

Your Transition Experience: Youth and Parents' Perspectives

Adapted from a summary report of *Qualitative Study of the Use and Impact of a Transition Coordinator and Youth KIT® among Adolescents with Chronic Medical Conditions* carried out by Dana Henderson, Shannon Hudson, & Evelyn Kosteltz, MScOT Candidates 2012, and supervised by Debra Stewart, MSc (OT), *CanChild* Centre for Childhood Disability Research



Why study transition to adult health care services?

For youth with chronic conditions, the move from pediatric to adult health care services is often associated with adjustment, uncertainty, and the lack of information and support.

About the study

The purpose of this study was to learn about the experiences of youth (and their caregivers) during the transition to adult health care services, as well as their perspectives on the two transition resources: the TRACE online mentor and Youth KIT.

11 youth and 7 caregivers participated in interviews and shared their views and perceptions that are summarised below.

1. About youth participants

18-21 years old; 5 males and 6 females attending 6 different clinics;

Most have begun college or university and are making new friends;

Most still live at home; several have jobs; most reported to be very busy.

2. Overarching themes of transition

Youth reported experiencing multiple transitions happening all at once.

Lots of life changes, including those related to becoming more independent with their health care as they get older as well as starting college or university.

3. Supports

Most use family and friends as supports.

Many participants said that a good doctor was a helpful support.

Participants in school reported using services on campus for help; e.g., campus healthcare clinic; student advisors regarding heavy course load, or recognizing personal limits.

4. Self-management and parent role

Most *youth* participants reported that they were taking care of their medical needs and going to medical appointments independently.

Yet, many youth continued to get help from their parents for reminders and transportation.

Several *parents* expressed concern and worry 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. Nonetheless, many parents reported letting their youth become more independent in taking care of their medical needs.



5. Perceived barriers to smooth transition

Little information available on the transitioning process;

Fewer services in the adult care system;

Transportation and distance to appointments;

A need to change physicians.

6. Perceptions about TRACE transition resources

Most participants reported that the Youth KIT binder was well organized.

However, many reported not using the Youth KIT and online mentor consistently because they didn't 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 the earlier stages of transition.

7. Recommendations for TRACE transition resources

Making the Youth KIT more suited to individual needs and changing the nature of some of the questions (e.g. more suitable to an adult audience);

Making the Youth KIT available through different avenues (i.e. online, Facebook, mobile phone applications);

Having healthcare providers (doctors, clinic staff) ask for the Youth KIT at every visit and provide some direction or assistance with its use, if needed.



Conclusions

- The transition from the paediatric to the adult health care system is very complex and influenced by a number of factors that need to be taken into consideration.
- Both the 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.
- The youth and caregivers going through this transition need support, guidance, and adaptable 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. Both healthcare providers and parents need to promote, encourage, and assist, when necessary, with the resource use.

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