Programs that aim to improve transition from pediatric to adult services: A snapshot

CFHI conducted an environmental scan of published and unpublished literature and resources to identify programs in Canada and abroad that aim to improve transition from pediatric to adult services for youth with chronic or lifelong conditions/disabilities. Below is the list of the 11 transition programs we identified, including descriptions of the target recipients; key program elements; information about program inception and ongoing management; and outcomes. Note that this list of programs is not exhaustive, but presents a snapshot of the programs that exist. References for the programs are embedded within the table and hyperlinks are provided where possible. Eight additional programs are included at the bottom of this document. Some overarching themes of the programs we identified include:

- Most services are hospital/healthcare institution based (e.g., Good 2 Go, YARD Clinic, OnTrac, Growing Up Ready). Few are community based (e.g., Maestro, Transition Residences).

- Target population is youth, typical age around 14 with service up to 25 (some inception for late childhood around age 10 and older).

- Eligibility criteria for enrollment in the transition programs are either broad or disease specific:
  - Broad: Special health care needs, complex care, physical disabilities, acquired brain injury, mental health, rehabilitation, developmental disabilities;
  - Specific: rheumatologic conditions, cardiac conditions, diabetes, cystic fibrosis.

- All programs have identified goals for youth related to:
  - Improving chronic health condition knowledge and skills for self-management in some domain (i.e., medication management);
  - Improving/preparing for transfer in to adult health system or adult community system.

- Key shared principles of the transition programs include:
  - Youth-focused/empowerment with inclusion of family;
  - Multi-disciplinary, coordinated care including both adult and youth agencies; stressed importance of including a designated transition coordinator to bring two service systems together and prevent loss of engagement;
  - Adaption of “Shared Management Model” (i.e., management is shared between service providers, youth, family, community).
• Core components and structures/techniques/tools varied based on program goals/needs; commonalities include:
  o Education, information and resources available in hardcopies and websites;
  o Defined pathways for service from start to “finish” with the need for these pathways to be flexible and developmentally appropriate (rather than age specific);
  o Individual counseling for support and overcoming obstacles, and managing emotional reaction to transfer (anxiety, depression);
  o Individual/centralized navigation via system (i.e., coordination of services program) or a coordinator/mentor;
  o Traditional self-management training.

• Very few (if any formal) evaluations of program effectiveness or impact exist. Data that do exist often focus on:
  o Patient/parent perspectives, satisfaction and changes in knowledge;
  o Medication/treatment adherence;
  o Improved continuity of care (i.e., decreased dropout in adult system);
  o Improvement of health-promoting/self-management behaviours;
  o Decreased morbidity;
  o Suspected financial savings.

• Published information on inception and management of the transition programs is limited, but some information is available to describe:
  o Dedicated staff funding;
  o Limited “1-time” program-limited funding (e.g., research project, donation);
  o In-kind/interested participants/stakeholders;
  o Dedicated public funding.

<table>
<thead>
<tr>
<th>Good 2 Go</th>
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<tr>
<td><strong>What is it and Who is it for?</strong></td>
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<tr>
<td>• A program to give youth with chronic conditions skills needed for transition to adult care.</td>
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<table>
<thead>
<tr>
<th>Key Elements of the Program</th>
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<tr>
<td>• A major goal is to prepare all youth with chronic health conditions to leave the pediatric hospital by the age of 18.</td>
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<tr>
<td>• Crucial to the model is the development of an early therapeutic alliance between children/youth, families and health-care providers, allowing young people with special health care needs to develop into independent, healthy, functioning adults who are able to:</td>
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<tr>
<td>o self-advocate;</td>
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<td>o maintain health-promoting behaviours; and</td>
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<td>o use adult healthcare services successfully and appropriately.</td>
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<td>• A weekly clinic is offered for SickKids patients ages 12-18, struggling with transition issues.</td>
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</table>
• **Readiness checklists** are developed for parents and teens to help determine readiness for transition.

• Timelines (for a number of health concerns) are provided as resources for parents of children going through transition, about the development of social independence.

• The term ‘graduation’ is used instead of transition to emphasize the celebration of a milestone achievement.

### Program Inception and Management

• The program was designed and implemented by a child and youth worker, a social worker, and an adolescent medicine physician.

• A symposium of community stakeholders was held at SickKids, and included talks from parents, youth, and transition experts.

• Currently, a core multi-disciplinary team is involved in day-to-day program management, including a clinical health psychologist, an advanced practice nurse, a social worker, a pediatrician, and administrative support.

### Outcomes

A 2011 internal review following the 5th year of the program demonstrated:

• Increased preparation and decreased anxiety (as a score on the Children’s Anxiety Inventory) regarding patient transfer to the adult care system

Improved continuity of care for patients

### Reference(s):

1. [http://www.sickkids.ca/good2go/](http://www.sickkids.ca/good2go/)
independent health care behaviors

Program Inception and Management

- Established in 1995, as a project at British Columbia’s Children’s Hospital, with the support of private funding due to the need to better prepare youth with chronic health conditions, pediatric staff and adult care providers about how to transfer to adult care.
  - Private funding ended before the model was fully implemented
  - Funding and in-kind resources provided by Child Health BC for ON TRAC2 has been promised
- The initiative team includes a medical lead, nursing lead, evaluator / shared care project manager, special services project manager, nurse clinician, youth engagement facilitator and a transition administrator (a full list of contributors to the program is listed here).
- The program has multiple partners and collaborators, including health and educational institutions.

Outcomes

- No formal evaluation of this program has been done, although an evaluator was established as part of the initiative team.

Reference(s)


Maestro Project System Navigator Model

What is it and Who is it for?

- A community-based navigation service for the care, education and support of youth with type 1 diabetes.
- This program has provided assistance in transition to adult care and support to over 1300 young adults 16-25 years of age living with diabetes in Manitoba.

Key Elements of the Program

- The Maestro Project is a resource of information, coordinated by a ‘Maestro’, for young adults regarding care services, education, advocacy, and diabetes research.
  - Contact with adolescents is maintained to provide support and assistance in identifying and overcoming the obstacles to accessing appropriate healthcare services.
- The primary goal is to increase the rate of medical and educational follow-up for young adults with type 1 diabetes, and reduce morbidity and mortality from complications.
- Examples of contact avenues include: bimonthly newsletters, and casual evening drop-in groups; Educational events designed to encourage socialization with peers and to facilitate relationships with diabetes educators, endocrinologists, researchers, and other service providers.
Program Inception and Management
- Launched by the Winnipeg Regional Health Authority in July 2002.
- Financial support from The Lawson Foundation was given in the grant amount of $75,000 that facilitated two years of project initiation.
- The program uses an administrative project co-ordinator and mentor, or ‘Maestro’ for the medical and educational patient follow-up.

Outcomes
- A lowering of adult care dropout from 40% to 11%, and a greater rate of access to adult programs following end of pediatric care.
- Improved reconnect with adult medical services, with fewer expressed difficulties in establishing regular follow-up.
- Improved medical surveillance.

Reference(s)

The Be Your Own Boss (BYOB) Programme (Formerly called Live Better Every Day – Be Your Own Boss)
What is it and Who is it for?
- A self-management programme, offered by Alberta Health Services, for transitioning young adult patients who are living with a chronic health condition (e.g., diabetes, multiple sclerosis, asthma, cancer).

Key Elements of the Program
- Community-based and peer-led
  - Workshops are led by volunteer young adults who have gone through a similar transition
- Designed to enhance regular treatment and disease specific education
- Transition workshops are offered to individuals, living with long-term illness and requiring complex care, between the ages of 14 and 24.
- Development of self-management skills through facilitated workshops
  - Workshops include discussions on transition issues, communication skills, symptom management, healthy lifestyle choices, symptom management and goal setting.

Program Inception and Management
- First official adaptation of the Stanford Chronic Disease Self-Management Program.
- Workshops were developed by an interdisciplinary team, including multiple registered nurses, a registered psychologist and Stanford Master Trainers (individuals who have completed training in patient education and self-management programs in the School of Medicine at Stanford University).
- Service providers are trained leaders within Alberta Health Services.
  - Young adults living with chronic illness, who have successfully transitioned through same/similar challenges, volunteer as mentors, and are assigned to lead workshop
Outcomes

- On adult populations, the intervention has been successful in increasing health-promoting behaviours, maintaining or improving health status and decreasing rates of hospitalization.
- No studies were identified to evaluate program effectiveness on adolescents.

Reference(s)
2. http://www.capitalhealth.ca/nr/rdonlyres/ec5be2u5ndssje4wbl2m5lknwlczb4qnkvzjb44use4be dfly5dfbrl5olptljw7pkmlnr4frqhpzi3qldghzfrhah/chq_summer08_final.pdf

**Young Adults with Rheumatic Diseases (YARD) clinic**

What is it and Who is it for?

- A specialized transition program for youth aged 18-23 with rheumatic diseases, to increase autonomy in their health care management.
- Seeks to provide continuity in transition from pediatric to adult care.
- Focuses on patient empowerment for medical decision-making, through the teens taking ownership of their treatment decisions.

Key Elements of the Program

- Facilitates successful transfer of rheumatology care to the adult clinic
  - Informs patients and families about YARD two years prior to transfer(patient age 16)
  - Re-education about disease basics is done in-clinic.
  - Teens are taught about healthcare coverage and insurance, as well as the availability of government support.
- Teaches strategies patients can use to manage their illness and other life transitions when they leave the pediatric system.
- Provides an opportunity for confidential discussions with the patient regarding adolescent health issues.
- Assists with separation from parents with respect to medical issues
  - After the first visit to the YARD clinic, parents are excluded from attendance, and are actively discouraged from taking a coordinator role in their child’s ongoing healthcare (e.g., reminding about appointments).

Program Inception and Management

- Functioning in its current format since 1995
- Operates through a multi-disciplinary team that includes pediatric and adult rheumatologists, a clinical nurse specialist, and a social worker. There are also links with physiotherapy, occupational therapy, vocational and sexual counseling services and a network of youth-friendly adult medicine subspecialists.
- Patients over 17 years of age who are newly diagnosed with a rheumatic disease are generally not accepted because of limited clinic capacity and resources, and because of fundamental differences between those having lived with child-onset rheumatic disease and patients with a new diagnosis at transitional age.
Outcomes
Shown through a preliminary evaluation of the Calgary YARD Clinic from 2006-2008:

- Clinics are well attended, with 94% of patient attendance rates
- Patients continue to have good disease management – only one patient required illness-related hospitalization following the YARD Clinic.
- 96% of patients are attending educational institutions or working.

Reference(s)

Congenital Heart Disease Transition Task Force
What is it and Who is it for?

- A program that aims to facilitate the transition between care from pediatric to adult care for adolescents and young adults with congenital heart disease.

Key Elements of the Program

- Goals of the program include preparing youth with chronic health conditions for transition through teaching skills and increasing knowledge to promote self advocacy; promoting healthy behaviors; utilizing adult health care services appropriately and successfully.
- The program has a three-part approach:
  - education and staff support;
  - resource identification and development; and
  - support and evaluation strategies
- Timelines are used as a self-management continuum for various developmental stages.
  - Cardiac-specific timelines have been customized from the more generic timelines used in the Good 2 Go program.
- Educational events are held, separately, for the support of health care management (for both parents, and youth).

Program Inception and Management

- Established in 2006, with a working group of pediatric and adult congenital heart disease nurses
- The task force is comprised of interdisciplinary team of pediatric and adult care providers, including physicians, cardiology fellows, nurses/nurse practitioners, and psychologists.
  - A specific transition coordinator is a recommended position, but does not currently exist (as of 2012).

Outcomes

- We did not identify any formal evaluations or outcomes of this program.
- An evaluation of the family perspective on the usefulness of the Timeline is currently underway.

Reference(s)
LIFEspan Clinic (Bloorview Kids Rehab and Toronto Rehab)

What is it and Who is it for?

- A two-year program for youth and young adults, ages 16-18, who have cerebral palsy or acquired brain injury.
- Focus is on healthy living to avoid complications incurring hospital stay.
- Seen as a “bridge” between pediatric and adult rehabilitation services through the provision of information and skills for active management of care needs.

Key Elements of the Program

- Provides a single point of access for lifelong, comprehensive, coordinated rehabilitation services
  - Services are incorporated in both pediatric and adult settings (Bloorview Kids, and Toronto Rehab, respectively).
- Collaborative work with Community Care Access Centres (CCACs), Community Health Centres (CHCs), family doctors and other care and support agencies
- Needs assessments are completed by a Nurse Practitioner before transfer from child to adult care, to properly identify any ongoing issues for transition.
- Services are offered for life skills development promoting independent living. Some examples are:
  - Pain management
  - Nutrition counseling
  - Speech language therapy
  - Mobility assessment and support
  - Learning to cook

Program Inception and Management

- In existence since 2008, with funding being received from Toronto Central LHIN
- Involves a wide range of skilled rehabilitation professionals who work collaboratively in an interprofessional team.
- Service team includes a life skills facilitator, nurse practitioner, occupational therapist, physiatrist, physiotherapist, social worker, and speech language pathologist.
- The clinic is offered at Toronto Rehab, in the Rumsey Centre

Outcomes

- A short term process evaluation was conducted by GTA Rehab Network through interviews of 8 steering committee members and 10 front-line staff. Results included:
  - 55-60 new clients were referred for transition to adult services, up from 43 in 2007/2008
  - 54-64 new clients gained access to LIFEspan services, up from 32 in 2007/2008
  - An increased in the number of annual visits, from under 500 in 2007/2008 up to 2000-2500
  - 85% of LIFEspan clinic patients use the Growing Up Ready tool at a satisfaction rate of
95%

- Long term outcome evaluation is being funded by the Ontario Neurotrauma Foundation (in progress)

Reference(s)
1. [http://www.uhn.ca/TorontoRehab/PatientsFamilies/Clinics_Tests/Lifespan_Clinic](http://www.uhn.ca/TorontoRehab/PatientsFamilies/Clinics_Tests/Lifespan_Clinic)

Community Living BC
What is it and Who is it for?
- Community Living supports services to eligible adults (over age 19) with developmental disabilities either through:
  - Paying for services directly using money received from CLBC;
  - Receiving support from organizations that are CLBC funded for the provision of services to eligible individuals and families.

Key Elements of the Program
- Collaborative work with youth and families, as well as government organizations, to support youth transitions to adulthood
- Focus on creating communities where people with developmental disabilities have more choices about how they live, work and contribute
- Assistance in steps towards independent community living examples include:
  - Finding housing options (supported, shared, or staffed residential living)
  - Family support
  - Community connections to service providers
  - Community inclusion, focusing on employment, social, and life skill building
- Offers help through direct financial aid, or receiving aid from organizations that are program-funded
- Community Living BC offers policy, program and initiative information in an ‘Information for Families’ section to help answer questions surrounding the CLBC services.

Program Inception and Management
- Provincial crown agency mandated under the Community Living Authority Act
- Started by individuals and families who wanted a special agency to help people with developmental disabilities with their unique needs.

Outcomes
- No formal outcomes of this program were identified.

Reference(s)
1. [http://www.communitylivingbc.ca/](http://www.communitylivingbc.ca/)

Growing Up Ready
What is it and Who is it for?
- A multi-faceted program at Bloorview Kids Rehab to help families understand the everyday
experiences and skills their children need to become mature, confident adults - and how to access them.

- Designed to help families support children with disabilities become more independent, through understanding and learning skills that youth require to become mature and confident adults.
- Used as a program tool within the LIFEspan Clinic program (Toronto), and at the KidsAbility Centre for Childhood Development (Waterloo).
- Rehab centres in Sweden, Ireland, the United States and Canada have adopted elements of Growing Up Ready, and Ontario health accreditation surveyors recently identified it as a best practice in transitioning children with disabilities to adulthood.

Key Elements of the Program

- Uses **timetables and checklists** to make parents aware of ideal progression of children at different ages and stages. The timetable includes social and recreation activities, everyday skills such as brushing teeth and household chores, teaching children about their health needs and how to advocate for them, and how to nurture interest in work experiences and a career.
- Demonstration clinics inform patients and families about factors that promote a smooth transition for teenagers, from child to adult rehabilitation services.
- Provides education sessions led by facilitators who are themselves parents of children with disabilities, so that families can network with other families facing similar experiences.
- Bloorview’s Life Skills and Wellness Institute complements the Growing Up Ready program with a wide range of recreation, creative, mentorship and skill-building programs for children aged seven and older.
- At the end of the program, a demonstration clinic run by Bloorview and Toronto Rehab aims to smooth the transition from child to adult rehabilitation services for teenagers by offering comprehensive, co-ordinated care with a network of specialists experienced in childhood-onset disabilities.

Program Inception and Management

- Bloorview Kids received program initiative support with a $500,000 gift from RBC Foundation
- Education sessions are facilitator-led.
  - These facilitators are parents of kids with disabilities, an additional tool in the networking process.
- At Bloorview Kids, transition demonstration clinics are led as a collaborative effort between Bloorview Kids and Toronto Rehab.

Outcomes

- No formal evaluations of this program were identified, although 85% of LIFEspan clinic patients use the Growing Up Ready tool at a satisfaction rate of 95%.

Reference(s)
**Transitional Care Planning Clinic**: London Health Sciences Centre

**What is it and Who is it for?**
- Aims to prepare youth with complex care needs for the transition to adult care at age 18.
- Prioritizes youth who will turn 18 within the year (but by 2015 this is intended to change to age 14 to better prepare youth for transition at age 18).

**Key Elements of the Program**
- The program is intended to lead to the creation of a comprehensive health summary and care plan, created with the patient and family.
- Participants are assigned to a 1:1 ratio in one of two programs:
  - An 18 month transition program, where pediatric care lasts six months, followed by one year of adult care; or
  - A standard diabetes care program.
- Follow up periods last one year, for outcome assessment.
- The Transitional Care Planning Clinic facilitates transition related activities such as formulating a partnership between medical and legal client support networks, addressing issues such as power of attorney, funding opportunities for youth, and creating wills.

**Program Inception and Management**
- This transition clinic is part of a multi-centre randomized controlled trial.
- It began as a collaborative effort between pediatric and adult diabetes centres throughout Ontario, and JDRF (Juvenile Diabetes Research Foundation) Canada.
- Initiative was a response from JDRF Canadian Clinical Trial Network to families’ and patients’ concerns about the lack of transition support.
- Launch date of the program was in April 2012, as the Transition from Pediatric to Adult Care in Type I Diabetes Trial.
- A dedicated coordinator is involved to aid in the transition process.

**Outcomes**
- The project is still in early stages and no formal evaluation has been done on this study.

**Reference(s)**
1. [http://www.lhsc.on.ca/About_Us/LHSC/Publications/Homepage/JDRFAnnouncement.htm](http://www.lhsc.on.ca/About_Us/LHSC/Publications/Homepage/JDRFAnnouncement.htm)

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**National Educational Association of Disabled Students (NEADS) – High School Transition Programs**

**What is it and Who is it for?**
- Network linking students with disabilities to services and resources that facilitate transition to adult services.
- Members include disabled students, educators, organizational, and professional service providers.

**Key Elements of the Program**
- Advocates for increased accessibility of resources for disabled students.
- Support and experiences are shared by instructors or administrators at potential colleges or
universities, or other students who have already made the transition to postsecondary school.

- Offers a variety of links to services and resources which help to facilitate the transition process.
- NEADS is partnering with CSS to perform an assessment of the academic/educational debt load and financial barriers of students with disabilities, in comparison to the overall student population.

Program Inception and Management

- NEADS was created by a group of students who were members of a disabled students club at Carleton University in 1981.
- Governed by a cross-disability, twelve-person board of directors.
  - The only exception is the position of open representative, which can be filled by anyone.
  - Members represent various geographical regions across the country.

Outcomes

- No formal evaluations were identified.

Reference(s)


Additional Transition Programs

<p>| Transition Program                          | Location            | Website                                                        |
|--------------------------------------------|---------------------|                                                               |
| Ability Online                             | Online community    | <a href="http://www.abilityonline.org/">http://www.abilityonline.org/</a>                                 |
| Bridges Transitional Care Program          | Kentucky            | <a href="http://kosairchildrenshospital.com/BridgesTransitionalCare">http://kosairchildrenshospital.com/BridgesTransitionalCare</a>     |
| DiscoverAbility                            | Bloorview           | <a href="http://abilities.ca/discoverability/">http://abilities.ca/discoverability/</a>                           |
|                                            | MacMillan Children’s Centre (Toronto) |                                                               |
| DO-IT Scholars program                     | University of Washington | <a href="http://www.washington.edu/doit/">http://www.washington.edu/doit/</a>                               |
| Erinoak Kids Independent Living Program (ILP) | Ontario          | <a href="http://www.erinoakkids.ca/">http://www.erinoakkids.ca/</a>                                     |
| Health Care Transitions                    | University of Florida, College of Medicine | <a href="http://hctransitions.ichp.ufl.edu/">http://hctransitions.ichp.ufl.edu/</a>                           |</p>
<table>
<thead>
<tr>
<th>Sibling Support Project</th>
<th>Seattle, WA</th>
<th><a href="http://www.siblingsupport.org/">http://www.siblingsupport.org/</a></th>
</tr>
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<tbody>
<tr>
<td>Thames Valley Children’s Centre Post-Secondary Preparation Workshop</td>
<td>London, ON</td>
<td><a href="http://www.tvcc.on.ca/">http://www.tvcc.on.ca/</a></td>
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