

Realized access to Services and Supports for Children with Neurodevelopmental Disabilities and their Families: Qualitative study

PRESENTER:
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BACKGROUND: Children with Neurodevelopmental Disabilities (NDD) and their families experience challenges getting support to meet their needs.

Provincial child disability support program that provides specialized service and funding options may be available for children or youth with support needs and their families.

Access to services is a modifiable barrier to improve overall health capacity from childhood onwards and achieving United Nations goals.

METHODS

? Which barriers and facilitators do children with NDD and families face to be eligible and access services and support from a service provider and decision-maker perspective?

Thematic data analysis on 15 semi-structured interviews of service providers and decision-makers from childhood disability services.

Purposive sampling strategy was used to identify key informants from provincial childhood disability services.

Interviews were conducted between January and September 2023.

PARTNERSHIP



Through our work and partnership with an Advisory council from the onset of this research, these findings can inform recommendations to improve realized access to services for children with NDD and their families.

Ethical approval. University of Calgary Review Board (REB21-1597).

Disparities in access to services and supports are related to system and family-level barriers and facilitators

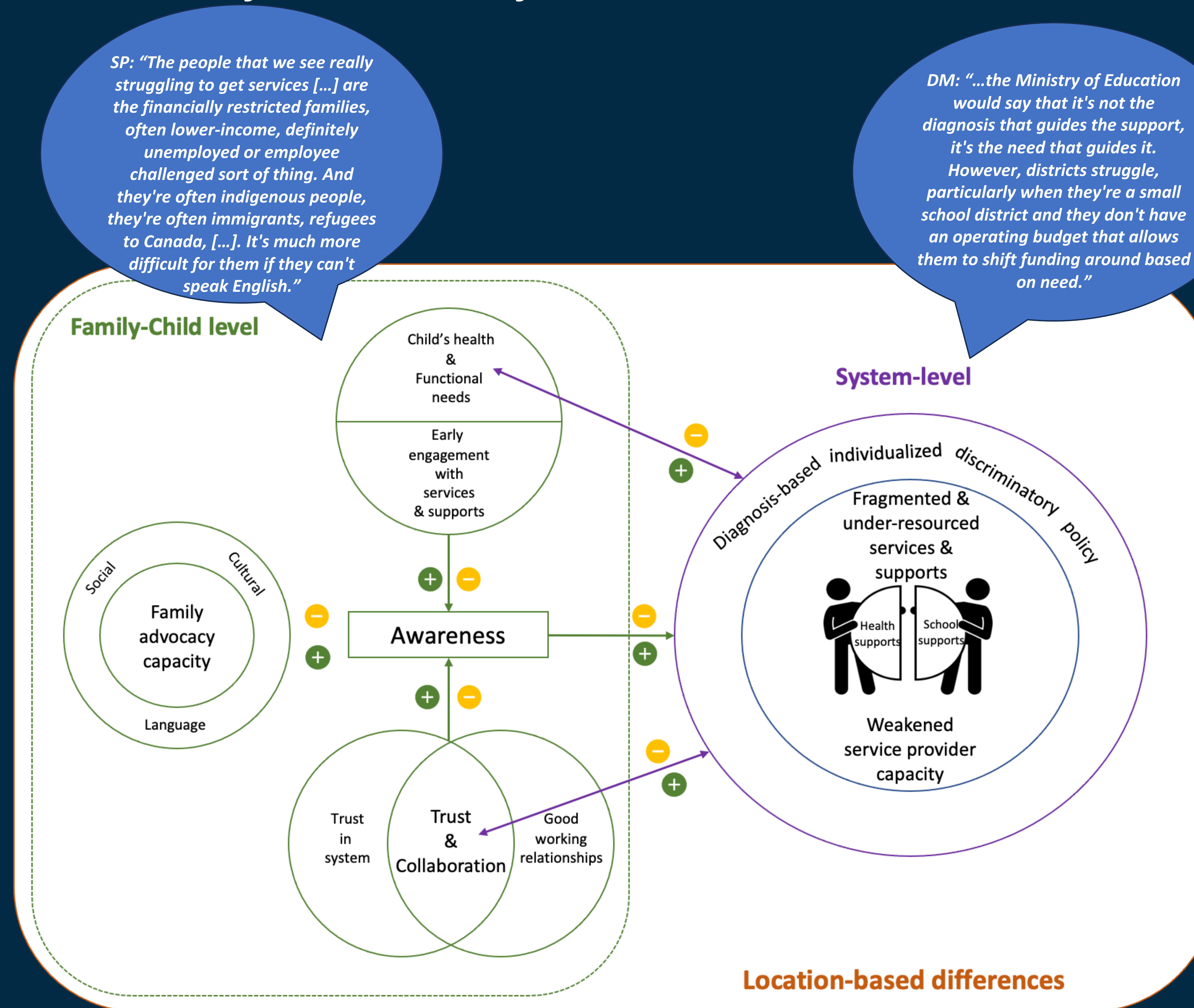


Figure 1. Barriers and facilitators for access to health, educational and social services and support: service provider and decision-maker perspectives.

Values & model of care	Improve services and supports implementation	Building relationships and collaboration	Funding changes
<ul style="list-style-type: none"> Family centred Functional and social outcomes centred Functional eligibility criteria Life course perspective Language and culturally informed 	<ul style="list-style-type: none"> Changes throughout the system Intersectoral and cross-ministry collaboration Improve system navigation Data collection Long-term case management Triage Training 	<ul style="list-style-type: none"> Promote partnership 	<ul style="list-style-type: none"> Increase funding Modify allocation

Table 1. Potential solutions: service provider and decision-maker perspectives.



Discussion

- Policy regarding eligibility criteria contributes to and encounters a fragmented and under-resourced system. Families are challenged in their capacity and resources to navigate a fragmented system to access services and support.
- Family and system-level barriers worsen in relation to the location where the family lives and services are provided.
- These findings support policy recommendations to facilitate the navigation, access and transition through services and support: integrate values and model of care, services and support improvements, build relationships and collaborations and funding changes.

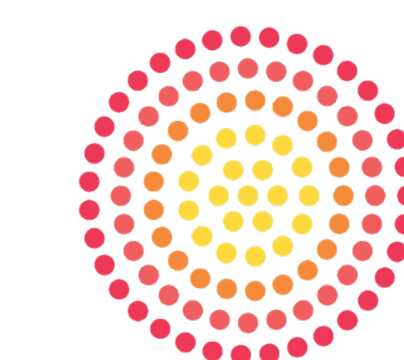


Future directions

- Data analysis done on fifteen interviews is currently a limitation with potential bias from low representativeness in the perspectives.
- Future analysis and studies should consider increasing the sample size and broadening the participant profile to strengthen the representativeness of these results.

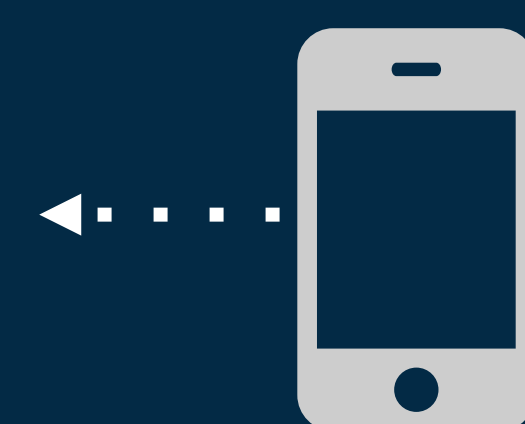
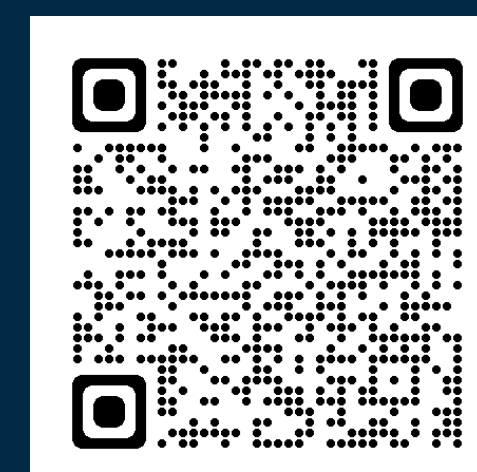
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Children's Healthcare Canada

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Disability Policy Research Program