
CONFERENCE ABSTRACT

Empowering the voices of persons with disabilities: Co-creating and implementing a community engagement framework for inclusive program design and organizational development

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Increasing efforts in public and patient engagement have resulted in several approaches, theories, models, and frameworks. While many of these efforts have merit, they tend to be designed for engagement in healthcare organizations and services, or research. Focusing on these specific areas is useful, but these approaches lack the contextual considerations community-based organizations must work through when looking to change or improve their engagement practices. March of Dimes Canada (MODC) is a complex national organization that serves people with disabilities, operating across multiple jurisdictions and health authorities to provide community health and social care services, conducts research, provides peer support programming, and engages in advocacy work. MODC recognizes the need to improve engagement practices across all aspects of the organization, however it is difficult to implement a single engagement model or framework consistently across the organization. For this reason, our study aimed to co-create a community engagement framework that is contextually relevant to MODC and our communities, supporting the improvement of engagement practices within all aspects of the organization.

We are using a co-design approach to complete the study; inviting MODC's clients, who are people with disabilities to participate as co-researchers in this work. The co-creation of the framework is currently underway and consists of three phases. Phase one included: conducting surveys, group interviews, and a document analysis of current organizational engagement practices. Phase two included: conducting an environmental scan of other community organizations' engagement practices; and completing a rapid review to identify theories, models and frameworks for client and public engagement. Phase three, which is currently underway, includes establishing an advisory committee of individuals who: 1) reside in Canada, and 2) have experience living with a disability. The advisory committee will co-design the engagement framework and co-create the implementation materials and processes for the resulting framework. During this phase we will also convene working groups with specific populations (i.e., caregivers, youth and their families, frontline staff, management etc.) to review the framework for validation and further refinement.

To date results from phase one have found Canadian non-profit organizations that provide services and supports for people with disabilities are moving towards including clients more meaningfully through advisory committees, having people with disabilities as board members, and moving away from the charitable model of disability and tokenism. Some barriers to meaningful client engagement include funding constraints, organizational policies, accessibility, and lack of action following client feedback. These findings, along with the rapid review findings will inform the engagement framework co-design with the advisory committee.

This study can provide insight on the process of developing and implementing a contextually relevant engagement framework that guides more meaningful community engagement for program design, creating organizational policies, conducting research and advocacy activities, and strategic planning. The framework will be evaluated following its implementation for continuous refinement and improvement across all levels of the organization. There will also be ongoing knowledge translation and mobilization activities to share the process, experiences, and results from the framework development within the disability and non-profit communities.