Navigating supports: Integrating service access for children with neurodevelopmental disabilities and their families

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Project Overview

- The Kids Brain Health Network Neurodevelopmental Disabilities (NDD) Resource and Navigation Initiative is addressing the challenge of ensuring that services are available to children with ND and their families in a timely way.
- This work is based on a Collective Impact approach in which ND service leaders developed system capacity in Alberta, British Columbia, the Yukon, and Quebec.

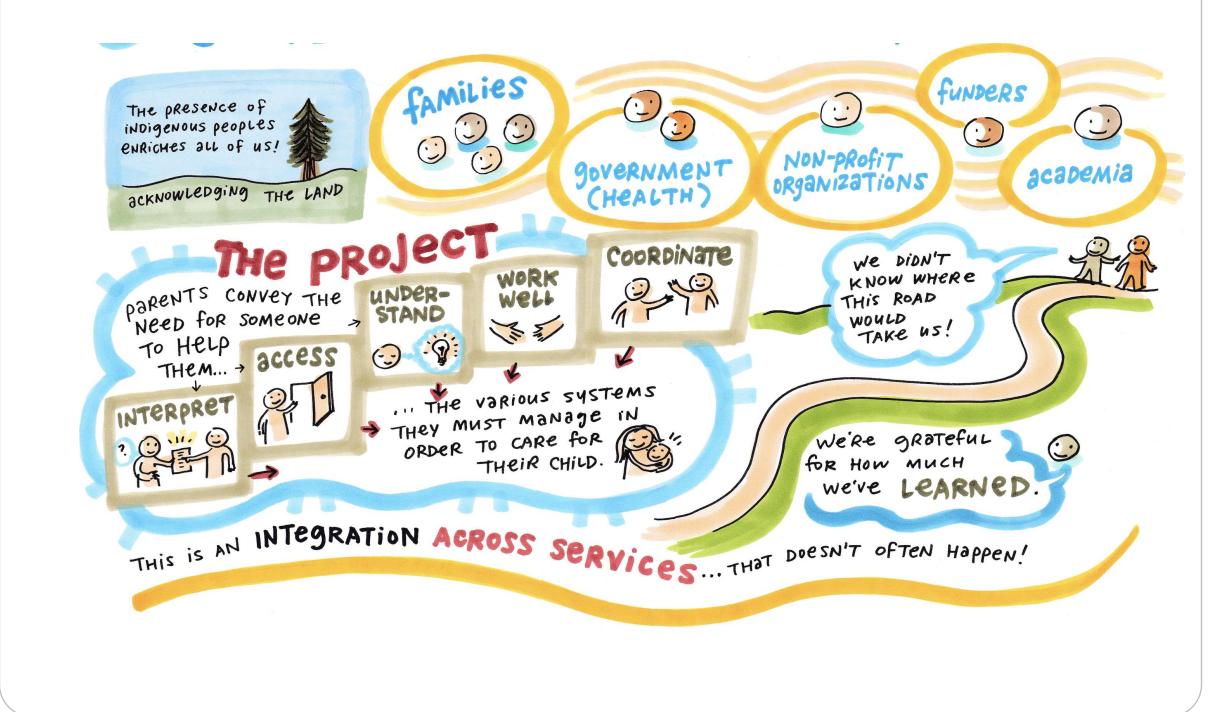
Phase 1: Community Conversations

Upon building capacity and evaluating shifts, we have worked to collectively document and share our learning and strategies to ultimately advance the likelihood that children with ND can more readily access the services they need when they need them.

Our team has collaborated on research



Project activities are overviewed in the image below:



contributions in support of this overarching goal.



Early Research Outcomes

- Research contributions included a mixed methods review cataloguing worldwide navigation websites' content and knowledge sharing methods.
- Focus groups identified parental navigation website needs and preferences.
- An exploratory qualitative study on parent-to-parent peer mentorship and navigation support interventions (mentors: n=5; mentees: n=10).

These studies add to the evidence-base highlighting the need for a central source of current (and continually updated) NDD information that is easy to access and that incorporates auxiliary supports, such as knowledgeable telephone operators and opportunities for collaborative peer support. Early results on peer support interventions highlight the perceived value, supportive factors in implementation, and challenges in peer support delivery.

Phase II: Pilot Project (*In-progress*)

Integrated Navigational Service System (INSS) Currently Being Developed

Results from Phase 1 led to the development of a pilot

INTEGRATED NAVIGATIONAL



model for integrative care that is responsive to the needs and preferences of children with NDD and their families.

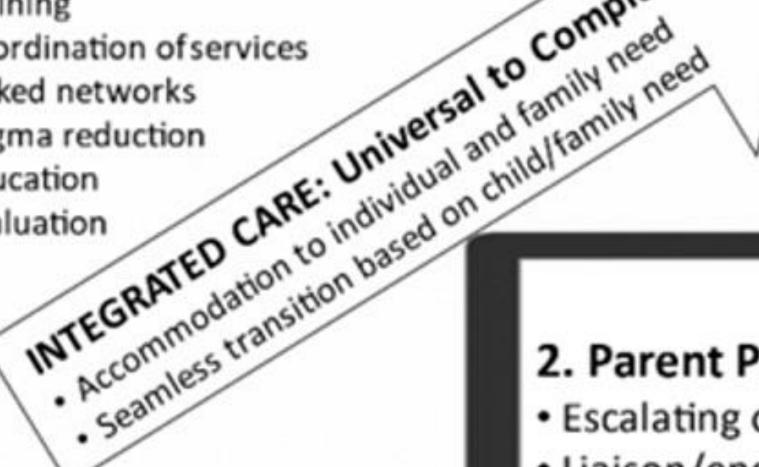
- Trials implementing the INSS are currently in development progress in select Alberta communities.
 - Edmonton
 - Calgary
 - Rural regions

Next Steps

- Pilot testing the model
- Based on pilot findings, expand and outreach to multiple communities, including:
 - Indigenous communities
 - Newcomer groups
 - Remote and Northern regions

INTEGRATED CARE: Universal to Complex Care

- Training
- Coordination of services
- Linked networks
- Stigma reduction
- Education
- Evaluation



3. Networked Services

- Paraprofessional telephone navigator
- Support in family managed plans and advocacy, as needed

2. Parent Peer Support

- Escalating care challenges and needs
- Liaison/engagement with community resources

1. Resource Information

 Online region- & province-wide NDD resource information offering navigational support for services and resources

Implications for Practice

This project supports a broad-based provincial effort to advance navigational resources for families of children with NDD.

Thank You to our Partners

The project represents many Partners across Alberta. Thank you to our partners for their engagement in this capacity building initiative.

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