

# CHRD 2024: Abstract Submission Form

**Presenter Name**

Omolara Akinwale

**Presenter Status**

Masters Student

**Role in the project**

Analyze Data

Write Abstract

**Research Category**

Basic Science

**Title**

Living Lab for Pediatric Development and Rehabilitation Research-Innovating to Integrated Family-Centered Care

**Background**

Living labs are user-centered, open innovation ecosystems used to catalyze research and evaluation. We co-developed Collaboration Station (CS) –the first living lab for youth neurodiversity – in partnership with a disability and rehabilitation care provider. We aimed to establish a sustained knowledge exchange platform with a family registry to generate and mobilize lived experience data through a storytelling database repository, to systematize the use of lived experience data and provide a sustained mechanism for integrated knowledge exchange,

**Objective**

Operationalize the living lab platform and storytelling feature to understand family experiences of neurodiversity.

Co-design an arts-based knowledge Translation resource to mobilize evidence of family lived experiences.

Conduct usability testing to inform subsequent research and system improvement

**Methods**

Neurodiverse youth, their siblings and parents/guardians are participating in a longitudinal, semi-structured narrative study using interpretive description and thematic analysis. Participants tag stories according to the 6 F-words (based on the International Classification of Function: Family, Fun, Function, Fitness, Friend, and Fun) and populate additional content tags (school), which are descriptively analyzed to provide insight into dominant experiential domains.

**Results**

35 registered participants (7 youth, 1 sibling, 27 parents) submitted 16 stories; data collection is ongoing until December 2024. Preliminary analysis emphasizes parenting, learning, school, bonding, trips and accessibility. Additionally, the frequent tags of F-words – 13 Function, 9 Fun, 5 Family, 5 Friend, and 4 Fitness – highlight their importance in the lived experiences of neurodiversity. Usability testing is forthcoming.

**Conclusion**

Research demonstrates that understanding and incorporating familial lived experience can facilitate family centered research, service provision, and the use of research in health decision making. Findings from this study will inform the co-creation of evidence-based knowledge translation resources, reflective of family experiences to support family centered, while providing important insights into the use and acceptability of a living lab platform for family knowledge exchange in youth neurodiversity.

**Do you have a table/figure to upload?**

No

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