

ABSTRACT

POSTER TITLE: Sibling Engagement in Research: An Illustrative Example of a Sibling-Researcher Partnership To Design a Study

AUTHOR(S) Linda Nguyen^{*1,2,3}, Hanae Davis^{*4}, Samantha Bellefeuille^{*}, Marjolijn Ketelaar^{1,5}, Briano Di Rezze^{1,2,3,6}, Susan Jack^{7,8}, & Jan Willem Gorter^{1,3,6} in partnership with the Sibling Youth Advisory Council

**INSTITUTION/
AFFILIATION(S)** ¹CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, ²McMaster Autism Research Team, Hamilton, Ontario, ³School of Rehabilitation Science, McMaster University, ⁴Department of Psychology, Neuroscience & Behaviour, McMaster University, ⁵Centre of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Netherlands, ⁶McMaster Children's Hospital and Hamilton Health Sciences, Hamilton, Ontario, ⁷School of Nursing, McMaster University, ⁸Offord Centre for Child Studies, Hamilton, Ontario

ABSTRACT

Background/Objectives:

1. To describe the development of a Sibling Youth Advisory Council (SibYAC)
2. To highlight how the SibYAC contributed to a doctorate research study

Description: In the field of brain-based disability research, there is an increasing recognition that collaborative and meaningful partnerships with patients and family stakeholders ensures that research findings are relevant and applicable to family-centred care. The SibYAC was established as a partner in a qualitative research study called, BrothErs and Sisters involvement in health care TranSition for youth with Brain-based disabilities (BEST SIBS) Study. The study purpose is to understand the role of siblings of a brother or sister with a disability who is in the process of transition from pediatric to adult health care. The SibYAC is comprised of five members who are young adults with a representation of gender (4 sisters, 1 brother) and different disability diagnoses of their sibling (autism spectrum disorder, cerebral palsy, genetic condition, and multiple sclerosis).

The SibYAC was engaged throughout the design phase and will continue to be involved in the execution and knowledge translation phases.

Examples of SibYAC contributions:

- a. SibYAC members shared their experiences and identified key issues, which helped to develop a research question that is meaningful to siblings.
- b. SibYAC members provided feedback on the study design, such as methods to recruit participants.
- c. SibYAC members helped create recruitment materials by sharing testimonial videos and photographs to highlight the importance of participating in this study.

At the beginning of the study, tools were used to establish clear roles, responsibilities, and expectations of SibYAC members, specifically the Involvement Matrix (Smits et al., 2019) and Patient Engagement Tool (Ontario Brain Institute, Canada). After the design phase, an evaluation will be conducted about the engagement and impact of the SibYAC-researcher partnership. The Patient and Public Engagement Evaluation Tool (Abelson et al., 2016) will be used to measure the level of involvement of researchers and SibYAC members in study design activities.

Significance: Key messages about siblings' roles in different contexts are important to share with a diverse audience who wish to engage with siblings in research, practice, and policy.