

Revealing The Potential of Sibling Engagement in Research

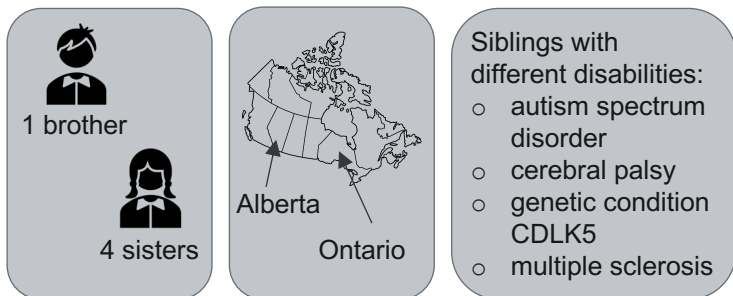
Linda Nguyen (PhD Candidate)^{1,2,3}, Hanae Davis^{4,5}, Marjolijn Ketelaar^{2,6}, Briano Di Rezze^{1,2,3}, Susan Jack^{7,8} & Jan Willem Gorter^{1,2,9}

¹ School of Rehabilitation Science, McMaster University, Hamilton, Ontario; ² CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario; ³ McMaster Autism Research Team, Hamilton, Ontario; ⁴ Department of Psychology, Neuroscience and Behaviour, McMaster University; ⁵ Sibling Youth Advisory Council; ⁶ Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Netherlands; ⁷ School of Nursing, McMaster University; Hamilton, Ontario; ⁸ Offord Centre for Child Studies, Hamilton, Ontario; ⁹ Department of Pediatrics, McMaster University and McMaster Children's Hospital, Hamilton, Ontario.

Our Partnership

Since 2018, the **Sibling Youth Advisory Council (SibYAC)** was established as a research partner in a doctorate research program to understand the role of siblings when their brother or sister has a disability and is preparing for the transition to adulthood.

The SibYAC comprises of:



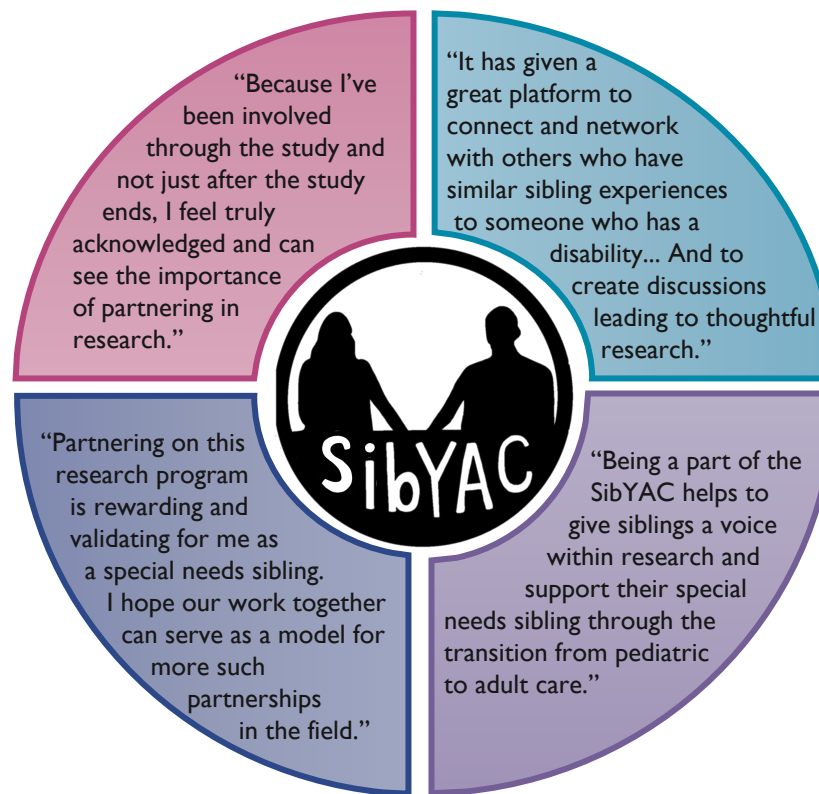
The Process and Evaluation of Engagement



Next Steps

Evaluate process of engagement using the **Public and Patient Engagement Evaluation Tool**³

Siblings' Experiences as Research Partners



SibYAC Partners: Samantha Bellefeuille, Hanae Davis, Julia Hanes, Jessica Havens, and James Koutrakos
Contact Information: Linda Nguyen, NGUYEL7@mcmaster.ca



Doctorate Research Program

- The Knowledge to Action Framework⁴ was used to guide the three studies in the doctorate research program.
- The SibYAC have been engaged in the design phase of each study, and will continue to be involved in the execution and knowledge translation phases.

STUDY 1	Knowledge Inquiry: A scoping review will be conducted about sibling support programs. The SibYAC identified that knowledge acquisition, skill development, and empowerment are important program outcomes to learn more about, which could then help other siblings support their brother or sister with a disability.
STUDY 2	Knowledge Contextualization: A qualitative case study will be conducted to understand siblings’ roles and responsibilities to their brother or sister with a disability during health care transition. The SibYAC partnered to develop the research question, identify creative study methods, and co-create recruitment materials.
STUDY 3	Knowledge Product/Tool: Based on findings from Study 1 and Study 2, a Sibling Kit will be co-created with the SibYAC as a resource to support siblings during the health care transition of their brother or sister with a disability.

References

1. Ontario Brain Institute. Ways community members can participate in the stages of research. 2019; 2. Smits D-W, et al. 2019. Available from: <https://www.kcrutrecht.nl/involvement-matrix>; 3. Public and Patient Engagement Collaborative. 2019. Available from: <https://healthsci.mcmaster.ca/ppe/our-products/public-patient-engagement-evaluation-tool>; 4. Graham et al. (2006). J Contin Educ Health Prof, 26(1): 13-24.

