

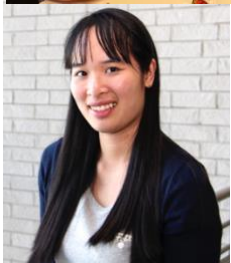
Family Engagement in Research Newsletter

May 2020

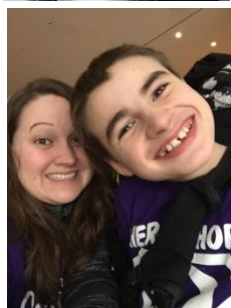
In this article, we share about establishing the Sibling Youth Advisory Council (SibYAC) and our experiences, motivations, and goals to partner in research.



Hanae Davis (HD) is a PhD candidate at McMaster University (Hamilton, Ontario, Canada), and an older sibling of a brother with cerebral palsy. She considers herself both a caregiver and companion to her brother. In addition to day-to-day activities, she has experienced being a sibling in both inpatient and outpatient clinical settings. She hopes a better understanding of the role played by special-needs siblings will improve support for the individual and the family as a whole.



Linda Nguyen (LN) is a PhD candidate in the School of Rehabilitation Science at McMaster University under the supervision of Dr. Jan Willem Gorter, a pediatric physiatrist. She graduated from the Bachelor of Health Sciences (Honours) Program, Child Health Specialization and continued with her Masters in the School of Rehabilitation Science to understand the perspectives of families of children and youth with disabilities in health care. Her current studies are focused on the role of siblings of a brother or sister with a disability during transition from pediatric to adult health care.



Samantha Bellefeuille (SB) is an older sister of her brother who is 16 years old and has a rare genetic condition of CDKL5, and currently living in (Ottawa, Ontario, Canada). She is a child and youth worker as well as a Registered Early Childhood Educator. As part of the SibYAC, she would like siblings to have a platform to be able to be a part of all aspects of their siblings' life, especially when they are transitioning from pediatric to adult health care.

Our Current Project

The **BrothErs** and **Sisters** involvement in health care **TranSition** for youth wIth **Brain-based disabilities** (BEST SIBS) Study

Siblings are part of the family who can support their brother or sister with a disability during transition from pediatric to adult health care. We are currently looking for siblings (ages 14-25) who have a brother or sister with autism spectrum disorder, cerebral palsy, epilepsy, fetal alcohol spectrum disorder or spina bifida and is in high school. We ask siblings to participate in a 1-hour interview, in which they can share photographs that describe their sibling relationship in preparing for health care transition. In light of COVID-19, all interviews will be conducted by telephone or online through Zoom.

We hope to raise awareness about siblings' experiences and their roles during health care transition. These stories can help us to create resources to support siblings, and shared with families and health care providers. More information can be found on the [study website](#) and [video](#). If you are interested in participating in the study, please email Linda Nguyen at: NGUYEL7@mcmaster.ca

What first inspired you to work?



LN: My research journey has focused on enhancing family-centred services to support families of children with disabilities, and siblings are part of the family. I reflect on my experience of having an older sister who supported me when I faced challenges. I have an older sister and growing up, she played the role of being my second mom who took care of me while my parents were at home and she was my sister who I could share my worries with. Every sibling relationship is different, and siblings can take on different roles and responsibilities that can change over time. After reflecting on my own sibling relationship, I was inspired to conduct my research about siblings' experiences when they have a brother or sister with a disability. Siblings share a lifelong bond, and it is important to conduct research to understand and support siblings in their roles.

What first inspired you to get involved as a family partner in research?



HD: I was motivated to get involved as a family partner in research for both personal and academic reasons. I am heavily involved in my younger brother's care, and consider myself a caregiver alongside my other family members. Given the importance of family-centred care in medical and rehabilitation settings, I believe the inclusion of siblings in that model is critical but not always present. My personal experience of being a caregiver and companion to my brother motivated me to lend my perspective to disability research. Academically, my impression is that the literature on special-needs siblings is small, relative to that on special-needs parents. I think more research would be instrumental to better understanding and supporting this particular cohort of caregivers.

SB: I have been a big part of Sean's life since he was a baby and was always interested in how things worked at the hospitals with regards to research. When I saw the post on Facebook about a course running out of McMaster's University, I was very intrigued. When I looked into the Family Engagement in Research (FER) course offered by CanChild, McMaster University, and Kids Brain Health Network, I decided that it would be a really interesting course! It was an amazing experience and I met so many great people!



How has the current pandemic affected your work?

LN: During this pandemic, it is important to ensure that any research being conducted would follow physical distancing guidelines. All interviews for the BEST SIBS Study will be conducted online through the Zoom program or by telephone. This study is currently recruiting participants for interviews, and all recruitment strategies have been conducted through social media such as Twitter, Facebook and online newsletters. Social media is a powerful tool, in which initial posts can be shared through multiple people and organizations who can then share it with their own networks, leading to a ripple effect to widely share information. An added benefit to virtual communication during this time is that I was able to personally connect with different people and organizations by email to share the study, and they also recognized the importance of this research to raise awareness about siblings' roles. I hope that potential collaborations, stemming from these connections, could occur in the future.

HD: Our communications for the SibYAC to date have been online, so that has not changed much under these circumstances. But because I am at home with my family, scheduling calls has become more challenging.

SB: All of our communications for the SibYAC to date have been virtual, so the pandemic hasn't really affected our meetings or work. However, having my sibling home 24/7 has been a struggle. Trying to care for him, complete my work and be a family partner has been challenging, however it helps that everyone is understanding and flexible.

LN: We continued to have virtual meetings for the SibYAC. At the beginning of each meeting, we took the time to check-in with each other. We provide meeting minutes and updates by email to keep everyone on the same page. We also welcomed any contributions that SibYAC members would like to share by email.

Have you heard anything from researchers about how COVID has affected their work?



LN: As a PhD student, I have connected with graduate students and researchers about how to ensure that research follows physical distancing guidelines. Some changes to research including putting research on hold, refine study methods, and/or change the study design. Yet, these changes also challenge researchers to think creatively in how to conduct research both for now and possibly in the

future. Additionally, the pandemic has affected our approach to how we share our research because conferences had to be postponed or cancelled. Some plans are currently being made to share our research online, such as virtual poster presentations and/or webinars. Despite these changes, there is potential in how research can be shared online to a wider audience.

Have you heard anything from other family partners about how COVID has affected their work?



SB: I have heard that COVID-19 has been a detriment to many presentations and conferences as they had to be rescheduled. It has also been a struggle to turn all communications onto a virtual platform with video conferencing, emailing and phone calls. It has been a learning curve for all!

HD: Everyone is adjusting as best as they can. The pandemic has made our respective working and personal spaces more intertwined, leading to scheduling conflicts that may not have been as prevalent before. Some individuals also work in settings outside the home, which has been stressful for them and their families. For the BEST SIBS study and the SibYAC however, I think we've been able to keep a relatively stable line of communication and workflow.

What advice would you have for advisory partners during this time and for researchers attempting to continue to work? How can they best support their advisory partners?



SB: The best advice I have is to be flexible and patient with everyone. With multiple barriers in place due to the pandemic, we all need to be mindful of these barriers. Having children and siblings home 24/7, trying to keep up their routines, take care of their personal care, possibly work full time at home as well as complete research projects can all impact the way advisory partners can work. Being patient and offering up alternative meeting times that work with a variety of schedules, offering phone calls versus video calls, and allowing for more time for projects to be completed can all be beneficial to support advisory partners. Another piece of advice I would give would be to be understanding. We are all in this pandemic together and sometimes it helps to lend a listening ear and talk about how the pandemic is affecting each other. To support one another will help all involved as we continue to work and settle into this new normal.

HD: The current circumstances may be different and stressful at times, but that does not mean partners do not want to stay involved in research. Their output or communications may be more irregular given the new work-home (im)balance, but I think the motivation is still there. Clear communication, patience, and reasonable accommodations are key to navigating group projects at this time.

Do you feel like there are important COVID-related research questions we need to be asking now about childhood disability?



HD, LN, SB: To ensure that the perspectives of families are represented, there could be a forum to provide opportunities for family partners to share research questions that are important to address during this pandemic. Some important questions include:

1. How do we conceptualize the meaning of “disability” during the COVID-19 pandemic?

One approach to conceptualizing disability during this pandemic may be to think about the functions that are deemed essential for maintaining well-being and those that are reliant on accommodations/services that are currently impacted. For example, physical exercise and social contact are essential for general well-being. How have these been affected?

2. How do we best support and provide care to families of children and youth with disabilities who are at home in physical distancing practice?

Support under these circumstances can involve regular or as-needed virtual communications and group discussions. Particularly for individuals with mobility challenges, these initiatives may prove useful in the future when physical distancing is no longer required.

3. How do we optimize the physical and mental well-being of the whole family during the COVID-19 pandemic and in the future (e.g., during health care transition)?

It is important to consider how families can continue to be supported in their plans and preparation for the future.

4. What is the economic impact of COVID-19 on funding for existing programs, resources, and services for families of children and youth with disabilities?

There can be ongoing communication and sharing of information to understand how COVID-19 might affect these programs, resources and services.