ON TRAC
(Taking Responsibility for Adolescent/Adult Care)
a Transition Service for Youth With Chronic Health Conditions

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ON TRAC began as a project in 1995 at British Columbia's Children's Hospital (now part of Children's & Women's Health Centre of British Columbia - C&W) to support the 1200 youth who transfer into the adult health care system annually. The ON TRAC Project was created with the support of private funding to begin to explore the needs of youth with diverse chronic health conditions as they reach the age of adulthood and prepare to leave Children's Hospital. Many youth and families had begun to voice their concerns that their transfer to the adult setting was neither prepared nor smooth. Pediatric staff were bothered by the lack of preparation yet unsure how or when to begin the process. Adult care providers also felt youth were being transferred without preparation and with few skills required by the adult system. The pediatric centre, beginning to look at the quality of care being provided to youth, was eager to support an initiative to create a pathway and process to ensure comprehensive, coordinated, continuous care.

Defining Transition Issues for Youth with Chronic Health Conditions

Transition, as a general term, describes movement from one state or place to another, a process of change or a passage from one life phase to another (*Chick & Meleis, 1986*). Transition for youth with chronic health conditions encompasses the health concerns and issues that affect youth as they prepare to move from pediatric health care services to adult health care services.

Transition has been defined as the "purposeful, planned movement of adolescents with chronic medical conditions from child-oriented to adult-oriented health care." *(Blum, Garell, Hogman, Jorissen, Okinow, Orr & Slap, 1993, p. 570)*. The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally-appropriate and psychologically sound prior to and throughout the transfer into the adult system *(Blum et al, 1993)*. Transition care then, needs to be much more than a well-organized transfer of care *(Sawyer, Blair & Bowes, 1997)*. In order to assist youth in a comprehensive, coordinated transition, preparation needs to begin early on in the adolescent's life, to ensure he/she develops the skills and knowledge necessary for adulthood and the adult health care system. This entire process, called '*transition',* involves developmentally-appropriate care within an environment that supports the unique needs of youth with chronic health conditions and their families.

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

Developmental Transitions
from childhood to adolescence to adulthood
from school to secondary education or work environments
from home to independent or community living

Health Care Transitions
from pediatrician to adult primary care physician
from pediatric to adult specialists/clinics
from parent health care benefits/insurance to personal options
from parental care to possibly attendant care

As well, youth with chronic health conditions may have a third transition from health to illness superimposed on these transitions dependent on the nature and trajectory of their illness (*Gravelle, 1997*).

Guiding Principles in Developing a Framework for Transition Planning

The youth, families and specialty health care team members form a unique partnership that requires support and resources throughout the transition process.

The planning and development of youth-focused, family-centered care requires active participation of the youth, family and health care team members.

A generic model can be developed and utilized in various clinical settings to ensure developmentally-appropriate care through adolescence and ensure continuous care into the adult health care system and adulthood.

The need to recognize and understand the existing personnel, cost and time constraints of the current health care system.

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.

A system or pathway is necessary to provide documentation of the process to ensure quality standards of care and coordination into the adult system.

The need to create a process that incorporates evaluation of the interventions, satisfaction of all involved stakeholders and long-term health outcomes for youth with ongoing health care needs.

Ongoing collaboration and partnerships must be formed between pediatric, adult and community agencies to streamline care of youth with chronic health conditions.

Early Adolescence Ages 10 - 12 Grades 5 - 7 The ***Youth*** and ***Family*** are introduced to the Transition process and the ***Youth*** begins to participate in his/her own care.
Middle Adolescence Ages 13 - 15 Grades 8 - 10 The ***Youth*** and ***Family*** gain understanding of the transition process and the ***Youth*** practices skills, gathers information and sets goals to participate in his/her own care.
Late Adolescence Ages 16 - 18 Grades 11 - Graduation The ***Youth*** and ***Family*** prepare to leave the pediatric setting with confidence and the ***Youth*** uses independent health care behaviors and consumer skills into the adult system.
Self-advocacy Independent health care behaviors Sexual Health Social Supports Educational/Vocational/Financial planning Health & Lifestyle

A Framework for Transition Planning

A model for youth-focused care and transition planning was conceptualized that follows normal adolescent development with early, middle and late transition stages. Within this framework, specific developmentally-appropriate strategies can be placed within six main content areas: self-advocacy, independent health care behaviors, sexual health, psychosocial supports, education/vocation & financial planning, and health and lifestyle choices.

Tools to Support the Transition Process

From this framework, many tools, strategies, and initiatives have been developed and are being integrated into clinical practice at Children's & Women's Health Centre. The ON TRAC Project, now within the newly established Youth Health Program, have developed three distinct tools to support youth and their families, as well as care providers and organizations, to initiate and develop youth-focused care practices.

Components of the Transition Framework		
1.	**Self-advocacy & Self-esteem**	
	is empowering youth to learn about their disability or chronic 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.	**information teaching practice resources**
2.	Independent Health Care Behaviors	
	include adhering to medication and treatment regimes, maintaining ongoing preventative health care, and seeking out health care information and services. The goal is for the youth to move from dependent to independent self-management dependent on his/her medical, physical and cognitive abilities.	**information practice resources**
3.	**Sexual Health**	
	addresses the impact of puberty on the youth's health condition and his/her condition's impact on sexual functioning, genetic considerations, safe choices, and identifying sexual health information in their community.	**information teaching resources**
4.	**Social Supports**	
	includes helping the family acknowledge and cope with their changing roles, identifying issues that are important to each family, linking with peer and parent support groups, recreational opportunities, and resources for ongoing support.	**information support resources**
5.	**Educational/Vocational/Financial Planning**	
	is helping the youth realize his/her abilities and potential, guiding them to resources and services that will assist in their educational/vocational plans for their future, and seeking out health care benefits, insurance, and financial planning.	**information resources**
6.	**Health & Lifestyle**	
	addresses the importance of nutrition, exercise, and taking care of oneself. Through resources and teaching, the risks of drugs, alcohol and smoking are identified and how to prevent accidents and injury to oneself.	**information teaching resources**

Setting The Trac: A Resource for Health Care is a manual of 250 pages written for health care providers / agencies supporting youth with chronic health conditions and their families interested in integrating transition planning into their care and services. The manual contains over 150 references supporting the design, tools, materials, and evaluation process of the **On Trac Transition Service** at C&W. The manual provides text and handout pages that can be used within various settings to support the initiation, planning, and evaluation of a program designed to support developmentally-appropriate

care and transition planning. This resource manual was developed in response to the many inquiries of others wanting to begin integrating youth-focused care and transition planning into their work / organizational environments. It also includes a literature review of over 140 articles, grant proposal outlines, many tools and worksheets to promote group discussions, a **Clinical Pathway for Transition Planning and Adolescent Care** and associated guidelines, and many evaluation tools and strategies. Also included, are guidelines to integrate the use of the *Workbook for Youth* and *Youth Health Planner* into clinical practice.

Your Plan-It – 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. Your 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; 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 is 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.

Getting On Trac: A Workbook for Youth contains over 70 exercises for youth living with chronic health conditions to help them learn and practice the skills necessary for adulthood and the adult health care system as outlined in the Clinical Pathway for Transition Planning and Adolescent Care. Through skill development exercises in this workbook, youth are supported and encouraged as they learn to participate in their health care and transition planning. This tool is also an excellent resource for families and persons involved in the youth's health care and/or education. It has been designed for youth to own and use with support, as well as 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.

We now want to pass these tools onto our colleagues working with youth with chronic health conditions. We hope that you find these tools useful in your efforts to involve youth and support their development towards a healthy future. The ON TRAC Service continues to support multi-disciplinary teams in developing and integrating transition planning and health promoting initiatives for youth with chronic health conditions and their families. If you would like any further information, please send your fax number or contact

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