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Poster Sessions

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KBHN2020 Poster Sessions

November 9th, 10th, and 12th

4:30 - 6:30pm EST

DAY 1- Poster Session (November 9th)		
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1	**Pascal Gagné** (Doctoral Student)	Review of Piolet Project for Young Adults with FASD Transitioning to Adulthood
2	**Christopher de Groot** (Research Coordinator)	The Impacts of COVID-19 Pandemic on Children with Neurodevelopmental and Intellectual Disabilities and Their Families: A Survey
3	**Ritvik Khanna** (Research Assistant)	Chatbot to improve access to information for individuals with neurodevelopmental disabilities
4	**Erin Klein** (Master's Student)	The Impact of Developmental Coordination Disorder: Parent Perspectives
5	**Carrie Smythies** (Faculty Investigator)	Identifying Gaps in Care: Perspectives from Caregivers of Children with Autism Spectrum Disorder and Self-injurious Behaviours
6	**Samantha Micsinszki** (Postdoctoral Fellow)	Learning Together: The Use of Simulation to Enhance and Enable Authentic and Meaningful Research Partnerships
7	**Michèle L. Hébert** (Postdoctoral Fellow)	Navigation-Building Training for Children/Youth with Neurodisability and Families
8	**Jeffrey McCrossin** (Doctoral Student)	The role of parent-to-parent support in navigating services for families of children with neurodisabilities: a BC case study.
9	**Lin Li** (Doctoral Student)	Building Successful Partnerships: A Conversation Guide to Researchers and Patient/Family Partners
10	**Preeti Kar** (Doctoral Student)	White Matter Alterations in Young Children with Prenatal Alcohol Exposure
11	**Marie-Eve Brien** (Doctoral Student)	In-utero exposure to sterile inflammation is associated with altered neurodevelopment
12	**Melissa Tremblay** (Faculty Investigator)	Supporting Indigenous Families to Foster Healthy Child Development through the Early Years Program
13	**Karys Peterson-Katz** (Master's Student)	Nurturing the Seed: Analysis of Early Developmental Assessment Data and Implementation in Canadian Pre-School Aged Indigenous Children
14	**Monika Novak Pavlic** (Doctoral Student)	Determinants of pain in children with cerebral palsy

15	**Monika Novak Pavlic** (Doctoral Student)	How do children with cerebral palsy view pain?
DAY 2 - Poster Session (November 10th)		
Abstract #	**Presenter/Author**	**Title**
16	**Samantha Micsinszki** (Postdoctoral Fellow)	Examining Factors Associated with Sleep Quality in Parents of Children 4-10 Years with Autism Spectrum Disorder
17	**Florence Deguire** (Doctoral Student)	The relationship between rapid head growth and neurodevelopmental outcomes in the first year of life
18	**Charlotte Rimmer** (Doctoral Student)	Phonological skills in autism spectrum disorder: A scoping review of intervention programs
19	**Dercia Materula** (Research Associate)	Improving Health Outcomes and Coordinating Care for Children/Families with Complex Health and Social Needs
20	**Brittany Finlay** (Research Associate)	Experience of Caregivers and Youth in Accessing Government Disability Programs Across Canada
21	**Samantha Wong** (Master's Student)	Neural tracking and neuroplasticity of social motor synchronization of children with autism spectrum disorder.
22	**Mira Kaedbey** (Master's Student)	Examining the effect of a music-making program on problematic behaviours and student-teacher relationships for children with autism spectrum disorder and typical development.
23	**Sandy Littman** (Faculty Investigator)	Key Features of an Online Navigational Service for Families of Children with Neuro-developmental Differences
24	**Nancy Lockwood** (Program Manager)	From a community-based navigation and education pilot project to a multi-systemic approach to supporting children and youth with FASD and their families.
25	**Flora Roudbarani** (Master's Student)	Lessons Learned from Moving In-Person CBT to Remote Delivery in Response to COVID-19: Therapist Perspectives
26	**Vivian Lee** (Postdoctoral Fellow)	Parent Perspectives on the Shift to Remote Delivery of CBT in Response to COVID-19
27	**Leo McKay** (Doctoral Student)	Acute Prenatal Alcohol Exposure Results in Oxytocin Deficiency and Maternal Care Deficits in a Mouse Model of FASD
28	**Praveen Kumar Raju** (Postdoctoral Fellow)	Cellular mechanisms of epilepsy in PIGB deficiency
29	**Samantha Noyek** (Doctoral Student)	Capturing Emotional Expressions of Children and Youth with Complex Motor and Communication Impairment.
30	**Veronica Smith** (Faculty Investigator)	Parent and Child Early (PACE) Coaching for Children at Risk for Autism: Understanding Implementation
31	**Crystal Shannon** (Doctoral Student)	Scoping Review of eHealth Strategies for Parents of Children Living with Autism Spectrum Disorders

32	**Jael Bootsma** (Doctoral Student)	Transitioning to online research study visits for the validation of an accessible language assessment test in response to the COVID-19 pandemic
DAY 3 - Poster Session (November 12th)		
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33	**Vanessa Fong** (Doctoral Student)	Understanding the impact of COVID-19 on mental health, quality of life, and service and support needs in families of autistic children in British Columbia
34	**Vivian Lee** (Postdoctoral Fellow)	An Integrated Knowledge Approach to Communicating the Impact of COVID-19 on the Mental Health and Well-Being of Caregivers and Available Resources for Families Living with Autism
35	**Ashish Seth** (Master's Student)	Exploring strategies on how governments could engage community organizations to co-design pandemic response plans for persons with disabilities.
36	**Wendy Mitchell** (Postdoctoral Fellow)	Individuals with Neurodevelopmental Disabilities: Information needs and effective methods for sharing during COVID-19
37	**Roz Zulla** (Doctoral Student)	COVID-19 focused websites focused on individuals with autism and intellectual disabilities
38	**Buse Bedir** (Doctoral Student)	Novel service delivery models for children with neurodevelopmental disabilities and their families in light of the COVID-19 pandemic
39	**Jessica Kohek** (Master's Student)	Academic, Political, and Community Engagement: Crafting Pandemic Preparedness Policies for Vulnerable Families
40	**Maude Champagne** (Doctoral Student)	Responding to the COVID-19 pandemic challenges for families with children impacted by Neurodevelopmental Disabilities (NDD)
41	**Jacelin Guy** (Postdoctoral Fellow)	A National Autism Strategy: A Catalyst for the Coordination and Development of a Research Framework
42	**Linda Nguyen** (Doctoral Student)	Growing Together: The Process and Initial Outcomes of Partnering with Siblings in a Doctoral Patient-Oriented Research Study on Transition
44	**Mahdieh Yousef** (Research Assistant)	Specific Engagement Tools Should be Implemented in Chatbot Technology for Neurodevelopmental Disability
45	**An Bui** (Research Assistant)	Tackling the spread of medical misinformation on the media: An artificial intelligence approach
46	**Elizabeth Keys** (Postdoctoral Fellow)	Child sleep in the context of COVID-19
47	**Nichole Scheerer** (Postdoctoral Fellow)	Associations between hyperacusis, misophonia, and quality of life in autistic and neurotypical adults
48	**Chantel Ritter** (Doctoral Student)	Recommendations following FASD assessment in Canadian diagnostic clinics: Understanding needs

Day #1 – Poster #1

Presenter: **Pascal Gagné, University of Ottawa/Able2**

Theme: **Community Engagement in Research**

Title: **Pilot Project review: Young Adults with FASD Transitioning to Adulthood**

Author(s): **P. Gagné[1], H. Courchesne[2]**

Institution/Affiliation(s): **[1]Feminist and Gender Institute, University of Ottawa; [2]ABLE2**

Context: This study reviews the outcome of a one-year pilot project funded by the Ontario Trillium Foundation (OTF). Fifteen young adults with Fetal Alcohol Spectrum Disorder (FASD) were each accompanied by a Transition Coordinator to help them achieve self-determined goals. Transition coordinators were tasked to facilitate community connections and help individuals in planning for their future. They met in-person in community settings, explored venues and tried out new activities. The overarching goal was to reduce social isolation and feelings of loneliness. This project sought to answer three questions: 1) what are the distinct needs of individuals with FASD transitioning to adulthood; 2) whether this transition model is adequate to support this vulnerable population; 3) what types of interventions contribute to reducing social isolation/feelings of loneliness among young adults with FASD and improve their sense of self-esteem and belonging?

Method: Participants were asked to complete a pre-assessment social provision scale survey prior to beginning the project, either in person or by phone. Questions were inspired by Russell et al. (1984) and were administered orally in plain language. After support ended, 11 participants were invited to voluntarily participate in an evaluation interview and were offered a $30 gift card for their participation. Eight individuals responded and confidential interviews were conducted by Zoom or by phone, as per their preference. In total, 18 interviews were conducted (8 participants, 3 caregivers, 2 professionals, 5 staff). Themes were coded with qualitative content analysis.

Results:

Distinct Needs: Individuals with FASD need accompaniment and regular check-ins, positive messaging, and ongoing support throughout their lifespan to help them with successful independent living; they need help with entering college life, moving out of either their parents' or foster care, managing their finances, and coping with rules and responsibilities related to becoming an adult. They do not always understand their rights and are vulnerable to abuse. Because of their disability, they in majority live in poverty and are at risk of being homelessness, having significant mental health and addiction issues, as well as being socially isolated and feeling lonely.

Transition model: On the basis of interviews conducted with young adults, caregivers, professionals, and staff involved with the pilot project, Independent Facilitation and Person-Directed Planning appears to be a positive model of intervention to support individuals with FASD. Support from a Transition Coordinator enabled participants to reduce social isolation and feelings of loneliness, build self-esteem, and work toward making friends, finding employment, and finding appropriate housing.

Successful interventions: Interventions that were successful to reduce social isolation and feelings of loneliness were driven by the individual. Caregivers have confirmed time and again that their child does not follow through on programs or services they do not have an interest in. Having a semi-structured environment (in-person or online) between individuals with FASD of an appropriate age group appears to a good way to create connections while exercising social skills.

Conclusion: Overall, the project was successful in reducing social isolation and feelings of loneliness, despite the advent of the Covid-19 pandemic.

Keywords (up to 6 words): FASD; Independent Facilitation, Social Isolation, Transition to Adulthood.

Funded By: Ontario Trillium Foundation

Day #1 – Poster #2

Presenter: **Christopher de Groot, University of British Columbia**

Theme: **Community Engagement in Research**

Title: **The Impacts of COVID-19 Pandemic on Children with Neurodevelopmental and Intellectual Disabilities and Their Families: A Survey**

Author(s): **M. Gitimoghaddam[1,2], *C. de Groot[1,2], M. Collet[1,2], J-P. Collet[1,2], L. Olsen[1], S. Glegg[1,3], and W. McKellin[1]**

Institution/Affiliation(s): **[1]University of British Columbia, [2]BC Children's Hospital Research Institute, [3]Sunny Hill Health Center for Children**

Background: The COVID-19 pandemic has affected the physical activity and social life of children with neurodevelopmental and intellectual disabilities (NDID) and their families significantly. Decreased physical activity (PA) and reduced social life may affect the learning and development of these children. In partnership with Special Olympics BC (SOBC) we conducted a survey to describe the consequences of the COVID-19 pandemic on children with NDID and their families, and to identify the supports they need.

Objectives:

1. To describe the consequences of social distancing and restriction of group activities on the lives of families with children with NDID
2. To identify the types of supports that families need to cope more effectively with this difficult and stressful situation

Method: A survey was developed to: (1) assess the consequences of the pandemic on children's PA, social life and daily life activities; (2) describe the supports families received, and (3) identify the help they still require. The survey included a combination of multiple choice and open-ended questions. It was sent by SOBC to all parents whose children were attending the SOBC youth programs (n=245).

Results: 35 surveys have been completed (14.3%). 75% of children were male with a mean age of 8.8 years old. The most common diagnoses were Autism Spectrum Disorder (56%) and Down Syndrome (25%).
Lack of PA was a serious concern for 63% of families; parents considered PA useful for their children's social development (78%), psychosocial functioning (75%), and mental wellness (81%). As a consequence of the pandemic, parents reported a decrease in their children's social interactions with peers outside of the home (90%), an increase in the amount of screen time (77%), deterioration of their children's condition (52%) and behavior (50%), and an increase in their children's anxiety (45%). They reported that the reduction in organized, group-based PA contributed to the deterioration of their child's behavior and self-regulation.
Parents also reported negative impacts of the pandemic on their families: 59% of families were strongly affected by social isolation and lack of contact with other families, and 51% reported negative impacts on their levels of depression and anxiety.
Parents indicated not receiving adequate support. In response to open-ended questions, parents provided the following suggested improvements: having PA programs provide more support for one-on-one home-based PA activities or group outdoor or indoor activities that respect the COVID-19 safety measures, organizing virtual PA with groups of children, and developing a parents' group to encourage communication and networking among families.

Conclusion: Our findings highlight the negative impacts of the COVID-19 pandemic on many aspects of the lives of children with NDID and their families. Lack of organized PA and social interaction with other children were major concerns because of their significant role in children's learning and development. Parents recommended that PA programs develop opportunities for both children and their families to be socially engaged with other children either virtually, or in small in-person PA groups that follow the COVID-19 public safety protocols.

Funded By: Kids Brain Health Network (KBHN), British Columbia Ministry of Health, Michael Smith Foundation for Health Research

Keywords: Pediatrics, COVID-19, Neurodevelopmental disability, Physical activity, Families

Day #1 – Poster #3

Presenter: **Ritvik Khanna, University of Alberta**

Theme: **Community Engagement in Research**

Title: **Chatbot to improve access to information for individuals with neurodevelopmental disabilities**

Authors: **R. Khanna[1], A. Singla[1], Y. Bekele[1], T. Sajed[2], T. Heise[1], S. Pei[1], C. Rosenfelt[1], K. Kelm[1], K. Whitlock[1], O. Zaiane[2], F.V. Bolduc[3]**

Institution/Affiliation: **[1]Neuroscience and Mental Health Institute, University of Alberta [2]Computing Science Department, University of Alberta, [3]Division of Pediatric Neurology, Pediatrics Department, University of Alberta**

BACKGROUND. Neurodevelopmental disabilities (NDD) affect an estimated 1 in 6 Canadians and include a group of disorders: autism, intellectual development, attention difficulty, and learning disability. With the limited medical and educational human resources, families frequently end up spending hours online for strategies to try to manage challenging behaviour on their own. Online browsing alone makes it difficult to judge the veracity of the information presented. Using a technological advance in artificial intelligence (AI), a personal assistant (also known as a chatbot), which is a computer program designed to answer questions using a database of relevant information, we will be able to combine cutting edge medical knowledge with the appetite of families to improve quality of life for their children.

METHODS. We have assembled a unique multidisciplinary team of experts from health science in NDD, AI engineering, social sciences, ethics and legal, parents, as well a knowledge user (KU) groups representing families (Canadian Autism Spectrum Disorder Alliance-CASDA), educators and frontline healthcare workers able to perform every steps from developing to evaluating a Chatbot to support individuals with challenging behaviours, their families, educators, and healthcare providers. We also developed a parent advisory board which has provided insight into development of the chatbot.

RESULTS. We developed a prototype to connect users with a database of trusted resources that were vetted by health professionals. Using a conversation, the chatbot is able to gather the necessary information in order to provide tailored resources that fit the needs of families of individuals with NDDs. Users are able to rate the resources provided in order to increase the quality of fit for future recommendations, as well as submit their own potential resources for consideration to be added to the database. Different modules are able to be created in order to address the various needs of families, such as help with challenging behaviours, accessing funding, or self-care.

FUTURE PLAN. We will validate the prototype using focus group sessions with potential users (parents of individuals with NDD, health professionals, educators) to assess user interface, impact on quality of life for families and access to resources. In addition, we will conduct implementation trial within family support/coaching program to assess usability and impact on workflow integration.

Keywords: Neurodevelopmental Disability, Chatbot, Engagement, Gamification, Challenging Behaviors

Funded By: CIHR and NSERC in partnership with WCHRI, KBHN and CASDA

Day #1 – Poster #4

Presenter: **Erin Klein, University of British Columbia**

Theme: **Knowledge Mobilization Initiative**

Title: **The Impact of Developmental Coordination Disorder: Parent perspectives**

Author(s): **E.S. Klein[1], M. Licari[2,3], S. Barbic[4,5,6,7] and J.G. Zwicker[4,8, 9,10]**

Institution/Affiliation(s): **[1]Graduate Programs in Rehabilitation Sciences, University of British Columbia; [2]Faculty of Science, School of Human Sciences, University of Western Australia, [3]Telethon Kids Institute4, Department of Occupational Science & Occupational Therapy, University of British Columbia, [5]Centre for Health Evaluation Outcomes Sciences, University of British Columbia, [6]Department of Psychiatry, University of British Columbia, [7]Foundry, [8]BC Children's Hospital Research Institute, [9]Sunny Hill Health Centre for Children, [10]Department of Pediatrics, University of British Columbia.**

Introduction: Affecting one in 20 children, developmental coordination disorder (DCD) is a common but under-recognized neurodevelopmental disorder that significantly interferes with a child's ability to learn motor skills, such as tying shoelaces, using cutlery, printing, or riding a bicycle. The motor difficulties affect academic, vocational, and leisure activities, and tend to persist into adulthood. Psychosocial difficulties often develop, including low self-esteem, depression, and anxiety.

Despite decades of research demonstrating the functional and emotional impact of DCD, children do not receive the support and services they need. To raise awareness and change policy, large-scale evaluation and translation of the challenges encountered by children and families are required.

Objectives: The primary aim of the study was to gather the perceptions of families in British Columbia regarding diagnosis, access to therapy, and educational support, as well as the physical, mental, and financial impacts of DCD.

Methods: The impact for DCD questionnaire was initially developed in Australia and was adapted for use in British Columbia. The online questionnaire was distributed from October 2019 to April 2020 to parents of children/adolescents aged 5-18 years with diagnosed or suspected DCD via the DCD Clinic waitlist, database of children diagnosed with DCD, health professional networks, child development centers, social media, and snowball sampling. Closed-ended questions were analyzed descriptively (frequencies/percentages for categorical data; medians/interquartile ranges for continuous data). Content analysis was used for open-ended questions to understand emerging themes and parent-identified needs and priorities. **Results:** A total of 244 questionnaires were analyzed. Barriers and facilitators were identified when families attempted to access supports and services. Parents identify their child's difficulties at a young age (median 3 years); however, approximately half of families waited several years for a diagnosis (median age of diagnosis: 8 years). Over one-third of surveyed of families (39%) paid privately for diagnostic services, due to the reported long wait-times and difficulty accessing clinical assessments. Almost 75% of families have previously accessed therapy services; however, only 40% are currently attending for active therapy, primarily due to cost. Families reported a lack of school-based supports, services, and resources, with only 31% (62/198) identified that their school offers therapy services. Even though 75% of teachers were aware of the child's movement difficulties, only 1 in 3 have access to services and supports. A small number (27%) of parents reported that their child has received adequate therapy. The lack of supports and services has led to emotional and psychological challenges. Half of the children in this sample have a co-morbid diagnosis of anxiety and all have been classified in the abnormal range for emotional difficulties (98/98) and peer relationships (146/146) on the Strengths and Difficulties Questionnaire. Families identified a need for coordinated service delivery with increased awareness, resources, and funding for early identification and treatment of DCD.
Conclusions and clinical implications: A standard of care for early detection and intervention is needed for a coordinated, funded and streamlined pathway to facilitate equitable and timely access to diagnostic and rehabilitative services and supports for children with DCD.

Funded By: Klein is funded by the UBC Faculty of Medicine. Zwicker is funded by the Canadian Institutes of Health Research, BC Children's Research Institute, and Sunny Hill Foundation.

Keywords: developmental coordination disorder, impact, diagnosis, therapy, mental health, school support

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Day #1 – Poster #5

Presenter: **Carrie Smythies, University of Regina**

Theme: **Community Engagement in Research**

Title: **Identifying Gaps in Care: Perspectives from Caregivers of Children with Autism Spectrum Disorder and Self-Injurious Behaviours**

Author(s): **C.Smythies[1] , A. Cullis, A. Richardson[1,2], M. Lee[3], A. McNeil[3], and E. Cooper[4]**

Institution/Affiliation(s): **[1]Faculty of Medicine, University of British Columbia; [2]BC Children's Hospital; [3]Faculty of Education, University of British Columbia; [4]Faculty of Kinesiology & Health Studies, University of Regina**

Introduction:
Self-injurious behaviours (SIB) in children with Autism Spectrum Disorders (ASD) and severe intellectual impairment have a significant impact on children, families and caregivers, and health care providers (HCP). SIB is common in the ASD population, but hard to manage SIB affects about 5% of these children, which is an estimated 150-200 children in BC. While SIB can cause visible physical injury, it also has significant 'silent' impacts on individuals and their support systems. This community-engaged research project works to amplify the voices of parents and caregivers in this patient population.

Methods: Pilot data collection activities included a single virtual focus group of 8 caregivers of children (aged 6-20) with both severe ASD and SIB, from various regions of BC, an initial survey collected basic demographic and risk perception data, and a post-focus group survey acted as an evaluation of the focus group and an opportunity to privately share further thoughts. Participation in the project was voluntary and was held within a virtual space. The focus groups were audio recorded and transcribed, and thematic analysis was completed via the Nvivo program. Additional data was obtained from the chat function during the focus group and free response survey questions. Quantitative data was obtained from objective survey questions done before and after the focus group.

Topics discussed included gaps in care, care needs not being met, concerns about the future, how the COVID pandemic has affected their families, self-care for caregivers, and any positive experiences. Recurrent themes included; difficulty accessing adequate care, lack of support, community support, financial burden, concern for future, lack of understanding by HCP, caregiver burnout, and lack of communication between HCP. Survey data indicates that a quarter of the families are in crisis and another quarter are almost there, lack of access to respite is common, financial burden is significant with almost 90% of households having to reduce work to care for their child.

Conclusion: Challenges, barriers and positive outcomes have not been previously assessed with this population of families and caregivers of children with ASD and SIB. This work provides a good starting point for reworking existing systems. A perceived lack of communication between, and lack of support from, HCP leads to family and caregiver frustration. Families and caregivers often feel unsupported by government agencies, and many experience financial stress, partly due to a lack of respite funding. For rural and suburban families, limited access to specialists may increase caregiver stress. The advent of telehealth has provided some relief, but the most meaningful solution will be increasing the retention of providers in rural/northern communities. While ASD is common, severe ASD with associated SIB is a separate and difficult to manage condition, and future research is needed to further explore these themes. There is urgency to support interventions to address this health inequity experienced by these families.

Keywords: Autism Spectrum Disorder, Self-Injurious Behavior, developmental disabilities, focus group

Day #1 - Poster #6

Presenter: **Samantha Micsinszki, McMaster University**

Theme**: Community Engagement in Research**

Title: **Learning Together: The Use of Simulation to Enhance and Enable Authentic and Meaningful Research Partnerships**

Author(s): **S. Micsinszki[1,2,3], K. Parker[1], N. Tanel[1], B. Dangerfield[1], D. Menna-Dack[1], A. Chu[1], B. Mistry[1], M. Phoenix[1,2, 3]**

Institution/Affiliation(s): **[1]Holland Bloorview Kids Rehabilitation Hospital; [2]McMaster University School of Rehabilitation Science; [3]CanChild**

Context: Involving patients and their families in applied clinical research as patient research partners (PRPs) can enhance the relevance, quality, and impact of research. PRPs can be involved in all aspects of the research process, from idea conceptualization and research design to dissemination through roles including consultant, advisor, collaborator, knowledge user, and co-investigator. Although evidence supports the benefits of partnering on research projects, such as increased participant enrollment and personal benefits to PRPs (e.g., enhanced communication skills), researchers and PRPs may lack the training and skills needed to authentically and meaningfully partner in research.

Issue and Purpose: Building patient engagement resources is important to support authentic and meaningful engagement in research but the majority of existing online learning programs are designed to provide training to either PRPs or researchers separately. Although helpful for basic skill building, online modules are not appropriate to address the complex relational challenges underpinning meaningful engagement, including trust, reciprocity, and communication. Therefore, this project leveraged a co- learning approach where researchers and PRPs experienced firsthand each other's challenges and co-created solutions to develop authentic patient engagement in research.

Method: A co-learning approach was used to design and develop four simulations with facilitation resources intended to support PRPs and researchers through complex and challenging situations associated with patient engagement in research. Participants from five stakeholder groups (i.e., researcher, research staff, trainee, youth, parent/primary caregiver) participated in a one-day, two-phase simulation build session. In phase one (2 hrs), three groups of 4-6 individuals shared stories around an identified challenge topic. A common story reflective of all stakeholders was co-created to build the simulation scenarios. In phase two (1.5 hrs), the simulation scenario was refined using standardized patient actors. All participants had the option to take part as research participants to explore how youth, parents/primary caregivers, trainees, clinicians, and researchers construct their experience of co-building collaborative research simulations. A case study methodology was utilized. Research participants were audio and video recorded in phase one and observational notes were taken. Videos were analyzed using embedded narrative analysis that captured group dynamics and relational and social interactions.
Results: A total of 13 stakeholders participated in the simulation build session. Four simulations were built around the following scenarios: (1) finding a family partner; (2) setting research objectives; (3) navigating concerns around knowledge translation and dissemination; and (4) reviewing results with youth partners. Of those who participated in the simulation build, 11 agreed to participate in the research component. Analysis of the research is currently underway.

Significance: Use of simulation and co-learning can provide research teams with training resources that support meaningful engagement in research throughout the research process. The relational and collaborative nature of co-created simulations mimic real-world challenges that stakeholders face when partnering in research. The simulation training materials developed during this session will be used in future training for Holland Bloorview employees, family leaders and trainees, as well as relevant stakeholders external to Holland Bloorview including the CHILD-BRIGHT network.

Keywords (up to 6 words): co-design, simulation, research partnership, patient engagement

Funded By: CHILD-BRIGHT Training Innovation Fund

Day #1 – Poster #7

Presenter: **Michèle Hébert, University of Calgary**

Theme: **Knowledge/Mobilization Initiative**

Title: **Navigation-Building Training for Children/Youth with Neurodisability and Families**

Author(s): **M. L. Hébert[1, 2], D. B. Nicholas[2], L. Lach[3], W. Mitchell[2], and J. Zwicker[1, 4]**

Institution/Affiliation(s): **[1]School of Public Policy, University of Calgary; [2]Faculty of Social Work, University of Calgary; [3]School of Social Work, Faculty of Arts, McGill University; [4]Faculty of Kinesiology, University of Calgary**

Background: Training for parents and professional navigators is an integral component to building navigation capacity and sustainable systems of neurodisability (ND) service for children and their family. Systematic reviews on training in other fields, highlight training effectiveness and impact on health outcomes, systems and policy. However, evidence-based training in the area of navigation support for children and families impacted by ND, and for navigator-based personnel, are under-developed. To address this gap, we are designing training focused on supporting parents and professional navigators. Specifically, this sub-project, as a part of a larger Navigator initiative, concentrates on parents and professionals as navigators whose role is to facilitate systems navigation.

Approach: The larger Navigation project entails a cross-regional, cross-sectoral, multi-systemic navigation capacity-building initiative for children with ND and families, which is being implemented in Vancouver, Edmonton and the Yukon. As part of this larger initiative, training across regions are being developed, with potential to adapt content to specific regions and jurisdictions, and resource contexts.

Findings: Our initial analysis reveals that training is a fundamental catalyst to navigation capacity building. Key multi-systems level principles of training addressing parent and professional navigator experiences, will be shared, as follows: ***microsystem*** – to foster a shared vision and approach to support child and family needs within their immediate environments (e.g., home, school, community); ***mesosystem*** – to train individuals within organizations that support children and families in co-designing navigation services with parents; ***exosystem*** – to build heightened awareness about the importance of collective community impact within regional contexts outside the immediate child and family environment.

Impact and ongoing work: Because training is so integral to navigation-building, yet needs to be malleable to adapt to context and region, both in person and online options are being considered (particularly important in a COVID-19/post COVID-19 context). We are working to balance priorities of being evidence-informed, with accommodating nuanced regional needs and priorities. Implementation science is being used to design, develop, adapt, build-on and evaluate the training. Evidence-based developmental and application processes of training include: (1) training orientation and communication (diffusion), (2) sharing the evidence (dissemination), (3) implementation, (4) adoption, (5) impact, and (6) sustainability. We anticipate the evaluation of the training to incorporate four levels: satisfaction, relevance of the learnings, prospective knowledge integration, and cost-effectiveness. These crucial principle-based, implementational and evaluative processes will be shared in this presentation.

This project demonstrates how co-design is possible through engagement from the outset with people who have lived experience and community service providers. This evidence-informed and novel training is expected to optimize navigation-building in ND service delivery, importantly, contributing quality of life for children with ND and families. Implementation strategies for applying such training across jurisdictions will be shared.

Keywords (up to 6 words): Neurodisabilities, autism, FASD, CP, navigation, coordination.

Funded By: Kids Brain Health Network, the Azrieli Foundation, an Anonymous Donor, the University of Calgary, Faculty of Social Work and School of Public Policy projects funding, and the Eyes High Postdoctoral Scholarship (M.L.H.).

Day #1 – Poster #8

Presenter: **Jeffrey McCrossin, McGill University**

Theme: **Clinical/Community Research**

Title: **The role of parent-to-parent support in navigating services for families of children with neurodisabilities: a BC case study.**

Author(s): **Jeffrey McCrossin (PhD Student)[1], Wendy Mitchell (PhD)[2], Angela Clancy (Executive Director) [3], Franceska Grantzidis (Provincial Network Manager)[3], Lucyna Lach (PhD) [1]**

Institution/Affiliation(s): **[1] McGill University, [2] University of Calgary, [3] Family Support Institute of British Columbia**

Background: The term 'navigation' refers to a service, program, or provider that aims to facilitate interactions between service users, families, and/or service providers with the ultimate goal of improving access to care, and often includes some provision of emotional support. Navigation and negotiation of meaningful resources are key processes of doing well in the face of adversity. Navigational support improves coping and adaptation for families with a child with a disability and improves their coping and adaptation by supporting a shift in family's belief systems around family stressors and increases utilization of available resources. The Family Support Institute of British Columbia (FSI) offers a peer-to-peer network of 300 persons with family members living with a disability trying to 'navigate' the system. This network is unique in Canada and the experiences of key stakeholders in this family support program are currently being explored in a systematic manner.

Research Question: To understand how the network is experienced by three groups of parents with lived experiences: parents seeking navigational supports, volunteer Resource Parents (RPs), and Regional Network Coordinators (RNCs) employed by FSI.

Methods: The present qualitative study piloted a single descriptive instrumental case study design to draw themes from interview transcripts from a parent-client, an RP, and an RNC. All 3 participants were mothers of children with neurodisabilities.

Findings: The pilot study has highlighted how peer navigation involves unique support to parents by drawing on their shared lived experience as parents of children with a neurodisability. The RP and RNC used a non-professional stance throughout their efforts to provide instrumental and emotional support to the parent. The informal approach to providing support and the shared lived experience facilitated rapport building with the parent. Their combined experience and knowledge gained from navigating the system themselves, the RP and RNC shared unofficial guidelines of what can be expected at different family lifecycle stages, what support the parent could ask for, and what steps to take in order to access support for their family. The RP reflected on her lived experience in order to provide empathy and bridge communication between the parent and service providers. The RP reported emotional challenges that come with the volunteer role as well as support provided by the RNC in this regard. Personal benefits to taking on the role of an RP included developing knowledge applicable to the RP's own family.

Implications: Peer support functions in a similar manner to other forms of navigation but operates through the shared lived experience. The emotional support role of the RP requires significant self-reflection which can be supported by the RNC. The findings provide a nuanced insight of the reciprocal benefit of the relationship between the parent seeking navigational support and resource parent. Findings suggest that RPs do not replace the role of any professional but are instead intended to compliment the role of professionals by tuning into the needs of parents and bridging communication with service providers. Beyond this pilot study, additional interviews with other parents, RPs, and RNCs are underway to explore the transferability of the results, and to continue to gather the experiences of key stakeholders.

Keywords (up to 6 words): navigation, neurodisability, peer support, family resilience, volunteering

Funded By: Kids Brain Health Network, McGill University

Day #1 - Poster #9

Presenter: **Lin Li, McMaster University**

Theme: **Community Engagement in Research**

Title: **Building Successful Partnerships: A Conversation Guide for Researchers and Patient/Family Partners**

Author(s): **L. Li[1] and C. Osterhues**

Institution/Affiliation(s): **[1]School of Nursing, McMaster University**

Context and Issue: In recent years, increasing attention has been given to engaging patients and their families (and/or caregivers) in the co-production of research. In the field of child health research, families can contribute their lived experience and unique expertise to ultimately lead to better research. Benefits of family engagement in research include: increased relevance, quality, and validity of research; improved translation of research into policy and practice; increased accountability and transparency of research; and the potential for new insights and discoveries. However, barriers exist to meaningful family engagement, such as power imbalances in the research relationship and tokenistic involvement of family partners. Recognizing that successful partnerships are grounded in strong communication, shared goals, and clear roles and responsibilities, we developed a knowledge translation tool to facilitate communication between researchers and family research partners. This tool is designed to be used by both researchers and family research partners, and includes a conversation guide paired with tips for communication and relationship building. Integrating key aspects of successful partnerships, this tool is designed to reduce power imbalances, improve communication, and facilitate relationship building between researchers and family research partners.

Aims: The goals of this knowledge translation tool are:

1. To improve communication and relationships between researchers and family research partners.
2. To empower family research partners to confidently convey the expertise they bring to a project.

Tool Description: This knowledge translation tool was co-created by a nursing PhD student and a parent of a child with neurodiversity as part of the Family Engagement in Research Certificate of Completion Program offered by CanChild/McMaster University and Kids Brain Health Network. Key topics were informed by course content and discussions. The flow of the conversation guide was based on the Serious Illness Conversations Guide developed by Ariadne Labs and the Dana-Farber Cancer Institute. Tips for communication and relationship building were based on the five core values of self-awareness, trust, respect, mutual understanding, and reciprocity. The guide structures the conversation using the following five stages: introduce, assess/identify, ask/share, explore, and close. There is a researcher version and a patient/family partner version of the guide, with sample statements provided for each. The guide is designed to be used when initiating a partnership. However, researchers and patient/family partners are encouraged to revisit these conversations throughout the research process in order to re-evaluate any changes to goals, responsibilities, commitments, and barriers related to the research partnership.

Relevance: This tool provides a practical template to guide conversations around research partnerships. By making these conversations easier for both researchers and family research partners, we hope to empower family partners to communicate confidently with researchers, to soften the power imbalance inherent in the research relationship, and to create stronger and more equal research partnerships.

Keywords: family engagement, partnership, communication, knowledge translation

Funded By: The authors' participation in the Family Engagement in Research course was funded by Kids Brain Health Network.

Day #1 – Poster #10

Presenter: **Preeti Kar, University of Alberta**

Theme: **Clinical Community/Research**

Title: White Matter Alterations in Young Children with Prenatal Alcohol Exposure

Author(s): **P. Kar[1,2], J.E. Reynolds[1,2,3]; M.N. Grohs[1,2], W.B. Gibbard[1,4]; C. McMorris[1,5]; C. Tortorelli[6]; C. Lebel[1,2,3]**

Institution/Affiliation(s): **[1]Alberta Children's Hospital Research Institute, [2]Hotchkiss Brain Institute, Departments of [3]Radiology, [4]Pediatrics, and [5]Werklund School of Education; University of Calgary, [6]Department of Social Work; Mount Royal University**

Introduction: Prenatal alcohol exposure (PAE) can result in a diagnosis of fetal alcohol spectrum disorder (FASD), a lifelong disorder with a prevalence of 4% in Canada (1). Previous research in youth and adults has shown cognitive, behavioral, and social-emotional challenges, as well as widespread reductions in brain connectivity (2, 3). Less is known about brain structure, especially white matter connectivity, in younger children. Extensive brain development takes place during early childhood and understanding neurological profiles of preschool children with PAE is critical for early identification and intervention (4). This study aims to examine differences in white matter connectivity in young, preschool children with and without PAE.

Methods: We studied 54 children (5.21±1.11 years; 27 males, 27 females) with confirmed PAE, compared to 54 age- and sex-matched typically-developing controls with no PAE. Children underwent diffusion tensor imaging between 2 and 7 years of age. Image processing was completed using ExploreDTI (V4.8.6) and semi-automated deterministic tractography was used to delineate 10 major white matter tracts: the corpus callosum (genu, body, splenium), fornix, as well as the bilateral pyramidal tracts, cingulum, inferior fronto-occipital fasciculus, inferior longitudinal fasciculus, superior longitudinal fasciculus, and uncinate fasciculus. Measures of white matter microstructure known as mean fractional anisotropy (FA) and mean diffusivity (MD) were obtained for the whole brain and each tract to reflect upon properties such as myelination and axon size/packing/coherence. A multivariate analysis of covariance was conducted to test for group differences (PAE vs. control) for FA and MD.

Results: Our results demonstrate that in the PAE group compared to unexposed controls, higher FA was observed in the genu of the corpus callosum ($p=0.003$) and lower MD was observed in the uncinate fasciculus ($p=0.001$). Differences in other white matter tracts did not survive correction for multiple comparisons.

Discussion: White matter microstructural differences are present in young children with PAE compared to unexposed controls. In the corpus callosum, which is associated with inter-hemispheric communication, and the uncinate fasciculus, which is associated primarily with social-emotional processing, the PAE group showed higher FA and/or lower MD suggesting more myelination and greater axonal size/packing/coherence. Previous research in school-aged children, adolescents and adults with FASD has consistently reported lower FA and/or higher MD which is contrary to our findings (3). Our results may reflect an altered developmental trajectory of white matter in young children with PAE. These early, rapid changes in microstructure may stem from compensatory mechanisms in response to PAE teratogenesis or reduced cortical plasticity. It is possible that young children with PAE show premature development of white matter that may plateau too early, leading to the lower FA/higher MD observed at older ages. Longitudinal follow-ups in this sample of children with PAE may highlight alterations to white matter development within individuals and across ages.

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4. Reynolds JE. Global and regional white matter development in early childhood. *NeuroImage.* 2019;196:49-58.

Funded By: Alberta Children's Hospital Research Institute, Kids Brain Health Network, CIHR, Hotchkiss Brain Institute.

Keywords: fetal alcohol spectrum disorder, neuroimaging, prenatal alcohol exposure, brain, preschool children

Day #1 – Poster #11

Presenter: **Marie-Eve Brien, University of Montreal**

Theme: **Basic Science Research**

Title: **In-utero exposure to sterile inflammation is associated with altered neurodevelopment**

Author(s): **Marie-Eve Brien[1,3], Ines Boufaied[1], Sylvie Girard[1,2,3]**

Institution/Affiliation(s): **[1]Ste-Justine Hospital Research Center, [2]Department of Obstetrics and Gynecology, [3]Department of microbiology, infectiology and immunology, Université de Montreal**

Prenatal inflammation alters placental function having a negative impact on fetal development and is associated with an increased risk of neurodevelopmental disorders. Infectious stimuli are commonly used in animal model; however, infections are often undetectable during pregnancy whilst inflammation is observed. We developed an animal model of prenatal non-infectious inflammation, induced by uric acid crystals, leading to placental inflammation and fetal growth restriction (FGR) (Brien et al., 2017). Our objective was to further study the long-term effect of prenatal exposure to non-infectious inflammation on the developing brain.

METHODS: The impact of *in utero* inflammation was determined on the brain from gestational day 22 (GD22) to postnatal day 50 (PND50) using our published model. Immunohistological analysis were performed for micro/astro-glial activation and neuronal precursors. Behavioral testing was performed to evaluate motor and cognitive function. We also investigated the therapeutic potential of targeting the interleukin (IL)-1 system.

RESULTS: Prenatal exposure to inflammation led to microgliosis in the corpus callosum at PND7 as well as in the hippocampus (CA3 and DG) at PND7/21. Astrogliosis was observed in the white matter (both cc and cg), in the motor cortex and hippocampus at PND7. Decreased number of neuronal precursors was also observed in the DG at later developmental stages. IL-1 receptor antagonist protected against most of the structural. Motor functions were also affected by prenatal uric acid exposure.

CONCLUSION: Prenatal exposure to non-pathogenic inflammation has important negative impact on brain development. Futures studies will investigate prenatal anti-inflammatory intervention to protect the developing brain.

Keywords (up to 6 words): Pregnancy, Alarmins, Uric Acid, Inflammation, Neuroinflammation, Neurodevelopment

Funded By: MEB receive scholarships from Brain Canada- Kids Brain Health Network, Fonds de recherche du Québec, Université de Montréal and Sainte-Justine Foundation

Day #1 – Poster #12

Presenter: **Melissa Tremblay, University of Alberta**

Theme: **Community Engagement in Research**

Title: **Supporting Indigenous Families to Foster Healthy Child Development Through the Early Years Program**

Author(s): **H. Downie[1], C. Rattlesnake[1], C. Ferguson,[2] M. Tremblay[3]**

Institution/Affiliation(s): **[1]Maskwacis Health Services; [2]Martin Family Initiative, [3]University of Alberta**

Abstract:

Laboratory animal and human clinical studies have shown that interventions beginning prenatally and in early childhood can produce substantial benefits, with human studies showing improved infant health, improved language development, reduced obesity, reduced participation in criminal activity, increased adult incomes and education levels, and lower risk for cardiovascular and metabolic diseases in adulthood. However, although early intervention programs have shown benefits for children facing adversity, there are limited data on how to replicate and scale up such interventions for all children and families within a community. This is particularly critical for Indigenous families in Canada, where the impact of colonialism has resulted in high levels of adverse life experiences for many Indigenous children, significantly impacting their life course.

With funding from Brain Canada, the Martin Family Initiative (MFI) has developed the Early Years (EY), in partnership with Maskwacis Health Services (MHS), Maskwacis Education Schools Commission (MESC), and Ermineskin Cree Nation. The EY is an innovative evidence- informed program that brings together community expertise and leadership across the health, education and social services domains to support Indigenous women and their families. It is a pre-natal to pre-school program that helps young families build a strong understanding of their child's early developmental process. The EY program was founded on the essential recognition that the support and development of strong Indigenous families and communities remain integral to fostering healthy child and brain development, protecting cultural identity and achieving long term health and wellbeing outcomes. In order to shape the research and evaluation of the EY Program, researchers from the University of Alberta and University of Lethbridge have been brought on board the project. Our research hypothesis is that early intervention, beginning prenatally and continuing through infancy and early childhood, will improve outcomes for Indigenous children across developmental domains.

The evaluation consists of a mixed-methods, quasi-experimental design where the intervention group will be compared to an older cohort of children who were born before the project's inception. This comparison will include assessment tools and a retrospective analysis of health and Child and Family Services records. Under the umbrella of this design, our approach to the evaluation is guided by community-based participatory research (CBPR).

This lightning talk will provide a glimpse into data that speaks to the program's impact in terms of providing parents with new and practical knowledge regarding their child's development, promoting language development, creating opportunities for cultural activities as well as connection with other parents, advocacy for families involved in the child intervention system, an increase in immunization rates, increased use of health and community services, as well as ways in which the program has successfully shifted to virtual service delivery methods due to the current health crisis. The audience will learn about the ways in which a community-based initiative that centralises Indigenous knowledge and cultural values is paving the way for improved child health and wellbeing, beginning with early brain development.

Keywords (up to 6 words): Indigenous child health; community-based participatory research; community engagement

Funded By: Brain Canada Foundation

Day #1 – Poster #13

Presenter: **Karys Peterson-Katz, Queen's University**

Theme: **Community Engagement in Research**

Title: Nurturing the Seed: Analysis of Early Developmental Assessment Data and Implementation in Canadian Pre-School Aged Indigenous Children

Author(s): K. Peterson-Katz[1], E. Collis[1], A. Chavez-Ramos[1], N. Khambati[2], J. Robertson[2], N. Tuzi[2], C. Kulkarni[2], J.N. Reynolds[1]

Institution/Affiliation(s): [1]Center for Neuroscience Studies, Queen's University; [2]Infant Mental Health Promotion, The Hospital for Sick Children

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INTRODUCTION

Nurturing the Seed (NTS), a culturally informed development assessment tool, was constructed to equip frontline childcare practitioners with the resources to support the developmental needs of Indigenous pre-school aged children, even in the absence of other services. Particularly during the isolating times of COVID-19, these children are more vulnerable in multiple areas of development. Developed by Infant Mental Health Promotion (IMHP), partnered with key stakeholders, *NTS* utilizes the Ages and Stages Questionnaires (ASQs), alongside Developmental Support Plans (DSPs) and practices distinct to Indigenous communities to provide insight on community health, program policy and parent-child relationships that can address the current lack of systematic assessment of developmental vulnerabilities in the pre-school population.

AIM

(1) train frontline childcare practitioners to utilize a culturally informed program;
(2) evaluate the efficacy of *NTS* by examining child development scores at two time points;
(3) provide a story of the community health in order to gain knowledge of child development and inform program policy

DESCRIPTION

NTS has currently been adopted by six Canadian Indigenous communities. The structure is as follows:

- **Advisory Community Meeting:** Indigenous community members and Elders partner with IMHP and Queen's University to design the program, culturally inform methodology, and champion implementation in the community.
- **Training:** IMHP trains frontline practitioners regarding infant mental health; the ability to administer the ASQ, and create individualized DSPs using *NTS*.
- **Evaluation:** Developmental assessments using the ASQ occur at 3-4-month intervals.
- **Analysis:** Child development scores from the first and second time point are analyzed

CONCLUSION

Preliminary data shows that this intervention model positively impacts the developmental trajectory of vulnerable Canadian children. The research team will establish proof of principle for scaling the use of this model to Indigenous populations across Canada, and the effect of family-centered assessments on child developments when other services are not readily available.

Day #1 – Poster 14

Presenter: **Monika Novak Pavlik**

Theme: **Clinical/Community Research**

Title: **Determinants of pain in children with cerebral palsy**

Author(s): Monika Novak Pavlic[1,2,3], Vlasta Vuković-Cvetković[1,4]

Institution/Affiliation(s): **[1]Faculty of Education and Rehabilitation Sciences, University of Zagreb, Croatia, [2]School of Rehabilitation Science, McMaster University, [3]CanChild Centre for Childhood Disability Research, McMaster University, [4]Glostrup Hospital, Denmark**

Introduction
Pain is a common problem in children with cerebral palsy (CP). Characteristics of pain in children with CP have often been assessed using proxy reports (e.g., parents, physicians) and less commonly as self-reports. Although proxy reports may facilitate the management of a child's pain in some situations, there is a possibility of making misconceptions about the children's pain. The primary objective of this study was to examine the determinants of pain, coping strategies, and impact the pain has on children's everyday life using self-report.

Patients and methods
Thirty-eight children and youth between 9 and 18 years with various types of CP and functioning levels participated in this cross-sectional study (45% boys, 55% girls). Participants were asked to complete a survey questionnaire about their personal experiences of pain. The survey included a variety of close-ended questions.

Results
Most children experienced pain only a few times a year (62.2%) and only the minority of children experienced everyday pain (5.4%). Younger children (9-11 years) reported less painful body regions than older children. The most commonly reported pain triggers were 'tiredness' and 'change in weather,' while most pain-relieving factors were 'rest' and 'hugs and tenderness.' Most children said that pain interfered with their performance in school, at home, or during play (87%).

Conclusion
Pain is a complex biopsychosocial phenomenon and should be self-reported whenever possible. Discovering comprehensive and efficient strategies for pain assessment and management for all children with CP is needed.

Keywords (up to 6 words): pain, children, cerebral palsy

Day #1 – Poster #15

Presenter: **Monika Novak Pavlic, McMaster University**
Theme: **Clinical/Community Research**

Title: **How do children with cerebral palsy view pain?**

Author(s**): Monika Novak Pavlic[1,2,3], Vlasta Vuković-Cvetković[1,4]**

Institution/Affiliation(s): **[1]Faculty of Education and Rehabilitation Sciences, University of Zagreb, [2]School of Rehabilitation Science, McMaster University, [3]CanChild Centre for Childhood Disability Research, McMaster University, [4]Glostrup Hospital**

Introduction
Children with cerebral palsy (CP) are believed to experience more pain than typically developing children. However, little is known about how the theories of cognitive development can be utilized for assessment of pain they are experiencing. We conducted a qualitative study to gain perspective on children's cognitive understanding of pain and pain behaviors when having CP in relation to Piaget's theory of child cognitive development.

Methods
Thirty-eight participants were included in this study. Participants were children and youth with CP from three age groups (4-8y, 9-11y, and 12-18y). Data was collected through a survey questionnaire using open-ended questions. Directed qualitative content analysis based on Piaget's theory of cognitive development was used for identifying themes and categories.

Results
Children's understanding of pain was hugely determined by their age. While younger children tended to see pain as an emotion or a single physical symptom (e.g., fever), teenagers had more advanced cognitive reasoning about pain. They were aware of the potential causes of it and saw pain as an event that manifests with a particular physical sensation. Children older than 12 years were aware that the pain they experience can be controlled and might affect their everyday functioning. The results are consistent with Piaget's theory of cognitive development.

Conclusion
The results indicate that children's understanding of pain is depended on their chronological and cognitive age. Before making an action plan in pain treatment when working with children with CP, it is recommended to determine and comprehensively assess child's understanding of pain and the impact it has on the child's functioning in everyday life.

Keywords: pain, children, cerebral palsy, Piaget theory of cognitive development

Day #2 – Poster #16

Presenter: **Samantha Micsinszki, University of Toronto**
Theme: **Clinical Community Research**

Title: **Examining Factors Associated with Sleep Quality in Parents of Children 4-10 Years with Autism Spectrum Disorder**

Author(s): **S. Micsinszki[1], M. Ballantyne[2], K. Cleverley[1,3,4], P. Green[2], and R. Stremler[1,5]**

Institution/Affiliation(s): **[1]Lawrence S. Bloomberg Faculty of Nursing, University of Toronto[2]Holland Bloorview Kids Rehabilitation; [3]Margaret and Wallace McCain Centre for Child, Youth and Family Mental Health, Centre for Addiction and Mental Health; [4]Department of Psychiatry, University of Toronto; [5]Hospital for Sick Children**

Background/Rationale: Sleep quality is an important health indicator, yet parents of children with Autism Spectrum Disorder (ASD) often report poorer sleep compared to parents of typically developing children. When parents do not obtain enough good quality sleep, health and daytime functioning may be compromised. This means that the onus of care is placed on already stressed and exhausted parents. Although poor sleep quality may lead to significant negative health consequences, it has been remarkably understudied in parents of children with ASD.
Purpose: This study examined the prevalence of poor sleep quality in parents of children 4-10 years with ASD and tested a model of parent factors (i.e., psychological resources, cognitive appraisals, and coping behavior) expected to moderate the relationships between child sleep problems, parenting stress, and parent sleep quality at a single point in time.

Methods: In this cross-sectional observational research, 214 parents of children with ASD completed the study. Parent sleep quality was examined using survey methods. Sleep measures included the Pittsburgh Sleep Quality Index (PSQI) (parent sleep) and the Children's Sleep Habits Questionnaire (CSHQ) (sleep in children of parents in this study). Six regression models were tested using multivariable linear and moderated regression.

Results: Mean (SD) PSQI scores for parents in this sample was 8.81 (3.76), with most parents scoring above the clinical cut-off of >5 (152, 77.6%). Mean (SD) CSHQ scores for children of the parents in this sample was 54.03 (8.32), which exceeds the clinical cut-off of >41, with most parents scoring their child above the clinical cut-off (182, 96.3 %). Overall, when parenting stress, child sleep problems, and all expected moderators were modelled together with parent sleep quality, child sleep problems was the only significant predictor (Beta = 0.081, p = 0.031).

Significance/Implications: Findings from this study suggest that children's sleep problems was the single most important factor when considering what impacts parent sleep quality. However, both parents and their 4-10-year old children with ASD experienced sleep disturbances. Although the expected moderators help to explain the variance in parent sleep quality, their buffering effects may not be enough when parents sleep poorly.

Take-Away: Future research should address both parent and children's sleep and evaluate the effect that altering children's sleep has on parent sleep. To improve sleep in parents of children with ASD, clinicians may consider focusing on improving children's sleep problems, which might have spillover benefits on the improvement of parent sleep quality.

Keywords (up to 6 words): ASD, parent's sleep, children's sleep, stress

Funded By: SM was supported by graduate funding from the Lawrence S. Bloomberg Faculty of Nursing, QEII-GSST, and the Bertha Rosenstadt Doctoral Dissertation Award.

Day #2 – Poster #17

Presenter: **Florence Deguire, University of Montreal**

Theme**: Basic Science/Research**

Title**: The relationship between rapid head growth and neurodevelopmental outcomes in the first year of life**

Author(s): **Florence Deguire [1,2,3], Gabriela López Arango, [1,2,3] Inga Sophia Knoth [1,2,3], Valérie Côté [1,2,3], Sarah Lippé [1,2,3]**

Institution/Affiliation(s)**: [1] Département de psychologie, Université de Montréal, [2] Centre de recherche en neuropsychologie et cognition, Université de Montréal, [3] Centre de recherche du CHU Ste-Justine, Université de Montréal**

Early childhood, especially the first two years of life, is the most important and dynamic period in brain development (Knickmeyer et al., 2008). The rapid brain growth during the first months of life is accompanied by an equally intense growth in head circumference. Macrocephaly, an abnormally large head circumference (more than two standard deviations above the norm) (Tan, Mankad, Gonçalves, Talenti et Alexia, 2018), is thought to be a sign of future neurodevelopmental disorders if presented in combination with rapid head growth during the first year of life. One way to assess typical and atypical brain development, and potentially predict future neurodevelopmental disorders, is through electroencephalography (EEG) recordings using a repetition suppression (RS) paradigm. RS is a cerebral learning response characterized by a diminution of neuronal activity in response to a repeated stimulus. The aim of this study is to investigate the relationship between head growth and adaptative behaviors and RS, measured in the first year of life. We hypothesized that infants with normal head growth will have more adaptative behaviors and better repetition suppression responses, compared to infants with rapid head growth.

This project is part of a longitudinal study in which 80 healthy infants and 50 infants with macrocephaly, but no known brain anomalies, were recruited between the age of 3 and 11 months. Head circumference was measured at birth, during the first year of life and at two years of age. The *ABAS-II* questionnaire was used to assess adaptative behaviors in the first year of life. An EEG RS task consisting of repeating audio-visual stimuli was used to assess cerebral activity. To determine RS, amplitude differences between each of the three subsequent stimulus presentations on the P2 and N2 ERP components were compared. Head growth from birth to two years of age was modeled using linear mixed models. ABAS-II and RS measures, gathered in the first year of life, were then added to the models. Results show that rapid head growth is associated with lower scores on the *ABAS-II* questionnaire (F (1, 168.6) = 4.38, p = 0.038) and with a tendency for decreased RS of the P2 component (F (1, 236.1) = 3.61, p = 0.05) during the first year of life. Our results indicate an important link between head growth velocity and basic learning mechanisms required for the development of higher-level cognition and coping skills in children - fundamental aspects of good overall child development.

Keywords (up to 6 words): Neurodevelopment, head growth, repetition suppression, adaptative behavior, childhood

Funded By: Canadian Institutes of Health Research (CIHR), Kids Brain Health Network (KBHN).

Day #2 – Poster #18

Presenter: **Charlotte Rimmer, McGill University**

Theme: **Clinical/Community Research**

Title: **Phonological skills in autism spectrum disorder: A scoping review of intervention programs**

Author(s): C. Rimmer[1,2], H. Dahary[1,2], and E-M. Quintin[1,2]

Institution/Affiliation(s): [1]Behaviour, Autism, and NeuroDevelopment (BAND) Research Group, McGill University, [2] Centre for Research on Brain, Language, and Music (CRBLM)

Background: The development of emergent literacy skills for children is crucial, as reading achievement promotes opportunities for establishing necessary academic, social, adaptive, and occupational skills (Nally et al., 2018; Westerveld et al., 2018). Two crucial emergent literacy predictors for reading success for typically developing (TD) children are phonological awareness (PA) (i.e., metalinguistic ability involving recognizing and manipulating spoken words in language) and phonics abilities (i.e., understanding letter-sound correspondences in reading and spelling) (Hudson et al., 2017; Moritz et al., 2013; NELP, 2008). The presence of a developmental disorder has been identified as a risk factor for delayed emergent literacy development (Justice & Pullen, 2003). Accordingly, many children with autism spectrum disorder (ASD) experience challenges associated with phonological development (Westerveld et al., 2016). The efficacy of intervention programs to enhance phonological skills has been well established for children with TD (NELP, 2008) but remains to be elucidated for children with ASD. The purpose of this scoping review is to identify and systematically review interventions targeting the development of phonological skills of children with ASD.

Research Questions: This review aims to investigate which interventions are reported as being effective or not in improving the phonological skills of children with ASD

Methods: A systematic search on electronic databases (PsycINFO, ERIC, and Web of Science) yielded a total of 563 unique articles, of which 15 studies met inclusion criteria and are included in this review.

Results: Findings revealed that the literature on phonological interventions for children with ASD could be separated into two categories, namely computer-based interventions and specific instructional practices. Fourteen out of 15 studies reported positive outcomes on the phonological skills of children with ASD, regardless of the computer program or instructional practice used, the interventionist, the delivery format, or the intervention setting. However, adaptations to standard teaching procedures (e.g., tutor sitting with child, discrete-trial teaching) were required. Common elements across successful interventions included spanning between approximately 6-24 weeks, with a minimum of a half hour of training per week for at least 7 hours total of intervention time. Further, knowledge gaps and limitations in participant characterization and the conceptualization of phonological skills were identified.

Conclusions: Findings from the current review are encouraging and suggest that children with ASD can benefit from computer-based interventions and specific instructional practices targeting oral and written phonological skills. Yet, research in this area continues to lack clear and consistent use of terms to describe phonological skills and tasks measuring these constructs. Moreover, results from this review reveal that there is a need for studies with larger sample sizes and detailed descriptions of participants. Providing professionals with a comprehensive investigation on phonological skill interventions for children with ASD can aid in identifying important factors (e.g., cognitive, language, and social) that impact response to intervention outcomes and can lead to informed instructional practices for teaching emergent literary skills to this population.

Keywords (up to 6 words): autism spectrum disorder, children, phonological awareness, language, interventions

Funded By: Joseph-Armand Bombardier CGS Doctoral Scholarship from the Social Sciences and Humanities Research Council of Canada

Day #2 – Poster #19

Presenter: **Dercia Materula, University of Calgary**

Theme: **Clinical/Community Research**

Title: **Improving Health Outcomes and Coordinating Care for Children/Families with Complex Health and Social Needs**

Author(s): **Dercia Materula[1], Brittany Finlay[1], Michèle L. Hébert[1,2], Genevieve Currie[3], Gina Lachuk[4], Nadine Gall[4], Ben Gibbard[5], Jennifer Zwicker[1]**

Institution/Affiliation(s): [1]School of Public Policy, University of Calgary, [2]Faculty of Social Work, University of Calgary, [3]School of Nursing and Midwifery, Mount Royal University, [4]Alberta Health Services, [5]Cumming School of Medicine, University of Calgary.

Context: Children with Neurodevelopmental Disabilities (NDD) have complex health and social needs. Previous research has shown that the complexity of these needs reduces the possibility that providers from a single discipline can provide the quality and breadth of care required. In most cases, families of children with NDD coordinate a myriad of interventions offered by the different agencies involved in the continuum of care. These families face challenges navigating fragmented social and health care systems to obtain the required services due to insufficient coordination, and lack of communication among care providers and across sectors. In this study, we evaluate the impact of the Neurodevelopmental Disorders Care Coordination (NDD-CC) project implemented with caregivers at the Alberta Children's Hospital on caregiver's and children's health and quality of life outcomes. The NDD-CC project addresses the multi-system needs of children with NDDs and chronic medical and social complexities using an innovative model of care coordination.

Research questions: 1) How does care coordination, provided by the NDD-CC project, impact care integration and coordination for families with children with complex care needs? 2) How does care coordination, provided by the NDD-CC project, impact caregiver stress and quality of life, child quality of life, and costs (from a health system and societal perspective) over time?

Methods: This study used a mixed-methods data analysis approach. Caregivers enrolled in the NDD-CC project completed surveys at baseline, 4-months, and 12-months. The surveys assessed critical domains of the NDD-CC program, namely, child and family demographics, uptake of disability-related services, and the impact of NDD-CC on caregiver and child quality of life. Data collected was stored in RedCap. Data analysis was conducted using Microsoft Excel and SPSS.

Results: By comparing the survey data collected at the three timeframes (50 respondents at baseline; 44 at four-months; and, 17 at 12-months), this study demonstrates the impact of the NDD-CC project in facilitating access to care for children with disabilities and families. Data was disaggregated by sociodemographic characteristics (children's developmental conditions, annual household income, and number of caregivers in the household). Respondents reported that the NDD-CC led to an improved quality of life for caregivers (average Care-related Quality of Life tariff rose from 59.52 at baseline to 64.13 at 12-months) and access to an extensive network of programs and services available to families caring for children with NDD in supporting care for their children. Furthermore, our results are showing that after enrolling in the NDD-CC, caregivers reported a significant reduction of emergency department (ED) visits and in-patient stays for their children. At baseline, 46 percent of caregivers reported zero ED visits, this percentage rose to 65 percent at 4-months, and 76 percent at 12-months.

Conclusion: Overall, the results of this study are showing that the NDD-CC project improved caregiver quality of life, and coordination of services available to children with NDD and families. The experiences of the caregivers included in this project can contribute to policy discussions to improve the delivery and coordination of services among providers for families caring for children with NDD.

Keywords: Care coordination, developmental disabilities, children, health outcomes, quality of life, caregivers.
Funded By: Canadian Institutes of Health Research, Owerko Family Fund for Brain Health.

Day # 2 – Poster #20

Presenter: **Brittany Finlay, University of Calgary**

Theme: **Community Engagement in Research**

Title: **Experiences of Caregivers and Youth in Accessing Government Disability Programs Across Canada**

Author(s): **Brittany Finlay[1], Dercia Materula[1], Krystle Wittevrongel[1], Michèle L. Hébert[1,2], Kathleen O'Grady[3], Lucyna M. Lach[4], David Nicholas[2], Jennifer Zwicker[1, 5]**

Institution/Affiliation(s): **[1]School of Public Policy, University of Calgary; [2]Faculty of Social Work, University of Calgary; [3]Simone de Beauvoir Institute, Concordia University; [4]School of Social Work, McGill University; [5]Faculty of Kinesiology, University of Calgary.**

Context: Government disability programs provide support to individuals with disabilities to address the economic, educational, and social barriers they face that hinder their full participation in society. Previous work shows that uptake of one such program, the Disability Tax Credit (DTC), is relatively low across Canada. However, uptake of other disability programs at the federal and provincial level, particularly for children and youth with disabilities and their families, is not well understood. This creates difficulties in understanding whether disability programs are accessible and are effectively meeting the needs of children and youth with disabilities and their families.

Aim: The aim of this project is to determine how Canadian youth with disabilities and their families experience the process of accessing government disability programs. We describe experiences accessing programs, and identify common themes among interviews across the country.

Methods: This study uses qualitative interviews with youth (18-30 years) with disabilities and parents/caregivers of youth (0-30 years) with disabilities across Canada. Maximum variation sampling was used among individuals that had completed an online survey to select participants for a 30- to 60-minute, semi-structured interview. Interviews were conducted in English and French. During this interview, participants discussed their experiences accessing government programs, and detailed barriers and facilitators that they experienced while trying to access programs. Interviews were transcribed verbatim and analyzed with NVivo. To date, analysis has included code generation and code validation. Subsequent analyses include generation of key themes and sub themes.

Results: Interviews were conducted with parents/caregivers of youth with disabilities (n=79), and young adults with disabilities (n=4), in both English (n=74) and French (n=10). We interviewed at least one participant in all provinces and two territories. Interview participants varied with respect to many demographic factors, including income, disability diagnosis, community size, and Indigenous status, among others. Qualitative analysis has identified a number of emerging themes relating to facilitators to program access, barriers to program access, changes to service access over time, process demands on parents/caregivers, and recommendations for changes to service delivery and design.

Conclusion: This study has revealed experiences associated with accessing government disability programs from the perspective of youth with disabilities and their parents and caregivers. These experiences provide insight into how service delivery and design can be changed to improve support for individuals with disabilities and their families. Future work will involve translating proposed changes into policy options and recommendations.

Keywords: qualitative analysis, interviews, disability programs, access

Funded By: Sinneave Family Foundation, SSHRC, Kids Brain Health Network

Day #2 - Poster #21

Presenter: **Samantha Wong, McGill University**

Theme: **Basic Science Research and Clinical Research**

Title: **Neural tracking and neuroplasticity of social motor synchronization of children with autism spectrum disorder.**

Author(s): **S. Wong[1], E. M. Quintin[1]**

Institution/Affiliation(s): **[1]Department of Educational & Counselling Psychology, McGill University**

Background: Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social challenges.[1] One example is impaired social motor synchronization,[2,3] with emergent research identifying associated neural correlates.[4,5] Electroencephalography (EEG) measures brain electrical activity and allows investigating neurophysiology during social motor synchronization. Thus, **objective 1** of my dissertation is to apply recent use of frequency-tagging techniques[6] of EEG signals to identify neural tracking of social motor synchronization[7] in children with ASD. Next, I will assess whether social motor synchronization and associated EEG signals can change after intervention. Musical programs could stimulate neuroplasticity given the musical strength of children with ASD.[8] Further, percussion training is associated with increased motor control and functional connectivity in motor regions.[9] Group percussion playing is also associated with interpersonal synchrony.[10] Therefore, **objective 2** of my dissertation is to investigate the effects of a group-based percussion training on social motor synchronization and associated neural signature. I **hypothesize** that children with ASD will show less synchrony than typically developing (TD) children on a social motor task in behavioral and neural measures (study 1), but they will show improvement in both measures after group percussion training (study 2).

Methods: Study 1: Thirty (8- to 12-year-old) children with ASD (Study 1 and 2) and with TD (Study 1), respectively, will be recruited. Diagnosis of ASD (or lack of) will be ascertained with standardized assessments (ADOS-2, SRS-2P, SCQ-L). Intellectual quotient, age, and gender will be covariates in analyses. Taken from a similar task in typical population,[7] participants and an experimenter are to produce novel synchronized forearm movements by varying movement speed and amplitude along the horizontal axis to assess social motor synchronization. We will measure the extent to which the participant can synchronize with the experimenter's movements and compare the amplitude of the EEG signal at inter-modulation frequency in both groups as a measure of synchronization. Finding a discrepancy in EEG signal between groups would demonstrate atypical social motor synchronization and its neural correlates associated with ASD. Study 2: For the ASD group, we will assess whether social movement synchronization and associated EEG signals change following a 16-week weekly group-based percussion training. Participants will perform our social motor synchronization task at the first time point (Time 1),16 weeks later (Time 2) to assess normal maturation, and again after a 16-week group-based percussion training (Time 3). Finding greater change from Time 2 to 3 than from Time 1 to 2 would indicate neuroplasticity associated with the group-based percussion training and possibly point to the social benefits of musical training.

Significance: EEG, a low cost, non-invasive method, allows neuroimaging during task performance. Findings from Study 1 may reveal neural markers underlying social motor ASD symptoms and clinical relevance of EEG techniques for early diagnosis of ASD. Findings from Study 2 may show that music programs can induce change in social motor functioning and neuroplasticity that will ultimately enhance the well-being of children with ASD. We hope to **gain feedback** on the study design and adaptation of this methodology for children with ASD.

Keywords: Electroencephalography (EEG), brain electrical activity, Neuroimaging, Autism Spectrum Disorder (ASD)

Title: **Neural tracking and neuroplasticity of social motor synchronization of children with autism spectrum disorder.**

Author(s): **S.Wong[1], E. M. Quintin[1]**

(Continued)

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Day #2 – Poster #22

Presenter: **Mira Kaedbey, McGill University**

Theme: **Clinical/Community Research**

Title: **Examining the effect of a music-making program on problematic behaviours and student-teacher relationships for children with autism spectrum disorder and typical development.**

Author(s): **M. Kaedbey[1], H. Dahary[1], and E.M. Quintin[1]**

Institution/Affiliation(s): [1] **Behavior, Autism, and NeuroDevelopment (BAND) Research Group, McGill University**

Many children with Autism Spectrum Disorder (ASD) demonstrate problematic behaviours such as property destruction, physical aggression, self-injury, and tantrums. These behaviours put young children at risk for exclusion and isolation from social, educational, family, and community activities. The presence of problematic behaviours at school also affects relationships with their teachers; in fact, research studies show that child-teacher relationships in ASD are marked by significantly more conflict compared to children with typical development (TD) or children with other neurodevelopmental disabilities, and that this is linked to a higher number or greater severity of problematic behaviours in this population. Music possesses an intrinsic communication potential that has motivated clinical researchers to test its efficacy in improving communication skills and social interactions. According to preliminary research, music-making programs can be a strengths-based approach for reducing problematic behaviours in ASD. The non-intimidating yet engaging nature of musical experiences and their ability to induce positive emotions while improving compliance may contribute to the behavioral effects of music therapies including a reduction in the frequency of negative behaviors. Reductions in problematic behaviours may in turn lead to improvements in child-teacher relationships, but this has yet to be investigated. This study aims to test whether the participation in a 14-week music-making program could yield a reduction in child problematic behaviours and child-teacher conflict, as well as show differences in the proportion of change between children with ASD and typically developing (TD) children.

I will recruit 40 children (20 TD children and 20 children with ASD) between the ages of 6 and 12 years from two elementary schools in the Montreal/Gatineau area. Both schools will follow a 14-week music-making curriculum instructed by ÉducaTED, an organization that consists of musicians who conduct music-making programs for individuals with developmental disorders. Students will learn to play the djembe primarily as well as other percussions including the drums, clave, maracas, cymbals, and chime. All children will be administered the Wechsler Intelligence Scale for Children – Fifth edition to measure general (full scale) IQ. Children with ASD will also be administered the Autism Diagnostic Observation Schedule- 2 to confirm the presence of ASD. The internalization and externalization subscales of the maladaptive behaviour domain of the *Vineland Adaptive Behavior Scales* (Vineland-3) will be used to measure problematic behaviour in students, and the 7-items from the conflict subscale of the *Student-Teacher Relationship Scale* (STRS) will be used to measure changes in teacher-reported child-teacher conflict before and after the intervention.

Findings may reveal that the music-making program can modify atypical social development trajectories of children with ASD and provide empirical support for the use of targeted music training programs that focus on disorder-specific strengths, such as musical ability in order to palliate weaknesses (e.g., social impairments). Increasing social functioning could help prevent the negative consequences often found in this population such as victimization, depression, and anxiety disorders. Further, the improvement in positive affective quality of child-teacher relations can potentially give rise to better social, cognitive and academic results.

We hope to gain feedback from the KBHN community on the study design and measures to ensure successful implementation of our music program for children with ASD.

Keywords: Autism Spectrum Disorder, Music Intervention, Problematic Behaviours, Teacher Relationship

Funded By: Social Sciences and Humanities Research Council (SSHRC) and Office des Personnes Handicapées du Québec (OPHQ)

Day #2 – Poster #23

Presenter: **David Nicholas, University of Calgary**
Theme: **Clinical/Community Research**

Title: **Key Features of an Online Navigational Service for Families of Children with Neuro-developmental Differences**

Author(s): **Sandy Litman[1], Sharon Lively[2], Rod Sutton[2], Mohammed Alsharif[2], Melissa Dobson[2], David B. Nicholas[3]**

Institution/Affiliation(s): **[1]Glenrose Rehabilitation Hospital, Edmonton; [2]Northern Alberta Institute of Technology, Edmonton; [3]University of Calgary**

Aims: The goal of the Navigation Alberta project is to improve *service navigation and access* for families of children with neurodevelopmental differences (NDD). This presentation will address preparatory work done in our aim of partnering with *211 Alberta* which is a call-in and web-based service designed to help Albertans find publicly funded services, in this case, specifically to better meet the needs of children with NDD and their families.

Background: To inform navigational web support access for families, this sub-project of the larger KBHN Navigation Project, was developed and conducted by trainees from the Northern Alberta Institute of Technology. A parent survey was administered, followed by a focus group, to elicit desired qualities of online navigation support in NDD. Participants first reviewed an array of NDD service navigation sites, offering recommendations for navigation sites. Websites as well as their features and functions, were ranked, along with weighting of the importance of features. Survey questions invited parents of children with NDD to identify the importance of features and functions that might help families searching for services. The online focus group elicited deeper insights into elements that are needed and desired by families in a centralized NDD navigation website and service.

Results: Strongly valued features of navigation were offered. These include a comprehensive online resource of relevant NDD services, augmented by ancillary telephone support and a transition timeline that allows searching by a child's age and developmental stage (e.g., age, school entry, transition to adulthood, etc.). Cues that enhance ease of access were sought in supporting families in better knowing where to start or what to look for in searches, which in turn, reportedly decreases feelings of parental helplessness and isolation. Survey and focus group feedback revealed parents' desire for a visually appealing site that is easy to navigate. Functionality was sought (e.g., usability, currency, menu and submenu topics specific to NDD, search ease). Training for online and telephone navigators was viewed as integrally important, in the aim of ensuring knowledgeable and family-centred navigational support. Opportunities for families to connect with peers was sought, in the aim of accessing 'on the ground' support and navigational ideas; this was viewed to be facilitated by various means including social media forums. Desirable website features comprised links to reputable and vetted educational materials specific to NDD. Inviting parents to share their journey in the form of video testimonies and posts were viewed as contributing to a sense of community even on a website. Sustainable infrastructure and online support were recommended for ongoing maintenance to ensure that resources remain up-to-date, with active promotion for additional relevant resources and information. Explicit invitation for user/parent feedback and collaboration was further suggested.

Impact: This presentation will offer key results and recommendations, with a focus on website features that optimize regional navigation, including content, functionality and usability considerations. Impacts of the project will address ways to enhance implementation, sustainability and ultimately, meaningful help to families. Practical and implementational strategies for development across jurisdictions will be offered.

Keywords (up to 6 words): neurodevelopmental differences, navigation, coordination, website.

Funded By: Kids Brain Health Network, the Azrieli Foundation, an Anonymous Donor

Day #2 - Poster #24

Presenter: **Nancy Lockwood, Able2**

Theme: **Community/Clinical Research**

Title: **From a community-based navigation and education pilot project to a multi-systemic approach to supporting children and youth with FASD and their families.**

Author(s): **N. Lockwood[1] and M. Champagne[1,2]**

Institution/Affiliation(s): **[1]ABLE2, [2]Queen's University**

Launched in 2015, the Fetal Alcohol Resource Program (FARP) at ABLE2 (formerly Citizen Advocacy Ottawa) is a stakeholder-driven project created in response to an identified need in the community to support children/youth impacted by FASD and their caregivers. The initial pillars of the program were navigation to community services, FASD training and research. However, based on program success, policy implementation of the FASD provincial initiative and needs identified by the community, FARP has grown into an eco-systemic model to support people with FASD and their families.

This eco-systemic model aims at supporting all systems around the person.

Ontosystem: FASD Workers/Coordinators provide clinical support and system navigation to individuals of all ages with FASD or suspected FASD. They offer support groups for individuals with FASD, mentorship opportunities for youth/adult clients, and recently completed a Trillium Pilot Project offering independent facilitation to assist with transition to adulthood.

Microsystem: FARP staff support the entire family, equipping caregivers with strategies, connecting them to resources, supporting siblings, hosting caregiver groups and facilitating peer mentoring. The team assists with navigation to FASD diagnostic services.

Mesosystem: FARP staff provide links between microsystems to provide wraparound care. They attend IEP/IPRC meetings as a link between home and school, and schedule Single Plan of Care (SPOC) meetings where warranted bringing key stakeholders supporting a family together around one table.

Exosystem: FARP builds capacity to support the FASD community in three Eastern Ontario regions through education and professional consultation. Since launching, they have provided customized FASD education workshops to over 5300 professionals/front line workers. FARP has taken a leadership role with the provincial FASD Workers hosting knowledge exchanges and quarterly virtual meetings.

Macrosystems: FARP runs FASD awareness events including an annual walk on Parliament Hill. They have built FASD knowledge among the medical community by hosting events such as Physician Grand Rounds. The team affects public policy through presentations and networking in the provincial and federal legislatures and have presented to the Senate of Canada on FASD and Justice. Their Manager provides advisory support to Health Nexus on their provincial FASD initiatives.

Through a collaboration with KBHN, several components of FARP are currently being assessed. The overall goal of the present study is to evaluate the effectiveness of the program by I: Assessing family quality of life using CarerQol at intake and after six months of receiving family support. II: Assessing the experience of the family support by the caregivers through qualitative interviews. III: Conducting a cost-utility analysis using the CarerQoL that will permit the calculation of quality-adjusted life years (QALYs). IV: Identifying changes in practice of stakeholders following training through post evaluation qualitative interviews. As FARP continues to expand, the data collected by this study will inform policy of relevance of this program to benefit other communities in replicating this eco-systemic approach to supporting children/youth with FASD and their families. This presentation serves to propose an eco-systemic model of care for supporting families impacted by neurodevelopmental disorders along with evaluation tools to measure impact.

Funded By: Kids Brain Health Network, ABLE2, CHEO, Ministry of Children, Community and Social Services, Children's Aid Society of Ottawa, Community Foundation of Ottawa through donor directed funds.
Keywords (up to 6 words): Fetal Alcohol Spectrum Disorder (FASD); family support; education; program implementation; eco-systemic model; neurodevelopmental disorders

Day #2 - Poster #25

Presenter: **Flora Roudbarani, York University**

Theme: **Clinical/Community Research**

Title: **Lessons Learned from Moving In-Person CBT to Remote Delivery in Response to COVID-19: Therapist Perspectives**

Author(s): **F. H. Roudbarani[1], V. Lee[1], P. Tablon Modica[1], and J. A. Weiss[1]**

Institution/Affiliation(s): **[1]Department of Psychology, York University**

Background: Emotional regulation and mental health problems are common for children with neurodevelopmental disabilities (NDD), and support often involves the use of in-person cognitive behaviour therapy (CBT). Prior to COVID-19, our research team was evaluating the efficacy of an in-person, spy-themed, manualized CBT program for children with NDD, called the Secret Agent Society: Operation Regulation (SAS-OR). In response to social distancing measures imposed by COVID-19, in-person sessions were postponed, and the SAS-OR program was adapted for virtual delivery.

Objectives: The objective of this study was to synthesize and evaluate, through qualitative interviews with therapists, the lessons learned in adapting, transitioning, and delivering the SAS-OR program remotely for families. We aimed to inform future clinical research for virtually delivered therapy for children and youth with NDD.

Method: We conducted a preliminary qualitative analysis using interpretative description from post-intervention interview transcripts with therapists (7 graduate students and 1 clinical supervisor). All therapists had prior experience delivering SAS-OR in an in-person format.

Results: Therapists indicated the importance of training, communication, flexibility and rapport-building in the transition from in-person to remote delivery. Therapists identified important preparatory measures for onboarding and the delivery of a remote intervention by the research team. Before starting the remote SAS-OR program, therapists participated in training to increase confidence and comfort to work with children online. Therapists valued key aspects of these training sessions, including addressing communication, problem-solving strategies for technical glitches, set-up tips (i.e., using cameras, organizing physical space), maintaining privacy, adapting therapeutic activities, and how to prioritize and set primary session goals. Therapists noted the importance of supporting families through a pre-session orientation to explain onboarding procedures and discuss significant concerns families experienced. Therapists also noted caregivers' appreciation for the dedicated time to learn how to use the videoconferencing technology, and the opportunity for their child to become reacquainted with their therapist before starting therapy. Therapists reported several strategies specific to delivering the intervention online to ensure families received optimal care. For example, therapists reported building rapport with the child and their caregiver by incorporating child-specific interests (e.g., virtual backgrounds, online games), and maintaining strong communication throughout the program (e.g., email reminders). There were also a number of challenges, including supporting children if they became inattentive, distracted or aggressive. They suggested recommendations to manage these behaviours, including the use of explicit reinforcement, frequent breaks and consistent validation. Therapists also incorporated several modifications to support family engagement, including shortening session lengths, changing the order of therapeutic activities, and increasing parental involvement as a "co-therapist" during in-session activities. Therapists noted the importance of being client-centred, flexible, and not being "attached to the manual" in the transition from in-person to online therapy successfully.

Conclusion: Overall, therapists felt that they could transition successfully to remote SAS-OR program delivery and provide a continuation of care to families of children with NDD. Generally, the lessons learned from the abrupt interruption of in-person delivery to this remote option can inform future online clinical training programs.

Funded By: York University Research Chair in Autism and Neurodevelopmental Disability Mental Health, and the Canadian Institutes of Health Research in partnership with Kids Brain Health Network.

Keywords: Covid-19, NDD, CBT, virtual delivery, qualitative research, therapist perspectives

Day #2 – Poster #26

Presenter: **Vivian Lee, York University**

Theme: **Clinical/Community Research**

Title: **Parent Perspectives on the Shift to Remote Delivery of CBT in Response to COVID-19**

Author(s): **V. Lee[1], F. H. Roudbarani[1], P. Tablon Modica[1], and J. A. Weiss[1]**

Institution/Affiliation(s): **[1]Department of Psychology, York University**

Background: Emotional regulation and mental health problems are concerns that impact the wellbeing of children with neurodevelopmental disabilities (NDD), and support often involves the use of in-person cognitive behaviour therapy (CBT). Prior to COVID-19, our research team was evaluating the efficacy of an in-person, spy-themed, manualized CBT program for children with NDD, called the Secret Agent Society: Operation Regulation (SAS-OR). In response to social distancing measures imposed by COVID-19, in-person sessions were postponed, and the SAS-OR program was promptly adapted for virtual delivery.

Objectives: The objective of this study was to synthesize and evaluate, through qualitative interviews with parents, their experience in shifting to in-person CBT to a remote, online option.

Method: A preliminary qualitative analysis using interpretative description from post-intervention interview transcripts with 13 parents of NDD children: ranging in 8 to 12 years in age, was performed.

Results: Parents noted the importance of clear and responsive communication with the research and clinical team in making the abrupt transition to online delivery a success. Parents highlighted their appreciation for therapists' willingness to provide a continuation of care, which was a key motivator to remain engaged throughout online delivery for most. Parents noted that their therapists' pre-intervention tutorial and orientation mitigated their initial hesitancy and lack of comfort level using technology and the online platform. These sessions were highly valued by parents and allowed them an opportunity to communicate with the therapists about potential behavioural concerns. Parents were encouraged to see their children build rapport and trust with their therapists, even through an online videoconferencing format. Parents noted that previous in-person meetings with therapists, and their flexibility and adaptability were key elements to building online rapport (i.e., allowing videos on or off, incorporating family pets into therapist sessions, engaging a child in their interests, etc.). Challenges noted by parents included an increase with in-home distractions and the limited ability to work in a quiet area in a busy household, and the need for parents to co-facilitate some sessions, especially when children became inattentive or aggressive. However, parents were generally impressed with their therapist's ability to engage and maintain their child's attention and interest throughout sessions. Although parents were concerned with screen fatigue for the child, they found the program useful, felt empowered with appropriate emotion-based language and were able to generalize emotion regulation strategies to their everyday lives. Parents suggested the addition of online group-based interactions with other children for an opportunity to practice the skills their children had learned. Some parents noted that the lack of commuting time eliminated an in-person barrier to consistent weekly participation.

Conclusions: Overall, parents were satisfied with the transition process and found the online delivery useful in building emotion regulation skills. The remote delivery of manualized CBT for children with NDD is possible, and according to parents, continues to have utility, even when compared to initial in-person experiences. Further research into the efficacy of remotely delivered CBT is warranted.

Keywords (up to 6 words): Covid-19, NDD, CBT, virtual delivery, qualitative research, parent experiences.

Funded By: York University Research Chair in Autism and Neurodevelopmental Disability Mental Health, and the Canadian Institutes of Health Research in partnership with Kids Brain Health Network

Day #3 – Poster #27

Presenter: **Leo McKay, University of Manitoba**

Theme: **Basic Science Research**

Title: **Acute Prenatal Alcohol Exposure Results in Oxytocin Deficiency and Maternal Care Deficits in a Mouse Model of FASD**

Authors: **Leo McKay, Berardino Petrelli, Molly Pind and Geoffrey G Hicks**

Instituions/Affiliation(s): **Regenerative Medicine Program, and the Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.**

Fetal Alcohol Spectrum Disorder (FASD) is the most common neurodevelopmental disorder in children, with a prevalence of 1-5% in Canada and can be as high as 11% in children from remote Manitoba Communities. To better understand the developmental origins of FASD, we designed a *Gsc:Cyp26A1* mouse model to biochemically mimic ethanol-induced retinoic acid deficiency at gastrulation. While *Gsc:Cyp26A1* mice phenocopy many traits of FASD, surprisingly, *Gsc:Cyp26A1* mothers also display aberrant maternal care behavior, with very few or no pups surviving past their first day. Human mothers with FASD also report having problems providing maternal care and are often prone to post-partum depression. We quickly recognized the maternal care deficiency observed in the *Gsc:Cyp26A1* mice is similar to the poor nurturing observed in mice with deficits in oxytocin directed signaling. Oxytocin is a small nonapeptide hormone well-known to regulate maternal behaviour in mammals. We hypothesized that prenatal alcohol induced-retinoic acid deficiency in early development leads to subsequent deficits in oxytocin signaling and maternal care. Oxytocin expression in the oxytocin producing centres of the brain, the supraoptic and paraventricular nuclei of the hypothalamus, was determined by immunohistochemistry and in-situ hybridization of forebrain sections of pregnant P90 *Gsc:Cyp26A1* and WT pregnant mice using oxytocin-neurophysin I antibody (N=3) or oxytocin-neurophysin I probe (N=1), respectively. Maternal care was assessed by pup survival (n=11 litters) and pup retrieval (n=6 litters) behavioural assays in *Gsc:Cyp26A1*, WT and *Gsc:Cyp26A1*^{KO} (phenotypically WT) mice. Immunohistochemistry and in-situ hybridization experiments revealed that *Gsc:Cyp26A1* mothers are deficient in Oxytocin-Neurophysin I expression compared to WT mothers. Examination of *Gsc:Cyp26A1* brain sections revealed paraventricular nuclei structural aberrations and other defects in maternal structures in the hypothalamus. All pups of *Gsc:Cyp26A1* dams failed to thrive in the pup survival assay (0% vs 100% for WT and *Gsc:Cyp26A1*^{KO} mothers). *Gsc:Cyp26A1* mothers also failed to complete the pup retrieval test within an established time frame (over 300 s vs 149 and 95 s for WT and *Gsc:Cyp26A1*^{KO} mothers, respectively). Our data revealed that *Gsc:Cyp26A1* dams are oxytocin deficient and have structural forebrain aberrations that appear to be of developmental origin. The established oxytocin deficiency can explain the poor results of the *Gsc:Cyp26A1* mothers in pup survival and retrieval assays, and suggests the underlying etiology for maternal care deficits in these mice. This work has the potential to reveal new treatments to alleviate post-partum depression symptoms in not only FASD afflicted human mothers, but may also apply to mothers suffering from post-partum depression in general.

Keywords (up to 6 words): FASD, neurodevelopment, oxytocin, maternal care, prenatal alcohol exposure, hypothalamus

Funded By: The Children's Health Research Institute of Manitoba, Research Manitoba

Day #2 – Poster #28

Presenter: **Praveen Kumar Raju Pedabaliyarasimhuni, CHU Sainte-Justine Research Center**

Theme: **Basic Science Research**

Title: **Cellular mechanisms of epilepsy in *PIGB* deficiency**

Author(s): **P. K. Raju* [1], K. Toulouse* [1] , T. T. M. Nguyen* [1] , L. Eid[1] , A. Lupien-Meilleur[1] , M. Lachance[1], P. Campeau[1,2], E. Rossignol[1,2,3] *These authors also contributed to the study**

Institution/Affiliation(s): **[1]Centre de recherche du CHU Ste-Justine; [2] Département de Pédiatrie, Université de Montréal; [3] Département de Neurosciences, Université de Montréal**

BACKGROUND. Epileptic encephalopathies (EE) are severe early-onset epilepsies, often refractory to therapies, with associated cognitive deficits and early lethality. Our group has recently identified recessive mutations in the *PIGB* gene, encoding the GPI mannosyltransferase 3 protein, a member of the glycosylphosphatidylinositol (GPI)-anchor biosynthesis pathway, in patients with global developmental delay, early epilepsy and axonal neuropathy. GPI anchors permit the anchoring of various receptors, ion channels and cell adhesion proteins on cell membranes. However, the exact mechanisms by which deficits in GPI anchors result in such a striking neurodevelopmental phenotype are unknown. Recent data from our group suggest that impairments in the early development or function of inhibitory GABAergic interneurons (INs) result in epilepsy and cognitive deficits in mice, suggesting a role for cortical disinhibition in the pathophysiology of specific genetic forms of EE.

HYPOTHESIS. We postulate that GPI anchor deficit results in an EE phenotype by impairing INs development.

METHODS. To investigate this hypothesis, we generated different murine models carrying targeted *Pigb* mutations in distinct neuronal populations. We combined high-resolution cell imaging, immunohistochemistry, neuronal quantification and morphological reconstitution, together with video-EEG recordings and behavioral analysis to characterize the models and investigate the underlying mechanisms.

RESULTS. While constitutive knock-out and pan-neuronal conditional mutant mice are not viable, mice with GPI deficiency carrying a targeted deletion of *Pigb* in MGE-derived INs are viable and develop spontaneous seizures as well as behavioral deficits reminiscent of those observed in patients. Furthermore, neuronal quantification at different key developmental stages (e13.5, e15.5, P0) revealed a delay in INs migration, with reduced number of INs at the migratory front embryonically (e13.5 and e15.5) resulting in a reduction of INs numbers at postnatal stages (P14 and P21). Notably, 3D reconstruction of e13.5 migrating INs revealed striking perturbations in IN morphology, including increased neurite length, number and complexity of leading and trailing processes. Moreover, live imaging of MGE explants suggests perturbations in cytoskeletal remodeling and migration kinetics in INs.

CONCLUSION. Our results reveal that the loss of GPI anchors, through *Pigb* recessive mutations, impair IN migration, resulting in epilepsy and cognitive deficits. Subsequent studies will help unveil the specific GPI-anchored proteins required to sustain IN migration, further clarifying the underlying disease mechanisms.

Keywords: Epileptic encephalopathies, GPI-anchor, GABAergic interneurons,

Funded By: CIHR, Savoy Foundation

Day #2 – Poster #29

Presenter: **Samantha Noyek, Queen's University**

Theme: **Community Engagement in Research**

Title: **Capturing Emotional Expressions of Children and Youth with Complex Motor and Communication Impairment.**

Author(s): **S. Noyek[1], C. Vowles[2], T.C. Davies[2], and N. Fayed[1]**

Institution/Affiliation(s): **[1]School of Rehabilitation Therapy, Queen's University; [2]Department of Mechanical and Materials Engineering, Queen's University**

Background: The emotional self-expressions of children with severe motor and communication impairments (SMCI) cannot be captured through speech, writing with a paper and pencil, or using a standard keyboard. Children with SMCI cannot be easily understood by unfamiliar people; primarily use a mobility aid to get around; and have difficulty handling objects. As a result, their emotional expressions can be missed or overlooked by individuals who do not know the child well.

Purpose: To identify the emotional expressions of children with SMCI from the perspectives of people who are closely involved in the child's life for knowledge sharing with unfamiliar caregivers and other providers.

Methods: Phase 1: The primary guardian of each child participant will capture photos/videos of 1) their child with SMCI demonstrating expressions of various emotions, 2) aspects that make child feel emotionally well or not (i.e. being outdoors, being surrounded by family), followed by 3) an online video meeting. The primary caregiver will interpret and teach the researcher about how they identify and interpret their child's expressions. Phase 2: Primary guardians involved in phase 1 will be asked to connect the primary guardian with up to 5 individuals that know their child/youth well who can also describe his/her emotional expressions (e.g. parents, siblings, teachers, respite worker). Those individuals willing to participate will be involved in an online video meeting to add an additional layer of understanding to the emotional expressions and well-being of the child.
Results: Nine child/youth participants have been recruited; the study is in data collection and interpretation. Preliminary results indicate that photos and videos will capture the emotional world of the participant; this included various emotions such as: empathy, excitement, boredom, and frustration.
Conclusions: The emotional lives of children/youth with SMCI are experienced and expressed in various ways. It is imperative that we take ample time and effort to interact with this group of children. Further, the insights provided by primary guardians and individuals personally close to the child/youth can be amplified to positively impact the care and experiences of children/youth with SMCI.

Keywords (up to 6 words): child, emotions, severe impairment, well-being

Funded By: The research was funded through the Ontario Child HealthSupport Unit through OSSU (the Ontario SPOR [Strategy for Patient-Oriented Research] SUPPORT [Support for People and Patient-Oriented Research and Trials] Unit), NSERC [RGPIN-2016-04669] and NSERC CREATE READi.

Day #2 - Poster #30

Presenter: **Veronica Smith & Lauren Trafford, University of Alberta**

Theme: **Community Engagement in Research**

Title: **Parent and Child Early (PACE) Coaching for Children at Risk for Autism: Understanding Implementation**

Author(s): **V. R. Smith[1], P. Mirenda,[2] P. Colozzo[2], K. Kalynchuk[2], N. Denomey[1], L. Trafford[1], & A. Altani[1]**

Institution/Affiliation(s): **[1]Department of Educational Psychology, University of Alberta; [2]University of British Columbia**

From 2017-2020 the Province of BC funded a province-wide project aimed at 1) identifying children at risk for autism spectrum disorder; 2) training community providers in an evidenced-based parent coaching program; 3) conducting a parent coaching community of practice; and 4) testing the effectiveness of the program via a randomized controlled trial. After considerable community consultation and partnerships with Child Development Centres (CDCs) across the province, the Parent and Child Early (PACE) Coaching was launched. This presentation reports on an implementation evaluation of the program, describing the barriers and supports to implementation. Interview data were collected with project participants in 14 CDCs across BC prior to, during, and toward the end of the project. The data were coded both deductively, using the Consolidated Framework for Implementation Research (CFIR), and inductively, to develop themes that might influence challenges or successful future implementation of PACE Coaching.

The CFIR was developed to support the systematic assessment of complex implementation contexts and to identify factors that might influence successful implementation and effectiveness across five domains - *Intervention Characteristics, Inner Setting, Outer Setting, Characteristics of Individuals, and Process of Engaging Participation and Conducting the Implementation*. Deductive coding of the participant interviews using the CFIR revealed that several of the PACE Coach program characteristics positively influenced implementation (i.e., evidence of strength and quality, relative advantage of the program, and design quality and packaging of the program) and, to a lesser extent, negatively influenced implementation (i.e., intervention source, adaptability, complexity, and cost). A factor influencing the potential for PACE to be successful was the deep understanding that the participants had of their local clients' needs and resources. An outer setting influence that somewhat detracted from recruiting participants in the community locations was the degree to which the CDCs were networked with each other and with potential referring agencies. Many aspects of the implementation climate within the CDCs supported the training efforts. The participants were receptive and demonstrated a capacity for change. Processes experienced implementing the program needed refinement but were appreciated by the community participants.

Inductive coding of reflections on participating in PACE coaching revealed the following 5 themes:

1. *The PACE Coaching experience created an opportunity for "working differently" which included reflective practice, data driven decision making, and family empowerment.*
2. *Participants described moving beyond learning how to implement PACE Coaching with children at risk for autism toward learning how to implement PACE Coaching more generally with children at developmental risk*
3. *Community partners were committed to understanding family needs and aimed to always put children and families first*
4. *Participants could imagine implementation ownership and intention to sustain what has been started, and*
5. *Participation in this project revealed tension between supporting families and participating in a research project.*

Day #2 Poster #31

Presenter: **Crystal Shannon, University of British Columbia**

Theme: **Knowledge Mobilization Initiative**

Title: **Scoping Review of eHealth Strategies for Parents of Children Living with Autism Spectrum Disorders**

Author(s): **Crystal Shannon[1], MSN, Lise Olsen[1], PhD, Robert Janke[1], MLIS, Catie Balehowsky[1], BSN Student**

Institution/Affiliation(s): **[1]University of British Columbia**

Issues addressed: The number of children with autism spectrum disorder (ASD) is on the rise with 1/66 children diagnosed with boys being 5:1 times more likely diagnosed than girls (Health Canada, 2016; Public Health Agency of Canada, 2018). This increased prevalence of children living with ASD indicates a growing need to provide support and accessibility to resources to their parents, particularly those families living in rural and remote areas. eHealth services can be a valuable and often more accessible option than in-person interventions for families to help manage demands associated with raising children living with ASD. Telehealth and online strategies may offer parents support and education from their homes; therefore, helping families decrease their stress and improve their quality of life. This scoping review aims to explore the nature of eHealth parent focused strategies and initiatives that have been used and evaluated to provide insight awareness of interventions available and to identify potential gaps in services for future research development.

Context: This scoping review aims to assess the literature on current eHealth resources available to support parents of children with ASD. The methodology is guided by Tricco et al.'s (2018) PRISMA Extension for Scoping Reviews. Search procedures were established in consultation with university librarian and include searches of six databases. Included articles are those addressing eHealth supports aimed at parents of children 0-19 years with ASD and that include parent-related outcomes. Abstracts and full text articles were assessed by 4 reviewers; two of whom also arbitrated disagreements.

Study questions and how these will be addressed: The research questions developed to guide this scoping review focused on identifying what eHealth interventions have been used and evaluated to support parents raising children with ASD. This included looking at what parent outcomes (attitudes or behaviours) have been studied in relation to eHealth resources for families living with ASD.

Learning outcomes: Participants will gain knowledge about what eHealth strategies and resources are available to support parents with children living with ASD. Audiences will also gain awareness about current research findings related to the existing parental resources and the associated outcomes of these various eHealth initiatives.

Keywords: eHealth, telehealth, parents, online support, resources, autism spectrum disorders

Funded By: Social Sciences and Humanities Research Council (SSHRC)

Day #2 – Poster #32

Presenter: **Jael Bootsma, McMaster University**

Theme: **Clinical/Community Research**

Title: **Transitioning to online research study visits for the validation of an accessible language assessment test in response to the COVID-19 pandemic**

Author(s): **J. Bootsma[1,2], S. ElMansy[1], D. McCauley[1], A. Fan[1,2], O. Kraus de Camargo[1,3], and J.W. Gorter[1,2]**

Institution/Affiliation(s): **[1]CanChild, McMaster University, Hamilton, Canada; [2]School of Rehabilitation Science, McMaster University, [3]Department of Pediatrics, McMaster University**

Background: The Computer-Based instrument for Low motor Language Testing (C-BiLLT)(J. J. Geytenbeek, Mokkink, Knol, Vermeulen, & Oostrom, 2014) is an innovative new tool to reliably measure spoken language comprehension in children with Cerebral Palsy who have low speech and motor function(J. J. M. Geytenbeek, Heim, Vermeulen, & Oostrom, 2010). It is the first standardized assessment tool to evaluate a child's language comprehension without requiring a verbal response or use of fine motor skills. The C-BiLLT is used in the Netherlands, Dutch speaking parts of Belgium, and Norway. In 2018, the adaptation and validation of the English language version commenced in Ontario, Canada. A minimum sample size of 80 English speaking Canadian children between the ages of 1.5 and 8.5 years old with neurotypical development was needed to reliably analyze the instrument's construct validity, test-retest reliability and interrater reliability. Participants were recruited from elementary schools and childcare centers across Hamilton, Ontario. Study visits typically took place at the participants' schools. During the study visit, participants were assessed with the C-BiLLT as well as up to three other language and cognition tests.

Challenges due to COVID-19: On March 11th 2020, the day the WHO declared the COVID-19 pandemic, our inclusion rate was at 65% of the target. With the Ontario school closures in effect starting March 14th and in compliance with the recent public health regulations, the data collection process had to be paused indefinitely.

Strategies to mitigate the challenge: Given the uncertainty about the future of direct in-person clinical research, our team embarked on a pursuit to complete the data collection for the C-BiLLT study using remote alternatives. Growing evidence shows that remote administration of neuropsychological tests yields results comparable to on-site administration (Brearly et al., 2017). Since the C-BiLLT is already a Computer-Based Program, our team collaborated into finding digital forms of the standardized language and cognition assessment tools. A user-friendly online video-conference platform has been selected for use. Feasibility of the use of the digital assessments was explored through pilot testing which revealed to have promising results. Following Research Ethics Board's approval, recruitment of new participants for the virtual study visits resumed early July 2020.

This presentation will describe in details how we transitioned from in-person to virtual study visits. It will highlight the challenges and the benefits of virtual data collection with children participants. Video materials will be shown to illustrate the current data collection process. Preliminary results from a parent questionnaire about the acceptability and feasibility of the online study visits will be discussed.

We anticipate that remote assessments will increasingly become an invaluable tool for clinicians and researchers in the field of brain-based childhood disabilities. We advocate for the creation of novel digital interactive versions of all standardized neuropsychological tests and encourage training of the medical and research community on their use.

Poster Title: **Transitioning to online research study visits for the validation of an accessible language assessment test in response to the COVID-19 pandemic**

Author(s): **J. Bootsma[1,2], S. ElMansy[1], D. McCauley[1], A. Fan[1,2], O. Kraus de Camargo[1,3], and J.W. Gorter[1,2]**

(Continued)

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Day #3 – Poster #33

Presenter: **Vanessa Fong, Simon Fraser University**

Theme: **MITACS-KBHN Community Internship**

Title: **Understanding the impact of COVID-19 on mental health, quality of life, and service and support needs in families of autistic children in British Columbia**

Author(s): **Vanessa Fong[1], Elina Birmingham[1], and Grace Iarocci[1], Deborah Pugh[2]**

Institution/Affiliation(s): **[1]Simon Fraser University; [2]ACT – Autism Community Training**

In response to the current pandemic, government action has been widely judged to have failed to address the major concerns and needs of families of children with a range of special needs in British Columbia. Parents of autistic children are facing severe challenges given the absence of the comprehensive supports and services most rely on to meet their child's specific needs. Prior to COVID-19, most caregivers of autistic children had to meet high demands requiring their time and energy. It is probable that already existing barriers faced by these families were exacerbated by COVID-19 restrictions, with families isolated and cut-off from most if not all of their support systems. Research is urgently needed to examine the impact of COVID-19 on mental health, quality of life and service accessibility to determine the most effective services and supports for this population and what essential services must be in place in times of emergency.

We have partnered with Deborah Pugh from ACT- Autism Community Training, a not-for-profit organization that provides information and training to families of autistic children and to professionals, to investigate the specific needs and experiences of families during COVID-19. The COVID-19 survey focused on the first 4 months of the pandemic and assessed child and family functioning, quality of life, access to services and supports, and satisfaction with government relief efforts.

Our research questions were three-fold: (1) How are families of autistic children living in BC coping during COVID-19?; (2) What family and service usage characteristics are linked to resilience?; and (3) What specific services and supports need to be in place to better support these families during the current and future pandemics?

This study adopted an Integrated Knowledge Translation (IKT) framework (Graham et al., 2006) to address the main research questions. Our community partner was engaged in formulating the research questions, developing the COVID-19 survey, recruiting participants, and will help disseminating research findings.

Our sample comprised of parents and caregivers of autistic children living in British Columbia. Participants that expressed interest in the study were contacted and provided with a link to complete a consent form and the online survey which was hosted by Qualtrics. Quantitative data gathered from the COVID-19 survey were analyzed using IBM SPSS Statistics version 24. Qualitative data from open-ended responses on the survey were coded and analyzed using NVivo software.

The results from this project will help identify the effects of COVID-19 on families of autistic children, including the factors that impact their quality of life specifically as this relates to access to services, and will inform both policy and practice recommendations to protect this population.

Keywords: family quality of life, service usage, autism spectrum disorder, survey, policy

Funded By: Mitacs-KBHN

Day #3 – Poster #34

Presenter: **Vivian Lee, York University**

Theme: **MITACS Community Internship**

Title: **An Integrated Knowledge Approach to Communicating the Impact of COVID-19 on the Mental Health and Well-Being of Caregivers and Available Resources for Families Living with Autism**

Author(s): **V.Lee[1], M. Spoelstra[2], and J. Weiss[1].**

Institution/Affiliation(s): **1. York University and 2. Autism Ontario**

Parents and families (i.e. siblings, grandparents) with children and adolescents with autism often experience demanding stressors associated with providing care to their autistic family member. Prior to COVID-19, it was well documented that parents of people with autism experience more stressors, more mental health problems and distress, and lower family quality of life, compared to the general population. As a result of the pandemic, these stressors and mental health outcomes have likely increased. Distancing requirements have halted many of the programs that parents rely on for respite and support (e.g. interventions, day programs, schools, adapted recreation and leisure, etc.). This means parents have little or no assistance outside of the family to care for their autistic child.

It is essential to recognize the service needs of families, and share the evidence-based best practices that have emerged to support parents of children with autism who are faced with pandemic-related demands. In partnership with Autism Ontario, my Mitacs-KBHN research internship has allowed me to explore the current literature on this topic and to create a report that will help identify what has been documented regarding the impact of the COVID-19 pandemic on caregiver and family functioning and to identify the supportive programs that have emerged as a result. My internship and results from the report will help Autism Ontario better **support families** living with autism.

Using a comprehensive family coping model (called the Family Adjustment and Accommodation Resource Model) as a framework, the proposed report will outline empirical evidence published during the pandemic that shows how families balance the many *demands* they experience with the services and resources that support their *capabilities*, and how they make *meaning* of this process as a means of coping during the COVID pandemic.

As part of the internship, results from the report will be shared in a presentation with the Autism Ontario Service Navigator team and members of the Board of Directors at Autism Ontario. For the Service Navigators, the presentation will focus on the current understanding of the impact of COVID-19 restrictions on the mental health and wellbeing of caregivers and families of individuals on the spectrum, and how the navigators can provide support to caregivers when caregivers use their service. For the Board of Directors and other key-decision makers, the presentation will focus on the role of Autism Ontario in informing and advocating for policy changes that would have an impact on mental health and wellbeing supports for caregivers and families of individuals on the spectrum. As an embedded intern at Autism Ontario and with my research expertise and knowledge in factors that may impact family wellbeing (especially within the context of COVID-19), I have contributed to a number of discussions about how best to support families during this time, and helped inform future initiatives that way impact caregivers and families.

Funded By: MITACS and Kids Brain Health Network

Day #3 – Poster #35

Presenter: **Ashish Seth, University of Calgary**

Theme: **MITACS Community Internship**

Title: **Exploring strategies on how governments could engage community organizations to co-design pandemic response plans for persons with disabilities.**

Authors: **Ashish Seth[1], Candace Parsons[2], Meaghan Edwards[3], Mezaun Lakha-Evin[4], Katrina Milaney[5], Jennifer Zwicker[6]**

Institution/Affiliation(s): **The School of Public Policy[1] - University of Calgary (UofC), The School of Public Policy[2]- UofC, Community Rehabilitation and Disability Studies[3] - UofC, Cerebral Palsy Alberta[4], Community Rehabilitation and Disability Studies[5] - UofC, The School of Public Policy[6] - UofC**

Persons with disabilities and their families are disproportionately impacted by the COVID-19 pandemic and the policy measures adopted in response. Given the increased risk for this vulnerable population group, the governments must engage stakeholders like community organizations and families of persons with disabilities to plan and co-design pandemic response plans. Harnessing experiential knowledge of and fostering collaboration with such stakeholders could aim in transforming services in crucial areas like health, where emergency policies and interventions are organized around the needs of persons with disabilities. Initiatives that enhance civil society participation in designing policies and interventions create a more transparent and responsive government. Participatory policies and interventions also improve buy-in of government programs.

Unfortunately, there is inadequate data collection and insufficient emergency preparedness planning and response for persons with disabilities. The goal of this research was to evaluate strategies and measures through which decision-makers could engage stakeholders like community organizations to design disability-inclusive policy responses during the COVID-19 outbreak Alberta. Qualitative interviews were conducted with key decision-makers from provincial, municipal governments, and disability advisory groups' members. Through interviews, the study attempted to understand the level of engagement, barriers to the engagement of community organizations and participatory policy aspects best suited to design with the decision makers.

Key findings from the research highlighted the participants' viewpoints on barriers, aspects and preferences, which are the critical approaches through which the Government of Alberta engages with community organizations. First, health emergency policy responses need to view disability and poverty as interconnected factors to improve the overall quality of life for persons with disabilities. Findings also highlighted that top-down and tokenistic consultation approaches further limit the disability community's engagement in co-designing pandemic planning and response. Inaccessible ways of consultation and navigation barriers exacerbate the impediments to stakeholder engagement.

Findings also revealed that communication of pandemic information in accessible formats and tools is the most preferred co-design aspect to engage community organizations in developing inclusive pandemic response. Stakeholders' engagement in the government's data surveillance efforts was unclear, and the overarching process of impact assessment needs to be strengthened. The research found that the COVID-19 disability group and advisory council's presence at the federal and provincial levels is a robust mechanism that connects communities with the government. However, the process of influencing government decision making and policy actions needs to be openly communicated to the civil society.

The research recommends that governments must transition from traditional consultative approaches to innovative engagement practices while sharing information on how public policies reflect communities' input. Decision-makers are further recommended to make financial investments to include priorities of persons with disabilities in the pandemic planning and response. The decision-makers should formally engage stakeholders like community organizations to co-design critical aspects of the response plan like, communication and monitoring and evaluation.

Keywords: Pandemic planning and response, persons with disabilities, participatory policy making, stakeholder engagement.

Funded by: MITACS, Kids Brain Health Network (KBHN)

Partner Support: The School of Public Policy - University of Calgary, Cerebral Palsy Alberta, Community Rehabilitation and Disability Studies - University of Calgary

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Day #3 – Poster #36

Presenter: **Wendy Mitchell, University of Calgary**
Theme: **MITACS-KBHN Community Internship**

Title: **Individuals with Neurodevelopmental Disabilities: Information needs and effective methods for sharing during COVID-19**

Author(s): **W. Mitchell[1], R. Zulla[1], D. Nicholas[1]**
Institution/Affiliation(s): **[1]University of Calgary, Faculty of Social Work**

Background: The COVID-19 pandemic has had a worldwide impact, including on children with neurodevelopmental disabilities (NDD) and their families. Findings from a recent Canadian Mental Health Association survey demonstrate increased mental health concerns, such as feeling anxious and worried, having trouble coping and having suicidal thoughts, since the start of the outbreak. These struggles are likely amplified for vulnerable groups like persons with disabilities given the disruption to routines, elimination or reduction in services, and uncertainty regarding future supports and services.

In this public-health crisis, web-based support offering such resources may help families manage the various strains associated with the pandemic by offering ways to navigate and cope. The Autism & Intellectual-Developmental Disabilities National Resource and Exchange Network (AIDE Canada), directed by the Pacific Autism Family Network, has sought to offer Canadians affected by NDD equitable access to credible, reliable and evidence-informed resources. Beyond its broader compendium of resources and in an effort to support individuals and their families specifically with pandemic-related challenges, AIDE Canada has developed a *COVID-19 specific website* (https://covid19.aidecanada.ca/) devoted to resources particularly focused on supporting individuals with NDD and their families as they navigate daily life in the pandemic.

Objectives:

1) To determine what information/resources are accessed during the pandemic and the perceived impact of that information/resources on children with NDD and their families.
2) To determine how the AIDE COVID-19 website is experienced by individuals with NDD and their families.

Method: A total of 20 self-advocates/parents are being recruited to engage in focus groups addressing the above objectives. Thematic qualitative analyses will be conducted that identifies what is needed and deemed important in terms of support/resources for individual and their families during the pandemic. Participants will further reflect on their experiences of utilizing and navigating the COVID-19 website developed by AIDE Canada. Lessons will be used to inform and refine website content and utility in optimizing its benefit to individuals and families.

Results: Learnings from parents thus far suggests that information/resources of paramount importance comprise: details about how to 'teach' their children, managing parent stress, and understanding federal funding resources. Feedback from parents about the AIDE Canada COVID-19 website has been positive, with participants indicating that they would definitely return to the site. They suggested use of social media connections to increase community awareness and participation in forums. Complimentary comments were provided about the landing page, tip sheets, inclusion of tweets, provincial categorization, and searchability features. Suggestions for potential refinement included incorporating the experiences of individuals from the disability community, emphasizing Canadian sources/content, increasing searchability functions, having a 'Hot Topics' tab, and possibly renaming 'Diversions' to something that resonates more with parents such as 'Fun Activities.' The content under the *Mental Health* and *Diversions* tabs were particularly appreciated by participants, and deemed the most helpful.

Conclusions: Findings are already informing website content and navigation elements, in the aim of optimizing website impact for families. Key information will inform the breadth of information needs and effective methods for information sharing.

Key Words: COVID-19, pandemic, neurodevelopmental disability, website, information/resources
Funded by: Mitacs Accelerate, Kids Brain Health Network, Pacific Autism Family Network

Day #3 – Poster #37

Presenter: **Roz Zulla, University of Calgary**

Theme: **MITACS-KBHN Community Internship**

Title: **COVID-19 focused websites focused on individuals with autism and intellectual disabilities**

Author(s): **R. Zulla[1], W. Mitchell[1], D. Nicholas, S. Samborn, E. Onofrychuk[1]**

Institution/Affiliation(s): **University of Calgary, Faculty of Social Work**

Background: Informational and service-based websites can be a source of social support including knowledge advancement and resources for individuals with autism and intellectual disabilities (A/ID) and their families. The need for information/resources specific to individuals with A/ID and their families has been heightened and shifted during the COVID-19 pandemic as services available to individuals with AI/D and their families have ceased or been disrupted, daily routines have been radically changed, and stress has increased due to uncertainties caused by COVID-19. Information/resources can offer insight and guidance, and help manage the various deleterious impacts of the pandemic. This study explores websites offering information to individuals with AI/D and their families that is specific to their needs during COVID-19.

Objectives: This environmental scan and review focused on the following questions: (i) What organizations have developed informational and resource websites addressing the needs of individuals with A/ID during COVID-19? (ii) What kind of information is being shared on informational websites? (ii) How is the information presented to individuals with A/ID and their families?

Methods: A scoping review of websites was conducted. The review was undertaken using Google Advanced Search. Keywords guiding the search included the following: COVID-19, coronavirus, resources, autism, intellectual disability, autism spectrum disorder, high-functioning autism, and Asperger's. Included websites met the following criteria:

- Presented in English
- National focus or Canadian site
- Focus on AI/D,
- Topics include COVID-19 and its impact on areas relevant to individuals with AI/D and their families (e.g., mental health, education, financial supports),
- Target audience is children, youth, and/or adults with AI/D and their families.

Results: Thirty-two websites were identified. Comprehensive reviews were conducted to evaluate each website's content, topics, features (e.g., videos, newsletter, etc.), searchability and general impressions. Preliminary findings suggested that the majority of websites include a combination of unique content and links to other websites. The number of website links to other sites ranged from zero to over 200. Websites tended to address multiple topics (health and well-being, government programs/supports, education, mental health), and a number of the websites included social media links to help people connect with one another. Gaps were noted as follows: (i) websites were focused primarily on children and adults with A/ID, but not adolescent/young adults, (ii) websites predominantly offered information in a textual format and did not include accommodations that may be needed by individuals with disabilities (e.g. larger font, audio output), (iii) websites searchability functions were often limited, and (vi) the majority of websites failed to include dates, making it challenging for users to determine the currency, relevance and accuracy of information.

Implications: Findings invite considerations for how websites can provide information and resources to families; namely, whether information offered can be comprehensive and inclusive to all individuals with A/ID and their families. The review will inform the ongoing development of COVID-19 focused websites, including that offered by the Autism and Intellectual Disabilities Knowledge Exchange Network (AIDE Canada), COVID-19 site: https://covid19.aidecanada.ca/.

Keywords: internet, information, education, COVID-19, autism spectrum disorders, intellectual disabilities

Funded By: Mitacs Accelerate, Kids Brain Health Network, Pacific Family Autism Network

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Day #3 – Poster #38

Presenter: **Buse Bedir, University of Victoria**

Theme: **MITACS-KBHN Community Internship**

Title: **Novel service delivery models for children with neurodevelopmental disabilities and their families in light of the COVID-19 pandemic**

Author(s): **Bedir, B.[1], Macoun, S.[1], and Katz, B.[2]**

Institution/Affiliation(s): **[1]Department of Psychology, University of Victoria; [2]The Centre for Child Development**

Early childhood has been identified as a critical phase of child development in setting the trajectory for development through childhood and into adulthood. Early childhood is a critical developmental stage as it sets the foundation for lifelong benefits for learning and behavioural patterns in children. Positive environments and experiences in early childhood, such as physically, emotionally and socially nurturing and stimulating experiences, establish the wiring of the brain connections by capitalizing on “sensitive periods” of brain development. Even though early childhood development is very important for success in many life domains, some children, particularly those with neurodevelopmental disabilities (NDD), may not always receive the resources they need for optimum success. Neurodevelopmental disabilities may impact children’s cognitive functioning, learning and memory as well as physical and social skills. In addition, deficits in executive functioning (EF; crucial cognitive skills for engaging in goal-directed behaviour) have been implicated in a variety of neurodevelopmental disorders. In addition to the difficulties experienced by children with NDDs, their parents are also prone to more stress in their parenting. Combined together, these put extra stress in children and their families. Parent support systems, such as having access to supportive community resources and family members/friends, may reduce the parenting strain and stress associated with belonging to an at-risk group and/or having a child with an NDD or another chronic condition. High levels of parent/child stress for families contending with NDDs/chronic conditions may be exacerbated in the presence of environmental stressors such as the COVID-19 pandemic, particularly under circumstances where protective/preventive services cannot be provided. Families who are at risk of experiencing difficulties, such as those from lower socioeconomic brackets, those with limited access to resources, immigrant and refugee families, cultural minorities, and families who have a child with NDDs, may experience uniquely elevated stress levels during the pandemic due to their vulnerable circumstances and difficulty accessing resources with the closure of standard service options. This research aims to engage with The Centre for Child Development in Surrey, BC, Ministry for Child and Family Development (MCFD), and other service providers to evaluate key changes in service delivery as a result of the COVID-19 pandemic, and how these changes affect the families. This research will address these concerns by collecting quantitative (i.e. questionnaires) and qualitative (i.e. interviews and focus groups) data on the impact that COVID-19 has had on parents, service providers, and funders of services for children with NDDs. Based on the data gathered, recommendations will be generated as to how the South Fraser region can best serve our early years families during and following the pandemic.

Keywords (up to 6 words): Covid-19; children; families; services; neurodevelopmental disorders;

Funded By: Mitacs; KBHN

Day #3 – Poster #39

Presenter: **Jessica Kohek, University of Calgary**

Theme: **MITACS-KBHN Community Internship**

Title: **Academic, Political, and Community Engagement: Crafting Pandemic Preparedness Policies for Vulnerable Families**

Author(s): **J. Kohek**

Institution/Affiliation(s): **The School of Public Policy (University of Calgary)**

Implementation of evidence-based practices is necessary to mobilize research into practice and improve outcomes for families who rely on services. Research attracts awareness to particular community issues; however, there is often a disconnect between research collection and subsequent translation into community-level policies. When research does inform policies, and programs, the process can take decades.

This project sought to identify the challenges community organizations face in accessing and providing evidence-based services, as these services promote optimal outcomes for families. COVID-19, as a focusing event, has highlighted pre-existing political, economic, and structural impediments to knowledge mobilization. The barriers and solutions proposed by participants in the research have pre-existed, but been exacerbated by, the context of a pandemic.

Prior to conducting research, a literature review informed the need for increased support, communication, and funding for community organizations. The Nominal Group Technique (NGT) was used after conducting the literature review to contextualize this need in Calgary. Five NGT groups were held over the course of two weeks to generate ideas surrounding barriers to evidence-based service provision throughout COVID-19, as well as solutions that have the potential to address aforementioned challenges.

The three main barriers prioritized by participants included reduced revenue streams, transition to online service delivery, and inadequate communication and collaboration with government. Participants emphasized two solutions: person-centred policies and programs, and reciprocal collaboration. The literature and NGT groups result both support a need for cross-ministerial collaboration, community-based research partnerships, and engagement and consultation with community organizations.

Policy recommendations promote the priorities iterated by participants in the NGT groups. To address the barriers to evidence-based service provision throughout COVID-19, three policy options are recommended: (1) education and consultation with community organizations, (2) subsidy and grant provision for community-based research, and (3) formalizing a local network of researchers, community organizations, and policymakers. Next steps include validating the results of this study with an online Delphi and conducting a multijurisdictional environmental scan to determine best practices to support families with evidence-based service.

Keywords: research partnerships, knowledge mobilization, community development

Funded By: Mitacs and Kids Brain Health Network

Day #3 – Poster #40

Presenter: **Maude Champagne, Queen's University**

Theme: **MITACS-KBHN Community Internship**

Title: **Responding to the COVID-19 pandemic challenges for families with children impacted by Neurodevelopmental Disabilities (NDD)**

Author(s): **M. Champagne[1], R. Willis[1], J.N. Reynolds[1]**

Institution/Affiliation(s): **[1]Queen's University**

CONTEXT: ABLE2 (formerly Citizen Advocacy Ottawa) is a community-based not-for-profit organization that provides support for people living with disabilities and their families in the Ottawa region. During the COVID-19 pandemic, ABLE2 offered three programs to support families with children impacted by NDD. Since the beginning of social distancing measures, there has been an increase in participation in online programs, and increased reports of caregiver burnout, social isolation and feelings of loneliness, mental health issues of all family members, and even increased violence in the home (through child-to-parent violence).

OBJECTIVES: The main objective of this project is to gain better understanding of the social support needs of families with NDD during the pandemic and how to adapt established support services to these emerging needs. The specific aims of the study are to (1) identify the needs of caregivers during the pandemic, (2) make recommendations to adapt ABLE2's services to best meet these needs, and (3) evaluate the accessibility to and satisfaction with: i) virtual training, ii) virtual support groups and iii) virtual family support services.

Expected outcomes of this initiative are recommendations for modification to service delivery specifically aimed at: (1) improving family dynamics, (2) reducing stress of family members, and (3) improving developmental outcomes for children and youth with NDD.

METHODS:

ONLINE SURVEY to capture information on (1) Family situation regarding COVID-19 (depression, anxiety, financial stress, family violence, placement disruption and other social issues); and (2) Virtual support group satisfaction.

QUALITATIVE INTERVIEWS: Semi-structured interviews to explore the needs and challenges of families during the pandemic and client satisfaction with virtual services. Interview transcripts will be coded and analyzed with NVivo analysis software using Interpretative Phenomenological Analysis (IPA).

PRELIMINARY RESULTS WILL BE AVAILABLE AT THE CONFERENCE

Keywords (up to 6 words):): family support; COVID-19; virtual support, neurodevelopmental disorders, pediatrics.
Funded By: Kids Brain Health Network, ABLE2, MITACS

Day #3 – Poster #41

Presenter: **Jacalyn Guy, McMaster University**

Theme: **MITACS-KBHN Community Internship**

Title: **A National Autism Strategy: A Catalyst for the Coordination and Development of a Research Framework**

Author(s): **J. Guy[1, 2], L. Marr[3], S. Chernyak[3], A. Kata[3], S. Georgiades[3], R. Stevenson[1], and J. Lai[2]**

Institution/Affiliation(s): **[1]Brain and Mind Institute, University of Western Ontario; [2] Canadian Autism Spectrum Disorder Alliance (CASDA); [3]McMaster Autism Research Team (MacART), McMaster University.**

The unique challenges created by COVID-19 have created additional strain for Autistic Canadians and their families. Information and surveys about COVID-19 have and continue to be developed and shared via various outlets throughout Canada. The abundance of online research has highlighted the crucial need to coordinate autism-related and pan-disability data collection initiatives as we rebound from the pandemic. Further, it has underlined that Canada does not currently have a comprehensive research framework to generate shared knowledge to serve Autistic Canadians.

This project aims to inform a National Autism *Research* Strategy, developed as part of the National Autism Strategy (NAS) advocated by the Canadian Autism Spectrum Disorder Alliance (CASDA). CASDA is a coalition of organizations and individuals focused on the development of a comprehensive strategy of which research forms one of the key pillars. The goal of such strategy is to address the critical gaps in funding and policies that are preventing Autistic individuals and their families from exercising their equal rights as Canadians.

- Building on this strategy, the project will answer the following question:
- How can we transform and improve the autism research landscape in Canada?

This question will be answered through the exploration of themes defined in a research framework. Themes will include aspects critical to research: plans, funds, implementation, translation, and usage.

A scoping review of the literature, comparisons to international research models and examination of Canada-wide commitments and community-priorities will assist in clarifying key concepts, identifying knowledge gaps and generating recommendations. National-level stakeholder engagement with autism researchers, persons with lived experience, and organizations in the pan-disability sector will also help to build and propose ways to transform the way research is coordinated and serves Autistic Canadians.

Project outputs will facilitate the understanding of research priorities and gaps in research-to-practice, including current barriers and facilitators to systematic, pan-Canadian data coordination. These outputs will also help to identify the potential for revising an autism-focused research strategy through a new framework. Additionally, the findings will help to advocate for local, provincial, and national changes that will promote the development of a National Autism *Research* Strategy through a NAS.

Funded By: MITACS, Kids Brain Health Network, Canadian Autism Spectrum Disorder Alliance (CASDA)

Day #3 – Poster #42

Presenter: **Linda Nguyen, McMaster University**

Theme: **Community Engagement in Research**

Title: **Growing Together: The Process and Initial Outcomes of Partnering with Siblings in a Doctoral Patient-Oriented Research Study on Transition**

Author(s)**: Linda Nguyen[1,2,3], Hanae Davis[2,4], Samantha Bellefeuille[4], Marjolijn Ketelaar[1,5], Briano Di Rezze[1,2,3] Susan Jack[6,7], and Jan Willem Gorter[1,2,8] in partnership with the Sibling Youth Advisory Council**

Institution/Affiliation(s): **[1]School of Rehabilitation Science, McMaster University, [2]CanChild Centre for Childhood Disability Research, McMaster University, [3]McMaster Autism Research Team, [4]Sibling Youth Advisory Council, [5]Centre of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Netherlands, [6]School of Nursing, McMaster University, [7]Offord Centre for Child Studies, [8]Department of Pediatrics, McMaster University and McMaster Children's Hospital.**

Objectives:
1. To describe the development of a meaningful partnership with the Sibling Youth Advisory Council.
2. To highlight how the SibYAC partnered in a patient-oriented research (POR) study.

Description In childhood disability research, there is increasing recognition that partnerships with people with lived experience and their families helps to ensure that research findings are relevant. Since 2018, the Sibling Youth Advisory Council (SibYAC) has been established as a research partner in a doctoral research study called, BrothErs and Sisters involvement in health care TranSition for youth with Brain-based disabilitieS (BEST SIBS) Study. This study aims to understand the role of siblings of a youth with a disability during transition to adult health care. The SibYAC currently includes six siblings (1 brother, 5 sisters) who are young adults (ages 21-26 years) with siblings with disabilities (autism spectrum disorder, cerebral palsy, genetic condition, multiple sclerosis). To build our partnership, SibYAC members and researchers collaboratively set goals together. The Engagement Tool (Ontario Brain Institute) and Involvement Matrix (Smits et al., 2020) were used to discuss roles, responsibilities, and expectations of SibYAC members during each study phase of preparation, execution, and knowledge translation. At the end of each phase, the Patient and Public Engagement Evaluation Tool (Abelson et al., 2019) will be used to evaluate the strength of our partnership.

Outcomes of our POR approach include:

Preparation Phase (Completed)

i. ***Study aim:*** The SibYAC identified a need to raise awareness about siblings' roles with youth with a disability, which informed our study aim.
ii. ***Study methods:*** The SibYAC encouraged the use of creative methods to engage with youth participants, such as photo elicitation where participants share photographs to describe their experiences during study interviews.
iii. ***Recruitment materials:*** The SibYAC co-created the recruitment video and poster by sharing testimonials and photographs to highlight the importance of this study.

Execution Phase (In Progress)

i. ***Interview guide:*** Each SibYAC member was interviewed to pilot test the interview guide and provide feedback about the wording of questions.
ii. ***Participant recruitment:*** This study is currently recruiting participants and the SibYAC shared recruitment materials in their social networks.
iii. ***Data analysis:*** The SibYAC are interested in data analysis, such as coding transcripts and sharing their perspectives for a summary of preliminary findings.

(Continued)

Title: **Growing Together: The Process and Initial Outcomes of Partnering with Siblings in a Doctoral Patient-Oriented Research Study on Transition**

Author(s): Linda Nguyen[1,2,3], Hanae Davis[2,4], Samantha Bellefeuille[4], Marjolijn Ketelaar[1,5], Briano Di Rezze[1,2,3] Susan Jack[6,7], and Jan Willem Gorter[1,2,8] in partnership with the Sibling Youth Advisory Council

(Continued)

Knowledge Translation Phase (Ongoing)
We want to share how siblings can have multi-faceted roles in POR and advocacy to inspire other siblings to take on different roles. A SibYAC member described positive experiences of our partnership and how *"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."* To date, we co-wrote a newsletter to share our partnership experiences during COVID-19, co-presented at a virtual conference, and co-created a logo.

Significance: Lessons learned from our partnership highlights the value of POR for student researchers, emp owers siblings to engage in research, and ultimately impact the creation of knowledge and tools that are meaningful for families.

Keywords (up to 6 words): Patient-oriented research, siblings, youth, transition, disability
Funded By: CIHR Fellowship: Patient-oriented Research Award – Transition to Leadership Stream – Phase 1 from the Canadian Institutes of Health Research (CIHR)

Day #3 – Poster #44

Presenter: **Mahdieh Yousef, University of Alberta**

Theme: **Community Engagement in Research**

Title: **Specific Engagement Tools Should be Implemented in Chatbot Technology for Neurodevelopmental Disability**

Authors: **M. Yousef[1], M. Pohl[1], C. Rosenfelt[1], and F. Bolduc[1]**

Institution/Affiliation: [1]**Department of Pediatrics, University of Alberta, Edmonton, Alberta, Canada**

Families of kids with neurodevelopmental disabilities (NDD) need access to an online menu of evidence-based options to obtain guidance and continuity of care especially in dealing with challenging behaviors. Our goal is to develop a chatbot that provides relevant resources for these families, educators and frontline healthcare workers. To increase the engagement of families interacting with this chatbot, our research team explored the utilization of gamification, which is the deployment of game-like elements into non-game contexts. Examples of these engagement tools include badges, points, and social networks in health applications. We sought to answer this question: what types of gamification strategies are most effective for our target population and how should they be implemented?

We conducted a literature review on gamification in healthcare and educational settings to determine which engagement tools would be the most relevant to our chatbot. From this, and further readings, we constructed a research-based focus group and a survey question set. The question set aimed to uncover perspectives on the utilization of gamification features in the chatbot i.e. goal-setting, social network, and unlockable content.

To finalize this question set and get the preliminary perspectives, we ran five virtual focus groups with 11 participants from our internal parent advisory board. The preliminary results showed a preference for the use of goal-setting in order to improve challenging behaviors and the use of social networks in order to obtain connections and supports. On the other hand, there was an overall hesitation to the concept of unlockable content. Additionally, participants raised novel ideas about implementation strategies, which include the goals being adjustable for each unique child's challenges and potentially using a moderator in the context of the social network.

These results indicate that specific elements of gamification in an NDD chatbot will increase engagement amongst users. Furthermore, these findings necessitate continuing focus group sessions and running the survey with our participant population.

Keywords: Neurodevelopmental Disability, Chatbot, Engagement, Gamification, Challenging Behaviors

Funded By: CIHR and NSERC in partnership with WCHRI, KBHN and CASDA

Day #3 – Poster #45

Presenter: **An Bui, University of Alberta**

Theme: **Community Engagement in Research**

Title: **Tackling the spread of medical misinformation on the media: An artificial intelligence approach**

Author(s): **A. Bui[1], A. Dhankar[2], O. Zaiane [2], F. Bolduc[3]**

Institution/Affiliation(s): **[1]Neuroscience and Mental Health Institute, [2]Computing Science Department,[3]Division of Pediatric Neurology, Pediatrics Department, University of Alberta**

Broadcasting media is a powerful avenue to disseminate education. In the past, only a few organizations could afford to communicate information and their biases were well-known. However, as the Internet became more readily available, a significant rise of false medical information has been recorded. Fabricated news can be found anywhere, including personal blogs, online articles, podcasts, chat rooms, games, forums, and social media. Unfortunately, most online platforms often lack a screening tool to verify if the information posted is supported by scientific evidence and medical research. This makes patients who seek medical facts online a vulnerable target of incorrect public health information as well as pseudo medicine and adverse treatments. Notably, most of these claims are written very persuasively, are 70% more likely to be shared, and usually prey on people suffering from chronic pathologies.

Our research project aims to design a digital filter for false medical contents called MedFact. Harnessing the power of artificial intelligence, MedFact could determine if a controversial online source contains fabricated medical claims. This can ensure that only valuable and reliable medical information is presented to the viewers, especially patients living in rural areas with limited access to professional assistance.

To train MedFact to recognize and identify fake news, we first generated a database comprised of verified false claims and search queries that could be used to look up more false articles. Well-known false claims were collected from medical literature (e.g. PubMed). Using these claims, we then formulated various search queries such as “cures”, “miracle”, “complete treatment”, and “controversies”. The queries were used to collect multiple websites and articles that potentially contain false information from Google. The websites were compiled, manually annotated, and sorted into one of the following: “false”, “exaggerated”, “unproven”, “misleading”, and “true” claims. Subsequently, they were fed into the training database. With the governing mechanism being machine learning, MedFact will use our database to identify true and false information from any given website.

We now have constructed a large database of more than 60 false websites for MedFact's training. We also have accumulated 13 false medical claims of various clinical disorders. Using these data, our trial runs have shown positive results with high accuracy of detecting false information from novel websites.

We aim to continue improving MedFact by adding more annotated websites to our database and expand the type of medical conditions MedFact can detect.

Keywords (up to 6 words): Neurodevelopmental Disability, Chatbot, Artificial Intelligence, Fake News, MedFact

Funded By: CIHR and NSERC in partnership with WCHRI, KBHN and CASDA

Day #3 – Poster #46

Presenter: **Elizabeth Keys, Dalhousie University**

Theme: **Clinical Community Research**

Title: **Child sleep in the context of COVID-19**

Author(s): **Elizabeth Keys[1], Nicole MacKenzie[1], Esmot Begum[1], Penny Corkum[1] & the BNBD Team**

Institution/Affiliation(s): **[1]Dalhousie University**

Background: Social and economic distress, reduced mental health, increased media consumption, and routine disruptions may be pronounced in the time of COVID-19. Combined with the known relationship between anxiety, fear, and sleep problems, the COVID-19 pandemic may significantly increase or exacerbate sleep problems in children and their parents. It would be predicted that this impact may be even more significant for children with neurodevelopmental disorders (NDDs).

Methods: Parents who currently or previously participated in our Better Nights Better Days (BNBD) eHealth interventions were asked to complete a survey about how sleep has been impacted by the COVID-19 pandemic. Parents of typically developing (TD) children who previously participated in the BNBD program (n=82) and parents who are currently participating in our transdiagnostic BNBD-NDD program (n=68) completed a short survey about their child's sleep during the pandemic. Quantitative and qualitative data was collected about the change in their children's sleep, the factors that contributed to this change, and the success of any sleep intervention strategies that were being employed.

Results: In the TD sample, parents reported that 43% of children have experienced changes for the worse to their sleep since the onset of COVID-19. In the NDD sample, 54% of parents reported that their children's sleep has worsened during the pandemic. Many parents of TD children and children with NDDs believed their child's sleep at least moderately influenced their child's stress and coping abilities. A range of factors were thought to have negatively impacted sleep including the increased use of electronics/screen time. Qualitative comments supported the quantitative results and highlighted the negative impact of disrupted routines on sleep and coping. Of interest, a small percentage of parents, both in the TD and NDD groups, reported that their child's sleep has improved during the pandemic.

Conclusions: The COVID-19 crisis has likely increased the prevalence and/or exacerbated sleep problems in children, including those with NDD. To support the sleep of children during the COVID-19 crisis, it may be advantageous to address parent-identified factors, such as disruption in routines, increased use of electronics and screen time, and changes in physical activity. Responding to recommendations from parents about mobilizing pediatric sleep interventions during and after COVID-19 will be critical for effective future implementation of these interventions. This is especially relevant, given that "stand alone" eHealth interventions (where there is no involvement of a healthcare provider) like BNBD will be a primary mode of delivering these interventions during future COVID-19 waves.

Action/Impact: This session will help researchers, trainees, and clinicians understand how COVID-19 is affecting children's sleep to identify what short- and long-term supports may be needed to promote parental and children's well-being through sleep.

Keywords: Neurodevelopmental Disorders, Insomnia, Intervention, eHealth, Transdiagnostic, COVID-19

Funded By: Kids Brain Health Network, CIHR

Day #3 – Poster #47

Presenter: **Nichole Scheerer, Western University**
Theme: **Basic Science Research**

Title: **Associations between hyperacusis, misophonia, and quality of life in autistic and neurotypical adults**

Author(s): **N.E., Scheerer[1*], T.Q. Boucher[2*], G. Iarocci[2], B. Bahmei[3]; S. Arzanpour[3]; E. Birmingham[4]**

Institution/Affiliation(s): **[1]Brain and Mind Institute, Western University; [2]Department of Psychology, Simon Fraser University; [3]Mechatronic Systems Engineering, Simon Fraser University; [4]Faculty of Education, Simon Fraser University; *Denotes co-first authors.**

Autism Spectrum Disorder is a neurodevelopmental disorder characterized by social difficulties and restricted and repetitive behaviours. Hypersensitivity to sound has been reported in a majority of autistic individuals, yet more research is needed on the rates and impacts of auditory sensitivities across autistic and non-autistic populations. Two types of sound sensitivity are known from research in the general population: hyperacusis (reduced tolerance to sound) and misophonia (sensitivity to specific sounds, often human-produced, such as chewing noises). While auditory hypersensitivity is common in ASD, the rates of hyperacusis and misophonia in this population have not been systematically examined. Using an online survey study with validated questionnaires, we explored this question, and additionally examined how these types of auditory sensitivities are associated with mental health and quality of life in both autistic and non-autistic individuals.

Forty-eight autistic adults (M_{age} = 33.84 years, SD = 12.59, 8 male, 31 female, 9 non-binary) and 77 non-autistic adults (M_{age} = 37.77 years, SD = 12.89, 70 female, 0 male, 7 non-binary) adults participated in this study. Participants completed the Autism Spectrum Quotient (AQ), Misophonia Questionnaire (MQ), Inventory of Hyperacusis Symptoms (IHS), Patient Health Questionnaire (PHQ-4) assessing depression and anxiety, World Health Organization Quality of Life Brief (WHOQoL-BREF), Autism Quality of Life Questionnaire (ASQoL), as well as questions adapted from the Auditory Sensitivity and Child Safety Questionnaire (ASCSQ).

Relative to non-autistic adults, autistic adults had higher misophonia, (MQ; t(123) = 2.474, p = .015) and hyperacusis (IHS; t(123) = 4.434, p < .001) symptoms, and lower levels of environmental satisfaction (WHOQoL; t (123) = 2.113, p = .037). Correlational analyses indicated that autistic traits were positively associated with misophonia symptoms in both autistic (r(46) = .314, p = .030) and non-autistic (r(75) = .670, p <.001) adults, and positively associated with misophonia symptoms for non-autistic (r(75) = .608, p <.001), but not autistic adults (r(46) = .140, p = .343). Overall, higher misophonia and hyperacusis symptoms were associated with more mental health symptoms (PHQ-4 (r(123) = .383, p <.001 and r(123) = .409, p <.001, respectively) and lower environmental satisfaction (r(123)= -.256, p = .004 and r(123)= -.453, p < .001, respectively).

The results of this study suggest that both misophonia and hyperacusis are more common in autistic adults. These results also demonstrate that misophonia and hyeracusis are related to higher levels of mental health symptoms (PHQ-4), as well as lower environmental satisfaction (WHOQoL-BREF).

Keywords: Autism, Misophonia, Hyperacusis, Auditory Sensitivity

Funded By: This research was funded by a Kids Brain Health Network grant, and undertaken thanks in part to funding from the Canada First Research Excellence Fund awarded to Nichole Scheerer as part of the BrainsCAN program at Western University

Day #3 – Poster #48

Presenter: **Chantel Ritter, University of Guelph**

Theme: **Clinical/Community Research**

Title: **Recommendations following FASD assessment in Canadian diagnostic clinics: Understanding needs**

Author(s): **Chantel Ritter[1], Kathleen Kennedy[2], Jocelynn Cook[3], Kathy Unsworth[4], Jacqueline Pei[2], Kaitlyn McLachlan[1]**

Institution/Affiliation(s): **[1]University of Guelph; [2]University of Alberta; [3]Society for Obstetricians and Gynecologists of Canada; [4]Canada FASD Research Network**

Background: Individuals with fetal alcohol spectrum disorder (FASD) experience a range of cognitive, affective, and physical deficits following prenatal exposure to alcohol (PAE). FASD is among the most common neurodevelopmental disabilities in Canada, with a conservatively estimated 4% prevalence. Individuals with FASD often experience complex comorbidities and difficulties and require a high number of services across the lifespan to reach healthy outcomes. To date, there have been a limited number of studies examining patterns of service needs recommended for children, adolescents, and transition-aged youth with FASD, particularly in the Canadian context. The current study aims to investigate the recommendations made following FASD assessment in a large Canadian cohort children and youth with PAE.

Method: The Canadian National FASD Database is a repository containing over 3,000 records, providing a unique opportunity to assess the clinical characteristics, experiences, and needs of individuals assessed for FASD across the country. Anonymized records are entered by participating diagnostic clinics from around the country. The current study will focus on a subset of the database and apply a secondary analysis approach.

Results: The final sample will include all school-aged children (6-11 yrs), adolescents (12-17 yrs), and transition-aged youth (18-24 yrs), with confirmed PAE, assessed for FASD at participating clinics between 2016 and 2020, with known diagnostic outcome. Recommendations to be characterized include: accommodations, anticipatory guidance, autonomy support, community-based services, developmental therapy, education/assessment, family support, FASD specific recommendations, legal, medical, mental health, safety, and social services/welfare. These will be compared across key clinical (e.g., FASD with and without sentinel facial features, neurodevelopmental domains of impairment) and demographic characteristics (e.g., age, sex).

Conclusion: Research characterizing service recommendations for individuals with FASD in the Canadian context is limited and greatly needed to inform policy and resource allocation for clinical service delivery. Characterizing the service needs and recommendations for individuals seen in Canadian FASD diagnostic programs is crucial as it provides insight into current practices of the diagnostic clinics based on clinical and demographic characteristics. Further, findings can better inform clinicians engaged in FASD service provision regarding common needs across the lifespan and provide data-driven evidence and policy guidance.

Keywords (up to 6 words): “fetal alcohol spectrum disorder,” “service provision,” “recommendations,” “policy”

Funded By: Kids Brain Health Network