Revealing The Potential of Sibling Engagement in Research

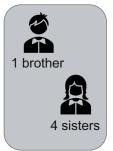
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Our Partnership

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:





Siblings with different disabilities:

- autism spectrum disorder
- o cerebral palsy
- genetic condition CDLK5
- o multiple sclerosis

The Process and Evaluation of Engagement





Engagement Tool^l

To provide examples of how to partner in a study



Involvement Matrix² To outline roles and responsibilities

Next Steps

Evaluate process of engagement using the Public and Patient Engagement Evaluation Tool³











Siblings' Experiences as Research Partners

"Because I've been involved through the study and not just after the study ends, I feel truly acknowledged and can see the importance of partnering in research."

"Partnering on this research program is rewarding and validating for me as a special needs sibling.

I hope our work together can serve as a model for more such partnerships in the field."

"It has given a great platform to connect and network with others who have similar sibling experiences to someone who has a

disability... And to create discussions leading to thoughtful research."

"Being a part of the SibYAC helps to give siblings a voice within research and support their special needs sibling through the transition from pediatric to adult care."

SibYAC Partners: Samantha Bellefeuille, Hanae Davis, Julia Hanes, Jessica Havens, and James Koutrakos

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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 I

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.

TUDY 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 I 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.





