



Transition to Adult Healthcare Services Work Group Inventory of Youth Transition Tools and Resources

Health Passports: Portable Health Summaries

Tool Name	Description, comments, website	Supporting Evidence
<p>Good 2 Go MyHealth Passport</p> <p>(SickKids Good 2 Go Program)</p>	<p>Customized, wallet-sized card that lists medical conditions, past procedures/ treatments, medications, allergies, and additional health information.</p> <p>Disease-generic and specific versions are available. With the current version, it is not possible to save (and later) update information.</p> <p>www.sickkids.ca/myhealthpassport</p>	<p>Wolfstadt J, Kaufman A, Levitin J, Kaufman M. The use and usefulness of MyHealth Passport: an online tool for the creation of a portable health summary. <i>Int J Child Adolesc Health</i>. 2011;3(4):499-506.</p> <p>Online and telephone surveys revealed that most users found the program easy to use. Most interviewees still had their passport and carried it</p>
<p>My Health Passport</p> <p>(University of South Florida)</p>	<p><i>Created to support individuals with intellectual and developmental disabilities to share critical health information at clinic and inpatient visits.</i></p> <p>http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf</p>	<p>Unaware of any literature support</p>
<p>My Med Schedule</p>	<p>Creates a medication schedule that is easy to read and update.</p> <p>https://secure.medactionplan.com/mymedschedule/transplantexperience/</p>	<p>Unaware of any literature support</p>
<p>Electronic Care Plan</p> <p>(University of Wisconsin)</p>	<p>A document that includes emergency contacts, brief medical history, medication information and <i>unique section about how the individual communicates.</i></p> <p>https://www.waisman.wisc.edu/cshcn/Health_IEP/packet%20Embedding%20Health%20Outcomes%20in%20the%20IEP/GHC_MedicalCarePlan.pdf</p>	<p>Unaware of any literature support</p>

Tool Name	Description, comments, website	Supporting Evidence
Electronic Transition Information Form (Healthy Transitions NY)	A transfer summary that includes patient information, health care provider list and other pertinent information. http://www.healthytransitionsny.org/data/6729_H.I._Doc_Final_408.pdf	Unaware of any literature support
Health Care Transition Summary (Florida Health and Transition Services)	A transfer summary that includes patient information, health care provider list and other pertinent information. http://www.floridahats.org/wp-content/uploads/2010/03/HCT-Summary.pdf	Unaware of any literature support

Timelines: Guidelines for Positive Skills Development

Tool Name	Description, comments, website	Supporting Evidence
Growing Up Ready Timetable and Checklists (Holland Bloorview Rehabilitation Hospital)	A timetable and a series of checklists to help clients and families prepare for transition to adult life. The tools were designed to be generic for use with the broad range of clients to reflect that preparations for adulthood should start early, and provide hope for the future. Timetable for Growing Up can be used both clinically and within families to promote discussion on developing age appropriate skills. The Growing Up Ready checklists are designed to further promote planning and encourage skill building and identify progress through transition planning milestones. They are designed to be completed by youth or family members and reflect the shared management philosophy. http://www.hollandbloorview.ca/resourcecentre/growing_up/growing_up_timetable.php	Gall, C., Kingsnorth, S. and Healy, H. (2006). Growing up ready: A shared management approach to transition. Physical and Occupational Therapy in Pediatrics, 38, 47-62.
Help them grow so they're Good 2 Go Timelines (SickKids Good2Go Program)	A handout for parents and patients describing age-appropriate tasks to encourage youth to take a more active role in their own health care management from a young age. http://www.sickkids.ca/Good2Go/Transition-Interventions-Tools/Timelines/index.html	Unaware of any literature support
Transition Timeline for Children and Adolescents with Special Healthcare Needs	A developmental timeline from birth to adulthood to assist in the transition to adulthood.	Unaware of any literature support

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(From Shriner's Hospitals and University of Washington)	http://www.floridahats.org/wp-content/uploads/2010/03/Transition-Timeline1.pdf	
Transition Checklist for students with disabilities in high school Transition Advisory Committee for the Region of Peel (TAC)	A 7-year checklist for youth with developmental disabilities, families and school personnel as a resource to identify different areas that students and families may want to explore when getting ready for the future http://www.cdrcp.com/transition/transition-resources	

Readiness Checklists

Tool Name	Description, comments, website	Supporting Evidence
Good 2 Go Readiness Checklist (SickKids Good2Go Program)	A self-report measure of a youth's level of preparedness for entering the adult health care system. Identifies skills needed to achieve readiness and increased self-management of health care. www.sickkids.ca/good2go	Unaware of any literature support
LIFESpan Clinic Questionnaire (Toronto Rehabilitation Institute-University Health Network)	This aphasia-friendly questionnaire is used to guide discussion with young adults in the clinic to help identify priority areas that they would like to work on.	Unaware of any literature support
Transition Readiness Assessment Questionnaire (TRAQ) Sawicki, Livingood and Wood, 2009	A tool to assess how youth describes their skills in the areas that are important in their care. The answers can help provide services and education that will be important in preparing youth to transition to adult health care. http://www.floridahats.org/wp-content/uploads/2010/03/traq_4.1.pdf	Minimal literature support. Sawicki GS, Lukens-Bull K, Yin X, Demars N, Huang IC, Livingood W, Reiss J, Wood D. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ--Transition Readiness Assessment Questionnaire. J Pediatr Psychol. 2011;36:160-71. Initial validation study revealed two domains with high internal consistency: Skills for Self-Management and Skills for

Tool Name	Description, comments, website	Supporting Evidence
		Self-Advocacy.
Transition to Adult Living in Pennsylvania (Pennsylvania)	This site provides a checklist, resources, and steps to assist youth and families to make a successful transition to adult living that includes health and health care. http://www.floridahats.org/wp-content/uploads/2010/03/PennsylvaniaChecklist1.pdf	Unaware of any literature support
ErinoakKids Transitioning Planning Tool (ErinoakKids Centre for Treatment and Development)	A tool developed to assist with the future planning for youth with disabilities and their families/caregivers. The tool provides a review of the client's current skills and resources. Based on this information, resources and recommendations will be provided to facilitate the youth's transition to adult services.	Unaware of any literature support

Knowledge and Skill Development for Youths and Young Adults

Tool Name	Description, comments, website	Supporting Evidence
The Best Journey to Adult Life for Youth with Disabilities: An Evidence-based Model and Best Practice Guidelines for the Transition to Adulthood for Youth with Disabilities	The Guidelines are organized into six main themes that emerged from comprehensive literature reviews, consensus meetings and focus groups with key stakeholders. http://transitions.canchild.ca/en/OurResearch/bestpractices.asp	Debra Stewart, Matt Freeman, Mary Law, Helen Healy, Jan Burke-Gaffney, Mary Forhan, Nancy Young, and Susan Guenther, 2009; Published and distributed by <i>CanChild</i> Centre for Childhood Disability Research
The Maestro Project: A Patient Navigator for the Transition of Care for Youth With Type 1 Diabetes (Winnipeg)	Patient navigator program has a coordinator and mentor who provide education and support through email, telephone, website, newsletters, drop in program, education events. http://spectrum.diabetesjournals.org/content/24/1/9.full	Van Wallegghem N, Macdonald CA, Dean HJ. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. <i>Diabetes Care</i> . 2008;31:1529-30. Van Wallegghem N, Macdonald CA, Dean HJ. The Maestro Project: A Patient Navigator for the Transition of Care for Youth With Type 1 Diabetes. <i>Diabetes Spectrum</i> . 2011;24:9-13. Systems navigator was associated with better medical surveillance.

Tool Name	Description, comments, website	Supporting Evidence
Video teaching modules (Florida Health and Transition Services)	This web-based training program is designed to help young people with disabilities and chronic health conditions and their families with the process of planning for and successfully completing a transition to adult oriented medical services. Professional training videos also available on this site http://jaxhats.ufl.edu/tc.php	Unaware of any literature support
3-Sentence Summary (SickKids Good 2 Go Program)	Tool for youth to develop the skill for talking about their condition and concerns to health care providers www.sickkids.ca/good2go	Unaware of any literature support
Guidelines for Transition from Pediatric to Adult Care Transplant Centre SickKids	Checklist for health care providers to use to make sure all steps are covered regarding preparing youth/families for transition/transfer (Guidelines are located at the end of the table on pages 88-90)	Unaware of any literature support
Youth KIT CanChild Centre for Disability Research	The Youth KIT is designed to help youth with disabilities give, get, and organize their own information, in a way that promotes self-management as they begin the transition from adolescence into adulthood. Youth KIT worksheets and training videos are also included. http://www.canchild.ca/en/canchildresources/youthkit.asp	Unaware of any literature support
<i>Health Care Transition Planning Guide</i> <i>(Institute of Child Health Policy at University of Florida and CMS)</i>	This planning guide assists parents and youth to identify things that the youth are doing now and in the future, to be independent in her/his health care. http://www.floridahats.org/wp-content/uploads/2010/03/HCT_Workbook_12-14.pdf	Unaware of any literature support
Condition-Specific Information (Florida Health and Transition Services)	Posted information on specific conditions and disabilities from different sources. http://www.floridahats.org/?page_id=608	Unaware of any literature support

Tool Name	Description, comments, website	Supporting Evidence
Be Your Own Boss self-management program (Alberta Health Service)	Self-management program for youth. Adaptation from the Stanford Self-management Program. http://www.albertahealthservices.ca/services.asp?pid=safandrid=1054311	Unaware of any literature support
Royal Children's Hospital Transition Program, (Melbourne Australia)	This site has factsheets, checklist and tools that cover a range of topics intended to support and inform young people and parents throughout the transition process. http://www.rch.org.au/transition/	Unaware of any literature support

Knowledge and Skill Development for Parents and Caregivers

Tool Name	Description, comments, website	Supporting Evidence
Teen brain education	We once thought that the brain was fully formed by the end of childhood, but research has shown that adolescence is a time of profound brain growth and change. http://teenagebrain.blogspot.ca/	Unaware of any literature support
A Parent's guide to the teen brain	Through the use of video, interactive segments, scenario-based role-playing experiences, and practical advice from experts, A Parent's Guide to the Teen Brain explores the science behind teenage brain development and how it shapes normal teenage attitude and behavior. http://teenbrain.drugfree.org/tools/index.html	Unaware of any literature support
Complex Care Transition Resource Guide (Good 2 Go Program SickKids)	A 3-page document summarizing services supports and information needed for families of adolescents with complex medical care needs during transition to adulthood. http://www.sickkids.ca/Good2Go/Transition-Interventions-Tools/Complex-Care-Resources-for-	Unaware of any literature support

Tool Name	Description, comments, website	Supporting Evidence
	families/Complex%20Care%20Transition%20Resource%20Guide.html	
<p>Connections - A Guide to Transition Planning: Initiated by the Toronto and York Region Innovation Fund 2005/06. Material was reviewed and updated by representatives from Wellington/Dufferin, Waterloo Halton and Peel communities in 2010.</p>	<p>A guide to transition planning for parents of children with a developmental disability.</p> <p>http://www.cdrcp.com/transition/connections-a-guide-to-transition-planning</p>	

Preparation for Adult Care

Tool Name	Description, comments, website	Supporting Evidence
<p>Getting ready for Adult Care Booklet (SickKids Good 2 Go Program)</p>	<p>A 4-page booklet for adolescents describing general ways to prepare for one's first adult appointment.</p> <p>www.sickkids.ca/good2go</p>	<p>Unaware of any literature support</p>
<p>Parent Tip Sheet (SickKids Good2Go Program)</p>	<p>A 2-page document describing parent/caregiver's role in preparing youth for transitions. Includes references for additional support.</p> <p>www.sickkids.ca/good2go</p>	<p>Unaware of any literature support</p>
<p>Taking Responsibility for Adolescent/Adult Care (On TRAC) Children's and Women's Health Centre, British Columbia</p>	<p>Tools include workbooks for youth and providers and a "You-plan it" book for teens.</p> <p>http://www.acsa-caah.ca/Portals/0/Member/PDF/en/documents/ontrac.pdf</p>	<p>Unaware of any literature support</p>

Transfer Summaries

Tool Name	Description, comments, website	Supporting Evidence
Transfer Checklist (Good 2 Go Transition Program)	A checklist used by paediatric providers to track and plan for activities required for successful transfer to adult health care.	Unaware of any literature support
Transfer Clinics – Evaluation Survey (Good 2 Go Transition Program)	A brief survey of patient's experience in a Transfer Clinic and its impact on readiness for transfer.	Unaware of any literature support

Models of Transition Clinics/Programs

Tool Name	Description, comments, website	Supporting Evidence
YARD: Young Adults with Rheumatic Diseases	A transition clinic that transfers medical information from a pediatric to adult provider. The unique aspect of this program involves the patient being seen by their pediatric provider in the adult setting. The care gradually shifts to an adult provider. http://www.arthritispatient.ca/index.php/resources/every-jia-kid-should-have-a-yard/	Unaware of any literature support
LIFEsan Service (Living Independently and Fully Engaged) Toronto Rehabilitation Institute and Holland Bloorview Kids Rehabilitation Hospital	LIFEsan offers a single point of access where clients can meet with an expert interdisciplinary team that is familiar with their specific needs. The primary goal is to effectively link clients with childhood onset disability to specialized adult services and maintain this linkage (and resulting service provision) over time. http://www.hollandbloorview.ca/programsandservices/childdevelopment/lifespan.php	Kingsnorth, S., Lindsay, S. , Maxwell, J., Seo, H., Tsybina, I., Seo, H, Macarthur, C, and Bayley, M. (2010). Implementation of the LIFEsan model of transition care for youth with childhood onset disabilities. <i>International Journal of Child and Adolescent Health (Special Issue on Youth Health Care Transition)</i> , 3(4), 547-560.
Managing the Transition of Care for Patients with Type 1 Diabetes	The Endocrine Society spearheaded an initiative to develop transition of care resources specific to type 1 diabetes., was formed to evaluate gaps related to care coordination and patient education. Following a comprehensive literature review, the working group found a number of gaps and developed the following	

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Hormone Health Network, American Academy of Pediatrics, American Diabetes Association, Pediatric Endocrine Society, American College of Physicians, Juvenile Diabetes Research Foundation, International Society for Pediatric and Adolescent Diabetes, and American Association of Diabetes Educators	resources to address these needs: http://www.endo-society.org/clinicalpractice/transition_of_care.cfm	

Training for Professionals

Tool Name	Purpose/description	Supporting Evidence
Health Care Transition Training Program (University of Florida)	A training program is available for CME/CEU credits developed by the Institute on Child Health Policy at the University of Florida. http://www.floridahats.org/wp-content/uploads/2010/03/floridahats_hct4hcp_brochure1.pdf	Unaware of any literature support

Graduation Tools: To Acknowledge Leaving the Paediatric System as a Sign of Achievement

Tool Name	Purpose/description	Supporting Evidence
Graduation certificate	A certificate congratulating patients on their graduation from paediatric health care. Symbolizes the significance and accomplishment of moving on to adult health care. http://www.sickkids.ca/Good2Go/Transition-Interventions-Tools/Graduation/graduation.html	Unaware of any literature support