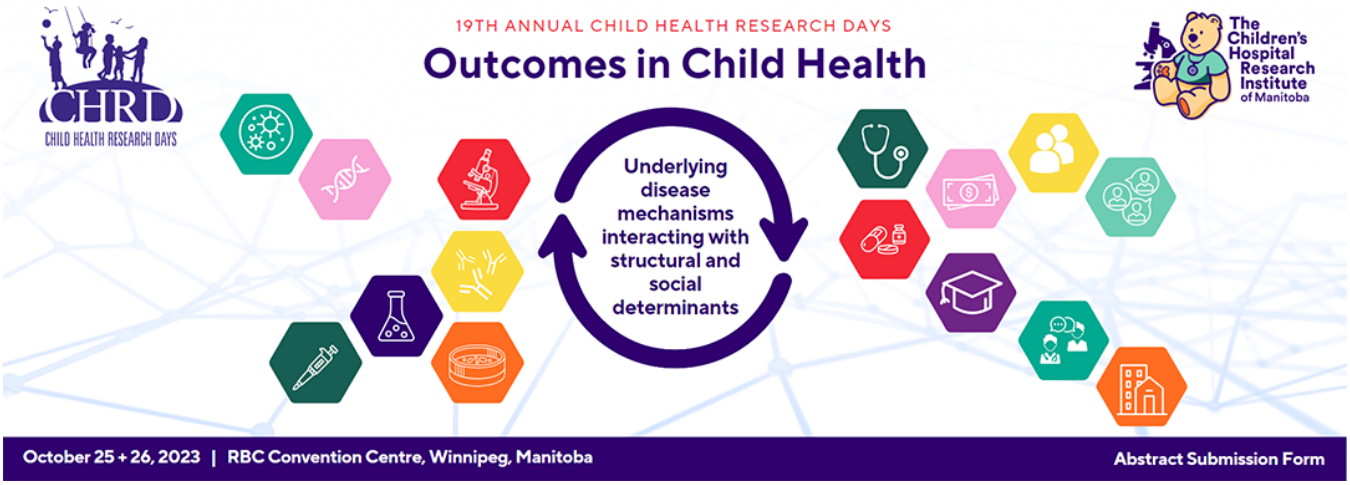

CHRD 2023: Abstract Submission Form

Submitter Name
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Presenter Name
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Presenter Status
Non-Trainee

Research Category
Community Health / Policy

Role in the project
Write Abstract

Title
Connecting for Care: Family perspectives on knowledge translation dynamics in child development and rehabilitation

Background
Knowledge translation aims to improve the use of up-to-date, relevant knowledge in healthcare.

Objective
Study aim: to understand how family members learn and share information about child development and rehabilitation, and what can be done to enhance access to healthcare services and information.

Methods
Family members (>18 years) of children with exceptionalities were invited to participate in a survey (REDCap). Information was gathered about participant characteristics, access to healthcare and information, safety and trust, and barriers and facilitators to knowledge sharing. Quantitative data were analyzed descriptively (proportions, frequencies, means/medians). Open-ended responses were coded deductively (Theoretical Domains Framework (TDF)), then thematically.

Results
The 206 participants spanned 11 provinces/territories and reported living in urban cities (23%), rural or remote communities (15%), or did not report (62%). Self-reported ethnic origins included European (54%), Asian (6%), Métis (6%), First Nations (4%), Other (4%), multiple selections (13%), not reported (13%). Participants most frequently received child development/rehabilitation information from physicians (93%), therapists (72%), and educators (70%). Information was usually shared verbally (84%), via handouts/pamphlets (46%), or through websites (35%). “Long waitlists” was the highest ranked barrier to connecting with others for knowledge sharing.

Knowledge sharing barriers most commonly referred to Environmental context and resources, Emotion, and Social influence domains of the TDF. Most reported facilitators aligned with Social influence, Environmental context and resources, and Social/professional role and identity (Table). Three key themes describing ways to support knowledge sharing were: Talking to people who ‘get it’; Trusting, non-judgmental relationships; and Safe and accessible spaces and services.

Conclusion
Access to and use of child development and rehabilitation services and information are affected by an interplay of environmental, social, and emotional factors. Shared experiences from other families are highly valued. Strategies to improve knowledge sharing should prioritize access, reduced wait times, safety and inclusivity, lived experience, and trusting relationships.

Table/Figure File
CHRD Abstract 2023_Connecting for Care_Table.pdf

Authors

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Table. Barriers and facilitators for knowledge sharing: most frequently coded TDF domains*

Barriers to Knowledge Sharing		
TDF Domain	**Definition**	**Representative Quote(s)**
Environmental context and resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour	"It always feels so hard to find the right services, and to find out all of the services that might be available, I feel like we are always fighting to get services, and then the waitlists are so long and it doesn't always feel like the right fit but we've already waited so long..." (P125) "Rural and Northern people are at a very big disadvantage. Telehealth helps but even then it feels rushed..." (P95)
Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event	Judgement definitely prevents people from feeling safe. Often when you have a child with special challenges you feel like you are constantly being judged and criticized..." (P71) "My daughter died at a children's hospital, and now all of the support services for my son is at children's hospital. I find it all very triggering and overwhelming." (P48)
Social influence	Interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours	"Approaches not aligned with parenting values, transphobia in institutions, lack of understanding of our family's queer cultural context...mistrust of institutions (our family has experienced health care discrimination), being treated as "difficult clients" when approaching as an advocate" (P189)
Facilitators for Knowledge Sharing		
TDF Domain	**Definition**	**Representative Quote(s)**
Social influence	Interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours	"Non-judgement, and a trust-based relationship" (P80) "The [specialty] team does it well. They have seen me at my lowest and continue to allow space and time for emotions. They take time to answer my questions...They take time to draw it out and teach

		me...most important, they care for us, like for real...” (P91)
Environmental context and resources	Any circumstance of a person’s situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour	“Social media is a great way to connect with other people who share my daughter’s diagnosis, both people who I know personally as well as others in the support groups I am in.” (P142) “...when I feel like I’m in a non-judgmental environment, I am more easily able to share the struggles that we are having and learn more about what we need to help our [child]…" (P51)
Social/professional role and identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting	“Knowing someone who has had similar experiences, or someone who shows compassion” (P10)

TDF: Theoretical Domains Framework
Definitions derived from Atkins et al, Implementation Science (2017)
*Note: Domains are not entirely exclusive; quotes may be coded to >1 domain but are only shown in a single domain in this table.