

# Aligning Service Provider Perspectives in Barriers and Facilitators in Services with Lived Experience for Youth with Neurodevelopmental Disabilities During Transition

\*Angela M. Senevirathna<sup>1,2</sup>, Patricia Basualto<sup>1,2</sup>, Ash Seth<sup>1,2</sup>, Gina Dimitropoulos<sup>1,3</sup>, Jennifer D. Zwicker<sup>1,2</sup>  
<sup>1</sup>Faculty of Kinesiology, <sup>2</sup>School of Public Policy, <sup>3</sup>Faculty of Social Work. University of Calgary

## Background

- Neurodevelopmental disabilities (NDD) affect the brain's development and function.
- Youth with NDD require specialized services and supports, particularly during the transition from pediatric to adult services.
- The Community Living British Columbia (CLBC) is a provincial crown corporation that funds supports and services to adults with developmental disabilities.
- However, there is a lack of comprehensive information on the utilization and effectiveness of these services.

## Research Question

What are the perspectives of service providers regarding access to services for youth with neurodevelopmental disabilities (NDD), and how can these perspectives be validated and enriched through the input of individuals with lived experiences of NDD?

## Methods

A qualitative study was conducted. Ethics approval was granted by the University of Calgary Conjoint Health Research Ethics Board (REB21-1597).

- 5 semi-structured interviews with service providers and 1 interview with a patient partner.
- Participants were recruited through purposeful sampling and snowball sampling.
- Inclusion criteria: Service providers have worked or currently working with different ministries providing services and support for youth with NDD and their families in British Columbia. Patient partner was a parent of a youth with NDD in British Columbia.
- Interviews followed informed consent and were recorded and transcribed.
- Using thematic analysis, data were analyzed inductively. The research team used Nvivo12 to store and code the interviews.
- Information from the service providers was presented to the patient partner for their perspectives.

## Key Takeaways

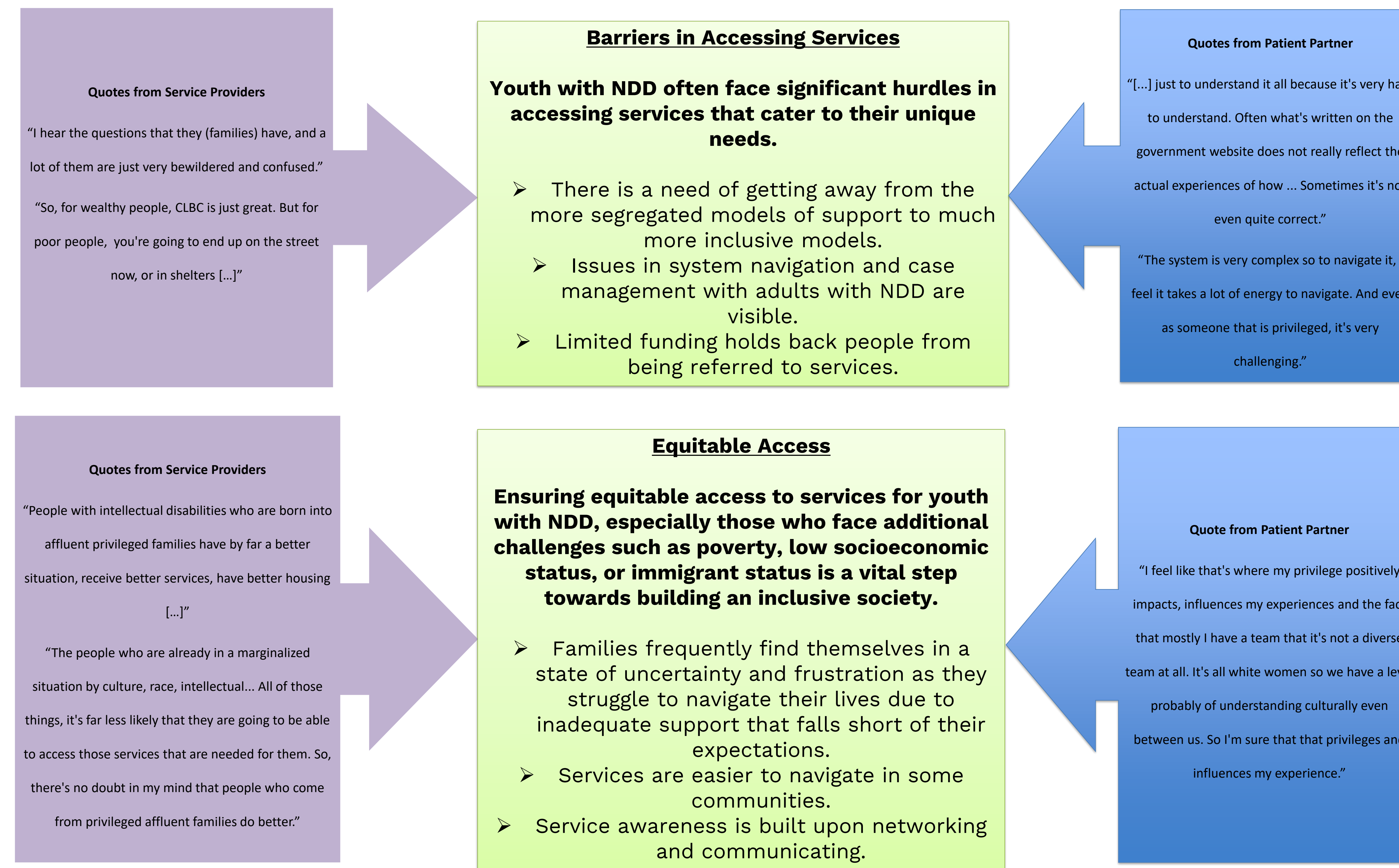


Figure 1: Key themes, sub-themes and quotes from service providers and patient partner.

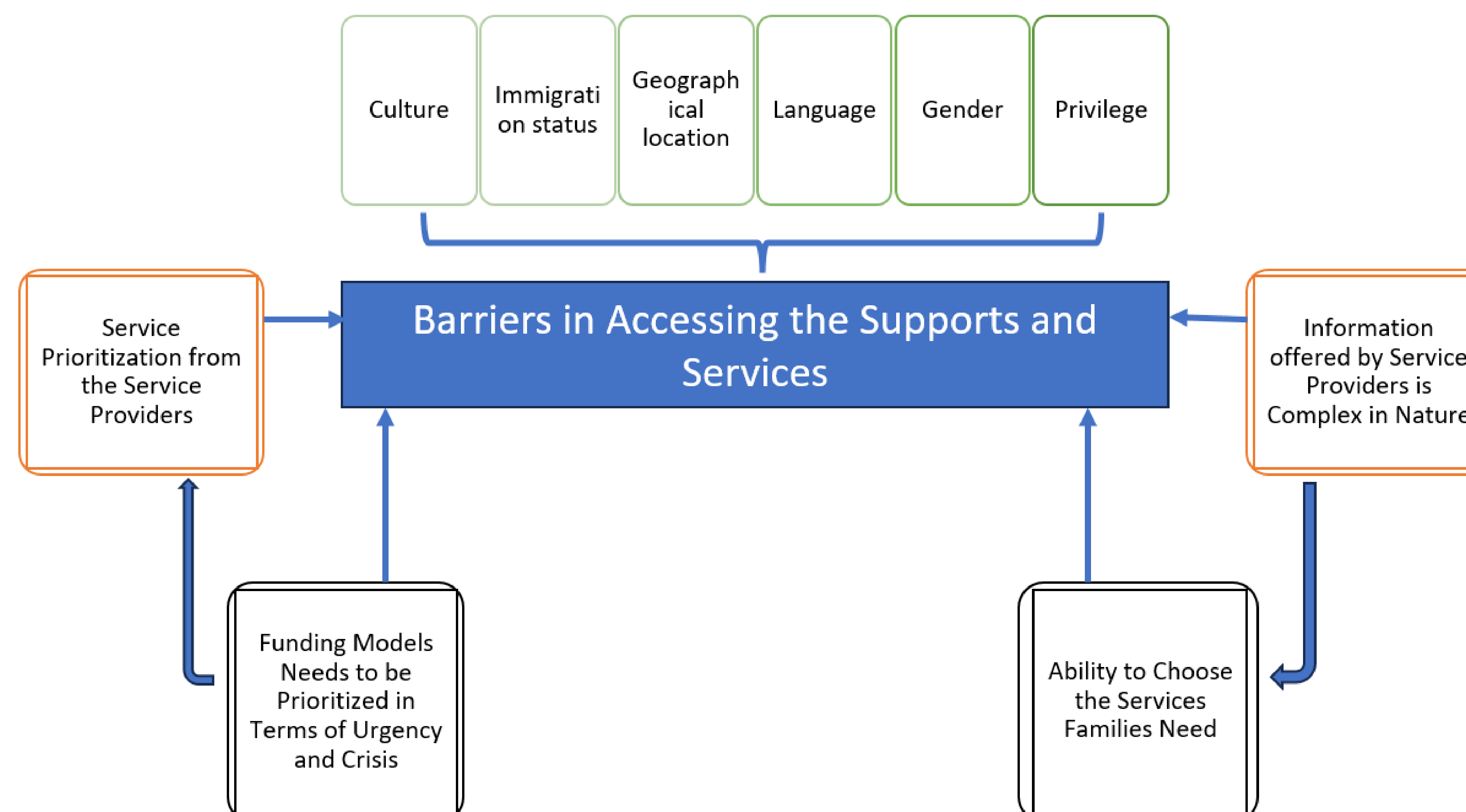


Figure 2: Key areas that were highlighted in the interviews as barriers and facilitators to service access for youth with NDD.

## Discussion

- Youth with NDD from disadvantaged backgrounds may face delays in receiving appropriate support, impacting their overall development and well-being.
- Limited awareness of available resources, cultural nuances influencing help-seeking behaviour, language barriers and potential discrimination based on immigrant status further compound the challenges faced by these individuals and their families.
- Accurate and up-to-date data on these populations is crucial for informing policy decisions, identifying gaps in services, and implementing targeted interventions to address specific challenges.
- Cross-ministry collaboration is needed to better support the families with NDD.

## Limitations

- Small sample size.
- Preliminary data.
- Potential biases.
- Limited geographical scope.

## Future Directions

- Conducting larger-scale studies.
- Incorporating decision-makers' perspectives.
- Mixed-methods approach.

## Acknowledgements



Angela M. Senevirathna, MSc is a recipient of the 2023 Alberta SPOR Graduate Studentship in Patient-Oriented Research. Alberta SPOR Graduate Studentships in Patient-Oriented Research are jointly funded by Alberta Innovates and the Canadian Institute of Health Research.