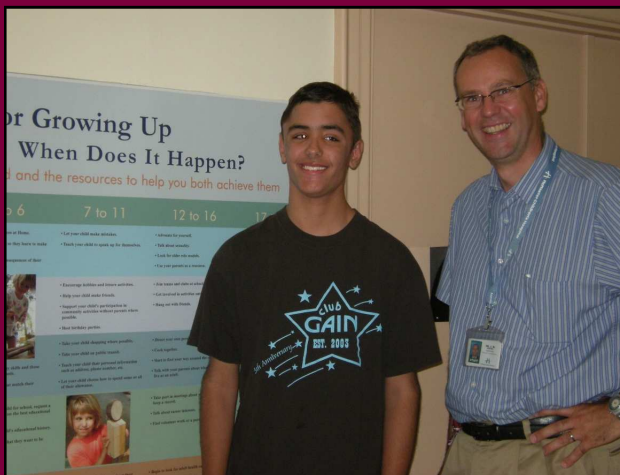


Innovative Transition Supports

For youth with chronic health conditions, transitioning into adult health services is commonly associated with poor continuity and health outcomes. Little is known, however, about the effectiveness of transition services and supports.

Investigators at *CanChild* and partners of the McMaster Child Health Research Institute (MCHRI) are conducting a pilot study called the TRACE Study: *Transition to Adulthood with Cyber Guide Evaluation*. Funded by the Alternate Funding Plan (AFP), this study will explore the use and impact of a transition program to promote an effective move from the pediatric health care team to adult-oriented health care. The investigators are taking a 'non-categorical approach' in this project since transition processes for youth with a variety of chronic childhood conditions have many commonalities for adolescents and their families.



Forty youth, aged 17 years with various chronic conditions, will participate in this project over an 18 month period. This innovative intervention will promote education and enable health self-management in order to enhance continuity of care into adulthood. A Transition Coordinator ("Cyber-guide") will be available via internet (email and chat box) for conversations about transitioning. *CanChild's* Youth KIT will be used to help the adolescent set personal goals for care, encourage and reinforce independence, and ensure that they maintain appropriate links with their adult health care providers. Consistent with the best-practice guidelines for transition, this ground-breaking research project incorporates a youth perspective of technology and their use of the Internet to interact with the world. The project hopes to identify how to improve health service delivery and knowledge translation to this population.

CanChild Centre for Childhood Disability Research

is a research and educational centre founded in 1989 with funding from the Ontario Ministry of Health and Long-Term Care. Over the years, *CanChild* has emerged as an international leader in the field of childhood disability through innovative research and a commitment to making research findings easily accessible to a wide range of audiences. As a research centre, *CanChild* conducts health services and systems research on child health issues that will make a difference for children and youth with physical, developmental and communication needs, and their families. To ensure *CanChild's* research addresses the real life concerns of children, families, and communities, our team of researchers works in close partnership with:

- Children and youth with disabilities and their families;
- Professionals who provide services for children and youth;
- Organizations such as the Local Health Integration Networks (LHINS), Community Care Access Centres (CCACs), the Ontario Association of Children's Rehabilitation Services (OACRS) and its member Children's Treatment Centres (CTCs), and Ontario Boards of Education;
- Researchers and university educators throughout Canada and around the world; and
- Policy analysts and decision-makers from government ministries, including the Ontario Ministries of Health and Long-Term Care, Children and Youth Services, Community and Social Services and Education.



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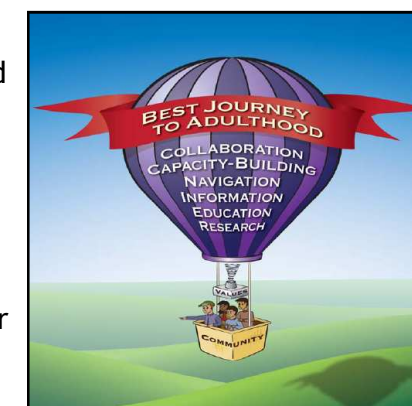
CanChild today

VOLUME ONE, FALL ISSUE 2009

Innovative Resources for the Journey to Adulthood

Researchers at CanChild have developed resources to assist youth with disabilities transition from adolescence to adulthood.

CanChild researchers, in collaboration with youth, parent groups, community networks and other agencies and services, have been working to learn about the complex process of transitioning to adulthood for the purpose of developing best practice guidelines and resources that will make a difference. Evidence indicates that individuals with disabilities go through the same transition processes as their non-disabled peers, and have the same goals and aspirations. Although personal challenges can influence the transition process, environmental and attitudinal barriers often present the most significant challenges. Unsuccessful transitions can result in prolonged dependence on family or social service systems, with considerable economic and social costs to the individual, their family, and society. Recent literature acknowledges that the transition to adulthood is a complex process of taking on new roles and adapting existing roles for both youth and their families. Current best practices use a family-centred approach and support a holistic, lifelong view of the transition to adulthood.



This "*CanChild today*" describes three projects focusing on transition. The first article outlines the development of a model for transition that takes a lifecourse perspective and recommends best practice guidelines for youth, parents, community members, service providers and policy/government decision-makers. The second article describes the development of a tool for youth with disabilities, The KIT: Keeping It Together™ for Youth (Youth KIT), that assists them in taking control of their lives through the transition process. The third article describes a new study that incorporates some of the key elements of 'best practices', including mentorship and collaboration, with the Youth KIT. We are excited to see our knowledge move into action. ✨

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CanChild today

Best Practice Guidelines and a Model for the Transition to Adulthood

Innovative research to improve service delivery for adolescents...

CanChild's research team along with other researchers from Bloorview Kids Rehab, Laurentian University, Sick Kids and Hamilton Family Network used an evidence-based approach to develop best practice guidelines and a model of transition. The approach involved critical reviews of the literature, an environmental scan conducted through focus groups and individual interviews, and a consensus exercise with an expert panel of young adults with disabilities, service providers, parents, community members and researchers.

The resultant "Best Journey to Adult Life" model represents the transition to adulthood 'journey' as a dynamic and developmental process. *Best Practice Guidelines for Transition to Adulthood* (full report) can be found on the CanChild website in the Lifecourse & Transition microsite (transitions.canchild.ca), under Resources.

The guidelines were organized into six main themes. Within each theme, specific guidelines for youth, parents, community members, service providers and government/policy makers were articulated. The six overarching guideline themes include:

- Collaborative initiatives and policies are necessary supports for the transition.
- Building capacity of people and communities will enhance the transition process.
- The role of a "Navigator" within communities facilitates capacity building.
- Information and resources should be accessible to all involved in the transition process.
- Education is a critical component of any transition strategy.
- Ongoing research and evaluation provides the evidence needed for success.

In this first stage of development, the guidelines are recommendations to guide thinking and planning for transition services and supports using a lifecourse approach that is positive, inclusive and collaborative. They are intended to be generic in their use for all populations of youth and all settings. The next step will be to apply and evaluate the usefulness of the guidelines in a variety of settings and with a variety of youth. The last article describes an example of such an application.

What *people* are saying about CanChild's Youth KIT

“From using the Youth KIT, I learned by completing the forms that I had more skills and abilities that I was aware of, and that I am a pretty cool guy.”

– 17 year old youth in Hamilton

Your resource reflects much hard work and excellent planning and direction for families!

– Case manager in Toronto

The Youth KIT

A tool for youth with disabilities

This collaborative project of CanChild and the Hamilton Family Network (www.hamiltonfamilynetwork.com) was funded by Easter Seals (www.easterseals.org) and the Pollock Foundation to develop a resource that supported the transition to adulthood. The Youth KIT provides youth with a tool to give, get and organize their information as they navigate their journey into adulthood.

The transition to adulthood is considered to be a critical journey within an individual's lifecourse, as there are significant changes taking place within the person and the environment.

Originating from the parent version of the KIT: Keeping It Together™ (KIT), it became apparent that youth on the research team wanted their own KIT in order to begin taking control of their own information. Research on the Youth KIT began in 2003 with direct input from a team of youth advisors. Youth input has continued through every stage of development.

Findings of this study include:

- All youth, regardless of disability or ability level, want to have some control over how their information is kept and shared with others.
- Using the Youth KIT leads to increased self-awareness of the youth.
- Youth are introduced to future adult roles and opportunities at their own pace through completing the sections for which they are ready.
- Parents have reported that assisting their youth in completing the Youth KIT has been an effective way to maintain communication with their adolescent.
- Youth who are getting started benefit from a mentor. An ideal mentor is someone chosen by the youth, and someone who promotes and values self-determination in youth.

The Youth KIT is a binder with worksheets for youth to fill in with information about themselves, their friends, their health, and other information needed for the transition into high school, post secondary education, employment, or future living arrangements. The Youth KIT should be available in late October 2009.



Over 4000 youth, parents, policy-makers, and therapists from over 150 countries visit the CanChild website each week. Documents on the website include past and current research, measures, articles, educational materials, and summaries of research studies.

More information on Transition to Adulthood can be found at www.canchild.ca

click on [Lifecourse & Transitions](#)

