

Angela Senevirathna - University of Calgary

Project: Co-designing Policy Recommendations to Improve Realized Access to Services in Transition from Paediatric to Adult Services for Youth with Neurodevelopmental Disabilities in Alberta by Integrating Patients' Lived Experiences



Background

The majority of youth with neurodevelopmental disabilities (NDD) have functional and/or behavioural challenges. Access to services and systems are important to reduce barriers to participation and enable youth with NDD to reach their full potential. Ninety per cent of individuals with NDD need access to services and professional supports spanning health, education and social services, but lack of access to these services is a critical gap impacting development and quality of life.

Our project is focused on identifying core challenges in access that youth experience during the transition from pediatric to adult services and

co-designing policy recommendations for improved and timely access to services in youth with NDD and their families.

Our approach to research is guided by the principles of Patient-Oriented Research, which engages patients and providers, focuses on patient-relevant priorities, and attempts to improve healthcare practices or policies to improve patient outcomes.

This project involves incorporating the perspectives of youth with neurodevelopmental disabilities and their families into the policy development process by identifying core challenges in access that youth experience during the transition from pediatric to adult services. Through qualitative interviews with a diverse sample of youth and their caregivers, the study will explore how structural and social contexts impact their experiences. The research process will be guided by patient partners, to ensure meaningful engagement and co-design.

Results of this study will provide policy recommendations for improved and timely access to the health, education, and social services that positively impact the health and wellbeing outcomes of individuals with neurodevelopmental disabilities and their families. We will use an integrated knowledge translation approach to change policy and practice to improve services and meet the needs of youth with neurodevelopmental disabilities.