UBC

Garey Mazowita summarized the key issues presenting:

- Need for cultural change

- Move from acute care leadership silo into programs
- Recognition that transition issues are difficult when patients move between programs
- Patient voice needs to be heard in decision-making—listen to youth

When generalism is compared with speciality, research already shows that origin- or disease-focused care models perform badly with multiple providers of care.

The medical home idea is gaining ground.

Dan Horvat emphasized the multidisciplinary approach for managing primary care and to support individual needs in complex cases.

Shared care with other health care providers is necessary, especially combining specialty with home care environments.

- Establish roles and responsibilities
- Ensure mutual respect among care providers, as this improves patient confidence

Dean Brown further explored ways to increase communication.

- Divisions of Family Practice can break down silos, bringing people working closer together and increasing effectiveness of service provision. This is an effective provincial initiative.
- Funding requires a rethink—lateral thinking is a must.
- Attachment initiatives, with funding across communities in BC, could break down silos at the community level.
- Technology must be exploited, but systems must be able to talk with each other.
- Build concrete care plans around the FP, assigning responsibility for tasks to FP, specialist, and patient.

Supports & Mechanisms to Move Forward in BC

Maureen O'Donnell, Executive Director of Child Health BC

Noting that sharing care with FPs when children are young is currently very poor, **Maureen O'Donnell** brought the workshop towards its final phase.

Her observation that Canada's approach to pediatric care differed from the US pediatrician-centric model interrupted the information flow from pediatrician to FP.

During the final workshop of the day—determining the next actionable steps in moving transition policy in BC forward—the audience was encouraged to develop working ideas around the day's overarching themes:

Theme 1: Youth empowerment

- Youth-friendly care

Theme 2: Inter/multidisciplinary service

- Structure—role of divisions and communities
- Processes to enhance—inter-disciplinary collaboration; coordination
- Enablers and considerations—geographical or population

Theme 3: Policies

- Silos
- Funding
- Background education
- Culture

Theme 4: Critical enablers

- Measures and indicators
- IT

Table Feedback & Discussion

Theme 1

- Recognize youth-specific attachment issues: youth with CHC may be more vulnerable and have a need to attach to their physicians; pay attention to caregiver burnout
- Recognize that attachment should be to the medical home, but the medical home must be responsive to this and competent in a youth-friendly manner
- Need to support change in culture at BCCH
- Ensure access to multiple points in youth and youth-specific hours and services
- Consider youth-only provision of services?
- Youth-friendly grouped medical visits, to access life skill development classes
- Examine at what age youth are capable of making independent health care decisions, realizing that individual variation is probable
- Tap into local youth resources to build locality-specific resource
- Ask parent to leave the exam room for some time during appointment to foster self-confidence in youth
- Make youth more and more responsible for appointment planning
- Ask youth to bring meds in by self each visit
- Allow youth to bring a friend or own supporter to appointments
- Encourage youth to assess own readiness for transition

Theme 2

- Explore the medical home concept more within divisions of family practice
- Involve public health as patient moves through the continuum of care
- Ensure FP attachment and engagement; encourage patient participation

- Improve access to information and resources at BCCH when developing care plans
- Share long-term care goals
- Develop multidisciplinary clinics and build a business case for running this practice model
- Explore alternative funding structures, ones that are not per patient
- Develop more affordable space for FPs, e.g. mall space
- Consider equipment needs for managing/examining complex cases
- Establish a database to define what a complex case is
- Develop medical home idea more—is it physical or virtual—through a pilot project that would build up expertise to aid others
- Ensure attachment to FP by age 13–14 — generate a list of local FPs willing to take on complex cases
- Encourage geographically-based specialists for outside urban area
- Use workshops to deliver education
- Start transition planning earlier
- Encourage lateral communications instead of just vertical responses
- Deliver clear instructions from specialist back to FP and try to alternate care visits

Theme 3

- Develop fee codes for transition planning in pediatrician billing
- Change fee codes to allow pediatric care to continue beyond age 20

Theme 4

- Ensure access to information by patients and professionals, for support
- Update policies re: use of IT
- Measure all alternate systems used to deliver services



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