

Presenting Author Name

Amy Abegglen

Presenting Author Category

Non-Trainee

Research Category

Community Health / Policy

Abstract Title

Title: Collaboration Station: Leveraging the power of storytelling to understand family lived experiences of neurodiversity within a family-centered living labs.

Background

Introduction: With 1 in 6 Manitoba children experiencing neurodiversity, there is a clear need to understand families' diverse lived experiences to inform care and research grounded in their needs and preferences.

Objective

To address this, the virtual living lab Collaboration Station (CS) was co-designed with families and a pediatric rehabilitation provider to support the systematized collection and sharing of family-centered data in neurodiversity. Storytelling offers insights into the complexities of familial lived experience but remains underutilized in neurodiversity and rehabilitation research.

Methods

We conducted a longitudinal storytelling study to understand families' experiences of neurodiversity using the F-words framework (Family, Function, Fitness, Friends, and Future), derived from the WHO's International Classification of Functioning. Families of neurodiverse youth who accessed services at the partnered rehabilitation site were asked to submit one story per month. Open-ended text and visual art entries allowed families to share experiences and use F-word content tags. Interpretive description and thematic analysis guided theme development.

Results

Thirty-five registered individuals (16 parents, 6 youth, across 4 diagnoses) contributed 22 stories (127–989 words; mean=447). Three themes were identified: Small Steps, Big Meaning, describing progress toward child-specific goals; Future Built Through the Present, showing how tomorrow is built on today's progress; and Pathways to Participation, highlighting family's navigation toward meaningful participation. F-word tag frequency emphasized Function (20), Fun (9), Family (9), Friends (7), Fitness (4), and Future (2).

Conclusion

Findings illustrate a strong focus on Function for parents, with emphasis on navigating the present. The quality of story entries suggests utility for this mode of data collection within CS. Next steps include exploring how families engage with deficit F-words (e.g., fitness and future), while expanding the family registry, enhancing knowledge translation resources, and increasing clinician involvement. Ongoing development and refinement will establish CS as a sustainable, family-centered hub for research and support.

Authors

Name	Role	Profession
Amy Abegglen	Presenting Author	Research Coordinator
Bunmi Adeyemi	Co Author	Undergraduate Student
Omolara Akinwale	Co Author	Research Coordinator
Michaela Bourque	Co Author	Graduate
Shahina Parvin	Co Author	Racial Literacy and Antiracism Lead
Kristy Wittmeier	Co Author	Physiotherapist Clinician Researcher
Elizabeth Hammond	Co Author	Assistant Professor
Mandy Archibald	Co Author	Associate Professor