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Project: Co-designing a Sleep Education Intervention to Improve Behaviors of Concern Amongst Youth with Neurodevelopmental Disorders

Background



Neurodevelopmental disorders (NDDs), which include intellectual disability and autism, impact up to 18% of Canadian children. Up to 80% of individuals with NDDs exhibit behaviours of concern, including aggression and self-injury. These behaviours consume a disproportionate amount of health resources and are associated with reduced quality of life for the child and their caregivers.

Behaviours of concern can get worse if youth don't get enough sleep, which is a common problem for many youths with NDDs. Sleep problems also negatively impact caregiver stress and family functioning. Conversely, improving sleep can improve child behaviour and reduce caregiver stress. Sleep education has been helpful in other groups of youth and their caregivers. However, there is no sleep education intervention specifically for this unique group of youth and their caregivers and there is no avenue for expert and timely delivery.

To address these problems, we have hired youth, caregiver, and physician partners to join our research team. Together, we will create (co-design) a sleep education intervention for youth with NDDs who have behaviours of concern and their caregivers. Our co-design methodology consists of unstructured discussion groups where we are recruiting up to 30 youth and caregivers and 12 physicians to explore barriers and facilitators of effective in-clinic, physician-delivered sleep education to youth and caregivers. We will apply thematic analysis to the transcripts of these discussions and use the synthesized themes to inform the first version of the sleep education intervention. Subsequently, consensus discussion groups employing nominal group technique will inform the final version of our sleep education intervention.

Sleep education is a low-cost, low-risk intervention that may have an outsized impact on behaviours of concern for youth with NDDs when delivered in a timely manner (in-clinic) from a trusted expert (physician). In the future, we will test the sleep education intervention in a real-world setting to measure its effectiveness. If our project is successful, this intervention has the potential to address and ameliorate long-standing health disparities for these youth and their families.

Ishnoor Kaur Nahal is a Master of Science student in the Medical Sciences program at the University of Calgary. She is supervised by Dr. Sarah MacEachern in the Precision Neurodevelopment Lab. Ishnoor completed her Bachelor of Science in Biological Sciences and Native Studies alongside a Research Certificate in Science at the University of Alberta.