

## POSTER ABSTRACT

### **“I have eight different files at eight different places”: Perspectives of youths and their family caregivers on transitioning from pediatric to adult rehabilitation and community services.**

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**Introduction:** Most of the existing research on the transition from pediatric-to-adult care has focused on healthcare and social care settings as a homogenous group of services, without a specific focus on community or rehabilitation services. As such, the facilitators and barriers to implementing and sustaining these services during the transition from pediatric to adult care are not well established. An understanding of such factors may help to identify strategies to promote continuous rehabilitation and community care, and improve experiences with health services and quality of life of youth with disabilities and their family caregivers.

**Purpose:** The purpose of this study was to explore experiences with transition from pediatric to adult community and rehabilitation services among youth with childhood-acquired disabilities and their family caregivers', as well as perceived facilitators and barriers to undertaking and sustaining community and rehabilitation services during such transitions. **Methods:** An exploratory, qualitative descriptive study grounded in naturalistic inquiry was conducted, as this methodology helps to produce a rich account of the data that is less interpretive than other approaches, thereby remaining true to the range and type of participant experiences. Data were collected through interviews with youth (n=12) and family caregivers (n=7). Data were coded and analyzed using thematic analysis. **Results:** The study included 18 participants, comprising 11 youth living with childhood acquired disabilities and 7 family caregivers. From the 18 participants, 4 individuals were interviewed as dyads (i.e., two pairs of related family caregiver and youth interviewed together). Youth and caregivers face multiple, simultaneous transitions during the transition from pediatric to adult community and rehabilitation services e.g., those related to education, living arrangements and employment. This transition is marked by feelings of isolation. Supportive social networks, continuity of care, and advocacy contribute to positive experiences. Lack of knowledge about resources, increased accountability due to decreased parental involvement without preparation, and lack of system responses to evolving needs served as

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barriers to positive transitions. Financial circumstances can be either a barrier or facilitator to service access.

**Conclusion:** The transition from pediatric to adult rehabilitation and community services can be a challenging experience for youth living with childhood acquired disabilities and their family caregivers. This study demonstrated that continuity of care, support from providers, and social networks contribute markedly to the experience of transitioning from paediatric to adult services for individuals with childhood-onset disabilities and their family caregivers. Future research is warranted to develop and evaluate interventions and programmes to increase knowledge of available resources, improve readiness for transitions, and reduce feelings of isolation caused by changes in care.