

**TRACE STUDY**  
**Transition to**  
**Adulthood with**  
**Cyber guide**  
**Evaluation**



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**Perceived Needs of Youth with Chronic Medical Conditions During the Transition to Adult Healthcare System**

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**BACKGROUND**

- Transition from pediatric to adult healthcare service is often associated with adjustment, uncertainty, and a lack of information and support, resulting in negative health outcomes (van Staa et al., 2011)
- Parents are often concerned about this transition and find it challenging to step aside and shift roles to allow their youth to accept more responsibility (Allen et al.; van Staa et al., 2011)
- This study is a part of a larger 4-year study that has been investigating the ways in which youth with chronic health conditions utilize resources designed to facilitate the transition process (Punthakee et al., 2009-2011)

**STUDY OBJECTIVES**

- To explore the experiences of youth and their caregivers during the transition to adult healthcare services and their perspectives on two innovative transition resources.

**TRANSITION RESOURCES**

**TRACE Mentor**

- TRACE is an online mentor that is available to interact with study participants through AbilityOnline
- TRACE provides participants with support, encouragement, and information.

**Youth KIT®**

- Helps youth obtain, organize, and share personal information as they transition into adulthood
- Modules on personal, social, school, work, finances, transportation, personal care, life skills and medical/health information

**METHODS**

- A qualitative phenomenological approach was used
- Youth already enrolled in the TRACE study and their caregivers were purposefully selected for interviews
- A conventional inductive content analysis process was used for data analysis

**PARTICIPANTS**

<b>Total # Youth Participants</b>		<b>11</b>
Age Range of Youth Participants (years)		18-21
Gender	Male	5
	Female	6
Clinics	Children's Development Rehabilitation Program – Teen Clinic	2
	Eating Disorders	1
	Epilepsy	3
	Inflammatory Bowel Disease	2
	Lipids	2
	Nephrology	1

<b>Total # Caregiver Participants</b>		<b>7</b>
Gender	Male	1
	Female	6

**SELECT THEMES**

**1. Perceived Needs for Transition Resources**

- Most participants reported that the Youth KIT® was well organized
- Many reported not using the Youth KIT® and online mentor consistently because they did not have a “problem,” had lots of supports in place, and/or were “too busy” to fully participate in the study
- Participants felt the Youth KIT® and online mentor would work better for youth with more severe disabilities, who have less supports, and/or who are younger and at an earlier stage of transition

“I remember thinking, “This is well put together and this can be very valuable for someone who has a need for it.” I just didn't feel there was a value to us, like we had to use it and there was a need that wasn't already being addressed in our social network here.” (Caregiver)

**2. Self-Management and Parent Role**

- Most youth reported taking care of their medical needs and going to medical appointments alone
- Many youth continued to receive help from their parents for reminders and transportation
- Several parents expressed concern about their youth taking care of their own health and said they would be involved in supporting their youth's needs well into the future

“I do make a lot of decisions on my own, my parents and everything are always there for support and they help me weigh out the options or so, but in the end it is my decision.” (Youth)

**3. Recommendations**

- Make the Youth KIT® more suited to individual needs and change the nature of some of the questions (e.g. more suitable for an adult audience)
- Make the Youth KIT® available through different avenues (i.e., online, Facebook, mobile phone apps)
- Have healthcare providers ask for the Youth KIT® upon every visit and provide some direction or assistance with its use

**CONCLUSIONS**

- Transition from the pediatric to adult healthcare system is complex and influenced by a number of factors
- Both youth and parents are going through multiple transitions during this stage in life
- Parents need to provide balanced “behind-the-scenes” support during their youth's transitions
- Youth and caregivers need support, guidance, and personalized resources at an early stage in the process to help make the transition smooth
- Effective use of transition resources depends on creative teamwork of healthcare providers, youth and their caregivers together
- Healthcare providers and parents need to promote, encourage, and assist, when necessary, with resource use by youth