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## CONFERENCE ABSTRACT

# "A program works better when the people using it help build it." Co-Designing for Organizational Change with a Trauma-Informed Advisory Committee of Service Users

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**Introduction:** In Canada, as in many parts of the world, people with disabilities experience structural violence; they are more likely to face social exclusion and stigma and to live in poverty than their peers without disabilities. March of Dimes Canada (MODC) is transforming its programming by centering service users' voices in decision-making, including program design, moving forward through an organizational initiative to emerge from this study. This paper focuses on a participatory action research project nested within a larger study Empowering Client Voices. The first half outlines what trauma-informed means in the context of a large cross-disability national advisory committee. How do we build awareness and sensitivity with senior-level management and staff about ableism and systemic barriers people with disabilities and frontline workers face daily? The second half focuses on operationalizing trauma-informed practices by working alongside March of Dimes Canada's clients to co-design community engagement principles.

**Method:** As part of a larger participatory action research project, we have assembled an advisory committee to co-design community engagement principles to inform MODC's transformation. We conduct monthly co-design workshops and focus groups. A researcher and facilitator with lived experience of caregiving/advocacy guides the discussion alongside service users taking leadership roles. All participants receive an honorarium in recognition of their efforts.

**Results:** As the project progresses (data collection begins in January 2023), we will have preliminary findings relevant to researchers and practitioners engaging through co-design in academic and community fora. We have already learned that being trauma-informed in our transformational initiative with a cross-disability community means 1) co-designing with service users as partners, 2) co-creating fully accessible spaces, and 3) understanding the impacts of navigating the daily trauma of structural violence brought about by ableism and lack of access to essential supports. Beginning in January, we will be unpacking the role of language by attending to questions such as: what language do we use when approaching our service users' complex and

intersecting identities? What language do we use when approaching diagnosis, service user feedback, goal setting, and well-being in client-facing materials and staff training?

**Discussion and Conclusion:** In running the advisory committee, at the heart of the study, we are developing and operationalizing a set of best practices to guide organizational trauma-informed practices in the context of community engagement. These best practices include 1) Community-based (co-designed) research, 2) strengths-based approaches, and 3) trauma-informed practices. MODC is intentionally shaping the advisory committees through well-established best practices of trauma-informed care in an organizational (rather than clinical) setting. These best practices along with the co-designed community engagement principles will anchor our organizational transformation in suggestions from MODC's service users.

**Lessons and Future Research:** In assembling our advisory committee, we are learning that (for MODC's service users) accessibility, and universal design for access, are the foundations of trauma-informed care in the context of a cross-disability advisory committee. Future research should build on this finding by examining the implications of dis/ability, and (normalized) forms of structural violence, such as poverty and ableism, within the context of co-design with service users.