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Abstract Title

Establishing Digital Storytelling as a Research Approach for Families Navigating Neurodiversity

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Background

Families of children awaiting assessment and treatment for neurodevelopmental differences (NDDs) often face prolonged wait times, sometimes exceeding three years, creating uncertainty and limiting access to the benefits of early intervention. Families have limited opportunities to meaningfully reflect on and express their waitlist experiences, particularly through creative, participatory approaches beyond conventional interviews or surveys. Digital storytelling offers a facilitated, multimedia approach to construct and communicate lived experience and has demonstrated transformative benefits, yet remains unexplored among families navigating NDD waitlists.

Objective

This project will address this gap by: (1) co-designing a digital storytelling approach and dissemination strategy with family partners; (2) piloting a participatory digital storytelling workshop with waitlisted families in Manitoba; and (3) assessing its acceptability, feasibility, and potential impact.

Methods

This three-phase study uses a qualitative, participatory, and evaluative design. Phase 1 involves three co-design workshops with three family partners using focused conversation to shape elements of the digital storytelling approach. Phase 2 involves a participatory digital storytelling pilot with up to six Manitoba parents or caregivers of a child (<18 years) with waitlist experience. Participants will attend a two-day, in-person workshop to create a 1.5–3-minute digital story. Phase 3 involves an interpretive qualitative descriptive evaluation using semi-structured interviews to assess the acceptability and feasibility of the digital storytelling approach. Story scripts, digital stories, and evaluation interviews will be analyzed inductively in MAXQDA.

Results

N/A

Conclusion

This project will provide early evidence on the feasibility, acceptability, and value of digital storytelling as a participatory approach for families navigating NDD waitlists, while generating deeper understanding of their lived experiences. The digital stories can be shared to raise awareness, inform research and policy, and improve services for families. Findings will also provide a foundation for refining and expanding digital storytelling in future research with families facing prolonged waits for care.