

Developing a
Transition Initiative for
youth and young adults with
chronic health conditions and/or special needs
in B.C.

ON TRAC Part 1

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Acknowledgements

This document addresses the issues in providing quality, comprehensive and continuous care for youth and young adults living with a chronic health condition. It reflects a belief that collaborating and sharing with others is essential to removing barriers and creating vision. We would like to acknowledge and thank the work of the many people and programs who have contributed to the development of this Service model.

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Executive Summary

In British Columbia, each year, approximately 1,700 youth with chronic diseases reach 17 years of age and are discharged into the adult care system. This process occurs in an ad hoc manner, is often poorly coordinated, and threatens continuity of care. Poor transition planning has been shown to have significant negative consequences, including deterioration in health status as well as increased morbidity and mortality. There is an urgent need for an organized, coordinated, and developmentally appropriate transition plan for every adolescent and young adult in British Columbia who lives with a chronic health condition. This document outlines plans for a provincial program called ON TRAC2, which has been designed to support the transition of youth with chronic conditions from pediatric to adult care. ON TRAC2 will enable the provision of developmentally appropriate care and continuity of care for every adolescent in British Columbia with a chronic health condition by providing organized, coordinated, and developmentally appropriate transition planning.

In response to problems identified worldwide with existing ad hoc transition practices between pediatric and adult care, a number of position papers have been published with guidelines for best practice. The overarching message is that care should be continuous, comprehensive, and coordinated as well as flexible and individualized. Transition is a process that occurs over time, beginning in early adolescence with gradually increasing personal responsibility. Best practice recommendations include a focus on developmentally appropriate care that will enhance autonomy and self-reliance, and addresses common concerns of adolescents such as sexuality, mood, mental health and the impact of chronic health issues on lifestyle and relationships.. There should be a written health care transition plan by age 14, and a skilled health care professional to take responsibility for facilitating transition. Transfer and follow up require formal systems in place that ensure accessibility and transfer of information, including a portable and accessible up-to-date medical summary. Finally, young adults should receive youth friendly, developmentally and culturally appropriate expert care in adult facilities.

Although a pioneering transition clinical pathway was developed at BCCH in 2000, this work was undertaken with project funding which ended before the project was fully implemented. The ON TRAC model laid the groundwork for much subsequent work in the field globally. This document builds the case for ON TRAC2, a comprehensive transition program, based on guidelines of best practice and supported by an extensive review of the literature.

Transition programs can be loosely grouped into three categories: programs which are disease-focused, programs which focus on primary care, and programs that target adolescent health services. Models of care need to consider the political, institutional and environmental factors relating to health care provision. ON TRAC2 focuses on integration of developmentally appropriate care into all health care settings and can

be incorporated into other models of care. It is based on the premise that youth and young adults need to develop skills and knowledge to utilize the adult health care system effectively, and may need assistance with adapting to the adult health care setting. ON TRAC2 transition program is particularly suited to British Columbia, where pediatric care is provided centrally, and patients transfer to a variety of health care settings, including remote regions. In this model a regional transition coordinator is available to facilitate access to services and oversees the transfer process.

ON TRAC2 incorporates best practices and strategies outlined in a number of transition models while considering the complex jurisdictional health care environment in British Columbia. The ON TRAC2 program reflects PHSA's strategic direction, incorporating the concept that clinical pathways support integrated care for patient groups with common co-morbidities. Whereas clinical pathways have traditionally focused on disease/illness treatment plans, they can be expanded to be patient-focused, long-term and applicable across health care jurisdictions reducing fragmentation during a time of transfer.

Section 1 of this document provides an overview of the history of transition planning, locating the groundbreaking ON TRAC program within that history. Section 2 reviews the current best practice standards and considerations for providing developmentally appropriate care to adolescents and young adults with chronic illness. Section 3 contains an in depth review of literature concerned with transition services, which serves as the evidence base for development of ON TRAC2. The design of ON TRAC2 is outlined in Section 4. On TRAC2 will integrate complex transition requirements through a clinical pathway embedded in the clinical care setting.

ON TRAC2 will improve efficiencies by decreasing Emergency visits, maintaining overall health status in young people with chronic illness, maintaining continuity of care, and streamlining care so that the best care is provided in the right place. Programmatic success will require resources: to provide an infrastructure framework, enhance clinical care through multidisciplinary education for health care providers, support transition coordination, integrate data collection and research to evaluate outcomes, and to facilitate the transfer of medical information.

While all levels of care practitioners and policies makers have accepted the definition, goals and objectives of transition, there are few evidence-based evaluations of specific interventions and no evaluated model or processes to ensure healthy outcomes for youth. This paucity of evidence has arisen in part because the transition from pediatric to adult care often involves multiple jurisdictions, each with their own data collection systems, which more often than not are incompatible. Hence, ON TRAC2 will include an evaluation plan, which includes a strategy for the development and collection of data resources as required to evaluate interventions.

Benefits of developing such a service will include improved health outcomes for youth/young adults with specific chronic health conditions in BC through identification of specific health outcome measures for sub-specialty populations, improved identification of youth/young adults in 'active phases' of transition or those facing

'difficulty' in transitioning, improved understanding of youth/young adults' use of hospital and community services resulting in identification of gaps in health services for youth and young adults, reduction in duplication of services and reduction in overage patients at BCCH (post 17 years). Engagement and education of health professionals, including family physicians, will increase clinical capacity and knowledge of providers. The use of virtual tools for learning and skill building will improve patient provider communication and facilitate the provision of clinical care. Overall implementation of ON TRAC2 will result in a reduction in post transition morbidity and mortality and reduction in proportion of 'orphaned' patients in transferring to adult care.

ON TRAC2 will reach beyond BCCH, throughout PHSA and neighboring Vancouver Coastal Health into rural practices. A core ON TRAC2 team will enable collaborative, strategic systematic engagement in regional and provincial planning that includes adult agencies and community providers. This proposal has received strong support from diverse stakeholders including Child Health BC, British Columbia Medical Association, B.C. Children's Hospital, Department of Medicine UBC, Vancouver Coastal Health Authority, and Ministry of Children and Families.

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Table of Contents

Introduction	9
Guiding Principles	11
Definition of Terms	12
Supporting Statements	15
Section 1: Health Determinants of Youth and Young Adults with Chronic Conditions in BC	
1.1 Defining the demographics of youth and young adults with chronic health conditions	17
1.2 Current health care statements impacting the care of youth and young adults.....	19
1.3 Developmental issues for youth and young adults with chronic conditions.....	22
1.4 Emerging adulthood 18-24 years.....	27
1.5 Youth in care.....	28
1.6 Youth with special developmental and cognitive needs.....	29
Section 2: Transitional Care – What does it mean for the youth in BC?	
2.1 Defining Transition – What is it?.....	30
2.2 Global position statements and recommendations for transitional care.....	32
2.3 Barriers to comprehensive transitional care in B.C.....	36
2.4 Key components for effective transitional care.....	41
2.5 Understanding roles in the transition process.....	45
2.6 The economics, access and transfer of health care information.....	49
2.7 Current transitional models of care.....	51
Section 3: A Framework for Transitional Care of Youth & Young Adults in BC	
3.1 Developmentally-appropriate guidelines for youth ages 10-24 years of age.....	55
3.2 Transition documentation and health care records.....	58
3.3 A Clinical Pathway for self-management, transfer and continuity of care.....	64
3.4 Transition research questions and evaluation methodologies.....	68
Section 4: ON TRAC2 Plan – ON TRAC2 Action Plan – System Requirements to Support a Transition Service in BC	
4.1 Proposing a Transition Service for BC.....	71
4.2 Building partnerships and capacity with local and global partners.....	74
4.3 Professional education and training.....	77
4.4 Research and evaluation.....	78
4.5 Resource considerations.....	80
Reference List	82

Appendices

Appendix A - Condition-specific Position Statements and Recommendations for Transitional Care.....	101
Appendix B - Developmentally-appropriate Transition Framework.....	103
Appendix C - Inventory of global programs, tools and strategies.....	105
Appendix D - Condition-specific Clinical Research Summary.....	113

Introduction

Many children with chronic health conditions cared for at British Columbia Children's Hospital lack a coordinated and developmentally appropriate transition process between pediatric and adult health services – this creates a substantial threat to their health status resulting in increased morbidity and even increased mortality (Prestidge, Romann, Djurdjev & Matsuda-Abedini, In Press). Improved medical technology and improved pediatric care has increased the survival of children with serious chronic medical conditions so that today over 98% will require transfer to adult care providers. Of the approximately 24,000 youth over 10 years of age seen at sub-specialty clinics at BC's Children's Hospital, approximately 1700 are transferred out into the adult world annually (Health Record Statistics, 2010). Currently, no comprehensive or continuous plan of care exists, leaving youth and families to navigate a fragmented care system on their own. There is an urgent need for an organized, coordinated, and developmentally appropriate transition plan for every adolescent in British Columbia who lives with a chronic health condition.

B.C.'s Children's Hospitals 2009 Strategic Action Plan sets forth “a call for transformation” that includes a focus on health as well as disease, improved service delivery and outcomes for patients and families through system-wide improvements, and province-wide partnerships. The Ministry of Health for BC and the Provincial Health Services Authority also recognizes the need to provide “innovative health care delivery systems and create health care pathways that extend beyond the point of discharge.”

ON TRAC2 (Taking Responsibility for Adolescent Care) was developed through extensive collaboration and consultation as a multi-faceted model in response to the needs of health care providers, policy makers and youth with chronic conditions and their families who experience the transition from pediatrics into the adult health care system. This model of care builds on the ON TRAC model first initiated in 1995 that has been accepted and implemented into pediatric health care practices worldwide (UK Royal College of Nursing; Sick Kids Toronto; UK Department of Health). Youth and their families will have the support and access to care they require to maintain their health and utilize services appropriately through continued integration of developmentally-appropriate care in pediatrics as well as young adult services, combined with documentation, care pathways, and educational, clinical, and online support. Evaluation of the services provided, and outcomes will be measured through integrated data collection embedded into the ON TRAC2 program.

ON TRAC2 responds to hospital and health authorities' need for a system-wide provincial program by focusing on developmentally-appropriate care, transfer of care, and continuity of care from pediatrics through adolescence and into young adulthood. ON TRAC2 recognizes that transition is a health care determinant that involves interaction, communication, and care on a provincial scale, crossing health jurisdictions and authorities. ON TRAC2 offers evidenced-based recommendations and practical

application of strategies and services to facilitate a coordinated and continuous plan of care for youth with chronic health conditions in BC. By collaborating with adult, community, and medical health authorities, a streamlined approach to transitional care in B.C. can be realized.

This document begins with an overview of principles which serve as the foundation for development of the ON TRAC2 program. Terms used throughout the document are defined, and are followed by statements from a few of ON TRAC2's many supporters. The bulk of the document contains a summary of research based evidence which has informed development of the ON TRAC2 program. The document's first section outlines the scope of the problem. It provides an overview of the health issues youth with chronic diseases face, outlines challenges associated with poor transitions, and outlines the prevalence of the problem in British Columbia. Section 1 also includes an overview of policy recommendations related to care of youth with chronic diseases, and recommendations from varied stakeholders about how to better meet this population's transition needs.

Section 2 defines transition, and provides an overview of what transition means for BC youth. Section 3 outlines a framework for transitional care of youth & young adults in BC. Finally, Section 4 offers an action plan outlining steps to be taken to bring ON TRAC2 to fruition.

Guiding Principles

The guidelines outlined in ON TRAC2 are based on the following principles:

- The transfer across health care jurisdictions is a time of increased clinical risk which requires particular attention to the passage of up to date, current health and clinical information to adult care providers and to youth/ young adult themselves.
- The youth, young adults, families and health care team members form a unique partnership that requires support and resources throughout the transition process.
- The planning and development of culturally-sensitive, youth-focused, family-centered, developmentally-appropriate care requires active participation of the youth, family and pediatric, adult, and community health care team members.
- A formal system provides the framework for transition care in various clinical settings to ensure developmentally-appropriate care through adolescence and ensure continuous care into the adult health care system and adulthood.
- A transition framework needs to be flexible to allow for differences in each young person's development, cognitive abilities, and the trajectory of his/her illness- beginning during early adolescence with gradual increase in personal responsibility.
- Transition planning is grounded in the evidence based principles of building autonomy, resiliency, self-management and competence while maintaining connectedness.
- Successful transition planning cannot occur without supporting linkages with other youth and adult programs, agencies and community services.
- A shift in the current health care practices from disease treatment to health promotion and health maintenance is required to facilitate empowerment of youth and families for ongoing health and lifestyle management.
- Successful transition requires a pathway that documents the process, ensuring standards of care, and coordination to support movement into the adult system and data collection for evaluation.
- To insure long term program sustainability, ON TRAC2 must incorporate data collection processes which can support evaluation of program interventions, satisfaction of all involved stakeholders and long-term health outcomes for youth with ongoing health care needs.

- Improved service delivery for youth and young adults with chronic health conditions necessitates system-wide improvements and provincial partnerships to affect health care delivery and health outcomes.

Definition of Terms

Ability

The skills and knowledge to do and to be.

Chronic Health Condition

Chronic health conditions include illnesses, conditions and/or disabilities that affects youth, impacting their health and development over an extended period of time.

Connectedness

The promotion of healthy development in youth is strongly linked to family connectedness. Youth require caring adults in their lives that promote independence, build capacity in the youth leading to self-esteem and skills needed to overcome obstacles and thrive in adult life. Youth who feel connected at home, school and in the community have fewer risk-taking behaviors and experience better health.

Continuity of Care

Continuity of care implies that clinical care is not interrupted during transition, transfer or handover from one practitioner to another, or one health care jurisdiction to another. Continuity of care includes the passage and accessibility of all the relevant patient information between health care providers and health care jurisdictions.

Developmentally-Appropriate Care

Improving health outcomes for young people requires that health professionals have an understanding of adolescent development and broaden their medical perspective to incorporate the developmental perspective. Satisfactory progress through developmental tasks contributes to the adolescent's self-confidence and self-worth

Emerging Adulthood

A newly recognized stage in later adolescents into young adulthood, from 18-24 years of age, distinctly different from both adolescence and adulthood behaviorally, demographically and subjectively. Although they feel they should make their own decisions, "emerging adults" may not yet feel committed to adult standards of behavior and an adult level of responsibility.

Family

Family is defined by the youth as his/her support system. In most cases it is a blood relation. Family may also include caregivers and guardians.

Family-Centered Care

Family-centered care is a philosophical approach that respects and supports the central role that families play in their youth's life. It is care marked by respect,

information sharing, collaboration, confidence building and family to family support (BCCH Partners in Care, 1997).

Health

A condition of body and mind.

Medical Home

The concept of a 'medical home' has been hailed as an effective model for implementing successful transitions for youth with complex chronic conditions. A medical home identifies primary care physicians as responsible for addressing the needs of children, youth and young adults with special care needs by ensuring continuity, coordinated, comprehensive care and access to community services.

Patient Navigator

A patient navigator is an individual who assists the patient through and around barriers in the complex care system to help ensure timely diagnosis and treatment and reduce or remove barriers to quality care.

Resiliency

Resilience is a capacity to overcome or recover when faced with an insult or threat. It is thought to be associated with personal characteristics such as strong social skills, higher intelligence and higher self-esteem. Resiliency is also associated with active social engagement, such as being connected to peers, family and the community. Having meaningful peer relationships also builds resiliency in youth.

Self-management

Self-management is the patient's ability to manage a chronic health condition through problem-solving, decision-making, resource utilization, the formation of patient-provider partnership, action planning, and self-tailoring. Self-management can be supported by knowledge-based education, psychological treatment, and technical skill building.

Shared Care

Shared care combines the skills and knowledge of a range of health professionals who share joint responsibility to manage an individual's condition. It also includes monitoring and exchanging patient data and sharing skills and knowledge between disciplines. The goals of shared care are to improve quality of patient care for those with complex chronic diseases measured by access, satisfaction, appropriateness, competence, continuity/coordination, effectiveness, efficiency, and safety.

Transition

Transition is defined as the purposeful, planned movement of adolescents with chronic health conditions from child-centered to adult-oriented health care. It addresses the developmental issues of adolescence while ensuring care is continuous, comprehensive, and coordinated into adulthood and the adult system.

Youth

Youth is defined as that period of life between childhood and the world of work, independence, and adulthood.

Youth-Friendly Care

Youth-friendly care focuses on the youth's interests and needs. It ensures that all teaching, guidance and care is provided in an environment that is developmentally, physically and emotionally comfortable for the youth.

Supportive Statements

Material presented in this document has been developed through a collaborative and consultative process. Below are some statements of support from a few collaborators and stakeholders we have interacted with in developing ON TRAC2.

“ I think your proposed collaborative youth transition project can complement, enrich and expand the recently initiated youth transition protocol by nine government organizations – Cross Ministry Transitional Planning Protocol for Youth with Special Needs – as your project focuses on some of the most vulnerable youth in the province, it will strengthen our ability to accomplish our mutual goal: a youth transition process that will be experienced as seamless by all youth with special needs and their families”.

Frank van Zandwijk
Director, Strategic Initiatives
Integrated Policy and Legislation
Ministry of Children and family Development

“I am writing to strongly support the proposal on transitional health of children from BCCH to the adult health care system. Urology is uniquely positioned by having strong services both at Children’s Hospital and the Gordon & Leslie Diamond Health Care Centre at Vancouver General Hospital. We do currently care for many of these young people as they transition to adulthood ... This tends to be on an ad-hoc basis and not as part of a comprehensive care package. A formalized program set up here at the ambulatory building would enable young adults to access different specialties on one clinical site. The Department of Urologic Sciences also has a strong interest in research and would be excited to collaborate with you and others in a group to study outcomes and the health economics of centralized care.”

Dr. Larry Goldenberg
Professor and Head, Department of Urologic Sciences
UBC Faculty of Medicine

“Vancouver Coastal Health supportstransitional services for patients/ clients from BC Children’s Hospital...We are aware that these individuals have many inter-related and complex medical and psychological and social conditions. We see the Gordon & Leslie Diamond Centre of VGH, an ideal site, with its proximity of highly specialized and experienced services as ideal to provide the comprehensive continuity of care that these individuals require”.

Dr. David N. Ostrow
President & Chief Executive Officer
Vancouver Coastal Health

“We are pleased to offer our enthusiastic support ... as you are seeking unique partners (researchers, clinicians, policy makers/leaders from BC Children’s, adult medicine at UBC and VGH, and the Ministry of Children and Family Development and primary care

from all health authorities) to come together to rethink, plan and test how we can provide excellent care to BC's young adults transitioning from pediatric care to adult services. This is a topic area of great interest to our network and the process you have outlined, and which we have been creating, is what we believe is required for success. For these reasons, we wish to endorse and support your ideas; however, in addition, we are pleased to formally partner with you through participation in and sponsorship of a transition workshop, for which we will provide funding as well as in kind resources."

Dr. Maureen O'Donnell
Executive Director
Child Health BC

"I would like to offer my support to the Division of Adolescent Medicine at BC's Children's Hospital to develop, implement and evaluate a comprehensive Transition Service for youth (ages 10-17 years) at BCCH and who will require ongoing medical and health services into adulthood (18-24 years)... This program will fill a gap and address developmental issues for these populations by creating a system-wide provincial program which focuses on both developmentally-appropriate care and continuity of care. I would like to offer my support ...in an advisory capacity."

Dr. Wilma Arruda
Chair, Advocacy Committee
BC Pediatric Society

"The BC Children's Hospital Partners in Care Family Advisory (BCCH PiC) recognizes the need for Youth involvement at the hospital and is therefore working in Partnership with the Youth Health program to establish a Partners in Care Youth Advisory Committee. The BCCH PiC recognizes that transition from youth care to adult care is not a smooth process and through the creation of a YAC and by supporting this comprehensive transition program as discussed above we hope to benefit all youth and their families across the province. As the Partners in Care Family Liaison I am happy to provide my support for the project."

Susan Greig (Parent)
Partners in Care Family Liaison
BC Children's Hospital

Section I

Health Determinants for Youth and Young Adults with Chronic Conditions in BC

1.1 Defining the Demographics of Youth and Young Adults with Chronic Conditions

In Canada, up to 20% of children and youth and their families are affected by chronic disease or health condition (Leitch, 2007). Of these, 6% are youth 12-19 years of age and 11% are young adults between 20-39 years (Broemling, Watson & Prebtani, 2008). It is reported that nearly half a million children in Canada live with either a long-term chronic illness, or a mental illness. Almost 8% of these children experience limitations because of their condition, and nearly half of these children have conditions that are considered to be severe (Canadian Institute of Child Health, 2000). For this population of children, the prevalence of educational and psychological problems is nearly double in comparison with the general population (Martinez & Ercikan, 2009). They need both the regular physical and emotional support of their parents or caregivers, and the support and care of the health care system (Canadian Pediatric Society, 2006).

In the developed world, 1% of all newborn babies have a congenital heart disease. Forty years ago 70% of these children would have died before their tenth birthday. Today, due to early diagnosis, intervention and pediatric care, it is estimated over 98% of children with a chronic health condition will live to 20 years and beyond (Sommerville, 1998; CICH, 2000). Young adults living with cerebral palsy and spina bifida have an increased life expectancy (Stevenson, Pharoah & Stevenson, 1997; Hunt & Poulton, 1995) and 53% of young men with muscular dystrophy are living beyond 25 years of age (Eagle, Baudouin, Chandler et al., 2002). In addition to a changing age range of pediatric populations, there is a significant increase in diagnosis of chronic health conditions during adolescence including diabetes and cancer (Bleyer, 2005; Bloomgarden, 2004).

"It is estimated over 98% of children with a chronic health condition will live to 20 years and beyond" (Sommerville, 2008).

In British Columbia and at BC Children's Hospital, (BCCH), 7% of all teens between 11 and 19 years suffer from a chronic illness such as cerebral palsy, cystic fibrosis, cancer or diabetes. Today, there are more patients in Vancouver's adult cystic fibrosis program, than there are in the pediatric program at BCCH, and the predicted survival age of cystic fibrosis has gone up to 40 years – from a disease that saw almost 100% fatality during childhood 50 years ago (Elborn, Shale & Britton, 2000). A youth with special needs in BC is identified as a young person between the ages of 14-25 years of age who requires significant additional educational, medical, health and social/ environmental support to enhance, improve his/her health, development and quality of

life (Government of British Columbia, 2008). From this definition, it is estimated that 8.3% of the youth population in BC will require some form of transitional planning annually (representing an estimated 4,400 youth).

While B.C. covers a large geographic area, most if not all children requiring specialized health care are seen at BCCH and SunnyHill Health Centre for Children. There are approximately 72,000 patient visits to these sites annually. One third of these visits (27,000) per year are for youth between the ages of 11-25 years who are attending sub-specialty clinics for a chronic health condition. (BCCH, Decision Support Statistics, 2010). In this setting chronic illness is defined as children and youth who have special health care needs for a chronic physical, developmental, behavioral or emotional condition and require health and related services of a type or amount beyond that required by children generally.¹

As most pediatric chronic illness is life long, the numbers of patients seen during the adolescent years continues to increase in most sub-specialty areas,. The highest volume of adolescent patients are in cardiology, dermatology, diabetes, endocrine, ear nose and throat, gastroenterology, neurology, ophthalmology, orthopedic-scoliosis, orthopedic, plastic surgery, renal and urology clinics. Over 1700 youth with chronic and ongoing health care needs age out of care each year at BCCH and are discharged (BCCH, Decision Support Statistics, 2010).

“Over 1700 youth with chronic and ongoing health care needs age of care and are discharged out of BCCH annually. “

An administrative concern at BCCH is the number of overage admissions. BCCH has adopted the policy of providing pediatric care in a child-centred environment to children and youth until the 18th birthday. There were over 300 patients aged 19 years attending the various ambulatory clinics in 2009. These patient numbers do not reflect other overage patients, numbers of visits, nor do they include long-term follow-up clinics or clinics specifically identified as 'adult' clinics.

¹ Chronic patients at BCCH are identified by matching any diagnosis (except type 0 history diagnosis) from the discharge abstract data to a corresponding diagnosis code in the FACCT Algorithm*. The FACCT Algorithm is a list of ICD-9 codes used to find a cohort of children with a higher probability of having a chronic or special health care need according to the survey-based CHSCN screener criteria**. The FACCT Algorithm was developed in the United States, and they have not yet moved to the ICD10 Coding Classification at this time. Once the specific diagnosis codes are matched to the code in the algorithm, the patient is then categorized into a broader Chronic Prescreen Category, e.g. a patient with a chronic diagnosis of a Congenital Ureterocele would then be placed in the Chronic Prescreen Category of Congenital Anomalies except Spina Bifida. Those patients that do not have a matching diagnosis with the algorithm are considered NonChronic.

1.2 Current Health Care Statements impacting the Care of Youth and Young Adults in BC

Publications about 'best practice' standards of care advocate that children and youth receive comprehensive, seamless services that provide access to community services and health care providers. While Canadian and provincial research on *health care services* for children, youth and young adults with chronic health conditions is limited (Miller, Condin, McKellin, Shaw, Klassen & Sheps, 2007), the health care needs of youth with chronic health conditions and disabilities and their required services in British Columbia have been documented in several ministry publications, including:

Reaching for the top: A report by the advisor on healthy children & youth. Ottawa, ON: Health Council of Canada. (Leitch, 2007)

There is a challenge ensuring appropriate care to adolescents, who have what are considered to be 'childhood' conditions, such as cystic fibrosis or spina bifida, when they become adults and no longer have access to pediatric specialists that have the expertise to treat their condition or access to appropriate resources. There needs to be a better process established for the transition of care from youth to adulthood, especially for individuals with specific 'pediatric conditions.' This document suggests the federal government can play a leadership role in this field.

"Chronic childhood illness should be a top priority for receiving government support. These are health issues where we know the potential outcomes and can affect the long-term health of our children." (Health Council of Canada, 2007).

It is recommended that a Transition of Care Strategy and best practices be developed by the Health and Human Resource Strategies Division of Health Canada in collaboration with the Royal College of Physicians and Surgeons, the College of Family Physicians and the College of Nurses. They should be encouraged to develop new fellowship and educational opportunities for undergraduate and post-graduate students in the field of transition of care for these adolescent patients.

BC Ministry of Health, Healthy Living and Sport, and Child and Youth Development

Model Core Program Paper: Healthy Child and Youth Development_Core Functions Steering Committee (2010).

This document provides direction for maintaining and improving child and youth health. A key principle is to support children and youth across the continuum/stages of growth with particular emphasis on key transition points, including continuity with early childhood development and transitions to adulthood. Overall specific objectives of the model are to enhance physical, emotional, intellectual and mental health of children and youth; strengthen connectedness with family, school, peers and the community; increase systematic support for promoting and maintaining healthy environments and healthy development at the school and community levels; and prevent or reduce vulnerabilities, risks and health disparities that represent a threat to healthy development of children and youth. Recommendations are based on evidence for

interventions supporting healthy child and youth development (Saewyc & Stewart, 2008)

Cross Ministry Transitional Planning Protocol for Youth with Special Needs (2009)

This provincial document focuses on youth in care with special needs and will be acted on by the Ministry of Children and Family Development. The recommendations include that youth begin planning for transition by 14 years of age and continue beyond age 19 to ensure that there is a coordinated and supported process during adolescence and into adulthood. This includes providing the youth and family with information on transition planning and the process, assisting them in choosing a transition team, and providing them with information and access to resources. This document also recognizes the need for a transition coordinator to support the process through writing the action plan as well as monitoring and evaluating progress. The protocol includes a summary of BC government services and supports available to support transition planning for youth with special health care needs.

Children and Youth with Special Needs (CYSN) Framework for Action (2008)

This provincial framework for action provides strategies to improve access, quality and coordination of services for children and youth with special needs. The framework provides a foundation for collaborative action among people working in the health, education and social service sectors in B.C. It recognizes the need to simplify and streamline the current array of services so it is easier for families to find information and access services. It also provides an opportunity to build on strengths and the excellent work already taking place in B.C. Some of the key recommendations include:

“Children and youth with special needs and their families require a clear and continuous pathway to services that will meet their individual needs” (Government of British Columbia, 2008).

- Strengthen the integration of services for children and youth with special needs across the health, education and social service sectors;
- Enhance the capacity and expertise of those serving children and youth with special needs and their families through cross-sectoral training and information;
- Use inter-ministry protocols so that services are provided in an accessible, understandable and coordinated manner;
- Use a quality framework and service quality indicators to improve performance and accountability across the health, education and social service sectors;
- Ensure an integrated approach across sectors to information systems and information management;
- Develop mechanisms for sharing and using evidence and best practices;
- Promote evaluation in the planning and development of services;
- Identify and address cross-sectoral program duplications and service gaps;
- Use electronic collaboration and communication tools

Canadian Pediatric Society Position Statement: The care of adolescents with chronic conditions (2006)

- Encourage adolescents to develop the highest level of independence based on a realistic and objective evaluation of their abilities and limitations;
- Encourage adolescent self-expression, discussion of peer relationships, exploration of death and dying and condition specific concerns and problems;
- Explore realistic goals for schooling, vocation and employment opportunities;
- Present questions on sexuality, sexual orientation, sexual activities, and physical and sexual abuse;
- Initiate conversations about transition and transfer of care between the ages of 10 and 12 years of age;
- Involve the adolescent in decision-making regarding treatment or referral;
- Discuss legal regulations and aspects of consent and confidentiality in their province;
- Facilitate involvement in social support groups, networking and community services;
- Act as community advocates for youth with chronic health conditions and their families.

Society for Adolescent Medicine Position Statement: Access to health care for adolescents (1992)

The Society for Adolescent Medicine argues that all youth, with and without chronic conditions, have the right to easily accessible health care. Health care for this population must reflect the unique needs and characteristics of adolescents. Criteria for establishing health care services for youth should include:

- Availability – age appropriate services facilitated by 'adolescent' trained health care providers offered at hours that reflect the behaviors of the target population;
- Visibility – services need to be recognizable by the adolescent, easily accessible and flexible to meet the 'spontaneous' needs of the adolescent population;
- Quality – the provision of developmentally-appropriate care, offering current information and guidance measured by the youth's level of satisfaction;
- Confidentiality – involvement of family to be encouraged where possible unless it will prevent the adolescent from seeking care, confidentiality must be assured;
- Affordability – ensuring youth have health care insurance into adulthood to ensure access to required services;
- Flexibility – services, providers, and agencies must consider the cultural, ethnic and social diversity among adolescents. In addition, understanding the youth's developmental readiness to transition between pediatric and adult health care;
- Coordination – offer access to and comprehensive coordination among community services, mental health, and specialty care services. Assisting youth with the referrals and teaching to encourage them to utilize the services available to them.

Provincial Health Services Authority (PHSA) Strategic Plan 2010-2013

The PHSA strategic plan outlines many care best practices that apply to youth and young adults with chronic health conditions across many sites. For example, the plan highlights the need to:

- Provide seamless patient-centered care for populations within our mandate;

- Implement (CIS) Clinical Information Solutions;
- Increase the application of evidence and leading practices;
- Enhance service delivery to provide safe, reliable, efficient care for patients and families;
- Improve childhood development;
- Promote health in high risk populations;
- Help people living with chronic disease maintain independence and stay as healthy as possible;
- Achieve economies of scale and integration within PHSA and with our partners;
- Optimize the use of our scarce resources and align them with the programs/services that provide best value to the people we serve;
- Leverage our clinical services and research expertise to generate revenue or added value.

BC Children’s Hospital (BCCH) Strategic Plan 2009

The plan sets forth a “call for transformation” that includes a focus on health as well as disease, improved service delivery for patients and families through system-wide improvements, and province-wide partnerships to affect health care delivery and health outcomes. The plan also recognizes the need to provide innovative health care delivery systems and create health care pathways that extend beyond the point of discharge. Key core actions include:

“The (BCCH) plan sets forth a ‘call for transformation’ that includes a focus on health as well as disease, improved service delivery for patients and families through system-wide improvements, and province-wide partnerships” (BCCH Strategic Plan, 2009).

- **Deliver innovative sub-specialized care;**
- Develop, test and evaluate new service delivery models that reflect the tiers of service concept and that consider disease management as well as health and well-being;
- **Work together as a caring team;**
- Use and, as necessary, develop tools to work as an effective, caring team focused on child and family and to ensure seamless transitions to their community;
- **Partner with families;**
- Strengthen our family centred care approaches, particularly as they relate to children and youth with chronic conditions who frequently need health services;
- **Plan provincially;**
- Build strong and active partnerships for planning and delivering children's health services;
- **Collaborate to create novel community-based approaches;**
- With partners from across BC, develop, implement and evaluate fresh community- based approaches to optimize child and youth health.

1.3 Developmental Issues for Youth and Young Adults with Chronic Conditions

Adolescence is a period of change involving extensive biological, cognitive, emotional and social changes. The Canadian Pediatric Society (2003) provides a functional,

rather than chronological definition of adolescence, stating “adolescence begins with the onset of physiologically normal puberty and ends when an adult identity and behaviors are accepted” (p. 577). This concept corresponds chronologically with ages 10 to 18 or 19 years of age, the legal voting and drinking age. Each person, despite their unique personal situation, is confronted with similar developmental tasks. For youth with chronic health conditions, the opportunity and ability to meet their own needs might be significantly altered by their health condition, family environment, health care providers and the availability of services (Blum, 1991; Baker & Coe, 1993; Gravelle, 1997; CPS, 2003). In addition, the strong desire ‘to fit in’ during this time may negatively influence adolescents adherence to medications and treatment plans (Kaplan & Friedman, 1994; Court, 1991, LaGreca, 1990; Rodin, Craven, Littlefield, Murray & Daneman, 1991; Court, 1993; Kyngas, Kroll & Duffy, 2000; Desir & Seidman, 2003; Jackson & Pencharz, 2003; Ullrich, Mattussek, Dressler & Thorn, 2002). It may be unrealistic for parents and health care providers to expect youth to take on responsibility for their own health management because of conflicting adolescent pressures, increased vulnerability, experimentation and inconsistency in behaviours (Sawyer & Bowes, 1999). In addition to their health condition, young people are more at risk to experience depression, emotional distress, self-harm, STD's, social disconnectedness, sexual abuse, substance abuse, and experimentation with alcohol, drugs and smoking (Jackson & Pencharz, 2003; McCreary Centre Society, 2003; Sawyer, Drew, Yeo & Britto, 2007; MCS, 2010). Childhood chronic conditions not only bear physical consequences, but also carry secondary psychological issues and have significant impact on individual quality of life (Shaw & Páez, 2002; Peterson, Rauhen, Brown & Cole, 1994; Chavira, Stein, Bailey & Stein, 2004). Adolescent health risk screening should be incorporated into their health care management (Goldering, J. & Rosen, D. (2004).

Improving health outcomes for young people involves health professionals having an understanding of adolescent development and broadening their medical perspective to incorporate the developmental perspective (Yeo & Sawyer, 2003; David, 2001; Lewis-Gary, 2001; Viner, 2001; Fleming, Carter & Gillibrand, 2002; Madge & Byron, 2002; Callahan, Feinstein Winitzer & Keenan, 2001). Satisfactory progress through these developmental tasks contributes to the adolescent's self-confidence and self-worth (Rosen, 1994). Research in promoting healthy development outlines several protective factors including having caring adults in their lives, engaging in strong youth-adult relationships, learning life skills and preventive strategies and providing opportunities where the youth can develop competencies and participate in decision-making (MCS, 2003).

“Improving health outcomes for young people involves health professionals having an understanding of adolescent development and broadening their medical perspective to incorporate the developmental perspective” (Yeo & Sawyer, 2003).

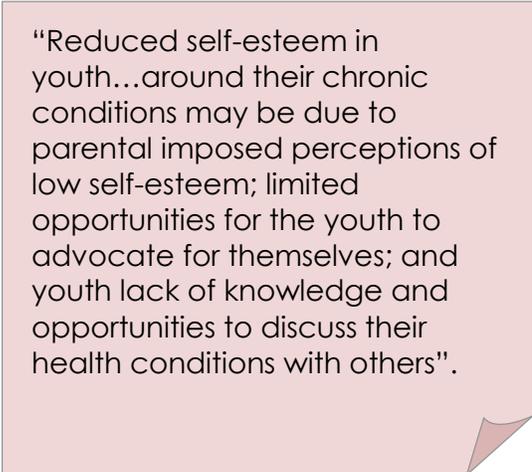
Development of self-esteem and identity

Self-esteem and self-acceptance are important requisites for youth to successfully advocate for themselves and participate in health relationships (Arnold & Chapman,

1992). Youth with chronic illnesses have expressed a negative body image twice as often as peers without (Wolman, Resnick, Harris & Blum, 1994). These findings of poor body image were linked to lower scores in emotional well-being (Lavigne & Faier-Routman, 1992).

Psychological health is closely linked to self-esteem and feelings of self-worth. Youth with chronic conditions show an increased incidence of psychological and social problems – 10-25% more than their peers without chronic conditions. Youth with chronic conditions report a relatively low level of social and emotional supports (MCS, 2003; Pless, Power & Peckman, 1993; Thompson, Hodges & Hamlett, 1990) and higher levels of stress about death, body image, school and the future (Wolman et al, 1994). Research findings shows children and youth with chronic conditions are at a higher risk for developing anxiety-related disorders (Hommel, Chaney, Wagner, White, Hoff & Mullins, 2003; Chavira et al, 2004).

Youth with 'Invisible' health conditions, such as diabetes, demonstrate a higher incidence of psychological problems over those with physical disabilities (Blum, 1995a). Possible causes for reduced self-esteem in youth around their chronic conditions may be due to; parental imposed perceptions of low self-esteem on their youth (Lindstrom & Kohler, 1991); limited opportunities for the youth to advocate for themselves without parental involvement (MacReady, 2002); and youth lack of knowledge and opportunities to discuss their health conditions with others (Rosen, 1995). Significantly impacting self-worth and psychological health may be fear of death depending on the severity of the condition and or number of peers with the condition who die during adolescence (CPS, 2006).



“Reduced self-esteem in youth...around their chronic conditions may be due to parental imposed perceptions of low self-esteem; limited opportunities for the youth to advocate for themselves; and youth lack of knowledge and opportunities to discuss their health conditions with others”.

Movement from parentally-guided to self-managed health care behaviours

Chronic health conditions can have a significant impact on a youth's opportunity to develop independence and function autonomously. Youth with chronic conditions often have high levels of dependency and limited opportunities to practice independence and adult behaviours on their own. Reasons can be related to cognitive restrictions, parental protection, lack of social opportunities, heightened perception of the severity of the health condition and potential for survival into adulthood (Blum 1995a; Rosen 1995; Blum, 1995b). To promote independence, youth need to be able to communicate their health needs to others. Studies have indicated that a limited number of youth are able to describe their health condition and or medications (Hostler, Gressard, Hassler & Linden, 1989). Youth 'cared- for' since the time of birth were less likely to take on the responsibility of their illness (Blum 1995b) yet those with high self-esteem were more likely to be knowledgeable about their health care regimes (MacReady, 2002).

It can be expected that social and psychological pressures of adolescence will interfere with treatment regimes. Adolescent psychological and cognitive development can significantly impact his/her ability to understand, accept and adhere to advice about medications and treatments (Court, 1993). In addition, drugs and treatments that alter appearance in perceived negative way by the adolescent can lead to non-adherence to medications and treatments (Bent, Tennant, Swift, Schuffham & Chamberlain, 2002; Rosen, 1995; Fiorentino, Phillips, Walker & Hall, 1998; Hallum, 1995; Betz, 1998a).

The American Academy of Pediatrics (2000) states that children with disabilities should be encouraged to develop the highest level of independence based on realistic and objective evaluations of their abilities and limitations. Peterson et al (1994) developed an independence framework for children and youth with spina bifida. They recognized there were situations in which youth can strive to be independent and other situations where they will need to rely on others. Working with youth with chronic health conditions and disabilities is helping them find that balance between dependence, interdependence to independence.

“Working with youth... is helping them find that balance between dependence, interdependence and independence” (Peterson et al, 1994).

Formation of a sexual identity

All youth need to support and opportunities to develop a healthy sexual identity. Youth with disabilities and chronic diseases are sexually active with first intercourse average at 16 years of age (Suris, Resnick, Cassuto & Blum 1996; National Centre for Youth with Disabilities, 1996; MCS, 2003). Male and female groups with chronic conditions, compared to youth without chronic conditions, are more than twice as likely to report a history of physical or sexual abuse, and sexual exploitation (MCS, 2010; Johnson, 1995; CPS, 1997). During adolescence the individual is challenged to learn responsible behaviours in sexual and interpersonal relationships to prevent being exploited by others.

It is essential that youth, families and health care providers understand the alterations in normal physiological sexual development associated with certain disease conditions, medications and treatments (Suris, Resnick, Cassuto & Blum, 1996; Boas, Falsetti, Murphy & Orientstein, 1995). Primary care physicians may not be aware of limitations or contraindications in contraception options for youth with special conditions and or treatments such as congenital heart disease, diabetes, liver disease, or youth who have received a transplant (Blum, 1995b). Pregnancy may significantly compromise health and medical treatments may seriously affect a developing fetus (Sawyer, Phelan & Bowes, 1995). Lack of access to appropriate, condition-specific sexual health

“It is essential that youth, families and health care providers understand the alterations in normal physiological sexual development associated with certain disease conditions, medications and treatments”.

information may lead to misinformation and lack of guidance on fertility (Nixon, Glazner, Martin & Sawyer, 2003; Packham & Hall, 2002). Limited sexual education due to absence from school, inadequately prepared health care providers and parents (and peers), leave youth vulnerable with inadequate information to make sexual health decisions (Cromer, Bendicta & McCoy, 1990; Kaplan & Friedman, 1994; Greydanus, Rimsza & Newhouse, 2002).

Establishing meaningful social and peer relationships

Adolescence is a time to develop close peer relationships with youth of the same age. An inability to conform, to fit into the crowd or belong to an accepting peer group may result in self-rejection and long-term psychological and social problems (Mulcahey, 1992). Youth with chronic illnesses often demonstrate social withdrawal and peer conflicts, problems with adaptive behaviours and peer relationships (Shaw & Páez, 2002).

Reduced parental supervision, peer influences and social engagements may interfere with medications and treatment schedules (Court, 1991; LaGreca, 1990; Blum 1995b). For youth with chronic health conditions, this normative desire for acceptance and closeness with others is often coupled with the feelings that few people, outside a circle of peers with similar experiences, are able to understand them (Asher, 1992; Chew, 1999; Wysocki, Haugh & Ward, 1992; Lindstrom & Kohler, 1991). Socialization and peer relationships are further hampered by physical restrictions and disabilities (Bozzaco, 1993). In contrast, family, school and cultural connectedness can assist even the most vulnerable youth in overcoming negative experiences and making healthier choices for themselves and others (Smith, Stewart, Peled, Poon & Saewyc, 2010).

Seeking vocational training or employment

Planning for the future, education and career planning are important in developing self-esteem, self-worth and self-sufficiency (Rosen, 1995; White, 1997). In Canada, failure to graduate from high school is associated with poorer health outcomes, increased risk of jail time and more reliance on government for living assistance. Comparatively, graduates from high school use preventative health services 11% more frequently, have 23% better knowledge of health behaviours, 13% better health status and 26% better family functioning than those who have not graduated (Representative for Children & Youth, 2007). The literature suggests youth with chronic illnesses and disabilities have difficulty with school attendance, impacting their opportunity to graduate. Depending on their medical health status, they may face problems with vocational planning or achieving the necessary skills for employment (Packham & Hall, 2002; Frank & Chamberlain, 2001; Foster, Marshall, Myers, Dunkley & Griffiths, 2003; MCS, 1994; White & Shear, 1992; Betz, 1998; Schidlow & Fiel, 1990). These concerns are reflected in demographic studies undertaken in B.C. that found youth with health conditions often have poor school attendance (30% less than their healthy peers) and problems with vocational

“Youth with CHC rely on continual access to health insurance and benefits to cover supplemental costs for medications, specialized equipment, transportation and services...all of which change at 18 years of age” (White, 2002).

planning and economic support (MCS, 2010). Only 21% of youth in care, in B.C. graduate from high school (Children & Youth Officer, 2006).

Youth and families with chronic conditions rely on continual access to health insurance and benefits to cover supplemental costs for medications, specialized equipment, transportation and services (White, 2002). Most, if not all, change as the adolescent reaches 18 years of age. It is essential that youth, young adults and families are aware of these changes and plan ahead accordingly (Kastner, 1991; Nelson, 1994).

1.4 Emerging Adulthood (18-24 years)

“Emerging adulthood” is a newly defined stage in the life cycle distinct from both adolescence and adulthood behaviorally, demographically and subjectively. In the social sciences “emerging adulthood” has been attributed to extended education, postponed marriage and reduced family obligations in developed countries (Nelson, 2009) and results in young adults remaining at home and reliant on their parents for support (Arnett, 2000; Dovey-Pearce, Hurrell, May, Walker & Doherty, 2005). Biological support for this delayed maturation has been demonstrated by longitudinal neuro-imaging studies. The adolescent brain continues to mature well into the twenties (Johnson, Blum, Giedd, 2009). Executive functions such as planning, working memory and impulse control are the last area of the brain to mature, and may not be fully developed until the latter part of the third decade of life.

Arnett (2000) describes thematic characteristics of “emerging adults.” He describes deep ambivalence about losing their exceptional financial and social freedom that coincides with a lack of social control. Although they feel they should make their own decisions they may not yet feel committed to adult standards of behavior and an adult level of responsibility. While young people recognize that certain attributes are necessary to become an adult (such as the ability to accept responsibility for one’s self, the ability to make independent decisions, and, the ability to become financially independent) the timing of acquiring these attributes differs (Roisman, Masten, Coatsworth & Teelegen, 2004).

Emerging adulthood is also a time of considerable instability. During their 20’s, 50% of young people move back into to their parents’ home, and on average they change jobs 7 times (Arnett, 2004). This erratic lifestyle can be exceptionally taxing on the management a chronic health condition. For example, college students with diabetes reported barriers to optimal self-care included time constraints, erratic schedules, limited food choices and concerns about hypoglycemia, absence of social support, attention to alcohol, sexual health, and sick day diabetes management plan. Not surprisingly positive self-identity and a high level of family support was the strongest predictor of adherence to the diabetes regimen, implying that connectedness and family engagement remain critical in this unstable period. (Weissberg-Benchall, Wolpert & Anderson, 2007). In this age range, young adults are more likely to be uninsured (White, 2002) and at high risk for not receiving care (Lotstein, Inkelas, Hays, Halfon & Brook, 2008; Callahan & Cooper, 2006).

“Services need to be created that will reflect the important transitions occurring between 16 and 25 years of age in terms of health self-management, education, vocation and independent living”.

The concept of “emerging adulthood,” has not been considered extensively in management of chronic illness and transition from pediatric to adult care. Developmentally-appropriate care for this age range is an essential component in comprehensive, health surveillance care as youth with chronic conditions may not enter into risk-taking behaviors until later in their young adult lives (Britto, Garrett, Dugliss et al,

1998). Studies of this age population with chronic conditions have identified significant health concerns as they reach adulthood - shunt failure in youth with spina bifida and hydrocephalus requiring revisions by their early twenties (Tomlinson & Sugarman 1995), and secondary illness and cancers in childhood cancer survivors (Bleyer, 2005), graft failure in renal transplant patients (Watson, 2000), and increased rates of death in young adult male and female patients ages 10-29 years (Laing, Swerdlow, Slater et al, 1999). Services need to be created that will reflect the important transitions occurring between 16 and 25 years of age in terms of health self-management, education, vocation and independent living. Transitional care may then be completed within adult facilities and improve the long-term outcome of these young people (Jordan & McDonagh, 2007).

1.5 Youth in Care

In BC, there are approximately 9,000 children in the care of the Provincial government (Representative for Children & Youth, 2007), equivalent to 1.5% of the province's 0-18 year old population in BC. Of these children, 6% have a chronic health impairment and or disability, 5% have a learning disability, and 38% have a behavioral disability requiring moderate to intensive support. More than 51% of these children in care are identified as having special needs including disabilities of an intellectual, physical, sensory, emotional or behavioral nature, or having a learning disability. By 16 years of age, 74% of males in care have been identified as having special needs. The highest proportion of special needs are intensive behavioral or serious mental health issues. Of all the children in care, 18% have moderate to severe behavioral and mental health issues. Children in care have a higher rate of respiratory conditions, death, accidents, injury, depression, anxiety, pregnancy, contraception and sexual health needs.

Children in continuing care use more health care services more often than children not in care. Children in care are 1.5 more likely to be diagnosed with obesity and endocrine conditions such as diabetes and obesity; circulatory conditions such as hypertension and irregular heartbeats; and congenital anomalies of the heart and musculoskeletal systems (Children & Youth Officer, 2006). Over time, as youth in care (ages 19 to 25) became adults in care, they had poorer health indicators and died at a rate of 6.5 times higher than the general population.

It is a social norm that parents emotionally, practically and financially support their children as they transition to adulthood. The nuclear family has been cited as an important resource for successful transition, which makes it more difficult for youth in foster care who do not have additional family support (Lopez & Jackson, 2007; McDonagh & Kelly, 2003). Children in care are more vulnerable and have fewer resources than children not in care (Children & Youth Officer, 2006).

1.6 Youth with special developmental and cognitive needs

Youth with complex cognitive and special care needs have unique needs in the transition process. Some youth have progressive metabolic, neurological, or chromosomal conditions with limited lifespan. Many of these youth have limitations in communications, problem-solving, learning and mobility and require extensive community-based health care support. In

addition, these young people with cerebral palsy, spina bifida, neuromuscular disorders lack access to comprehensive adult health care services or staff with specialized training to meet their needs (Binks, Barden, Burke & Young, 2007). They may face additional transitional issues such as family fatigue, need for respite and financial support for ongoing care, and end of life issues (Peter, Forke, Ginsburg & Schwarz, 2009).

Canuck Place, the pediatric palliative care hospice associated with B.C. Children's Hospital, cares for children and youth who were considered to have terminal conditions and limited lifespan. Transition programming for their adolescent population includes planning for youth who have lived beyond their predicted limited lifespan and require adult services before entering a stage of palliative care (Siden, Steele, Brant, Cadell, Davies, Straatman, Widger, & Andrews, (2010).

"These populations may face additive transitional issues such as end of life issues, family fatigue, need for respite and financial support for ongoing care" (Peter, Forke, Ginsburg & Schwarz, 2009).

Section 2

Transitional Care – What does it mean for the youth in BC?

2.1 Defining Transition – What is it?

Transition is defined by the Society for Adolescent Medicine as “the purposeful, planned movement of adolescents with chronic medical conditions from child-oriented to adult-oriented health care” (Blum, Garell, Hogman, Joissen, Okinow, Orr & Slapp, 1993; SAM 2003). A consensus statement from the American Academy of Pediatrics (AAP), the American Academy of Family Physicians, and the American College of Physicians – American Society of Internal Medicine outlines the goal of transition for all youth with or without special health care needs is “to maximize lifelong functioning and potential through the provision of high-quality, developmentally-appropriate health care services that continues uninterrupted as the individual moves from adolescence to adulthood” (2002, p.1304). The work of transition is to ensure that care is uninterrupted, coordinated, developmentally-appropriate and psychologically sound prior to and throughout the successful transfer into the adult system (Blum et al, 1993).

“The goal of transition for all youth with or without special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally-appropriate health care services that continue uninterrupted into as the individual moves from adolescence to adulthood” (AAP, 2002)

Transition is not the same as transfer of care. While transfer of care is an important component of transitional care (Sawyer, Blair & Bowes, 1997), transition is not a single event but rather a complex process that occurs overtime (Culter & Brodie, 2005). During the transition process, health care is transferred from one organization to another. Often these organizations fall under different health care jurisdictions, which have different management and information systems and continuity of care between jurisdictions is a significant issue. Continuity of care then requires an uninterrupted flow of clinical care, information, and services across pediatric, adult and community jurisdictions (Haggerty, Reid, Freeman, Starfield, Adair, & McKendry 2003).

Regular continuous medical care with ongoing monitoring and adjustments that extend beyond pediatric care and into adult care are major factors in improving health and quality of life (Robertson, McDonagh, Southwood & Shaw, 2006) and maximizing life-long functioning (Stewart, Antle, Healy, Law & Young, 2007). Transition requires developmentally-appropriate care within an environment that supports the unique needs of the youth and young adults with chronic health conditions encouraging self-management until they are safely and securely in the adult health care system (Blum, Hirsch, Kastner, Quint & Sandler, 2002; Viner, 2006; Remorino & Taylor, 2006).

Specifically, it requires a systematic process initiated in pediatric care to help youth and their families learn the skills and knowledge necessary to manage their health care in a very different adult system (Whitehouse & Paone, 1998). Once the youth and family are engaged in the process, they can begin to adopt and practice the health care behaviors required of the adult health care system. The process is complete once the young adult not only transfers to the adult system but is actively participating in activities of self-management and decision making (Telfair, Alexander & Loosier, 2004).

Youth with chronic conditions can be described as facing many simultaneous transitions:

Developmental transitions:

- From childhood to adolescence to adulthood
- From school to secondary education to employment
- From home to independent or community living

Health Care Transitions:

- From pediatrician to adult primary care physician
- From pediatric to adult subspecialist / clinical teams
- From parent health care benefits / insurance to personal options
- From parental care to independent / interdependent or attendant care

Why is transition so important?

Transition services have been recognized as an essential component of high-quality health care (Jackson & Pencharz, 2003). The lack of planning and preparation, combined with ad hoc systems for transfer of services and an absence of youth-appropriate care in the pediatric and adult health care systems at a very vulnerable period in their lives can lead to:

1. Measurable adverse outcomes including increased mortality, morbidity, and poor long-term prognosis and quality of life (UK Department of Health, 2006; Jackson & Pencharz, 2003; Forbes, While, Ullman, Lewis, Mathes & Griffiths, 2001; Kaufman, Terbrock, Winters, Ito, Klosterman & Park, 1994; Stewart et al, 2007; Remorino & Taylor, 2006).
2. Increased risk factors including a decline or cessation of medical care leading to secondary disease or illness (Kipps, Bahu, Ong, Ackland, Brown, Fox, et al, 2002; McManus, Fox, O'Connor, Chapman & Mackinnon, 2008; Blum 1991; Blum et al., 1993; Giordano & Igoe, 1991; Frank, 1996; Kaufman et

Lack of transition can lead to:

- *Less than 50% transfer to adult care*
- *Decline in long-term medical care*
- *Inappropriate use/costs of medical services*

al, 1994; Palfrey, Levy & Gilbert, 1980; Rettig & Athreya, 1991; Salmi, Huupponen, Oksa, Oksala, Koivula & Raita, 1986; Rosen, 1995; Somerville 1997; Watson, 2000; Eiser, Flynn, Green, Havermans, Kirby, Sandeman & Tooke, 1993). Several studies have shown follow up rates in adult clinics after transfer to be less than 50% for several chronic conditions including congenital heart disease, diabetes and spina bifida (Kipps et al, 2002; Tomlinson & Sugarman, 1995; Reid, Irvine, McCrindle, Sananes, Ritvo, Siu, et al 2004). Renal transplant patients who have not been engaged in transition planning have exhibited unexpected poorer outcomes and unexplained increased mortality after transfer compared to those who were in a transition program (Watson, 2000; Prestidge, Romann, Djurdjev & Matsuda-Abedini, In Press).

3. Remaining in pediatric care well past the age of 18 years of age can lead to negative effects on their well-being (Lam, Fitzsgerald & Sawyer, 2005; Fiorentino, Phillips, Walker & Hall, 1998; Sloman, 2005; Cameron, 1996; Madge & Byron, 2002; Palsy, 1994; Brumfield & Lansbury, 2004; Jackson & Pencharz, 2003; Bennett, Towns & Steinbeck, 2005).
4. Inappropriate use of emergency service and expensive use of the adult health care system (Rianthavorn, McDonagh, Southwood & Shaw, 2008).

In summary, youth not transferred effectively can fall out of care and be lost or orphaned by the system leading to disastrous outcomes (Kennedy, Sloman, Douglass, & Sawyer, 2007; McDonagh & Viner, 2006). Youth themselves have described an

“Youth themselves have described an unplanned or unsupported transition as being ‘dumped, abandoned, thrown out, tossed aside or lost in the shuffle’.”

unplanned or unsupported transition as being “dumped, abandoned, thrown out, tossed aside or lost in the shuffle” (Shaw, Southwood & McDonagh, 2004; Scott, Vallis, Charette et al, 2005).

In contrast, controlled trials showed significant improvement in health related quality of life, health condition knowledge, better disease control, improved documentation, and satisfaction in health care for youth who had received transitional care (Robertson et al, 2006; Court 1993; Nasr, Campbell & Howatt, 1992; Blum et al, 2002). Other benefits include increased sense of independence and control in making health care decisions (Miles, Edwards & Clapson, 2004), improved follow-up (Rettig & Athreya, 1991), and enhanced autonomy, increased sense of responsibility and facilitate self-reliance (Rosen, Blum, Brittol, Sawyer & Seigel, 2003).

2.2 Global Position Statements and Recommendations for Transitional Care

Transition planning has become a major concern for children's health policy makers and practitioners, resulting in the publication of position statements from organizations in the United States, Canada and Britain. The overarching message is that care should

be continuous, comprehensive and coordinated in order to meet the wide range of needs of young people. Many of these position statements date back two decades from pediatric and adolescent based societies (Blum et al, 1993; SAM, 1993; APA, 2002). More recently, regional health boards and adult medicine societies (Royal Australasian College of Physicians, 2007; UKDH, 2006) and disease-specific and discipline-specific groups (Royal College of Nursing, 2004; Cystic Fibrosis Foundation, 2010; CPS, 2007; North American Society for Pediatric Gastroenterology, Hepatology, 2004; Greater Metropolitan Clinical Taskforce, Australia, 2006) have written statements calling for increased transition support. Recommendations of best practices for primary care physicians, pediatricians, general practitioners, nurses and adult practitioners, and all who provide care to youth and young adults to facilitate successful transition, include:

Canadian Pediatric Society Position Statement: Transition to adult care for youth with special health care needs (2007)

The Canadian Paediatric Society supports the provision of developmentally appropriate care for youth with special health care needs as they move into the adult-oriented health care system. Recommendations include;

General principles

- Pediatricians should be aware that transition is an ongoing process that may begin as early as the time of diagnosis and ends sometime after transfer.
- Appropriate resources and educational materials should be provided for youth throughout the process of transition.

Individual and family issues

- Transition planning must be youth-focused within the context of the family.
- Appropriate attention and supports should be provided for family members.
- Transition should occur at the youth's pace.

Multidisciplinary teams and community resources

- Transition planning and preparation should be integrated into existing specialty clinical settings.
- Teams must provide developmentally appropriate care, including a stepwise plan of increasing responsibility for self-care. The family physician should be an integral part of the treatment team. If the adolescent does not have a family physician, the team should facilitate a referral as soon as possible.
- Teens should be given information about their condition and available resources, including clinics providing sexual health screening for young adults.
- Skills training in communication and negotiation should be provided to enhance navigation in the adult care system.
- The provision of transition services may include individual counselling; psycho-educational groups; posters and checklists for staff, patients and parents; joint transition clinics and Web-based tools.

American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians – American Society of Internal Medicine: Health care transitions for young adults with special health care needs (2002)

- Ensure all young people with special care needs have a health care provider who is responsible for transition, care coordination and health care planning;

- Ensure all care providers have core competencies in providing developmentally-appropriate transitional care;
- Develop a portable, accessible, medical summary to facilitate the transfer of care among health care providers and agencies;
- Develop an up-to-date detailed written transition plan in collaboration with the young person and his/her family;
- Ensure the same standards of primary and preventative health care are given to young people with chronic conditions as their peers;
- Ensure affordable, comprehensive, continuous health insurance and care to youth with chronic conditions throughout adolescents and into adulthood.

This process has begun in some subspecialty areas in the United States. The American College of Cardiology has mandated training in pediatric cardiology and adolescent health to increase the skill set and number of cardiologists trained in congenital heart disease. They have developed training guidelines including indications for referral to a specialized adult CHD (ACHD) center, issues unique to adults with CHD, and recommendations regarding care of adult patients with CHD. They note it will be at least a decade before graduates of the adult cardiology training programs are sufficiently numerous and adequately trained to staff specialized, adult congenital centers (Murphy & Foster, 2005).

UK Department of Health Transition: Getting it right for young people. Improving transition of young people with long-term conditions from children’s to adult health services (2006)

- Staff working with young people should balance the need of the young person for privacy and confidentiality, and their wish to take increasing responsibility for their own health care, with the need for their parents to have sufficient information to provide the support that these young people often require.
- There are several models for good transition and there is no clear evidence that one is superior. Different approaches may be needed for different types of conditions according to their prevalence and the ways in which specialist health care is organized.
- Implementing transition involves flexibility in timing; a period of preparation for the young person and family; information transfer; and monitoring of attendance until the young person is established in the appropriate adult oriented service.
- Professionals need to consider development of their knowledge and skills in working with young people, including; the biology and psychology of adolescence; communication and consultation; multi-disciplinary and multi-

“Improving transition takes time, resources and commitment – but these are tiny compared to what was invested in the health care of each child and young person throughout childhood. It makes sense to ensure that this is not wasted because of poor or no transition” (UK Department of Health, 2006)

agency teamwork; and the evolution of a condition and consequences in adult life.

- Young people with complex disability present particular problems because often there is no equivalent adult service able or willing to take on their long-term health care and medical supervision.

Society for Adolescent Medicine Position Statement: Transition to adult health care for adolescents and young adults with chronic conditions (2003)

Despite a lack of meaningful data, the Society for Adolescent medicine endorses a number of fundamental principles to govern transitional care:

- Health care in all settings to youth and young adults should be chronologically and developmentally appropriate;
- Transitional health programs should address normal developmental issues of adolescents and young adults including but not limited to growth and development, sexuality, mood and mental health disorders, substance use and health-promoting and health damaging behaviors;
- Transitional care should promote autonomy, increase personal responsibility and facilitate self-reliance;
- Transition programs should be flexible and the time of transfer individualized;

Royal College of Nursing, United Kingdom Adolescent Transition Care: Guidelines for nursing staff (2004)

- Adolescents should be involved in planning and delivery of health care services
- Nursing across all agencies require ongoing training in adolescent care.
- Planning should include frameworks as part of a comprehensive strategic plan
- Expertise and resources should be shared across agencies.
- While the process should be flexible, all youth should leave pediatric agencies by 18 -19 years of age.
- Each youth should be assigned a key coordinator to facilitate the preparation and movement to adult care.
- The entire process should support adolescent development towards independence, accompanied by formal documentation.

Further, condition-specific groups and foundation have deemed it necessary to develop and publish their own recommendations for best practice and care of youth with specific health conditions. See **Appendix A** for examples.

Greater Metropolitan Transition Taskforce, NSW, Australia: Principles for Practitioners on Transitional Care for Young People (2006)

- Planned transition should facilitate access to adult health care providers and relevant support services thus ensuring optimal use of health services.
- Transition planning should utilize a clinician and consumer designed framework, which supports a team/partnership structure approach to continuity of care in order to achieve better outcomes for chronically ill young people.
- Transition planning should develop and strengthen clinical networks, which improve access to the best possible care.

- Successful adolescent transitional services require the support of general practitioners, community resources and non-government organizations.

2.3 Barriers to Comprehensive Transitional Care

The literature identifies numerous barriers to the development and implementation of comprehensive and integrated transition services designed to support the needs of youth as they move into adult care. While the literature abounds with the understanding that transition is the 'right' way to provide holistic and comprehensive care, many barriers still exist at all levels. The unique needs of this growing population are poorly understood. Additional problems arise when this lack of understanding is combined with uncertainty about who is responsible during transfer. As health care services become increasingly specialized and siloed, collaboration between hospital divisions and departments as well across health care jurisdictions becomes increasingly difficult and complex. As pediatric centres reduce the age of discharge and youth live longer with chronic illness and move onto adult care providers unaware of the new emerging population of previously 'pediatric only' conditions (Sawyer & Bowes, 1999; Madge & Byron, 2002), problems associated with transition are exacerbated.

Differences in care cultures between pediatrics and adult services

There is a distinct difference in how care is provided in pediatrics and in the general adult health care systems (Rosen, 1995; Sawyer, Collins & Bryon, 1998). Differences in pediatric and adult care include differences in; age range, cultures of care, communication skills, role of parents, expectations of patients, confidentiality issues, service provision, and acknowledgement of issues of growth and development (Eiser et al, 1993; Rosen 1995). The adult system differs from the pediatric system in terms of the type and level of support from health care providers, decision-making and consent processes, and the amount of family involvement (Brink et al, 2002; Betz & Redcay, 2005).

In pediatric care the family is considered an active partner in the health care team. The parent or guardian is expected to ensure compliance, understand the condition and take responsibility for consent, treatment and daily care needs. Often subspecialty pediatric care is provided in a multi-disciplinary clinic by a range of health care providers. Many adolescents with chronic illness visit the physician together with their parents, and are used to their caregivers playing a strong advocacy role.

"There is a distinct difference in how care is provided in pediatrics and in the general adult health care systems (Rosen, 1995; Sawyer, Collins & Bryon, 1998). Differences between pediatric and adult care include; age range, cultures of care, communication skills, role of parents, expectations of patients, confidentiality issues, service provision, acknowledging issues of growth and development."

In direct contrast, a patient in the adult health care system is expected to be knowledgeable about their condition and involved in planning their own care. Adult care focuses on the risks of long term complications rather than taking a developmental perspective (Eiser et al, 1993; Betz & Redcay, 2005). The young adult patient can feel threatened and overwhelmed because of the expectation the adult practitioner's style of communication and limited time and resources for teaching and counseling (Beresford & Sloper, 2003).

Pediatric Care systems	Adult Care Systems
Care provided in a multi-disciplinary clinic by a range of health care providers	Care provided by adult specialist with referrals to other health care providers as needed. Limited time and resources available for teaching and counseling
Family insurance coverage	Independent insurance services
Adolescent clinics encouraged with and youth friendly care,	Few young adult clinics
Family is active partner in health care team	Independent consultation
* Parent or guardian ensures adherence and understands the condition and has a strong advocacy role	Patient is assumed knowledgeable about their condition and plans their own care
*Parent or guardian gives consent	Patient responsible for consent
*Parent or guardian takes responsibility for treatment and daily care needs	Patient expected to self-manage personal care and decision- making
Child/adolescent visits the physician together with their parents	Physician visits encouraged to be independent of family/carers
Specialist knowledge with rare conditions	Lack of experience with rare pediatric conditions
Focus on developmental perspective	Focus on risks of long term complications

Lack of trained sub-specialists and allocated resources in the adult setting

There are many hurdles adult health care providers face when caring for young adults with chronic illness (Laurvick, Christodoulou & Ellaway, 2006; Leonard, 2005; Leonard, Bower, Petterson & Leonards, 2000; Viola & Rosano, 2005; Madge & Byron, 2002). Young adults make up a small but increasing component of adult clinical practice as the survival rates for many conditions improve. Many adult health care providers have not been trained to care for what are essentially pediatric conditions; the relevant medical literature is usually published in pediatric journals and most lack training in adolescent and young adult development. Adult physicians are often unfamiliar with managing the psychosocial needs of the patient/ family unit. It is also challenging for adult physicians to manage new patients who are facing end of life issues early in the relationship or who face new financial burdens as pediatric benefits are discontinued (Peter et al, 2009). This relatively 'new' population of patients is entering the adult health care system where there are a limited number of practitioners educated and prepared to take on the care of these young adults with special health care needs (Lam et al, 2005; UKDH, 2006; Reiss, Gibson & Walker, 2005; Reiss & Gibson, 2002; Peter et al, 2009; Murphy & Foster, 2005).

From the adult health care provider's perspective, there are inadequate resources to duplicate the multidisciplinary care provided in pediatric settings (Konsler & Jones, 1993; Steinbeck, Brodie & Towns, 2007; Bennett et al, 2005); adult care providers lack formal experience caring for this complex pediatric population (Lam et al, 2005; Shaw et al,

2004); and there is a lack of time and financial reimbursement to provide the extensive care required by this population (Johnson, 2007).

Lack of interagency communication and documentation

Overall there appears to be a general lack of planning and collaboration between agencies or across health care jurisdictions (O'Sullivan, 2007). This might be in part to differences in clinical practice and cultures between pediatric and adult care services (Rosen, 1995; Sawyer et al, 1998). From the pediatric position, there may be lack of information provided to patients before leaving the pediatric system due to their own lack of knowledge of the adult medical and community-based services available (Beresford, 2004). There is also a significant lack of transfer of medical records/information because of incompatible programs (While, Forbes, Ullman, Lewis, Mathes & Griffiths, 2004). As addressed, this 'new' young adult population might not have an adult health care counterpart (Chamberlain & Rooney, 1996). Particularly for youth with complex, multi-system chronic health conditions like spina bifida, which requires care from a number of sub-specialty areas including - neurology, urology and orthopedics, there is confusion about who is responsible for transition and patient management overall (While et al, 2004; Sawyer et al, 1998).

"Without clear communication amongst care providers as to who is covering what or documentation to outline it, it is hardly surprising that patients and their families struggle to bridge the gap between pediatric, adult and community-based services"

Communication and documentation between services is lacking. One survey of adult practitioners indicated that 54% of the adult specialists surveyed did not have any contact with their pediatric counterparts and 59% did not have any established protocol (Suris, Akre & Rutishauser, 2009). Further, liaison with primary care physicians was also lacking despite findings that primary physicians can support transition if involved in the process (Viner, 1999; Zack, Jacobs, Keenan, et al 2003). Without clear communication amongst care providers as to

who is covering what or documentation to outline it, it is hardly surprising that patients and their families struggle to bridge the gap between pediatric, adult, and community-based services (Britto et al, 1999). Many youth and families have themselves expressed their frustrations at the limited coordination and communication of care between services (Chamberlain & Rooney, 1996).

"Some youth and families are unaware of the need to transfer to adult care and inappropriately use their sub-specialist to meet their primary care needs ... who are often unaware how to access community and adult services that all change as the youth reaches adulthood at 18 years of age' (MacReady, 2002).

Lack of Information, awareness and resources

A lack of awareness of available community and adult resources is a significant barrier to transition planning and continuity of care. Some youth and families are unaware of the need to transfer to adult care and inappropriately use their sub-specialist to meet their primary care needs (Carroll, Massarelli, Opzoomer, Pেকেles, Pedneault, Frappier, & Onetto, 1983). Specialized

pediatric clinicians are often unaware of how to access community and adult services, that all change as the youth reaches adulthood at 18 years of age (MacReady, 2002; Shaw et al, 2004). A lack of information about insurance and financial aid for services can leave a young adult destitute (White, 2009).

Lack of motivation to transition

Youth, young adults and families, and pediatric care providers present their own personal barriers to effective transition planning and behaviours. Long-term relationships with pediatric care providers and a security in 'what is known' can make youth and families fearful and resistant to change (Bent et al, 2002; Cowlard, 2003; Fiorentino et al, 1998; Frank, 1992; Sawyer et al, 1998; Reiss et al, 2005). Parents themselves have indicated a strong reluctance to transition because of their concern that their youth will not be able to self-manage their treatment regimes and health condition adequately (Boyle, Farukhi & Nosky, 2001). For some parents 'do not want to change' was the only significant barrier in stopping both adolescents and parents from considering transitional care. When pushed further, reasons included not understanding transitional care, fear of a new environment or maladjustment (Wong, Chan, Wong, Heun, Yeoh, & Fok, 2010). Part of the youth's desire to appear and be 'normal' may result in the young adult's refusal to seek out adult medical care (Desire & Seidman, 2003; Jackson & Pencharz, 2003; Kyngas et al, 2000; Ullrich et al, 2002). This may also be in part due to a lack of personal confidence to contact referred adult practitioners (Fiorentino et al, 1998). Many of these factors can also be tracked back to the youth and family not being included in transition planning discussions (Beresford, 2004; O'Sullivan, 2007).

In addition, some pediatric health professionals themselves are hesitant to relinquish responsibility for the young people whom they have cared for through many stages of their lives, and whose complex needs they know in detail (Blum, 1995; Fox, 2002; McDonagh, 2005; Lewis-Gary, 2001; Bent et al, 2002; Flume, Taylor, Anderson, Gray & Turner, 2004). Some pediatric subspecialists 'hold onto' their patients longer than necessary because they too lack the confidence in the adult health care system to properly manage their patients (Flume, Anderson, Hardy & Gray, 2002; Rosen, 1994; Betz, 1998; McDonagh & Kelly, 2003; Viner, 2001). In addition, there may be few general practitioners in the community prepared to provide comprehensive care to youth/ young adults with complex health care due to their lack of training (Sanci, Coffey, Patton, & Bowes, 2005).

External social barriers

Other factors that inhibit or complicate transition need to be recognized and studied further. These include homelessness, domestic violence, family conflict, sexual abuse, parents with mental or social problems, substance misuse, unemployment, poverty, teenage pregnancy or young parenthood, school expulsion, and ethnic or immigration issues (Lotstein et al, 2005; UKDH, 2006; Viner,

"Other factors that inhibit or complicate transition ... include homelessness, domestic violence, family conflict, sexual abuse, parents with mental or social problems, substance misuse, unemployment, poverty, teenage pregnancy or young parenthood, school expulsion, and ethnic or immigration issues" (Lotstein et al, 2005).

2006). Youth who live under the care of the government are more vulnerable and have fewer resources than children not in care. Lack of resources has a direct impact on their ability to transition effectively a multiple level of services (Children & Youth Officer, 2006).

Barriers specific to the needs of youth and young adults in BC

At BC's Children's Hospital, despite efforts to establish a process for transitional care, many of these barriers remain. Many adolescents and families are experiencing first-hand the effects of inadequate transition planning and preparation. Lack of transitional information and teaching, inconsistencies in medical record transfer, limited access to supportive community-based services, and in some cases, lack of access to primary and or adult care specialists have all compromised the care of youth leaving BCCH.

Based on Blum & Bearinger's (1990) survey of 3,066 pediatric health care professionals, a questionnaire was developed with the permission of the authors to explore the perception of attitudes, knowledge and skills around youth health issues and developmentally-appropriate care at BC's Children's Hospital. The questionnaire contained four main content areas: demographics of youth seen in the clinics, perceptions of barriers to implementing developmentally-appropriate care, perceptions of skills and resources in providing youth-focused care, and competencies in providing education and counselling for youth with chronic health conditions. This tool was completed by 12 subspecialty clinics' multidisciplinary staff in 1998 and 2006.

In 1998, the questionnaire was offered to all pediatric team members with 62 respondents completing the tool from 12 different sub-specialty clinical areas. The teams members included nursing 36% (n=21), medicine 31% (n=18), as well as social workers, physiotherapists, occupational therapists, nutritional therapy, psychiatry and psychology. The survey indicated that clinic time and access to youth-specific teaching materials and resources were the most significant barriers to providing developmentally-appropriate care. All groups of disciplines indicated that they felt comfortable dealing with the adolescent population. When questions were broken down into specific content areas for developmentally-appropriate care the results became more indicative of the possible barriers to adolescent-focused care. Competency and skills levels were low in topics related to eating disorders, depression/anxiety, suicide risk, alcohol/drug use, physical/ sexual abuse, contraception, sexual orientation, gang related activities, dating/vulnerability, and driving risks. Competence was rated high in areas pertaining to the chronic condition, treatment modalities, and encouraging skills of independence, but rated significantly lower on related issues such as peer support, contraception/ pregnancy impact on treatment, fertility, and legal rights to information and consent.

"At BCCH, the most significant barriers to transition identified by staff in (2006) were the lack of community resources to refer adolescents and limited clinic time... to address the issues."

In 2006, this survey was repeated with revisions to further access specific staff competency questions (Evans, Bearinger, Ireland, Shew, Neumark-Sztainer, Story et al, 1998; Saewyc, Bearinger, McMahon & Evans, 2006) following the integration of the ON TRAC transition education program into the sub-specialty clinics at BCCH. While the tools of the program were available, there was minimal staff support or training. Eight years later, only 36 staff members were available to complete the survey for the second time. Therefore, analysis primarily focused on global changes in practice and provider perceptions. The barriers to transitional care were again rated. The most significant barriers included lack of community resources to refer adolescents and limited clinic time. Moderate barriers were lack of training and support to deal with adolescent issues and communication difficulties with adolescents. Skills in providing developmentally-appropriate and transition care ranged from very low to very high for various topics. Staff skills ranked lowest in topics of adolescent pregnancy, gay or lesbian sexuality, gang related activities, testicular or breast exam, sexually transmitted diseases, and suicide risk. There was an increase in skills associated with talking to youth about eating disorders, depression anxiety, alcohol and drug use, smoking, physical and sexual abuse, psychosomatic complaints, and contraception choices over the 1998 findings. Staff ranked themselves a highly skilled in discussing body image, parental conflict, peer relations, dating, exercise, nutrition, and driving risks with adolescent patients.

2.4 Key Components for Effective Transitional Care

Multiple transition programs have been initiated, but few have been evaluated. In 2000, the first conference focusing on Transition Care was held at Bloorview, Toronto. This biannual conference has led to international collaboration. The goal is to have those working on transition programs and care to share their strategies, protocols and findings and to focus on the best way to help youth lead a normal life (Steinbeck et al, 2007; Cowlard, 2003). The ability to navigate the maze of accessing changing and appropriate health care services requires a transition model that is flexible and can accommodate these differences. Whereas many models have been proposed, most lack significant long-term follow-up. However, key components to an effective transition program have been identified as:

Transition not transfer

While once understood as a medical transfer of care, transition planning is now recognized as a necessary educational and therapeutic process to support the ongoing health of an individual that begins much earlier than the age of discharge (Sawyer et al, 1997).

Flexible and individualized

Transition requirements for youth range from simple to complex based on the severity of their condition. Therefore a flexible process that is able to adapt to the individual capacities of each youth and his/her family is needed (White, 2009). Transition is a coordinated process that occurs overtime. While most formal programs are aimed at

young people of high school age, the process should begin gradually in childhood, perhaps as early as diagnosis (Osteogenesis Imperfecta Foundation, 2006). The timeline can follow normal adolescent development of early, middle and late adolescence starting at 10 years of age (Whitehouse & Paone, 1998; White, 2009; Rosen et al, 2003). Care should be chronologically and developmentally appropriate (SAM, 2003) throughout adolescence and into adulthood (Sawyer et al, 1997). While most pediatric centres mandate an age for transfer to the adult system, at BC Children's Hospital the age of discharge is 17 years. However consideration should be made regarding other issues in the youth's life which may impact successful transfer. Some argue transfer to the adult system should not occur during a stressful time; final exams, graduating high school, or entering college (Sloman, 2005; Viner 2001). Pediatric care providers must be flexible in providing transitional care and base interventions and counseling on the developmental age of the adolescent (CPS, 2003).

“Active” transition planning to ensure transfer readiness

While the transition planning process is initiated early on to encourage the youth's involvement and participation in his/her health management (Frank, 1992; Rosen, 1992; Palys, 1994; Peterson et al, 1994), youth need to move into an 'active phase' beginning around 16 years of age to prepare for transfer. This phase should focus on attendance at clinic, self-management skills, orientation to adult services, and identification of a primary care physician (Craig, Towns & Bibby, 2007). Patient readiness and maturity are key predictors to initiate “active” transition planning (Capelli, MacDonald & McGrath, 1989; Blum, 1991; Reiss & Gibson, 2002; Schidlow & Feil, 1990; SAM, 1995).

“Transition starting at 10 years of age...moving into an active phase by 16 years ... focusing on the skills of attendance at clinic, self-management skills, orientation to adult services, and identification of a primary care physician.”

Developmentally-appropriate and patient-centered strategies

Developmentally-appropriate and patient-centered care strategies are content areas identified by youth, families and care providers as essential for transition planning and preparation for adulthood (Baker & Coe, 1993; Betz, 1998b; Betz, 1998a; Court, 1991; Hauser & Dorn, 1999; Igoe, 2000; Hostler et al, 1989; Johnson, 1995; Patterson & Lanier, 1999; Peterson et al., 1994; Rosen, 1993; Telfair, Myers & Drezner, 1994; Warnell, 1998; Whitehouse & Paone, 1998). These include teaching on condition-specific information, health maintaining skills, life skills, self-advocacy, peer support, psychosocial support, educational and vocational planning, sexual health information, drugs and alcohol, fertility, and genetic counseling (Geenan, Powers & Sells, 2003; Sloman, 2005; Rosen et al, 2003; Paone, Whitehouse & Stanford, 1998).

Practitioners need to ensure youth have clear information about their condition, and are able to recognize signs of deterioration or complications, understanding treatments or medications and how to seek help from appropriate health care services (Viner, 2001). Youth and families have also identified needing information and education about adult services and long-term health issues as essential in transition planning

(Telfair et al, 2004). It is evident that three main groups – youth, families and health care providers form a triad to successfully navigate the transition process (Miller, 1996; Paone et al, 1998; Rosen, 1995). There needs to be a gradual shift from focusing on the strengths and skills of the family to self-management skills and abilities in the youth/young adult (Sawyer & Aroni, 2005). This anticipatory guidance and supportive teaching can take place in the sub-specialty clinics and is most effective when integrated into regular health care visits where teaching takes place in an environment that is supportive and familiar (Nasr et al, 1992).

Youth sensitive services

“Best practice” dictates the growing need for ongoing financial support for transition programs embedded into pediatric sub-specialty care. In addition, adult care providers need to be open to training on “best practice” of caring for young adults with chronic/ life-long health conditions (SAM, 2003). When young people are asked about youth-sensitive services they want active management of their transition process; involvement in service design and delivery; to have a trusted professional who acts as an advocate for them; and professionals on either end who understand adolescent / young adult issues (Viner & Barker, 2005).

“There needs to be a gradual shift from focusing on the strengths and skills of the family to self-management skills and abilities in the youth/young adult” (Sawyer & Aroni, 2005).

Services for youth need to be provided within an environment that fosters openness, advocacy, support and comfort (Miles, Edwards & Clapson, 2004). A multi-service approach to transition planning is essential to ensure all the areas of normal adolescent development are addressed; insurance, housing, vocational planning, sexual health and recreation (AAP, 2002; Cowlard, 2003; UKDH, 2006). A co-operative model of planning and care in utilizing better existing community-based services and ensuring youth and families have access to these services is imperative (Pownceby, Ratcliffe, Abbott & Kent, 1997; UKDH, 2006; Vogel, Klaas, Lubicky & Anderson, 1998).

Written transition plan

As transition involves multiple stakeholders at the individual (patient-centred), organizational, and inter-organizational levels, documentation of the process should be mandatory (Blum 1995a; Forbes et al, 2004; Sawyer et al, 1998). It is essential that the transition plan is individualized, developmentally-appropriate and written (Brumsfield &

“A written transition plan should be individualized and include set protocols, roles for staff, developmental skills and knowledge, goals, dates and identification of primary and adult care providers”.

Lansbury, 2004). It needs to identify set protocols and roles for staff to follow (Por, Golberg, Lennox, Burr, Barrow & Dennard, 2004). Developmentally-appropriate skills and knowledge can be documented throughout the process using clinical pathways or checklists (Whitehouse & Paone, 1998; RCN, 2004; Paone, Wigle & Saewyc, 2006). Checklists and pathways need to span the adolescent period including

developmental milestones as well as condition specific information (Blum, 1995a; Betz, 1998b; Hallum, 1995; Pacer, 1991; Rosen, 1994; Whitehouse & Paone, 1998). Effective plans may include dates, services, health education goals and identification of adult services and providers (AAP, 2002; Shaw et al, 2004) and should be written in collaboration with their families and or care providers (SAM, 2003). The written transition plan should be based on a formal assessment so that individualized goals to gain independence and areas in need of support can be determined (Kelly, Kratz, Bielski & Rinehart, 2002). Youth themselves recognize the importance of ongoing communication and a documented transition plan (Zack et al, 2003).

Transfer of health care information

It is essential for continuity that there is an accurate and up to date flow of information between the youth, family and health care providers and agencies (Steinbeck et al, 2007). A portable, accessible, up to date, summary of care is required to facilitate smooth collaboration and transfer of care between health care professionals (Dovey-Pearce et al, 2005; Miles et al, 2004; SAM, 2003). As technology changes in the health care system, it has been proposed that the youth/young adult themselves should have a personally held, portable, accessible, up to date, summary of care to facilitate the transfer of information (Dovey-Pearce et al, 2005; Miles et al, 2004; SAM, 2003). In addition, health care providers from the pediatric site should provide a written summary of health requirements at the time of discharge. This sharing of medical information and patient history is essential for the young adult's ongoing care. At a minimum, transition documentation should include a portable medical record, key summary points and written plans/requirements for adult care (Blum, Britto, Sawyer & Siegel, 2003; Sawyer et al, 1997; Viner, 1999; Sloman, 2005) in order to make the move towards adulthood and adult care coordinated, continuous and comprehensive (AAP, 2002). Unfortunately pediatric centres do not recognize or compensate the time required to complete the transfer record/letter (Steinbeck, et al, 2007).

"A portable, accessible, up to date, summary of care is required to facilitate smooth collaboration and transfer of care between health care professionals" (Society for Adolescent Medicine, 2003).

Time of overlap

Meeting with adult care providers, accessing adult services and navigating adult health care benefits should be done in the active phase of transition while youth are still receiving pediatric care. It can be part of the transition/transfer of care process, part of 'graduation' clinics and/or can include a trial visit to the adult site (Fiorentino et al, 1998; Miles et al, 2004; Soanes & Timmons, 2004). Joint clinics shared between pediatric and adult clinics can improve the transfer of individual patient knowledge, promote collaboration in patient care, facilitate continuity and build confidence

"Meeting with adult care providers, accessing adult services and navigating adult health care benefits should be done in the active phase of transition... as part of 'graduation' clinics and or can include trial visit to the adult site"

and understanding in all practitioners, patients and family (Kennedy et al, 2008; Tucker & Cabral, 2005). Young people themselves choose services which actively involve both paediatric and adult providers if they are available. Joint services have been associated with improved adherence to appointments following transfer (Vallis, Charette, Murray & Latta, 2005; Warnes, 1995; Miles et al, 2004; Ullrich, Muller, Fabel, von der Hardt, 2001; Kipps et al, 2002).

From the top down

The success of a transition program is dependent on executive, regional and health care jurisdiction support and collaboration (Sloman, 2005; Viner, 2000; Viner, 2001). Overall, a systematic investment in regional/provincial clinical service planning is needed between pediatric sub-specialty care, primary care, community services and adult specialists (Kennedy & Sawyer, 2008). It is essential all services are guided by policies and protocols to ensure consistency and sustainability (UKDH, 2006). Once organizations recognize that transitional care is an essential quality of care issue, there are three key factors to consider: a cultural shift in attitudes and training, transition programs embedded in care practices, and ensuring youth are effective partners in their own transition (Viner, 2006).

Training of health care professionals

Health care providers delivering care to youth require the educational competencies and skills that facilitate the process and provide anticipatory guidance for parents to address techniques to foster independence, competence and self-care in their youth (SAM, 2003; White, 2009). Primary care physicians and general adult practitioners are acknowledging the need to learn and understand developmentally-appropriate care for youth and young adults. Education of family physicians on adolescent health and transition shows a substantial gain on self-knowledge, clinical skills, and self-perceived competency in caring for adolescents (Sanci et al, 2005). Training in these areas for both children's and adult health care staff will be crucial in the development of transitional care programs (McDonagh, Southwood, & Shaw, 2002). Pediatric and adult care providers are not well versed in providing developmentally-appropriate and transitional care to adolescents and young adults (McDonagh, Southwood & Shaw, 2006; Fuglinitti 1992; Sawyer & Bowes, 1999; Lotestein et al, 2005). Therefore, it has been recognized that developmentally-appropriate education and planning is essential for effective transition planning and should be a certified component of resident, physician nursing and social work training (AAP, 2002; UKDH, 2006; RCN, 2004).

Evaluation of the transition process

To further the knowledge and to develop an evidence-based model for transition – each program should be evaluated and results shared in the literature (Bennett et al, 2005; Forbes et al, 2001; Cowlard, 2003; UKDH, 2006).

2.5 Understanding individual roles in the transition process

Role of youth

Adolescents who have been 'cared for' since the time of their birth may have false assumptions that their condition is the responsibility of others (Blum 1995a). They need to develop the knowledge and skills to interact with adult health care providers effectively, to ask questions about their condition, medications, side effects, complications from use of other substances, and how to access additional services (Robertson et al, 2006; Kyngas et al, 2000; Canobbio, 2001). Youth and young adult patients need to take on the responsibility of self-management and learn about their own disease, indicators of increasing or secondary illness, and develop problem-solving and strategies for when and where to seek help (Bloomgarden, 2004; Lorig & Holman, 2003; Dee & Byers, 2003; Fiorentino, 1998). Youth themselves have identified transition as being difficult and complex (Steinbeck & Brodie, 2006; Farrant & Watson, 2004). Young adults need to continue voicing their opinions and suggestions about ways that facilitate effective transition (Coupey, 1997). They have identified connecting with mentors and peer support groups, and having a health care professional oversee the transfer phase whilst having knowledge and personal understanding of the condition (Kyngas et al, 2000).

"Youth and young adult patients need take on the responsibility of self-management and learn about their own disease, indicators of increasing or secondary illness, problem-solving and when and where to seek help" (Bloomgarden, 2004).

Role of the family

Care of the adolescent occurs within the context of the family (Blum, 1991; Paone, 2000; Patterson, 1991; Rosen, 1995) influencing health behaviors, compliance and outcome (Cameron, 1996; SAM, 1995; Peterson et al., 1994). Families need to be recognized as the most important resource in a young person's informal health care delivery system (Lynam, 1995). While it has been identified that families can be over-protective and fearful of encouraging independence in their youth (Alvin, 1992; Blum 1995a; Court, 1993; Hallum, 1995), families need to be supported to encourage autonomy and independence in their children and youth. Families need to encourage their youth to take ownership of his/her condition and support the development of skills for self-management by setting small attainable goals (Bloomquist, Brown, Peterson & Presler, 1998; Blum et al., 1991; Hallum, 1995; Kaufman, 1995; Pacer, 1991; Pacer, 1993; Rosen, 1994; Shapland, 1997; Schultz & Liptak, 1998; Vivian, 1996). Discrepancies are apparent between health care providers and parents perceived roles and responsibilities in teaching and content areas required in transition planning. Unfortunately, many parents feel they lack the skills, knowledge and resources to help guide their youth through the transition process (Geenan et al, 2003). The aim of initiating transitional care early on is to involve the family in all levels of

"Families need to be recognized as the most important resource in a young person's informal health care delivery system (Lynam, 1995). Families need to encourage their youth to take ownership of his/her condition and support the development of skills for self-management by setting small attainable goals".

planning, while promoting adolescent self-management and encouraging increasing self-care by the youth (Peter et al, 2009). Many families and youth indicated that involvement in a transition study triggered awareness of transitional issues and areas in need of development. (Williams, Sherman, Dunseith, Mah, Blackman, Latter, Mohamed, Slick & Thornton, 2010; McDonagh et al, 2002).

Role of pediatric health care providers (sub-specialty team members)

Care of the youth throughout their pediatric journey needs to be developmentally-appropriate and supported by psychosocial services for adolescents (Bennett et al, 2005; Morris, 1999). Pediatric care providers need to initiate and facilitate developmentally-appropriate care at set stages throughout adolescence ensuring all the steps of the transition plan occur (Sia, 1992; Reid et al., 2004; Whitehouse & Paone, 1998). Health providers for youth should have consultation skills that encourage the discussion of their specific health condition, interactions of medications with drugs and alcohol, sexual development and contraception options, pregnancy, and risk –taking behaviours (Cowlard, 2003). Moreover, opportunity must take into account the health care goals of the adolescent and how that fits into their short term and long-term lifestyle choices (Dovey-Pearce et al, 2005). Health care providers who demonstrate respect through communication and

interactions contribute to the development of self-esteem and self-confidence in the adolescent (Miller, 1996). Youth are more likely to follow treatment regimes when they have knowledge and personal understanding of the condition, reasons for the treatments or medications, positive attitude, and family support (Kyngas et al, 2000). Core behaviors of health care professionals to engage in effective relationships with youth should include caring



“Pediatric care providers need to initiate and facilitate developmentally-appropriate care at set stages throughout adolescence ensuring all the steps of the transition plan occur.”

behaviors of honesty and respect; asking open-ended questions; actively listening to answers; and ensuring confidentiality and privacy (Ginsburg, Menapace & Sipa, 1997). By far the most important issue in the eyes of young people is communication. Working with adolescents requires different consultation skills from those needed for children or adults in addition to the technical knowledge relevant to each individual specialty (UKDH, 2006). Young people also expect their specialist team to be future-focused and help them set long-term goals with increasing control and self-management (Robertson et al, 2006; Nasr et al, 1992; Anderson, Flume, Hardy & Gray, 2002). Health care providers need to balance guiding youth towards self-management of their health care needs with respect for the family's role in providing care to the youth (Pownceby et al, 1997). Through the transition process health care providers reconfigure the care relationship by gradually guiding youth towards self-management and simultaneously respecting the family's role (Pownceby et al, 1997; Paone 2000). This creates a partnership with the youth, shifting the focus of teaching and consultation to the youth while role modeling support and anticipatory guidance to the parent.

The sub-specialty clinic visit offers ongoing developmentally-appropriate and disease-specific education for the youth and the family throughout adolescence and into

adulthood. The integration of transition planning into the clinic visit offers an opportunity to address the changing needs of the adolescent and promote skills and knowledge necessary for adult care and health planning into the future (Bent et al, 2002; Blum et al, 1993; Blum, 1995; Hallum, 1995; Reid et al., 2004; Reiss, 2002; SAM, 1995; Schidlow & Fiel, 1990; Whitehouse & Paone, 1998). Studies indicate that youth are more likely to discuss risk-taking behaviors if clinicians open up discussion on repeat visits (Steiner & Gest, 1996). The importance is in creating a partnership with youth shifting the focus of teaching and consultation to the youth while role modeling support and anticipatory guidance to the parent (Frank, 1996; Lynam, 1990; Schultz & Liptak, 1998). Unfortunately, many pediatric care providers feel they lack the skills, knowledge and resources to provide this type of counseling and care (Blum & Bearinger, 1990) and this is also voiced by parents involved in the process (Geenan et al, 2003).

"New knowledge (for adult care providers) should include understanding the concept of adolescent development, engaging youth in discussions, promote a collaborative approach to patient care and help them build confidence in their new setting" (Betz, 1999).

Role of adult health care providers

Similar to the responsibilities and expertise required of the pediatric sub-specialist, the adult practitioner requires specific skills sets. Adult health care providers need to acquire the knowledge and skills to best treat and care for youth with chronic health conditions. New knowledge should include understanding the concept of adolescent development, and expertise should include the ability to engage youth in discussions, promote a collaborative approach to patient care and help them build

confidence in their new setting (Betz, 1999; Kennedy et al, 2008). There is a need to recognize the differences in adult chronic versus acutely ill population where patients need additional time in clinical visits to address their needs (Suris et al, 2009). Skills include being sensitive, non-intrusive, non-judgmental, supportive and providing positive encouragement to foster an environment of acceptance (Bennet et al, 2005; Kyngas et al, 2000; Pownceby et al, 1997; Visentin, 2003).

"There is little reference to the role of the primary care provider in the transition process - this is a significant deficit in the system" (Scal, 2002).

Role of primary care physician

Throughout the literature, it is noted that community-based, primary care physicians should take on greater responsibility for youth with chronic illnesses (Dovey-Pearce et al, 2005; Miles et al, 2004; Scal, 2002; Kelly, 1995). Once youth leave the pediatric system they are reliant on general, primary care physicians for referrals and access to community and adult health care services. A significant barrier is that general practitioners lack the needed expertise in caring for youth and young adults with special care needs. This can be counteracted by offering specialty education programs on topics of specific disease conditions and treatments as well as developmentally-appropriate care (Sanci et al, 2005; CPS, 2006; McDonagh et al, 2002). While transition has become a focus for government agencies, disease-specific organizations, and sub-specialty care providers, there is little reference to the

role of the primary care provider in the transition process (Scal, 2002). This is a significant deficit in the system and gap in the research.

Transition coordination role

Health transition is most successful when there is a designated professional to coordinate and oversee the process (SAM, 2003; AAP, 2002; Nasr et al, 1992; Canobbio, 2001; Myers, 2002; Sawyer et al, 1998; Sloman, 2005; Viner, 2001; Rosen et al, 2003; Reiss et al, 2005). This is a specialized role that requires dedicated time (UKDH, 2006). The role of this professional can be diverse and may include required skills of a clinical expert, consultant, educator, researcher and/or change agent (Betz & Redcay, 2005). Modes of interaction might include clinical time, telephone and email contact to access appropriate adult health care services (Van Wallegghem, MacDonald & Dean 2006; Weissberg-Benchall et al, 2007). This role has been recognized as essential by researchers and youth themselves (McDonagh et al, 2006) and is expressed in most position statements. This person might also be required to specialize in patient navigation to see the patient securely entrenched into the adult system and community based services (Van Wallegghem et al, 2008). A designated transition or project coordinator at each site, pediatric and adult, showed a 30% reduction in overage patients in the pediatric site (Sloman, 2005).

This is a specialized role that requires dedicated time (UKDH, 2006). The role of this professional can be diverse and may include clinical expert, consultant, educator, researcher and/or change agent".

The transition coordination role does not diminish the role and responsibilities of youth, their families or health care providers. Transition coordination should begin with the health care consumer, in this case youth and families, creating a partnership with health care providers to ensure continuity of care (GMTT, 2006; Blum et al, 2002; UKDH). Just as important, is that the youth/ young adults themselves take responsibility for the transition process and their ongoing health needs (Rosen et al, 2003).

2.6 The economics, access and transfer of health care information

Burden on the health care system

The Provincial Health Services Authority (PHSA) became involved in the shared-care model and chronic conditions because of the need for better prevention and management of chronic illness. It is estimated in BC that the incidence of chronic disease is a small fraction of the population requiring health services, yet as frequent users of the health care system are estimated to consume 80% of all provincial health care services (PHSA, 2010). More specifically, people with chronic health conditions use health care services more often and more intensely; 33% of Canadians with a chronic health condition

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account for approximately 51% of family/physician consultations, 55% of specialist consultations, 66% of nursing consultations and 72% of nights in hospital (Broemeling et al, 2008). The Health Council of Canada (2007) released its findings of providing care to children, youth and adults with chronic health conditions. It found that these conditions impact health and well-being and represent a significant and growing health care and economic burden to society. The report focused attention on prevention and management of these conditions through better access to services.

With health care expenditures in BC continuing to increase and resources decreasing, the provincial model must give priority to value or the 'best bang for your buck'. These will include health care strategies that prevent illness or complications, reduce duplication of services, engage in information technology to improve monitoring and surveillance of activities, increase quality of care and decrease duplication of services (PHSA, 2010). Evaluating the economic burden of transition is not possible presently due to challenges of tracking patients across health care jurisdictions and paucity of economic health services data. However, we can estimate that preventative, bi-annual health care visits are much less expensive than visits made by youth who fall out of care and use emergency department and intensive care beds as their health care options.

Accessing medical and community services

A key piece to successful transition is continuity of care during transfer. This "continuity" can be defined as continuity of clinical care, continuity of information flow, and continuity during transfer between health care providers (Haggerty et al, 2003). Where health care providers are concerned with transfer of health care information and referral, families evaluate continuity as being able to see the same practitioner and care provider on a continual basis.

"Integral to continuity of care into adulthood is the identification of a primary care physician. When children have chronic illnesses, the family practitioner role often becomes diminished or blurred with that of the pediatrician or sub-specialist, resulting in gaps in health care".

Integral to continuity of care into adulthood is the identification of a primary care physician. In BC, there are an estimated 4,500 family practitioners and approximately 270 pediatricians (Miller, Recsky, Ghazirad, Papsdorf & Armstrong, 2007). Most pediatricians restrict their practices to consultations, leaving the primary care of children and youth to family practitioners. When children have chronic illnesses, the family practitioner role often becomes diminished or blurred with that of the pediatrician or sub-specialist, resulting in gaps in health care. A long-term family physician who has known the patient and continues to see the patient during transfer may be able to bridge gaps in information when necessary, facilitating the transfer process. However, many young adults with chronic illness do not have family doctors and at this stage in life other transitions, including changes in school, education, employment and insurance, may impact the young person's ability to retain the same family doctor if they have one.

When practitioners meet to discuss transition and requirements of transferring care, many youth and families are not included in transition discussions (Beresford, 2004; O'Sullivan, 2007). In some studies, only 50% of parents report discussing their adolescents changing health care needs with a pediatrician (Lotestein et al, 2005) and of those only 42% had discussed switching to an adult provider (Sanders, 2009). A US national survey suggests that only 41% of adolescents receive appropriate transition guidance and support (Lotestein et al, 2005). Of the youth who do transfer to adult services, some may experience a lapse in care of a number of months or be lost to follow-up entirely (Pacaud, McConnell, Huot et al, 1996; Reid et al, 2004).

Transfer of Health Care Information

The transfer of information is integral to continuity of care and successful transition for youth between agencies, across health care jurisdictions, between multiple health care providers and community based services (Steinbeck et al, 2007). Health care agencies and authorities are engaged in using computer systems to transfer information and support continuity of care across jurisdictions. PHSA has prioritized information technology as critical to the development of the health care through computers and other electronic systems to enhance monitoring and surveillance, increase quality of care and reduce duplication of services (PHSA, 2010). However, the effectiveness of these initiatives to ensure continuity of care is not clear (Reid, et al, 2003). In BC, there is no one electronic platform that can cross between pediatric, adult, and primary care systems. Of the five provincial health regions, each has independently chosen their electronic charting tools. BC Children's Hospital (part of PHSA) has adopted "Cerner" as their e-charting system, whereas VGH (part of Vancouver Coastal Health) uses a product called the Patient Care Information System (PCIS), and an entirely different computer system to support community-based care. The capability and effectiveness of transferring charts between information systems at BCCH and VGH remains unresolved.

"The transfer of information is integral to continuity of care and successful transition for youth between agencies, across health care jurisdictions, between multiple health care providers and community based services (Steinbeck et al, 2007). In BC, there is no one electronic platform that can cross between pediatric, adult and primary care systems".

Pediatricians surveyed throughout BC identified improved communication, access to local community services and clinical data transfer between care providers as essential in meeting the needs of the families they serve (Miller et al, 2007). The ideal situation from the parent's perspective is that health care providers facilitate continuity of care through communicating with each other and discuss the patient's clinical situation and the information that would be helpful for ongoing care (Miller, Condin, McKellin, Shaw, Klassen & Sheps, 2009).

2.7 Current Transitional Models of Care

The extensive literature on transition needs, perceptions and programs has led to the development of models for transition (McDonagh & Viner, 2006). To be effective, any model must incorporate the political, institutional and environmental factors which may enhance or impede coordination of care (Scal et al, 1999). The most prevalent model for transition is merely a transfer of care to a general practitioner or an adult service provider. In general, three models for transition exist: disease-focused, primary care, and generic adolescent health services (Sawyer et al, 1997). While, Forbes, Ullman, Lewis, Mathers & Griffith (2004) completed a systematic review of the literature and identified 126 programs for transitional care sorted into six categories, each of which is described briefly below.

Direct Pediatric to adult sub-specialty model

The youth is transitioned from a pediatric to an adult condition-specific sub-specialty clinic or program at a pre-determined age. Preparation takes place during adolescence at clinic visits. The preparation continues with a graduation clinic on the date of his/her final appointment, meeting the adult sub-specialists at the pediatric site and transferring a patient health record summary. The next clinic visit is at the adult agency (Gravelle, 1997; Flume et al, 2002). The emphasis of the direct style model is on relations between services, continuity of information and crossing over to the adult service. It is a suitable model when pediatric and adult services are comparable and few extraneous services are required (While et al, 2004).

Example: Cystic Fibrosis and Cardiology from BCCH to St. Paul's Hospital adult programs

Intermediary or sequential model - Pediatric to young adult sub-specialty clinics

The youth is transitioned from a pediatric to a young adult condition-specific sub-specialty clinic or program. The pediatric physicians and multidisciplinary team members also provide the care at this clinic. Young adult issues are discussed as they pertain to their illness (Tucker & Cabral, 2005). The intermediary model provides care as an extension of pediatric care with care provided jointly between adult and pediatric providers (While, et al, 2004). This gives the youth time to plan, prepare and practice behaviors required by the adult health care system and fits with the new concept of emerging adulthood.

Example: Young Adults with Rheumatic Diseases (YARD) Clinic BCCH and Arthritis Association

Developmental transitional model

This model is based on the premise that the youth and young adults need to develop the skills and knowledge necessary to utilize the adult health care system effectively (Whitehouse & Paone, 1998). This model, which can be incorporated into other models of care focuses on integration of developmentally-appropriate care into all health care settings (While et al, 2004). This model requires a specialized team to support the different sub-specialties in the pediatric clinics to ensure that all young people in the different specialties go through appropriate transitions.

Example: ON TRAC Model (1998-2000)

Primary care model

The primary care model identifies a general practitioner as the key coordinator to ensure continuity and comprehensive care. The GP, long recognized as the gatekeeper to health care services, is recognized as an essential player in transitional care (Scal, 2002; Dovey-Pearce et al, 2005; Miles et al, 2004; Cooley, 2004). A primary care model can incorporate a transition coordinator role to help youth and families navigate the health care system and create linkages between the pediatric centre and adult general hospitals (Bennett et al, 2005). The Society for Adolescent Health has established a core principle for transition "that health care transition is most successful when there is a designated professional who, together with the patient and family,

takes responsibility for the process" (2003). However, many barriers to this model exist due to lack of education, training, time, reimbursement, and access to general practitioners willing to take this role on (Lam et al, 2005; Johnson, 2007). In BC, youth who leave pediatric care require a physician referral to access adult health care services on an annual basis.

Shared care model for youth with multiple and complex health issues

Youth with multiple diagnoses, disabilities and complex health issues are the most difficult to transition. For many of these young adults, there are no services available to meet all their needs, care is fragmented and requires extensive coordination (Sawyer et al, 1998; Fiorentino et al, 1998; Rosenbaum, 2003). At this time, many experience ad hoc transition planning which includes locating multiple adult health care sub-specialists and community resources. The 'shared care' model strives to improve provider satisfaction, reduce inappropriate utilization of tertiary services, and increase use of primary care and community based services. The joint provision of clinical services requires comprehensive referral guidelines, shared responsibility for patient care, clear differentiation of roles, ongoing communication and information exchange and collaborative professional education. It means the inclusion of patient and family in planning and decision-making and a patient-centred focus on supporting self-management. The overall benefits of 'shared care' are increased patient access to care; reduced fragmentation of care, increased integration and continuity of care; strengthened links between primary, secondary and tertiary sectors; improved working relationships between providers; and improved satisfaction among patients and providers (Millar, 2009; Charles, Gafni, Whelan, 1997).

Youth with degenerative health conditions may require additional hospice, palliative and end-stage health care planning (Siden et al, 2010). Many children leaving BCCH are also technologically dependent and will require a change of supportive services as they reach 18 years of age. At a minimum, these youth require a team approach to transitional planning including a general practitioner with an interest in disability, rehabilitation consultant, nurse specialist for transition/patient navigation, and an occupational therapist (UKDH, 2006).

Examples: Spina Bifida, Muscular Dystrophy, Neuromuscular Disorders and Canuck Place

Regional care model

A regional transition model with generic transition coordinators can serve large geographical areas and cross health care jurisdictions. It is particularly suited to situations where pediatric care is provided in centralized tertiary care facilities, and patients, when they transition are going to receive care in a variety of health care settings including remote regions. In this model, the pediatric sub-specialty clinics identify the adult health care provider, the organization and their region where future services will occur. They provide this information to the patients and family as well as the responsible transition coordinator for that region. While the transfer may be from pediatric specialist to adult specialist or family doctor, the regional transition coordinator assists the youth and their family access to services and completes the

transfer process. The benefits to this model include the transition coordinators understanding of the unique characteristics of the region and ability to navigate the patient into adult health care services after the pediatric discharge. Gaps in services or problems with the transition process can be referred to the state, or provincial coordinator who works with the Ministry of Health and oversees the regional transition coordination.

Examples: Greater Metropolitan Transition (GMIT) Taskforce, New South Wales

Section 3

A Framework for Transitional Care of Youth & Young Adults in BC

3.1 Developmentally-appropriate guidelines for youth ages 10-24 years of age

In 1995, BC's Children's Hospital pioneered the On TRAC Program, a transition framework and teaching tools that have been adopted and used extensively in Canada and internationally in Australia, the US and the UK (RCN, 2004; UKDH, 2006; CPS, 2007). On TRAC's goal was for all youth with chronic health conditions to leave pediatric care with the necessary skills and knowledge to advocate for themselves or through others, maintain health-promoting behaviours, and utilize adult health care services appropriately (Whitehouse & Paone, 1998; Robertson et al, 2006). A developmental framework was conceptualized within the three stages of adolescence: early (beginning at 10 years of age), middle, and late. As the framework was being implemented, a fourth stage, 'emerging' adulthood, was recognized for youth ages 18-24 years of age as an essential stage in the process (Arnett, 2004; Dovey-Pearce et al, 2005). Through each stage it is understood that transition planning and timing needs to be flexible to meet the individual needs of each youth and family. Variations may occur due to severity and exacerbation of the youth's/young adult's condition; physical and cognitive abilities; psychological and emotional stability; family and social supports; and the onset or readiness to begin the transition process (Gravelle, 1997; Brumsfield & Lansbury, 2004; Chamberlain & Rooney, 1996; UKDH, 2006; Soanes & Timmons, 2004; Myers, 2002; Salmi et al, 1986). Transition, as a process, is seen by many to begin as early as diagnosis. Activities to promote independence could include:

"In broad terms the adult seeks care, the child receives care. The developmentally immature adult in the adult system of care is a victim since he or she is assumed to be autonomous" (Stineman, 1989).

Birth – 3 years of age

- Encourage the child to assist with all activities
- Allow the child time to complete tasks
- Talk with your child about his/her condition

Childhood 3-5 years

- Teach the child about his/her special needs related to the condition/illness
- Encourage your child to participate in self-care
- Help the child to interact socially in various settings
- Assign household chores or responsibilities

Childhood 6-12 years

- Allow the child to relate his/her experiences and concerns about their condition
- Help the child interact appropriately with health care providers
- Talk about career options, interests and abilities

- Encourage participation in making choices
(Osteogenesis Imperfecta Foundation, 2006)

The ON TRAC Developmental Framework for Transition Care begins in early adolescence, and continues through the period of emerging adulthood, during which successful transition to adult services should occur.

Table 1: ON TRAC Developmental Framework for Transitional Care

Stage / Age range description	Key issues/ goals per stage
<p>Early Adolescence (10-12 years) initiated at 10 years of age to coincide with onset of puberty; 5th year of school that introduces life skills curriculum; assumes patients have the capacity to read, write and start to talk about their future.</p>	<ul style="list-style-type: none"> • Introduction of the transition process • Opportunity for youth to ask his/her own questions • Begin to discuss developmental issues of adolescence and impact on health condition • Identify personal responsibilities for health and skills that can be promoted at home/ or school
<p>Middle Adolescence (13-15 years) changes in peers, relationships, and parental supervision; possible onset of risk-taking behaviours; strive to fit in may reduce adherence to medications/ treatments; looking for opportunities for health care discussions.</p>	<ul style="list-style-type: none"> • Visit with youth alone to identify health related problems • Take on 'ownership' of health condition and responsibility for consequences of decisions and actions • Accessing health information not available in the public domain – complications of medications with drugs, alcohol and contraception • Discussion about the future, educational/ vocational planning.
<p>Late Adolescence (16-18 years) realization of impending transfer of care; all health care related systems change at 18 years of age; questions of educational/ vocational/ financial needs; required access to primary care physician and adult sub-specialists; fear of leaving pediatric care.</p>	<ul style="list-style-type: none"> • Support the grooming of independent health consumer skills – meeting on their own, asking questions, collecting pertinent health care information. • Signing-on with a primary care physician • Meeting with adult sub-specialist/team • Transferring health care benefits and accessing applicable community-bases supportive services • Collection of health care documents
<p>Emerging Adulthood (18-24 years)</p>	<ul style="list-style-type: none"> • Acquiring primary care in living

<p>discharge from pediatric care, transfer of care and initiation of adult care; changes in health care status such as insurance; managing multiple transitions; independent living, further education and employment, moving living locations and financial concerns; requires ongoing support and guidance to access health services and information.</p>	<p>location</p> <ul style="list-style-type: none"> • Attend adult clinics • Self-monitor health condition and treatments* • Identify needed resources, services, supports to maintain health • Participate in educational/ vocational activities
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Each stage of the process incorporates the developmental and health challenges that affect healthy outcomes for youth; self-advocacy, independent health care behaviours, sexual health, social supports, educational/vocational planning, and health and lifestyle decision-making. Each developmental component can be defined and provided with a rationale from findings in the literature.

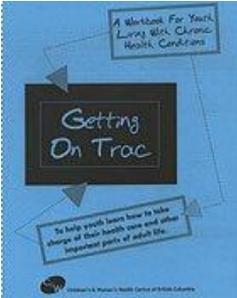
NB: * Self-management does not imply isolation or rejection of supportive family or community relationships.

Table 2: ON TRAC Developmental Components

<p>Self-advocacy and Self-management – empowering youth to learn about their chronic health condition, to understand their rights and responsibilities, to understand their medical, physical and social needs and to be able to express those needs to others and the community.</p>	<p>Initiate separation from parents to foster independent decision-making and voicing concerns (Dee & Byers, 2003; CPS, 2006; Soanes & Timmons, 2004; Visentin, 2003). Youth need to make informed decisions, know their rights and have the ability to provide own consent to treatment (UKDH, 2006; Morton & Westwood, 1997).</p>
<p>Independent Health Care Behaviours – includes understanding their own health condition and able to explain to others, adhering to medication and treatment regimes, ability to recognize complications and increasing illness, ability to make appointments and seek health care information and services, and to strive for independent self-management dependent on his/her medical, physical and cognitive abilities.</p>	<p>Build competence in health care knowledge and management (Yeo & Sawyer, 2003). Health care providers meeting with you alone can encourage independent health care and self-management, to the level they can achieve (Kennedy et al, 2008; Tuchman, Slap & Britto, 2008; Zack et al, 2003; Forbes et al, 2001; Kelly et al, 2002). Build independence from parents and control in decision-making and personal satisfaction (Miles et al, 2004; Soanes & Timmons, 2004). Support development of self-care skills (Robertson et al, 2006).</p>
<p>Sexual Health – addresses the impact of puberty and the health condition on sexual functioning, genetics, safe choices, and identifying sexual health information on his/her community.</p>	<p>Youth need to learn differences in normal sexual development due to disease conditions, medications and treatments (Suris et al, 1996; Boas et al, 1995). Discuss contraception, pregnancy and fertility</p>

	issues unique to their health condition (Nixon et al, 2002). Discuss risks and prevention of sexual abuse (Cromer et al, 1990; Kaplan & Friedman, 1994; Greydanus et al, 2002).
Social Supports – acknowledges the importance of peer relationships and socialization, the families changing role, linking to community services and groups. Knowing who to contact for what. Aware of impact of health condition, changes on health on mental well-being.	Strengthen connectedness with parents, school and peers to increase resiliency (Yeo & Sawyer, 2003). Discuss importance for youth and families to connect to others, the community and social networks (Pownceby et al, 1997; Vogel et al, 1998).
Educational/Vocational/Financial Planning – realizing his/her full potential, access to resources and services to support education and career options and planning for health care benefits, insurance and financial planning.	Youth require skills in managing social, education and employment opportunities (UKDH, 2006). Youth and families need to make plans for housing and recreation (Vogel et al, 1998; Beresford, 2004; UKDH, 2006; APA, 2002). Education and vocational planning can be strengthened by a family-professional partnership (AAP, 2000).
Health & Lifestyle Behaviours- addresses the importance of nutrition, exercise and healthy choices. Identifying the risks of drugs, alcohol, smoking and impact on health.	Health care providers need to screen for risk behaviours and protective factors (CPS, 2006; MCS, 2010). Youth need to learn about nutrition and exercise patterns that promote health (White, 2007).

To review original ON TRAC Transition Framework see **Appendix B**.



Next is to take these developmental indicators and create exercises for youth to gain the knowledge and skills required for adult health care and management. *Getting On Trac: A Workbook for Youth* (Paone, 1999) contains over 70 exercises for youth living with chronic health conditions to work with health care providers, parents and educators. Through skill development exercises in this workbook, youth are supported and encouraged as they learn to participate in their health care and transition planning (Pinzon, Jacobson & Reiss, 2004). The workbook includes a guide for youth-focused care and

education (with pages specifically designed to be photocopied) to be used in private consultation or group workshops, and as a personal support tool.

3.2 Transition documentation and health care records

Just as critical to the movement of the youth to the adult care system, is the health care documentation that must accompany the patient transitioning from the pediatric system into adult care. Many programs have developed checklists and tools to

facilitate the transition process. An extensive review of transition programs, tools and strategies being used globally can provide significant direction for BC Children's Hospital. For each program located, components have been indicated that would support the implementation of a comprehensive transition approach for BC. A complete list of transition programs, tools and strategies being used globally has been provided in the **Appendix C** for review.

Three main groups of individuals require documents that have been identified as necessary to support comprehensive transitional care:

- 1) Youth and or young adult
- 2) Families or guardians
- 3) Health care professionals

The tools can be varied but address two main issues:

- 1) Transition Planning: transition process documentation (checklist/ clinical pathway)
- 2) Health Care Information / Record

Transition Plan Timelines/Checklists

Many studies have solidified the need for a developmentally-appropriate, youth focused, culturally-sensitive framework of care for general or condition-specific populations. Some are based on the developmental framework and tools developed at BC's Children's Hospital (Robertson et al, 2006; UKDH, 2006; Reiss & Gibson, 2002). Many programs have developed checklists and tools to facilitate the transition process. Most of these tools are not validated or evaluated but serve as a starting point for transitional care, addressing a young person's readiness to transfer and direct skills necessary for self-management..

- **Preparing to Transition from a Pediatric to an Adult Care Practitioner; Transitioning to Adulthood with IBD.** Sponsored by Proctor & Gamble. Describes knowledge needed by youth, responsibility indicators and health and lifestyle behaviors. Checklist revised from ON TRAC framework. <http://www.cdhnf.org/user-assets/documents/pdf/TransitionTeen.pdf>
- **Readiness Checklist** developed by Sick Kids Hospital in Good to Go Program. Based on ON TRAC framework. <http://www.sickkids.ca/Good2Go/index.html>
- Royal Children's Hospital, Melbourne **Health Care Skills Checklist** http://www.rch.org.au/transition/factsheets/index.cfm?doc_id=13740
- **Planning Checklist and Evidence Record.** Developed from competency-based framework by ON TRAC; identifies personnel involved in the transition process; includes start dates for early, middle and late transition; lists 1-2 indicators per developmental stage to be achieved (RCN, 2006).
- **Canuck Place Transition Checklist** for children and youth with complex physical, cognitive and often end-stage conditions

Determining transition readiness and self-management skills

While many programs have developed tools to assess a youth and family's planning and preparation for transition, few focus on the youth's readiness to transfer into the adult system (Scal et al, 1999). Readiness is the most important predictor for successful transition over age (Capelli, et al 1988). Forty-nine youth ages 11-15 years in a neurology clinic and their parents found a correlation between medical self-management and adaptive functioning. Many families and youth in the study indicated that involvement in the study triggered awareness of transitional issues and areas in need of development (Williams et al, 2010). It is understood that transition is a process of independence acquisition and self-management skills throughout adolescence (Sawyer & Aroni, 2005). Self-management does not mean management in isolation. Knowing when to ask for help is an important part of self-management. The goal is to involve the family in all levels of transition planning, while promoting adolescent self-management and encouraging increasing self-care (Peter et al, 2009).

To measure self-management, a validated assessment tool is needed that consistently measures stages of the youth's readiness to transfer. This would help identify education and training needs of the youth to families and health care providers throughout the transition process. Skills for self-management should include:

- Ability to explain their condition to others
- Knowledge of their medications - purpose and side effects
- Ability to recognize complications and how to seek help
- Ability to make appointments
- Knowing who to talk to and for what (Kennedy et al, 2007)

The Transition Readiness Assessment Questionnaire (TRAQ) developed by Sawicki, Lukens-Bull, Yin, Demars, Huang, Livingwood, Reiss & Wood (2009) is the only validated tool that has been developed to assess youths' skills for self-management and self-advocacy along a continuum of health care behaviors. This group of researchers condensed nine checklists, (including the Transition checklist developed by ON TRAC at BCCH; Whitehouse & Paone, 2000), developed for use with various groups of youth. Using a five point ordinal scale, the youth identify their level of competency and preparation in these areas. The TRAQ, like the ON TRAC checklist, lists indicators which can be used to assess the youth's readiness to transfer.

ON TRAC 'Are you ready to transition?' Questionnaire

TRAQ 'Transition Readiness Assessment Questionnaire

Health Care Information/ Record

The transfer of pertinent health care information between pediatric and adult health care agencies, as well to the primary care physician, is vital to ensure transition efficacy (Dovey-Pearce et al, 2005; Miles et al, 2004; SAM, 2003). Transfer of medical information to date occurs on an ad hoc basis (Steinbeck et al, 2007; Viner, 2001). This is a significant issue in transitioning youth from pediatric care as it is essential for continuity of care that there is an accurate and current flow of information between the youth,

family and health care providers and agencies. Multiple barriers to this seemingly simple task continue to exist. For example, physicians have limited time for such tasks and do not receive financial reimbursement to complete the forms (Steinbeck et al, 2007). In addition, there is a lack of consistency in what information is required during care transitions. Incompatible data collection practices and electronic medical record (EMR) platforms used in different jurisdictions such as health care agencies and health authorities further impedes information transfer during care transitions.

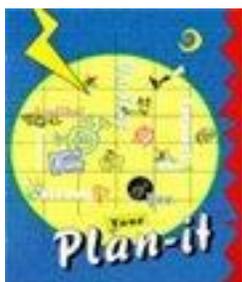
At a minimum, pediatric health care providers should provide an accessible, up to date, summary of care to facilitate smooth collaboration and transfer of care between health care professionals and services (CPS, 2007; RCN, 2006). This written summary should contain requirements at the time of discharge, including the condition, clinical findings, medications, pediatric, and adult care providers and services, primary care physician as well as psychosocial and transitional issues (White, 2009; Sawyer et al, 1997; Viner, 2001; Sloman, 2005).

Challenges regarding information during transfer have led many patients and their families to develop personal methods to track their health information that coincides with the recent interest and growth in personal health care records. Until a seamless system of medical transfer of information exists, it is recommended that youth, young adults and or their families or guardians (depending on developmental/ cognitive abilities of the youth) have their own comprehensive health care record.

White (2009) has compiled a list of required components for a hand-held or ideally electronic form of portable, medical summary to include;

- medical summary
- allergies
- immunizations
- family history
- surgical history
- critical or life-threatening issues
- health care providers/ contact information
- community services
- treatment protocols and medications, and
- any significant guidelines such as 'do not resuscitate' orders, power of attorney or health surrogate or guardian
- developmental milestones

The On TRAC program at BCCH developed the Plan IT (1999) and Family Care Book to address the youth and family's needs of a personal, home health care record.



The Plan-It is a youth health planner designed for youth with chronic health conditions, was designed by and for youth to assist them in learning about their health condition and participating in their care management. Plan-It provides a medium for youth to record, sort and organize health care information they require on a daily basis or when arriving at a new stage in their development such as school

entry, changing care requirements, new health care personnel, or transitioning to adult care. This bright blue binder with full colour pages and graphics is designed for youth ages 10-18 years. The youth are encouraged to bring the planner to all health care visits and in the event of emergency care. Care providers, teachers and families are encouraged to work with youth at home, in school, and at health care visits to plan for and participate in their health care as they are interested and able. The use of the tool encourages skill and knowledge building required in preparation for the adult world and health care system.



The **Family Care Book** (FCB) was created for youth with complex, special health care needs and their families to help them prepare for adult care and adulthood. Divided into four sections, the FCB addresses daily care needs, health condition summaries, issues to consider when planning for adulthood and adult care and a progressive plan and resources to get there. The home health record was developed to help families record and sort information, think about and plan for the future, and

look up and connect with resources in their own community. To date over 500 copies of the health care binder have been distributed throughout BC via BCCH Family Resource Library, hospital nurse clinicians, social workers and community health nurses.



The **Health Passport** developed by the Hospital for Sick Children, Toronto is an online health summary tool called "Good2Go" which provides patients with both a paper health record summary that fits inside a wallet, and an electronic version that can be emailed to a cellular phone and stored electronically. It gives a patient instant access to his/her medical information (conditions, past procedures,

treatments, allergies as well as a list of current and previously used medications). They also have the option of emailing an electronic version to themselves or someone else. Youth create their own passport by logging onto www.sickkids.ca/myhealthpassport and follow the simple directions to complete their record in about 10 minutes. To date there are 747 youth in Canada, 181 in the US and 109 internationally registered with a health passport.

Web-based applications

Overwhelmingly health care consumers are turning to internet resources as a source of health information and to access emotional support. Youth and young adults expect to access online information and communication as part of their daily lives (Steeves & Young, 2005). Up to 94% of Canadian children and youth have access to the internet at home and most report accessing the web daily (Steeves & Young, 2005). As adolescents are increasingly using the Internet as a means of acquiring information, managing tasks, communicating and socializing the web – with limitations - holds promise as an effective medium for supporting transitional care through a comprehensive, multifaceted intervention, educational program and clinical tool.

The internet offers contradictory information to youth, both lifesaving resources and harmful misinformation (Lombardo & Skinner, 2004; Ridgley, Maley & Skinner, 2004; Goodstein, 2007). Perhaps this is why youth surveyed want health information driven by peers, yet overseen by health care professionals. There is also an expectation by the youth visiting health sites that all information is current and safe (Skinner, Biscope, Poland & Goldberg, 2003). Teens have also expressed a need for a safe, non-threatening and confidential mode of two-way communication surrounding health topics as well as a desire to connect with others that share similar coping challenges (Moreno, Ralston & Grossman, 2009). Teen health portals could increase access to care and improve communication with health care providers (Bergman, Brown & Wilson, 2008). In addition, the literature has suggested that providing opportunities for adolescents to exercise increased responsibility online may assist the transition to independently managing their own health care as adults (Steeves & Young, 2005). However, the internet should be used in conjunction with clinical consultation, a tool to seek information about a health condition in order to make health related decisions for planning or to learn about resources or support systems (Balka, Krueger, Holmes & Stephen, 2010; Skinner et al, 2003).

“The internet offers contradictory information to youth, both lifesaving resources and harmful misinformation (Lombardo & Skinner, 2004; Ridgley, Maley & Skinner, 2004; Goodstein, 2007). Perhaps this is why youth surveyed want health information driven by peers, yet overseen by health care professionals.”

Online health care records

Persons with chronic health conditions require easy access to their personal health care information. Once thought of as the property of the health care provider, patients now are demanding up to date, current access to their health information. The Internet is now being used as a medium to store current health information, accessible via computer or phone (Nugent, Tina, Sandborg, Chira, Soni, A. & Donahue, 2010). In B.C., TELUS Health Solutions © (based on Microsoft Vault ©) has the expertise to develop an online personalized health care chart for consumers. This health care application offers the opportunity to develop an electronic health care record for youth with chronic health conditions, providing a place for youth and families to input and store all their pertinent health care information to be accessed via the internet whenever they need it. In addition, youth can give permission for others to review their health care information as required for their care. In partnering with TELUS health space applications, youth with chronic illnesses and special care needs will be able to create, store and manage all aspects of their health information such as immunizations, allergies, medications, height, weight, symptoms, key medical measurements, pre-existing conditions, as well as their medical history.

Texting and social media

Health care providers are beginning to use social media and other electronic communication tools to connect with patients. Health care provisions to youth have already changed (SAM, 2009). Youth and young adult clinics are being offered later in

the day or evening so they do not interrupt school or work. Appointments and questions are being addressed through text messaging. 76% of teens living in a family where total income is between \$30,000-\$50,000 own a cell phone; the average time to respond to a text message is 3 minutes. 'Text in the City' is a text messaging service for teens attending the Mount Sinai Adolescent Health Center (MSAHC) in New York. This project offers question responses to youth within 24 hours as an adjunct to clinical care. See www.textinthecity.posterous.com for further details.

3.3 Clinical Pathway for self-management, transfer and continuity of care

Planning has been identified as the most important component of transitional care (Viner, 2000) and must occur at the individual (patient-centred), organizational, and inter-organizational levels (Forbes et al, 2004; Sawyer et al, 1998). It is essential that the transition plan is individualized, developmentally-appropriate and written (Brumfield & Lansbury, 2004) and that it identify set protocols and roles for staff to follow (Por et al, 2004). Effective transition plans should include dates, services, developmentally-appropriate health education goals, adult services and providers (AAP, 2002; RCN, 2004; Shaw et al, 2004; Whitehouse & Paone, 1998; Paone, Wigle & Saewyc, 2006) and should be written in collaboration with the youth, families and or care providers (SAM, 2003; Zack et al, 2003).

Clinical pathways have been created and used to map a patient's journey through the health care system. Whereas pathways have been focused on disease/illness treatments plans, they can be expanded to be patient-focused, long-term and applicable across health care jurisdictions to reduce fragmentation during a time of transfer. The PHSA (2010) has identified clinical pathways as a key strategic directive to provide seamless, patient-centered care and has acknowledged the use of pathways as a tool to promote linkages across care delivery organizations. This integration will require a patient centered approach that encourages collaboration and information sharing among the patient, families (as required) and health care professionals. The key actions for providing seamless care include:

- integrated care plans for patient groups with the most common co-morbidities,
- establishing standard referral, intake and discharge information sets for patients who use our services, and
- developing inter-professional care pathways, focusing on key transition points in our highest volume services, and creating patient navigation vehicles to link care along the continuum (p.11)

This model is ideal for transitioning patients from pediatric to adult care as it offers a continuous opportunity to facilitate developmentally-appropriate, transitional care. Documentation of the transition process is essential to ensure coordinated, navigated, seamless, ongoing health care for youth and young adults with special health care needs (RCN, 2004) and to monitor and evaluate outcomes.

Anticipated Outcome of using a Clinical Pathway

1. Improved continuity of care and coordination of care throughout the adolescent period that incorporates the roles of all stakeholders involved.
2. Improved documentation of patient knowledge and skills in transition issues, variances of care, and a mechanism for quality of care review.
3. Increased youth and young adult health-promoting and health-maintaining behaviors.
4. Increased youth and young adult involvement and participation in decision-making and treatment plans.
5. Improved goal setting, identification of readiness to transfer and realization of personal progress.

In 2000, a clinical pathway was designed and introduced at BC's Children's Hospital to ensure that developmentally appropriate, comprehensive, quality care was provided to all youth with chronic health conditions attending BC's Children's Hospital. The pathway was based on the psychological, social and emotional tasks of youth during the adolescent years (10-17 years of age). The aim of the clinical pathway was to improve quality of care for youth by educating and supporting staff, coordinating the utilization of available resources and evaluating patient outcomes. This pathway was developed for use by a multi-disciplinary team to outline the optimal timing and sequence for providing developmentally appropriate care throughout adolescence by encouraging increasing self-management and independence in health care behaviours. It was also designed to be used as a transfer summary record indicating youth's readiness to transfer and as a tool to identify those in need of additional transitional support. Each indicator reflected a developmental task or skill set needed by youth to move towards health maintenance and self-management into adulthood. Indicators not met or requiring further support were considered variances which required further investigation or intervention.

"In a clinical pathway that spans 10-24 years of age, certain times for 'active' transition planning with specific skill indicators, can be identified".

Variance Indicators & Referral for Specialized Care

The indicators on the pathway are the outcomes to be achieved by the youth and/or family following the teaching, discussions and tools provided by the health care team members. Skill and knowledge development by the youth and family is encouraged by thorough completion of these tools and opportunities in the clinic and in the home to practice learned behaviours. In a clinical pathway that spans 10-24 years of age, certain times for 'active' transition planning with specific skill indicators, can be identified. In cases where the youth is not able to achieve an indicator within a certain timeframe, it will be considered a variance and will be documented. The purpose of variance tracking is to continuously identify areas that will improve patient care and identify when the patient requires more intense health care support. Most variances will reflect necessary adjustments to the plan in response to the youth's/ young adult's health condition by health care team members. These variances can be tracked to see if they

have deviated significantly from the clinical pathway, and, if so, if such changes have any impact on health outcomes for the patient population.

Issues/ Problems with existing BCCH Clinical Pathway

The BCCH (2000) pathway was developed under the direction of nursing documentation committee and Quality Assurance committees of the time. The nurses and staff of the pediatric sub-speciality clinics identified a number of barriers to the use and integration of the tool. For example, there was a lack of training and support, the pathway was seen as too extensive and complicated and health care providers lacked clinical time implement the tool. In addition, while transition has been a long-time concern for health care providers in B.C., the required funds to support an ongoing transition referral service were not maintained.

Required components of ON TRAC2 revised clinical pathway for BC

While the ON TRAC clinical pathway has been adopted internationally it requires revision. Review of the literature supports the need for a written, comprehensive health care transition plan that facilitates the communication and documentation between the youth, family, pediatric, primary and adult care providers (AAP, 2002; RCN, 2004; Shaw et al, 2004).

Key components for the ON TRAC2 pathway will

1. Encompass the medical, psychological, emotional, social, sexual and future needs of the youth, young adult and family;
2. Focus on the youth's/ young adult's abilities and competencies;
3. Remain family centered/ youth focused;
4. Ensure cultural sensitivity;
5. Include community based teaching and use community based resources;
6. Offer identification of local coordinated services;
7. Ensure accountability through ongoing evaluation
8. Identify key pediatric, adult and primary health care professionals;
9. Include knowledge and skills for youth/ young adult beginning by 10 years of age;
10. Incorporate developmentally-appropriate long-term planning into adult services until 24 years of age;
11. Ensure the use of an up-to-date accessible and portable medical summary (APA, 2002; SAM, 2003; CPS, 2006; NASPGHN, 2002);
12. Identify health care practitioners; general practitioner, pediatric, adult and community based services;
13. Identify access points to a generic, specially trained transition team;
14. Identify a qualified patient navigator/ case coordinator as required (RCN, 2004; UKDH, 2006; GCTT, 2006); and
15. Include areas to integrate disease/condition-specific issues and learning (Murphy & Foster, 2005; RCN, 2004).

The framework for transitional care developed by the Greater Metropolitan Clinical Taskforce in Sydney, Australia (GCTT, 2006) encompasses many of these components. It

is comprised of three phases: preparation, active transition, and integration that identify specific areas of development for the emerging youth population (ages 18-24 years). The preparation phase includes formal identification of a pediatric coordinating team, planning and preparation for active transition, baseline assessment of readiness completed for and by young person, family and staff and identification, selection and inclusion of appropriate adult services. The active phase of transition encompasses ongoing evaluation of assessment and readiness, engagement of combined pediatric and adult transition team in partnership with the young person and family and the successful transfer to adult services. Finally, the integration phase requires a completed transfer and integration into adult services, outcomes evaluation and assessment of readiness evaluated.

Documenting the transfer of care

Integral to the success of the revised transition clinical pathway is ensuring the 'transfer of care' tool is completed. Health care providers must take responsibility for navigating, initiating, and ensuring completion of the transfer of care. For youth leaving B.C. Children's Hospital, future care may include many adult and community care services, and successful transition may require visiting different sites. Successful transition requires that a relevant, concise and complete summary of the medical record must be transferred, and should also be supplied to the youth and/or the family – depending on their level of care requirements. Transfer documentation must include, but not be limited to communication with the physician in the home community; the adult specialist or care team chosen, and an indication that the adult specialist has received appropriate clinical information. In addition, documentation should indicate that the youth has attended a transition clinic or workshop (if available), that a 'portable' personal health record exists and is up to date, that the youth has toured the adult clinic, and that an appointment with an adult specialist has been set up. Finally, the documentation and signature process should indicate that the transfer of records has taken place. Finally, after the first appointment in the adult clinic the accepting physician should provide follow up information to the referring clinician, confirming that transfer was successful.

Medico-legal issues and transfer:

Transferring patients between health care jurisdictions has implicit liability concerns. Clarity around issues regarding "who is responsible for what" will help reduce potential risks to patients, physicians and institutions. The CMPA warns that courts may interpret physician accountability from the moment the referral is accepted. As such, the CMPA recommends that Health Authorities establish clear accountabilities, communicate those accountabilities across their services. (*"Wait Times: A medical liability perspective," The Canadian Medical Protection Agency (CMPA) provides risk management recommendations for policy, health care institutions and physicians in the context of wait time issues.*)

The CMPA recommends the following procedures:

Referring physicians:

1. Should note the date of appointment with the consulting physician, and determine if this timing is due for significant clinical concern.
2. Consider ongoing appropriate care for patient while on waitlist.
3. Warn patient about the signs and symptoms for which to seek additional care.
4. Physician should communicate with consulting physician any significant clinical change in patient.
5. Attempt to negotiate an earlier appointment if clinical condition necessitates, or exceeds benchmark. If not possible, consider referring elsewhere.
6. Document assessment and attempts to arrange earlier appointment.
7. Monitor patients and re-prioritize.
8. Communicate patient's needs to institutions, consulting physicians, and others as required.

Consulting physicians:

1. Notify referring physician of the appointment date
2. If, at time of referral, wait time exceeds the benchmarks, consider declining and referring elsewhere, and notify appropriate institution the wait times are beyond expectations and the need to refer elsewhere.
3. If wait times of the existing patients begins to exceed benchmarks, consider informing the patients and discuss consequences of continuing to wait, discuss alternative treatment options, if available, and offering possible referral elsewhere.
4. Be aware of any legislation or institutional requirements with respect to managing wait times.
5. Monitor patients and re-prioritize queues as ongoing responsibility.
6. Communicate patients' needs to care providing institutions, primary care providers and others as required.
7. Document all actions.

3.4 Transition research questions and evaluation methodologies

While all levels of care practitioners and policies makers have accepted the definition, goals and objectives of transition as essential for maintaining ongoing health for youth with chronic health conditions, there appears to be no evaluated model or processes to ensure healthy outcomes for youth (While et al, 2004; Stewart et al, 2007; Forbes et al, 2001; Kennedy & Sawyer, 2008). Some research has been done with condition-specific cohorts to demonstrate outcomes of transition planning and/ or components of transition during the adolescent years. An extensive condition-specific list of studies is included in **Appendix D**. In order to assess the impact of interventions aimed at improving transitions on health outcomes, larger cohort studies of youth with different

conditions are required, so that it is possible to understand different and similar needs related to transition, across health care populations (Kennedy & Sawyer, 2008).

In a summary of over 126 transition programs and practices, only three had an explicit methodology to guide evaluation, survey/interview or review to generate evidence (While et al, 2004). There is little research in the areas of long-term follow-up, evaluations of practice and models of service delivery (Beresford, 2004). Although transition programs have infrequently been evaluated, researchers and practitioners have identified several aspects of transition interventions which should be measured. For example;

- Significant improvement in child/youth health based on a change in practice and access to ongoing health care into adulthood;
- Evaluation of practice and models of service delivery (Beresford, 2004; While et al, 2004);
- Long-term follow-up of the transition processes (Beresford, 2004);
- Views and experiences of adolescents themselves, parents and clinicians (Craig et al, 2007);
- Examination of specific factors that contribute to a successful transition process (Craig et al, 2007);
- Efficacy of education and support on youths' self-management skills (Sawyer & Aroni, 2005; Jordan & Osborne, 2007);
- Patient, family, physician, nursing satisfaction;
- Evaluation of the transfer of medical records, information to adult care providers and young adult;
- Systematic review of gaps/barriers to transition planning and accessing adult services (Steinbeck et al, 2007);
- Auditing the use of health care services - adult services, primary care services, community-based resources and emergency care (UKDH, 2006);
- Health outcomes and cost benefit analysis (Bennett et al, 2005);
- Effects of curriculum-based education for primary care physicians and adult care practitioners on developmentally-appropriate care for youth with chronic conditions (Sanci et al, 2005); and
- Comparative examination of access to adult specialty care for youth transitioning in rural versus urban centres (Craig et al, 2007; Steinbeck et al, 2007).

In addition, in some cases, specific metrics have been identified through which the success of transition programs have been measured. One example is the Sick Kids Hospital programs measures listed below.

Sick kids Good to Go Program suggested targeted research and evaluation measures	
Outcome	Operational measurement
Duration until first adult appointment	Number of days between the last pediatric appointment to the first adult health-care appointment minus the number recommended
Patient adherence to	Number of refills in last year minus the number

medical regimen	recommended
Decreased depression	Score on the Children's Depression Inventory (CDI)
Decreased anxiety	Score on the Children's Anxiety Inventory
Patient satisfaction with the pediatric health-care system	Satisfaction questionnaire (ON TRAC tool)
Parents satisfaction with the health-care system	Satisfaction Questionnaire
Patient satisfaction with the adult health-care system	Satisfaction questionnaire
Parent satisfaction with the adult health-care system	Satisfaction questionnaire
Increase quality of life for the patient	Quality of Life questionnaire
Patient acquisition of employment	Number of days working in the past year

Section 4

ON TRAC2 Plan – Systems Requirements to Support a Transition Service in BC

In this section, we identify what system changes that will be required to move from the current situation in British Columbia, to a fully integrated transition service, which includes an evaluation component.

4.1 Proposing a Transition Service for BC

The overarching goal of ON TRAC2 is to improve the long term health of British Columbia's children, youth and young adults with chronic health conditions by providing developmentally-appropriate care and continuity of care across the transition pathway. Based on Ministry guidelines, all services created for children and youth with special needs should be integrated and comprehensive, accessible, youth-centred and family-focused, functionally-based, evidence-based, culturally competent and safe, responsive to change, fair and equitable, evaluated and sustainable (Government of British Columbia, 2008). ON TRAC2 proposes the establishment of an evidence based Transition Service to improve care for young people transitioning from pediatric to adult health care services. ON TRAC2 will improve health outcomes for youth/young adults with specific chronic health conditions in BC through

- Establishing a database to identify the capacity and requirements for effective transition care
- identification of specific health outcome measures for sub-specialty populations
- improved understanding of transitional needs for diverse patient populations
- effective management of the 'active phases' of transition
- rapid identification of youth/young adults who have 'difficulty' in transitioning
- appropriate use of hospital and community services
- identification of gaps in health services
- reduction in post transition morbidity and mortality
- reduction in overage patients at BCCH (post 17 years)
- reduction in "refugee" young adults for whom no adult services exist
- reduction in duplication of services
- education and training of health professionals in transition and young adult care
- development of home-based, virtual tools for learning and skill building
- new capacity to evaluate transition care

ON TRAC2 provides a framework and backbone to foster and maintain the development of a multifaceted provincial intervention with four components: clinical care, multidisciplinary education for health care providers, information and access to resources for patients, families and providers as well as outcomes and research evaluation. A systematic investment in regional and provincial planning is needed that

includes a collaborative approach with adult agencies for clinical service, staff training and research initiatives (Kennedy & Sawyer, 2008).

Provincial health authorities, pediatric and adult agencies, policy makers, educators and sub-specialty clinical practitioners have demonstrated an overwhelming response of support for this initiative to improve transitional care provincially. Therefore implementation will need to be undertaken through partnerships and collaboration.

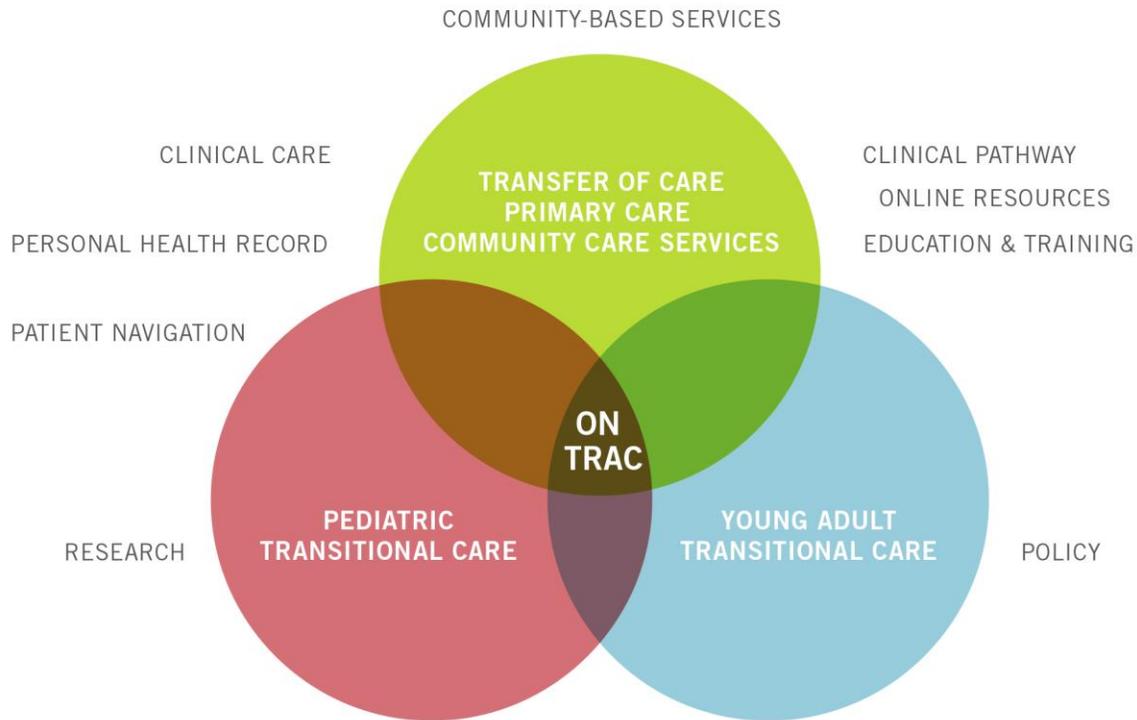
The scope of the proposed Service includes;

- A model of care encompassing client and family consultation and engagement in the transition process
- Protocols, standards of practice, documentation, and clinical pathways that facilitate continuity of care, timely and appropriate transition from and into adult services
- Referral and linkages to specialist services for the management of young adults with complex needs
- Appropriate linkages and partnerships with community-based general practitioners and services
- Mechanisms to facilitate collaboration, knowledge-sharing, education and research amongst professionals and agencies caring for youth and young adults with chronic health conditions.
- Mechanisms to ensure youth and young adults have access to their personal health care information at all times

The Greater Metropolitan Clinical Taskforce Transition Care for Young People with Chronic Illness and Disability Arising in Childhood (GMTT, 2006; Steinbeck, Brodie & Towns, 2008; Stewart & Dwyer, 2006) has been in operation for 8 years and is the only integrated transition service in the world.. Critical ongoing evaluation and data collection has provided evidence on the strengths and weaknesses of such an endeavor. This program highlights the importance of transition at a regional or provincial level, intersecting across health care jurisdictions and encompasses data systems, the role of transition team members, youth readiness and screening, information and resources, education and training, research, policy development, self-management, and disease/health condition understanding.

A Proposed transition Service Model for BC

TRANSITION SERVICE MODEL FOR BC



(ADAPTION FROM SAWYER & KENNEDY, 2008)

A Transition Service for BC can be conceptualized as an intersection of pediatric and adult services overlapping primary care and community-based resources. Central to the service is a mechanism for transfer and patient navigation to appropriate adult services. Cornerstone are the fundamentals of research, education & training, policy and agency support. This schematic model indicates equal responsibility between the adult and pediatric systems to support developmentally-appropriate, comprehensive, preventative clinical care. It is a regional model that encompasses different agencies and health care jurisdictions while incorporating the principles of the developmental, shared care and medical (primary care) models outlined earlier. Transition care for youth with chronic illness and disabilities is complex and multi-faceted, a service, well positioned within both pediatric and adult centres, supports developmentally-appropriate care, patient navigation, access to resources while specialists provide expert condition-specific care. The primary care physician, essential in the team, monitors health and provides referrals to specialists as required.

4.2 Building partnerships and capacity with local and global partners

Coordination and interagency liaison between specialized pediatric, adult and community services is essential for collaboration and continuity of services and care of the individual but the complexity of health systems has frustrated attempts at integration (Gortmaker, Perrin, Weitzman, Homer & Sobol, 1993; Kelly, 1995). To ensure a continuum of coordinated care throughout adolescence and into adult health care, the process requires specially trained and educated general physicians and adult practitioners, transference of medical records, and adult care providers skilled in the care of chronically ill young adults (AAP, 2002; Baldassano, Ferry, Griffiths, Mack, Markowitz & Winter, 2002).

This development of a comprehensive Transition Service for British Columbia has strong support from an extensive and diverse provincial network including, but not limited to, Vancouver Coastal Health, Provincial Health Services Authority, Child Health BC, British Columbia Medical Society, BC Pediatric Society, Ministry of Children and Family Development, University of British Columbia (Departments of Medicine, Pediatrics, Social Work, Nursing and Professional Development), Simon Fraser University, Emily Carr University of Art & Design, private industry, and Telus Health. The youth and parents at BCCH and Sunnyhill Health Centre, represented through the Partners in Care committee and Youth Advisory Committee have also articulated a need to improve transition planning through a Transition Service. The ON TRAC2 team has developed collaborative partnerships with international leaders in Transition planning and care, Hospital for Sick Children, Toronto and Ministry of Health, NSW, Australia. Specific areas of contributions and collaboration are outlined below.

Sub-Specialty Clinics and Multidisciplinary Staff at BC's Children's Hospital

Through partnering with the multidisciplinary teams in every step of development, integration and evaluation, ON TRAC2 will be integrated into clinical structures at BCCH and specialty adult agencies. Ten sub-specialty clinics representing a variety of chronic conditions, (cystic fibrosis, renal, cardiac diseases, endocrinology, rheumatology, eating disorders, neuromuscular disorders, gastroenterology, spina bifida and oncology), have been identified to study, integrate and evaluate effective transitional planning.

Vancouver Coastal Health Authority (VCHA)

Many patients from BCCH will transfer to VGH. VCHA recognizes that the ON TRAC2 transitional health project is critical for success in developing youth appropriate services, increasing access and developing comprehensive continuity of care as well as expanding access for youth with chronic medical conditions that live outside the area of VGH. VCHA support will allow ON TRAC2 to develop youth friendly transition services nested in the adult healthcare system.

Child Health, BC.

Child Health BC engages researchers, clinicians and policy makers from all health authorities to improve the health of children in BC. Child Health BC has agreed to formally partner with this project through sponsorship and participation in a provincial

workshop. This workshop will provide an opportunity for health care providers and other stakeholders from different regions and communities in the province to provide input and discussion concerning the development of a transition program that is broad in scope and will meet their needs.

BC Pediatric Society

BC Pediatric Society, will provide access to general pediatricians throughout the province to identify further educational and research recommendations.

British Columbia Medical Association (BCMA)

The BCMA is sponsoring a Practice Support Program Module (PSP) for Family Physicians and sub-specialists to gain skills in the transition management of adolescents with chronic illness, with the goal in increasing the capacity and role of family doctors in transition care. Collaboration will include curriculum development and discussion with community health providers. Through representation at the Shared Care Committee this professional organization will support access to physician lists identifying family practitioners throughout BC prepared to provide primary care services to youth and young adults with chronic health conditions.

Ministry of Children and Families

On TRAC2 aligns with the purpose and goals of the recently published Cross-Ministry Transition Planning Protocol for Youth with Special Needs, endorsed by nine government organizations. In addition, the Ministry of Children and Family Development's work with the Michael Smith Foundation for Health Research in developing a Framework for evaluating the Cross-Ministry Transition Planning Protocol will also link well, especially as it relates to outcome measures and data collection. Collaborations between these projects will present opportunities to clarify and streamline transition processes and eliminate unnecessary duplicative processes for transitioning youth and their families with whom our organizations are connected.

Healthlink BC

On TRAC2 plans to partner with Healthlink BC, the provincial portal for health care information and services. A 'transition-based' topic centre for youth, young adults and families to access support services and information provincially, would be a 24 hour resource and fit well with other patient navigation strategies.

Sunnyhill Health Centre

Sunnyhill Health Centre cares for children with developmental physical and intellectual disabilities. The pediatric population transitions to adult care and Community Living services provided by the Ministry of Children and Family Development. Youth with special needs and their families will continue to be a central focus of all transition tools and processes developed. Ongoing collaboration will ensure the Service meets the needs of this population.

Partners in Care

The Partners in Care Family Advisory (PiC) of BC's Children's Hospital is a group of family members and hospital staff who are dedicated to promoting excellence in principles and practice of family centered care. As a collaborative partner, they have the capacity and membership to offer parental views and ideas about innovations in the health care services and systems, help develop or review informational materials for families, and provide the parent's voice in educational sessions and materials on family-centred care.

Youth Advisory Committee

Developed in collaboration with the partners in Care group the "Youth Advisory Council" (YAC) engages youth in discussions that directs youth-focused, culturally-sensitive, developmentally-appropriate care. Engagement with the Youth Advisory committee will ensure ON TRAC2 is relevant to the needs of youth with chronic conditions.

Simon Fraser University

SFU School of Communications offers access to experts in the area of health informatics. Specifically in studying issues related to utilization of computer mediated group communication and utilization of information technology in varied healthcare contexts. Dr. Ellen Balka and her colleagues at SFU will offer leadership for information technology aspects of the project including assisting with platform selection, implementation and evaluation.

McCreary Centre Society

The McCreary Centre Society is a not-for-profit research based organization concerned with the health of young people in British Columbia. The research team at McCreary conducts community-based research and projects addressing current youth health issues. In working with McCreary, the ON TRAC2 transition team will gain guidance and parameters in developing youth-based research. Future plans include increasing chronic illness questions in bi-annual provincial youth health surveys and working towards a chronic illness survey for BC.

Hospital for Sick Kids Transition Program.

Dr. Miriam Kaufman and the Good2Go programme at Hospital for Sick Kids in Toronto have included the original On TRAC material in the development of a transition program for their population of youth with chronic illness. Dr. Kaufman developed the Good2Go Program and health care passport, available online, to assist youth in having independent health care information. The ON TRAC2 team continues to have ongoing collaboration and sharing of ideas in program development and research initiatives.

Emily Carr University of Art and Design

Through the departments of Industrial Design and Social and Interactive Media, students at Emily Carr University of Art and Design will collaborate with researchers and transition staff to suggest innovative, youth-friendly tools for communication. Youth are particularly sensitive to the method in which messages are contained; they use technology to communicate and Emily Carr students will provide a creative framework to ensure our messaging is meaningful.

Healthy Adolescent Healthcare Transitions Adolescent Research Team (HART)

The Healthy Adolescent Healthcare Transitions Adolescent Research Team, led by Dr. Lynn Straatman has completed a CIHR development grant and is submitting a Human Development, Child and Youth Health CIHR application to explore transition issues for adolescents and young adults with chronic life-limiting cardio-respiratory disease. As co-investigators in this study, ON TRAC2 will collaborate to expand and facilitate their research goals, while contributing to other concurrent research projects on transition that originate from BC Children's Hospital.

TELUS Health

TELUS Health Solutions represents a unique set of technology, expertise and resources to help transform how information is used in the healthcare industry. TELUS Health Solutions has years of expertise in successfully implementing healthcare applications and information communication technology processes through industry leading solutions and consulting services to customers in Canada and around the world. TELUS health space is the first consumer health platform in Canada to gain Canada Health Infoway pre-implementation certification for providing a secure, interoperable application environment and personal health information platform. In partnering with TELUS health space applications, our goal will be that youth with chronic illnesses and special care needs will be able to create, store and manage all aspects of their health information such as immunizations, allergies, medications, height, weight, symptoms, key medical measurements, pre-existing conditions, as well as their medical history.

4.3 Professional Education & Training

Education and training is a fundamental component of the ON TRAC2 model. Through professional development and knowledge transfer offered to general practitioners, pediatricians and adult sub-specialists, nurses and other health care providers, ON TRAC2 will increase capacity for developmentally-appropriate transition care. There is evidence that this approach is effective. Several education programs developed for health care professionals (medicine and nursing) have been shown to improve adolescent health care knowledge and skills (Brink, Miller & Moltz, 2002; Payne, Martin, Viner & Skinner, 2005; Sawyer, Sanci, Conn & Patton, 2007). A randomized controlled trial focusing on the training of medical professionals rather than on the transition of adolescents, evaluated the effectiveness of an educational intervention in adolescent health designed for general practitioners (Sanci, Coffey, Veit, Carr-Gregg, Patton, Day et al, 2000). The program covered adolescent development, consultation and communication skills, health risk screening, health promotion, risk assessment of depression and suicide and issues in management of psychosocial health risk including interdisciplinary approaches to care. Doctors completing the training had substantial gains in knowledge, clinical skills and self-perceived competency. At the 13-month follow up most improvements were sustained, the confidentiality rating by almost all (98%) the participants reported a change in practice attributable to the intervention. A 5-year follow-up of this study indicated that improvements were sustained in all

measures from 12 months to 5 years after the intervention in those participating in the second study (Sanci et al, 2005).

This will be achieved by developing and implementing an interdisciplinary education and training program for physicians, nurses and other health care providers in partnership with Child Health BC, UBC Division of Continuing Professional Development and other interested parties.

The goals include

- Developing curricula to address key competencies for transitional health based on best evidence for students of nursing, education and medicine in collaboration with the relevant university departments and in partnership with the UBC Faculty of Continuing Professional Development;
- To increase the capacity and sustainability of youth appropriate transitional health care in the pediatric and adult health care systems and community;
- Making available on-line developmentally-appropriate resources, teaching and training tools for health care practitioners and students through Child Health BC; guiding the development of curriculum through establishing stakeholder forums including youth at BCCH, young adult graduates/alumni of programs, parents, and community based support services
- Developing, with the Division of Internal Medicine a residency rotation focused on care for the youth and Young Adult with Chronic Illness. This rotation would expose residents to current transition and young adult clinics.

4.4 Research and Evaluation

While ON TRAC 2 is a clinical care framework based on program development, health service innovation and health promotion, it offers a rich environment to advance interdisciplinary research on transition and transition outcomes. ON TRAC2 has the potential to increase research capacity and improve the health of youth with chronic illness through providing an opportunity for engaging a collaborative research network to support a coordinated research agenda across sites, health care jurisdictions and disciplines. Individual researchers and research teams will be invited to collaborate, share data, and integrate research. An ON TRAC2 research hub will generate opportunities for researchers from a variety of disciplines to engage in ON TRAC 2 for the benefit of patients and the development of *the Transition Service*, and to help advance research in transition health. Opportunities for future collaborative research include:

- Understanding chronic illness in youth in British Columbia through partnering with the McCreary Centre Society, and accessing provincial health survey data to

better understand the impact of chronic illness on youth and youth's access to appropriate health services;

- Monitoring all youth and families at BCCH who are transitioning by obtaining ethics approval for data collection. Informed consent will include the use of health care and community services, type of practitioner, type of care required, tracking medication use, baseline measures of their health at 14, 16 years, and post 18 years, follow-up two years post transfer to adult care, and contacting youth and families via phone and internet;
- Identifying effective methods to improve data collection and monitor health outcomes for youth with chronic illnesses;
- Analyzing how health care information is transferred between pediatric, adult, and primary practitioners;
- Developing collaborative partnerships and creating a blog between transition programs in Canada, the US, Australia, and globally to further develop policy initiatives that support transitional care.

Evaluating outcomes using the ON TRAC2 clinical pathway

Transition, defined as a process, will be evaluated within the context of the clinical pathway. This evaluative tool is being used extensively in clinical situations to map the most effective practice to improve patient outcomes, and as a result, reduce health care costs (Schriefer, 1994). A standardized, clinical pathway to guide transitional care for youth and young adults (10-24 years) will be integrated into clinical practice at both the pediatric and adult agencies. As a tool to monitor and document the transition process over a number of years and with a high volume of patients (over 1700 youth seen monthly in the sub-specialty clinics at BCCH). Transition, as a process occurs over a number of years and the outcomes and effectiveness of interventions may not be realized until adulthood and transfer from the pediatric system. A clinical pathway provides the opportunity to

- track developmentally-appropriate care strategies and transition planning across the care trajectory;
- document developmentally-appropriate skills for self-management
- collect workload data;
- collect data to support outcome and longitudinal measures;
- monitor and identify of needed services and referrals for comprehensive care through ongoing quality improvement.

A structured evaluation for ON TRAC2 will be integral to program development. This includes detailed identification of indicators for each set of interventions including assessing appointment completion and successful linkage of adolescents transferred from pediatric subspecialty clinics to specialty care services in the adult medical system and to primary care providers. Other indicators include reduction in over-age patients at BCCH (post 17 years) tracked through decision support services and reduction in number of patients who do not have a medical home in pediatric or adult health care

centres. Monitoring of referrals to the ON TRAC2 Transition Service will identify the numbers for youth and families facing challenges to transition and the extent of the issues and will assist in identification of gaps in health services for youth with chronic illness. Transfer and post transition integration can be followed by tracking medication adherence as reflected in prescription completion documented through Pharmanet.

Equally important will be an assessment of perceived value of transition services from the perspective of patients, their families, and health care providers. Evaluation of the transition process and ON TRAC2 could be undertaken through the use of standardized health outcome indicators for the most common chronic conditions as well as incidence of post-transition morbidity, alterations in mental health status, coping, quality of life, and stress. Evaluation processes will utilize quantitative and qualitative methods, to address process as well as health outcomes.

The creation of a research hub will provide the opportunity for researchers to engage with ON TRAC2 through grant funding. However, depending on the extent of the research undertaken, a research coordinator may be required. Areas of intervention include strategic changes in clinical care, research and health service management across health jurisdictions, policy development, information transfer, patient and provider education, patient navigation and electronic and paper transition tools for health care providers and patients.

4.5 Resource considerations

A Transition Service model should provide long-term benefit for patients and families demonstrating significant improvement throughout the health care continuum from pediatrics to adult centres. This requires an integrative approach. We have engaged the support and collaboration of international and national colleagues, pediatric, adult and family health care providers, Child Health BC, Ministry of Children and Families, University of British Columbia, Simon Fraser University, Emily Carr University and private industry,.

Any Transition Service Model will need to take into consideration the current economic environment, constraints in health care budgets, and the importance of lean management. It should build on existing services, supplementing the excellent care already provided in the variety of clinical settings that adolescents and young adults attend. The conceptual framework of ON TRAC2 emphasizes integration and enhancement of existing service provision rather than replication of systems that are already in place. A core ON TRAC2 team would work alongside their clinical colleagues, addressing the specific transition needs through knowledge translation, resources and patient navigation. We anticipate cost savings through decreased use of Emergency Services and decreased morbidity

This document provides the conceptual model for an ambitious program: it crosses health care jurisdictions and offers opportunities for development in the areas of clinical

service, health care communication, professional and patient education, health services and clinical research. The budget and staffing requirements will depend largely on the priorities of our health care partners.

This document initiates the dialogue to move forward in determining priorities and building a sustainable strategy for enhanced transition services with maximum stakeholder buy-in. A transition model for BC will shape how transitional health care is provided provincially, nationally and globally. With the breadth and depth of our extensive collaborative team we have the opportunity to design and evaluate innovative and strategic interventions in health care service delivery while providing leading edge and evidence based knowledge on key issues in the transition process.

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Appendices

Appendix A

Condition-specific Position Statements and Recommendations for Transitional Care

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition Position statement: Transition of the patient with inflammatory bowel disease from pediatric to adult care

1. Meet with patient without their parents to build a relationship that promotes self-reliance.
2. Emphasize the benefits of transition; normalization of development, promotion of independent behaviour, promotion of self-reliance, improvement of compliance with therapy and planning long-range goals.
3. Support in selecting a physician with expertise in IBD in adult care services that can guide health management of pregnancy, fertility and cancer surveillance.
4. Transfer to include a medical summary and letter with a copy to the youth, general practitioner and adult specialist.

Cystic Fibrosis Foundation (US) Cystic Fibrosis Adult Care: Consensus Conference Report

- Clinicians should introduce the concept of transition early, even as early as the time of diagnosis, when outlining the long-term care of CF.
- Children should be introduced to the concept of adult center care in an age-appropriate way. The adolescent can be given more responsibility for self-care and decision making, health education, and self-care training, and should be seen alone in clinic visits.
- More intensive preparation can take place during the year before transfer to the adult clinic. This may include visits by adult care team members to the pediatric clinic, touring the adult care clinic, and discussions about doubts and anxieties.
- Adult care physicians should be sensitive to the transition process and make an effort to know their new patient before transfer. Other strategies include inviting parents to the first visit in adult care (even though parents are not ordinarily involved in internal medicine clinics) and introducing any changes in medical treatment gradually, since abrupt changes can be perceived as disapproval of previous care.
- Transition materials, such as adult program pamphlets, education packets, and readiness questionnaires are used in some CF centers to prepare patients and their families for adult care.

- Appropriate timing for transfer should be evaluated beginning in the high school years. In most cases, transfer will coincide with graduation from high school.
- The pace and progress of transition is expected to vary for individuals, depending on developmental maturity, self-care skills, special characteristics of the family, availability of adult clinicians, and, in some cases, stage of illness. Those who are medically unstable, nearing death, or waiting for a lung transplant may defer transfer until stability is restored.
- It is ideal to have a coordinator (eg, social worker or nurse) for the transition process. This person can ensure that a transition plan is created among the patient, family, and pediatric and adult care teams. The coordinator can schedule, facilitate, and track transition clinic and initial adult clinic appointments, and address any psychosocial issues of the patient, family, and clinicians throughout the transition process until the patient is adapted to adult care.

Appendix B
Developmentally-appropriate transition framework

Early Transition	Middle Transition	Late Transition
<p>The <i>Youth</i> and <i>Family</i> are introduced to the Transition process and the <i>Youth</i> begins to participate in his/her own care.</p> <p>Ages 10 - 12</p> <p>Grades 5 - 7</p>	<p>The <i>Youth</i> and <i>Family</i> gain understanding of the transition process and the <i>Youth</i> practices skills, gathers information and sets goals to participate in his/her own care.</p> <p>Ages 13 - 15</p> <p>Grades 8 - 10</p>	<p>The <i>Youth</i> and <i>Family</i> prepare to leave the pediatric setting with confidence and the <i>Youth</i> uses independent health care behaviors and consumer skills into the adult system.</p> <p style="text-align: center;"><i>Ages 16 - 18</i></p> <p style="text-align: center;"><i>Grades 11 - Graduation</i></p>
<p>Dependent on...</p> <ul style="list-style-type: none"> ... Severity & exacerbation of condition ... Physical and cognitive abilities ... Psychological and emotional stability ... Family and social supports 		

... Onset of transition preparation

Appendix C
Inventory of global programs, tools and strategies

Canada

Holland Bloorview – Kids Rehabilitation Hospital

Contact Number: 416 425 6220 ext 3498

Email: resourcecentre@hollandbloorview.ca

Website: <http://www.hollandbloorview.ca/foundation/newsletter/expertiseshowcase.php>

Youth Summary: "Prepares family and youth dealing with transition. Provides the family and youth with a quick tip sheet of transition. No other information is provided, and no information given to the health care workers."

Resources:

The LIFE span clinic – located at Toronto Rehab – offers a single point of access for youth to receive comprehensive services from a rehabilitation team that includes a nurse practitioner, a physiatrist, occupational, physical and speech therapists, and a social worker.

**The Hospital for Sick Children
Toronto, Ontario**

Contact Number: 416 813 1500

Email: sarah.mcbain@sickkids.ca

Website: <http://www.sickkids.ca/good2go/>

Youth Summary: "The information found in this website has more detail. Not very organized though. According to the website, it is based on the shared management model, developed in Seattle Washington. Seems to lack information regarding specific topics such as clinical pathways. Besides check list, not much information given to family/friends."

Resources:

Many excellent across site programs all outlines on transition-specific Good 2Go website
Transition Treatment Clinic - Good 2 Go has a weekly clinic for SickKids patients (12-18) who are struggling with transition issues--adherence, acceptance of their condition, becoming more autonomous.

Readiness Checklist (from ON TRAC)

Clinical Pathway (ON TRAC)

MyHealth Passport

Good2Go Website

Clinic Transition Letter

Materials for Families

Transition/Graduation Events & Tools

(References the support of ON TRAC in developing resources)

The Maestro Project

Winnipeg, Manitoba

Contact Number: 204 789 3719

Email: camacdonald@exchange.hsc.mb.ca

Website: http://www.maestroproject.com/info_ya/letterya1.html

Youth Summary: "The information found in this website mainly introduced the transition program."

No checklists were found or detailed information regarding what can and should be done. No age groups that explains what one has to prepare for at every stage. This website is more of an introduction and if more information is required, contact information is given."

Resources:

Building Connections: A Resource for Young Adults with Type 1 Diabetes

Canadian Pediatric Society

Contact Number: 613 526 9397

Email: info@cps.ca

Website: <http://www.cps.ca/English/statements/AM/AH07-01.htm>

<http://www.caringforkids.cps.ca/growinglearning/specialnedds.htm>

Youth Summary: "The information found on both the website and the attached (transition to adult care for youth with special health care needs) did address the problem regarding the transition from child to adult care. Information was provided to us regarding what should be done such as talking to adolescents and health care workers. But tools were not given that explain how it can be done. What could be the core problems that adolescents, family and health care workers deal with?"

Resources:

Pediatric Transfer Record

Position Statements

- 1) Special considerations for the health supervision of children and youth in foster care
- 2) Transition to adult care for youth with special health care needs
- 3) Care of adolescents with chronic conditions

Markham Stouffville Hospital

Contact info: 905.852.9771 or 905.472.7000

Email: myhospital@msh.on.ca

Website: http://www.msh.on.ca/programs_and_services/paediatric_diabetes

Youth Summary: "The youth adult transition program is briefly mentioned. Just provides the readers with a brief explanation regarding transition, doesn't explain how the program is run".

Resources:

Not available

United States

Jack's Hats

Contact Info: (for the clinic) 904 244 9233

Direct Email: <http://jaxhats.ufl.edu/contact.php>

Website: http://jaxhats.ufl.edu/youth_families.php

Youth Summary: "Provides the youth and friend/family with a lot of information. Gives the youth and parents recommended websites to visit and provide them with more information. The website gives the family and youth tools and answers questions to prepare them for their first visit at the transition clinic."

Resources:

Health Care Transition Workbook for Ages 12 to 18 & up

Envisioning My Future: A Young Person's Guide to Health Care Transition
Transition Readiness Assessment Questionnaire
Health History Questionnaire
Social Services Questionnaire

PACER

Contact info:
Direct email:
Website: <http://www.pacer.org/publications/transition.asp>

Youth Summary: "Extensive library of information, resources, and technical assistance to parents of young adults, 14 through 21, with disabilities and the professionals who work with them on transition topics such as; post-secondary options, housing, employment, and recreation."

Resources:

Transition Trek Board Game
Mapping Your Dreams: Making the Transition Team Work (Handouts)
Go For Your Dream video
Transition Parent Briefs

The Children's Hospital

on the Anschutz Medical Campus in Aurora, Denver, Colorado.

Contact info: 720 777 1234
Direct Email: <http://www.thechildrenshospital.org/about/contact.aspx>
Website: <http://www.thechildrenshospital.org/about/why-childrens/transitioning-to-adult-doc.aspx>

Youth Summary: "Transition is just mentioned on the website. No tools or check list given. A small paragraph explains what transition is. Asks the youth or family to talk to their doctor for more information."

Resources:

None available

Cincinnati Children's Hospital

Contact Info: 513 636 4611
Email: TrYAD@cchmc.org.
Website: <http://www.cincinnatichildrens.org/svc/alpha/d/disabilities/clinical/transition.htm>

Youth Summary: "Briefly mentions that they help with transition. But no further information is given that explains what transition is or how the youth, family or health care workers can deal with it."

Resources:

None available

Nationwide Children's Hospital

Main contact person: Curt J. Daniels
Contact number for Dr. Daniels: 614 722 2530
General Direct Email: <http://www.nationwidechildrens.org/contact-information>
Website: <http://www.nationwidechildrens.org/news-room-articles/transition-program-aims-to-provide-life-long-cardiac-care-for-adolescents-with-congenital-heart-disease?contentid=46021>

Youth Summary: "The transition program cannot be found on their website. But an article is found that explains that the hospital does have a transition program and how useful it is. The Doctor who runs the program is also the developer of the program and has written at least two articles regarding transition. Not too much information is given to the youth or family members about what they can do in the article."

Resources:

None available

Monroe Carell Jr. Children's Hospital at Vanderbilt

Contact info: 615 936 1000

Email: susan.kohari@vanderbilt.edu.

Website: <http://www.vanderbiltchildrens.org/interior.php?mid=6755>

Youth Summary: "Brief information is given to the parent and the youth. Things like encouragement and education. A short check list is given to the social workers dealing with transition. Also provides the youth and family with few goals that they can try to achieve."

Resources:

Transition Clinic outline for Sickle cell

Sickle Cell Transition Clinic Social Worker Checklist

Johns Hopkins Children's Center

Contact info: 410-955-5000

Direct email: <http://www.hopkinschildrens.org/form.aspx?ekfrm=1744>

Website: www.hopkinschildrens.org/Transitioning-to-Adult-Care.aspx

Youth Summary: "A one page article is written regarding the importance of transition. Gives a few checkpoints that can make transition easier. Briefly mentions and explains the key points regarding transition."

Resources:

None available

Children's Hospital Boston

Contact info: 617-355-2994

Direct Email: http://www.youngwomenshealth.org/contact_form.html

Website: <http://www.youngwomenshealth.org/transitions.html>

Youth Summary: "Gives a brief explanation about what transition is. Doesn't provide the youth with too much information. Just gives the basic information that allows the youth to begin understanding what transition means. No information given to the family or health care providers".

Resources:

None available

The Children's Hospital of Philadelphia

Contact Number: 215 590 7444

Direct Email: <http://www.chop.edu/contact-us/general-contact-form.html>

Website: <http://www.chop.edu/service/transition-to-adulthood/transition-programs.html>

Youth Summary: "The website provides the youth and parents with information about transition, what they need to know, how to guide them and a lot of general information. All the information provided is divided according to the age groups. Information also provided to the care givers. The hospital has also set up programs such as REACH, REACH out, REACH for college and CHOP, all programs help the youth in different areas of transitioning."

Resources:

REACH (Rapport, Empowerment, Advocacy, through Connections and Health) is a program for teens and young adults ages 12-24 with special healthcare needs and their families, created by

teens and young adults with special healthcare needs.

Tips for parents and caregivers

- [First Steps to Teach Children About Their Health Ages 4-6\(PDF\)](#)
- [Next Steps to Help Children Understand Their Health Ages 7-10\(PDF\)](#)
- [Preparing Children to Take Charge of Their Health Ages 11-13\(PDF\)](#)
- [Guiding Youth to Take Charge of Their Health Ages 14-17\(PDF\)](#)
- [Transitioning Young Adults from Pediatric to Adult Healthcare Ages 18-21\(PDF\)](#)

Tips for patients to take charge of their health

- [It's Your Health: What You Need to Know Ages 11-13\(PDF\)](#)
- [It's Your Health: What You Need to Know Ages 14-17\(PDF\)](#)
- [It's Time: Are You Ready to Transition to Adult Healthcare? Ages 18-21\(PDF\)](#)
- [Taking Charge of Your Health – A Guide for Teens and Young Adults Brochure\(PDF\)](#)
- [Taking Charge of Your Health – A Guide for Teens and Young Adults \(Flyer\)\(PDF\)](#)
- [Emergency Information Wallet Card\(PDF\)](#)

Tips for young adults with intellectual challenges

- [From Pediatric to Adult Medical Care\(PDF\)](#)
- [Beyond High School Graduation\(PDF\)](#)
- [Planning for Education and Training After High School\(PDF\)](#)
- [Get Ready. Get Set. Let's Go To Work!\(PDF\)](#)
- [Moving into a Home of Your Own\(PDF\)](#)

Children's Hospital of Wisconsin

Contact info: 414 266 2800
Email: webmaster@chw.org
Website: <http://www.chw.org/display/PPF/DocID/43541/router.asp>

Youth Summary: "Offers a lot of information to the family and youth. This includes information dealing with self-management, legal issues, independent living, housing and just general information about transition."

Resources:

Website based questions and discussions

Michigan Department of Community Health

Contact number: 1 800 359 3722
Email: mccurtisj@michigan.gov and kruegerj2@michigan.gov
Website:http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_35698-135030--,00.html

Youth Summary: "Provides the family and young adults with a 16 page guide book for transition planning. Provides information regarding health care, education, adult living, community agencies". (http://www.michigan.gov/documents/mdch/trans_final_308093_7.pdf)

Sickle Cell Disease Association of America

Contact info: (office)410.528.1555 (fax) 410.528.1495
email: scdaa@sicklecelldisease.org
website:http://www.sicklecelldisease.org/research/scd_manage2.phtml

Youth Summary: "Transition is very briefly mentioned. Not too much information is given to the youth, family and friends or health care workers as to how to transition properly. Basically just explains why transition is important."

Resources:

Not available

Medical Home Portal / Utah Health Pediatric Health Partnership

Contact Info: 801 584 8584

Direct email: <http://www.medicalhomeportal.org/feedback>

Website: <http://www.medicalhomeportal.org/living-with-child/transition-issues/transition-to-adulthood>

Youth Summary: "Provides you with a top ten list for a successful transition. Provides you with a lot of information that explains transition and what can be done to ease the youth's transition. A lot of resources for the youth, family and health care workers. Have different sections such as education, health insurance, independent living, self-advocacy, social issues, sexuality/reproduction, travel, finding adult health care and so on. Each section provides information for youth, family and health care workers."

Resources:

Extensive list of resources for youth, young adults, families and health care providers

<http://www.medicalhomeportal.org/living-with-child/transition-issues/transition-to-adulthood/resources-checklists-etc>

Children's Memorial Hospital

Author of the article: Parag K. Shah

General contact info: 773 880 4000

Email:

Website: <http://www.childrensmemorial.org/cme/online/article.asp?articleID=239>

Youth Summary: "Detailed information is given to the youth and family. Provides us with a simple transition checklist helping the youth for medical, financial, skills and social transition. Really helpful information is given to the family and youth that can help for the transition process. But no information is given to the health care providers."

Resources:

Transition Checklist

Osteogenesis Imperfecta Foundation

Gaithersburg, MD

General contact info: 301 947 0083

Email: bonelink@oif.org

Website: <http://www.oif.org/site/PageServer>

<http://www.oif.org/site/DocServer/Transition from Pediatric to Adult Care.pdf?docID=7236>

Youth Summary: "Not too much information is available. The information available is not too personal. The information is mainly directed to the family/parents of the youth. Information for the health care workers of the youth themselves is not found."

Resources:

Timeline of activities to Encourage Independence from Birth-21 years of age

United Kingdom

Diabetes UK Central Office

Contact Number: 020 7424 1000

Email: info@diabetes.org.uk

Website: <http://www.diabetes.org.uk/Guide-to-diabetes/My-life/Teens/Me-and-my-diabetes/Transition-to-adult-clinics/>

Youth Summary: "This website mainly offers help and information to the youth who have diabetes. Explains why transition is important and what the responsibilities are for the youth. Also provides the youth with different transition stories. No information for parents/family or health care workers."

Resources:

Interactive website for youth dealing with transition needs

Great Ormond Street Hospital for Children

Contact Number: Adolescent Medicine service: 020 7813 8541

Email: foiteam@gosh.nhs.uk

Website: http://www.childrenfirst.nhs.uk/families/children_hospital/adolescent.html and http://www.gosh.nhs.uk/gosh_families/information_sheets/transition/transition_families.html

Youth Summary: "Provides parents with different examples of taking care of their youth and how to give them more responsibility. Gives a lot of information regarding what transition is, how to prepare for it, understand it and talk about it. Provides youth and family with detailed information, not too much information given to the health care workers."

Resources:

Online text and discussions

Australia

The Children's Hospital at Westmead

Westmead, Australia

Patricia Kasengele

Contact Number: 9845 7787

Email: Patricia.Kasengale@swahs.health.nsw.gov.au

Website: <http://www.chw.edu.au/prof/services/transition>

Youth Summary: "Explanation is given to the family and the youth regarding what can be done. However no checklist is provided. Not too much information is given, a brief explanation is given which only educates the family and youth to a limit. No information given to the health care workers."

Resources:

Transition information evening for parents

Self-management Checklist for 14-16 yrs

Self-management Checklist for 16-18 yrs

Individual Transition Plan

Transition Form

The Royal Children's Hospital Melbourne

Victoria, Australia

Transition Manager: Sarah Macnee

Contact Number: 9345 4858

Email: sarah.macnee@rch.org.au

Website: http://www.rch.org.au/rch/index.cfm?doc_id=1495

<http://rch.org.au/blogs/transition/>

Youth Summary: "Talks about GYST program – for youth with diabetes transition to adult care. Since the RCH has a transition program already set, they have an RCH Adolescent Transition Manager and an Adolescent Transition Project Officer. Therefore, the advice given is not as detailed, as there is always someone to contact for questions. Well made brochures each for adolescent transition, parents info, differences between adult and pediatric care, different models created for parents and youth. Not too much information for the health care workers."

Resources:

Health Care Skills Checklist

Transition Plan (template)

Readiness to Transfer Checklist

USB memory stick Health Information

Goal Setting Worksheet

Young Person's Self-referral Letter

Find a GP webpage

Pre & Post Pilot Evaluation – link to Survey Monkey

Tools, articles and resources

Personal Testimonials and Stories

Transition Blog

New South Wales (NSW) Health

North Sydney, Australia

Lynne Brodie

Contact Number: 9887 5578

Email: lbrodie@nscchhs.nsw.gov.au

Website: <http://www.health.nsw.gov.au/utilities/contact.asp>

<http://www.health.nsw.gov.au/gmct/transition/index.asp>

Youth Summary: "One of the main websites used in Australia regarding transition. All of the other Australian websites refer to this website as a main source of information. Really detailed website. Gave a lot of information to parents and youth. Also provided a checklist and was age appropriate. No information was given to health care workers."

Resources:

Newsletter

Transition Checklists

Fact Sheets

References and websites

Appendix D Condition-specific clinical research summary

Cancer

Bleyer (2005)

The adolescent and young adult gap in cancer care and outcome

Cardiac Diseases

Canobbio (2001)

Health care issues facing adolescents with congenital heart disease

Knauth, Verstappen, Reiss & Webb (2006)

Transition and transfer issues of complex heart patients

Reid, Irvine, McCrindle, Sananes, Ritvo, Siu, et al, (2004)

Rate of transfer completion following transition referral and discussions with patients with congenital heart defects

Cystic Fibrosis

Anderson, Flume, Hardy & Grey (2002)

Multi-site patient's perceptions of transition concerns

Boas, Falsetti, Murphy & Orenstein (1995)

Validity of self-assessment of sexual maturation in adolescent male patients with CF

Boyle, Farukhi & Nosky (2001)

Strategies for improving adult cystic fibrosis care, based on patient and parent views

Brumsfeild & Lansbury (2004)

Qualitative study of patient's perspectives of transfer

Capelli, MacDonald & McGrath (1989)

Readiness to transfer questionnaire on the youth's knowledge base of medications, health condition and making healthy choices

Coe & Baker (1993)

Transition issues for young people with cystic fibrosis

Craig, Towns & Bibby (2007)

Evaluation of the preparation and transfer of care of youth

Flume, Anderson, Hardy & Grey (2001)

Multi-site pediatric and adult managers' perceptions of transition

Flume, Anderson, Hardy & Gray (2002)

Multi-site perceptions of pediatric and adult program directors of transition practices

Flume, Taylor, Anderson, Gary & Turner (2004)

Multi-site staff perceptions of transition issues

McLaughlin, Diener-West, Indurkhira, Rubin, Heckmann & Boyle (2008)

Summary of lessons learned from a variety of current practices

Nasr, Campbell & Howatt, (1992)

Satisfaction with transition planning of youth with CF

Nixon, Glazner, Martin & Sawyer (2003)

Female's living with CF experiences around their sexual health care

Pownceby, Ratcliffe, Abbott & Kent (1997)

A study of the transition from pediatric to adult care and treatment adherence amongst young people with CF

Zack, Jacobs, Keenan, et al (2003)

Perspectives of patients with CF on preventative counseling & transition to adult care

Diabetes

Court (1991)

Issues faced by youth and families in transitioning to adult care

Dovey-Pearce, Hurrell, May, Walker & Doherty (2005)

Young adults (16-25years) suggestions for providing developmentally-appropriate diabetes services

Frank (1992)

Medical stability in diabetes patients after transition planning and transfer of care

Kipps, Bahu, Ong, Ackland, Brown, Fox, et al (2002)

Current methods of transfer of young people with Type 1 diabetes to adult services

Pacaud, McConnell, Huot, Aebi & Yale (1996)

Diabetes patient's difficulties with transition – differences between services

Scott, Vallis, Charette, M. et al (2005)

Transition of care: Researching the needs of young adults with type 1 diabetes

Salmi, Huupponen, Oksa, Oksala, Koivula, & Raita (1986)

Measured metabolic control in diabetes patients one year post transfer

Van Wallegem, MacDonald & Dean (2008)

Transition system evaluation of a patient navigator

Inflammatory Bowel Diseases

Desir, & Seidman, (2003)

Issues facing the pediatric IBD patient with transitioning to adult care

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