The use, utility and impact of the Youth KIT™, a tool to aid transitioning youth: Lessons learned from a longitudinal study

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Introduction
Youth with disabilities often experience poor health outcomes when transitioning from pediatric to adult care due to the lack of resources and supports.

Purpose
The primary objective of this study is to learn about the use, utility and impact of the Youth KIT: Keeping it Together™, a tool consisting of 10 modules designed to facilitate transition planning in various life domains (social, personal, medical care etc.) during transition to adult health care.

Design
Data were collected as part of a 4-year mixed methods longitudinal study supporting transitioning youth with disabilities and chronic medical conditions.

Participants & Setting
- A convenience sample of 58 youth aged 16-21 at baseline, not fully dependent on their caregivers, spanning 20 diagnoses (developmental disabilities and a wide range of chronic conditions), transitioning from 13 clinics at two major pediatric hospitals in Canada received the intervention and completed questionnaires.
- A purposive sample of 11 of these youth, 7 parents and 7 of their healthcare providers participated in interviews.

Results
- For use, the most often used modules were the personal (89%), school (85%), medical and health (85%), and personal care and life skills (81%) sections.
- For utility, participants gave the highest ratings to the intervention’s organization, as well as helpfulness in the areas of goal setting and taking charge of healthcare.
- For impact, interview responses revealed that tailored integration of this support into healthcare may enhance its use, relevance, and impact. Healthcare providers and parents reflected that having a protocol that made the Youth KIT a mandatory tool at every appointment may have encouraged its use.

Conclusions
- The value of the Youth KIT lies in its broad applicability to youth with disabilities.
- These study findings about use, utility, and impact of the Youth KIT indicates that it can assist with transition planning, as well as inform planning and timing of similar transition interventions.

Implications for Practice
- The Youth KIT may become a vehicle for promoting organization and readiness during transition to adulthood if used collaboratively by youth, parents, and healthcare providers.
- There is great variability in patients’ progression towards self-management and independence.