

# 2019

## KIDS BRAIN HEALTH ANNUAL CONFERENCE

### PROGRAM & ABSTRACT GUIDE



December 10 – 11, 2019  
Ottawa, Ontario / The Westin Hotel  
#KBHNCnf2019

[kidsbrainhealthconference.com](http://kidsbrainhealthconference.com)

Conference in English / Conférence en anglais

SFU

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# About Kids Brain Health

Kids Brain Health Network was established 10 years ago as a network of researchers and clinicians seeking to understand brain development, with the specific goal of mobilizing this knowledge to improve the lives of children living with neurodevelopmental disabilities and their families. As the Network moves towards its final cycle of funding, this is the perfect time to reflect on the past decade, and the evolution of KBHN to be an entity dedicated to the implementation of research innovations that impact the lives of children and families. To this end, we recognize and celebrate the essential role that partner organizations, front line service workers, educators, and parents, embedded as *active, contributing* members within research teams, play in achieving our shared vision; namely, that all children living with neurodevelopmental disabilities enjoy quality of life, inclusion in all aspects of society and reach their full potential.

# About the Conference

The goal of the 2019 KBHN Annual Conference is to celebrate the past 10 years of KBHN funded research, partnerships and successes. We have adopted the theme of **"Building Partnerships that Impact Communities"**. It will be a venue for sharing and listening to the perspectives of researchers, partners, families and stakeholders across the full spectrum of the Network's programs, from research discoveries and implementation strategies to policy dialog.

A combination of plenary talks, an interactive panel and round table discussions, and trainee presentations (both oral and poster) will display the breadth and depth of the Network's research programs and knowledge mobilization activities.

[kidsbrainhealthconference.com](http://kidsbrainhealthconference.com)

**Kids Brain Health Network**

Simon Fraser University  
Suite 295 - 13450 102 Ave.  
Surrey, BC V3T 0A3  
Canada



## Conference Program Committee

### James Reynolds, PhD

Chief Scientific Officer  
Kids Brain Health Network  
Associate Dean, School of Graduate Studies  
Professor, Department of Biomedical  
and Molecular Sciences Queen's University

### Francois Bolduc, MD, FRCPC, PhD

Associate Professor  
Department of Pediatrics  
Division of Pediatric Neurology  
University of Alberta

### Sarah Raza, MSc, PhD candidate

Department of Pediatrics  
University of Alberta

### Christiane Rohr, PhD

Alberta Innovates Fellow  
Child and Adolescent Imaging Research Program  
University of Calgary

### Douglas Swanson, PhD

Research and Training Manager  
Kids Brain Health Network

### Jennifer Zwicker, PhD, MPP

Director, Health Policy  
Assistant Professor, Kinesiology  
University of Calgary

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## Acknowledgements

Kids Brain Health Network is funded by the Networks of Centres of Excellence, a program of the federal government to advance science and technology.



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Kids Brain Health Network also proudly acknowledges our Host Institution Simon Fraser University



# Welcome

Kids Brain Health Network is proud to present our 9<sup>th</sup> Brain Development Conference.

This year, we are holding our conference in conjunction with Children’s Healthcare Canada (CHC)—a long-time partner of KBHN—to build new connections. Our network communities share a common vision and strive to meet the challenges of children and families with complex medical and psychosocial needs.

In Canada today, 10-17% of all children live with a neurodevelopmental disability. Over the course of their lives, more than 90% of these children will experience limitations that affect their quality of life.

Kids Brain Health Network believes that all children with neurodevelopmental disabilities should enjoy inclusion in all aspects of society and reach their full potential. We aim to understand brain development, and to develop innovative solutions and services with the potential to use this knowledge to improve their lives.

This year marks our 10<sup>th</sup> anniversary as a Network of Centres of Excellence. Over the past decade, KBHN has empowered our partners to mobilize early identification, effective intervention and family support to improve outcomes for children with neurodevelopmental disabilities.

As we embark on our 9<sup>th</sup> KBHN Conference here in Ottawa, we seek to both celebrate and share our achievements as well as create a venue for listening to the perspectives of stakeholders across the full spectrum of the Network’s programs.

Over the next two days, our speakers will share their knowledge and enthusiasm on topics ranging from research discoveries & therapeutic innovations to informing policy & changing work. With a theme of **“Building Partnerships that Impact Communities”**, this unique gathering aims to engage, inspire and encourage exchange of ideas among researchers, communities and patients and families. In doing so, we will continue to seek solutions to address the challenges faced by children and families impacted by neurodevelopmental disabilities.

With that said, we would also like to take this moment to thank the program committee, KBHN staff, contractors and conference sponsors who have worked tirelessly to provide you an immersive, inspiring and thought-provoking two-day conference.

Without their efforts, this would not be possible.



**James Reynolds, PhD**  
Chief Scientific Officer



**Nicky Lewis**  
Chief Executive Officer

# Conference Sponsors

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## Supporting



## AGENDA at a GLANCE

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### DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>

12:00 pm	<p><b>Lunch</b> ➤ Governor General Ballroom foyer</p> <p>Open to all registered KBHN Conference delegates</p>
12:00 pm	<p><b>“Meet the Experts” Trainee Lunch</b></p> <p>➤ Governor General Ballroom</p>
1:00 pm	<p><b>Opening Remarks</b></p> <p>By the Hon. Senator Colin Deacon</p> <p>➤ Governor General Ballroom</p>
1:10 pm	<p><b>Plenary Session: What the Science of Implementation can tell us about Changing Health Practice</b></p> <p>➤ Governor General Ballroom</p> <p><i>Sponsored by Title Sponsor Simon Fraser University</i></p> <p><i>Speaker</i> <b>Melanie Barwick</b>, PhD, CPsych (Senior Scientist, Child Health Evaluative Sciences, Research Institute, The Hospital for Sick Children)</p> <p><i>Discussant</i> <b>Kathryn Graham</b>, PhD (Executive Director, Performance Management &amp; Evaluation, Alberta Innovates)</p>
2:30 pm	<p><b>Trainee Lightning Talks</b></p> <p>Facilitated by Douglas Swanson, PhD</p> <p>➤ Governor General Ballroom</p> <p><i>Sponsored by AIDE Canada and CHEO</i></p> <p><i>Speakers</i> <b>Analyssa Cardenas</b> (University of Toronto)  <b>Sarah Raza</b> (University of Alberta)  <b>Emily Collis</b> (Queen’s University)  <b>Christiane Rohr</b> (University of Calgary)  <b>Heather Schearer</b> (University of Toronto)</p>
3:00 pm	<p><b>Health Break</b> ➤ Governor General Ballroom foyer</p> <p>Refreshments will be served in the Governor General Ballroom foyer for all registered KBHN Conference delegates</p>



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**AGENDA at a GLANCE**

**DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>**

3:30 pm

**Fraser Mustard Lecture -  
From Evidence to Influence: Making a Difference  
for Children and Families Through Health Research**

➤ **Governor General Ballroom**

*Sponsored by Children's Healthcare Canada*



*Speaker* **Christine Chambers** PhD (Canada Research Chair (Tier I) in Children's Pain, Killam Professor, Departments of Pediatrics and Psychology & Neuroscience, Dalhousie University; Scientific Director, Solutions for Kids in Pain (SKIP))

4:30 pm

**Trainee Lightning Talks**

Facilitated by Douglas Swanson, PhD

➤ **Governor General Ballroom**

*Sponsored by AIDE Canada and CHEO*



*Speakers* **Brittany Finlay** (University of Calgary)  
**Ayesha Siddiqua** (McMaster University)  
**Sarah Hutchison** (University of British Columbia)  
**Gabrielle López-Arango** (Centre de recherche du CHU Saint-Justine, Université de Montréal)  
**Kinga Ponziak** (McMaster University)

5:00 pm

**Poster Session and Networking Reception**

Open to all registered conference delegates

➤ **Governor General Ballroom III**

*Sponsored by The Azrieli Foundation*



## AGENDA at a GLANCE

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### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

7:00 am	<p><b>Breakfast</b> ➤ Governor General Ballroom foyer</p> <p>Open to all registered KBHN Conference delegates</p>
8:00 am	<p><b>Policy Forum: Breaking down barriers: Informing policy through research</b></p> <p>Facilitated by Jennifer Zwicker, PhD</p> <p>➤ Governor General Ballroom</p> <p><i>Panel</i> <b>Julia Hanigsberg</b>, President &amp; CEO, Holland Bloorview Kids Rehabilitation Hospital &amp; KBHN Board Director</p> <p><b>Heather Lacey</b>, Executive Director, Citizen Advocacy Ottawa</p> <p><b>Krista Wilcox</b>, Director General, Office of Disability Issues, Employment and Social Development Canada</p>
9:30 am	<p><b>Part 1: Implementation Team Talks</b></p> <p>Facilitated by James Reynolds, PhD</p> <p>➤ Governor General Ballroom</p> <p><i>Sponsored by School of Medicine, Queen's University</i></p> <p><i>Presenters</i> <b>Better Nights Better Days- An eHealth intervention for children with neurodevelopmental disorders and insomnia; from a parent and researchers perspective</b></p> <p><b>Shelly Weiss</b>, MD, Neurologist at SickKids and Professor of Paediatrics, University of Toronto</p> <p><b>Benjamin Seligman</b>, Parent Advocate</p> <p><b>Dino Island: A novel university-community partnership to improve executive functioning in children with neurodevelopmental disorders</b></p> <p><b>Sarah Macoun</b>, PhD, Assistant Professor, Psychology Department, University of Victoria and a registered clinical psychologist</p> <p><b>Brian Katz</b>, PhD R.Psych, Vice President, Child and Youth Services at The Centre for Child Development (Surrey BC)</p> <p><b>Physical Activity Programs for children with neurodevelopmental disabilities and their families: Community partnerships to implement a new physical activity coaching intervention</b></p> <p><b>Mojgan Gitimoghaddam</b>, MD, PhD(c), Department of Pediatrics, University of British Columbia</p> <p><b>Chelsea Rogers</b>, Community Development Coordinator, Special Olympics BC</p>
10:30 am	<p><b>Health Break</b> ➤ Governor General Ballroom foyer</p> <p>Refreshments will be served in the Governor General Ballroom foyer for all registered KBHN Conference delegates</p>
11:00 am	<p><b>Family Engagement in Research Workshop</b></p> <p>Facilitated by Andrea Cross, Donna Thomson, Connie Putterman, Rachel Martens, Kirsti Mardell, Crystal Shannon</p> <p>➤ Governor General Ballroom</p> <p><i>Sponsored by Child-Bright Network</i></p>





## AGENDA at a GLANCE

### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

12:30 pm

#### Lunch Break

➤ Governor General Ballroom foyer

A lunch buffet will be served in the Governor General Ballroom foyer for all registered KBHN Conference delegates

1:00 pm

#### Plenary: The Changing World of Human Genomics

Facilitated by Francois Bolduc, MD, FRCPC, PhD

➤ Governor General Ballroom

Speaker **Peter Goodhand**, (B.Ed), CEO, Global Alliance for Genomics and Health (GA4GH)

2:00 pm

#### Part 2: Implementation Team Talks

Facilitated by James Reynolds, PhD

➤ Governor General Ballroom

Sponsored by School of Medicine, Queen's University

Presenters

##### **Development of a genomic assessment tool for early identification of children at-risk for FASD in Manitoba**

**Geoff Hicks**, PhD, Professor, Department of Biochemistry and Medical Genetics, University of Manitoba

**Daphne Lafreniere**, BA, FASD STAR Program Coordinator, Cree Nation Tribal Health Centre (CNTHC) in The Pas, MB

##### **Nurturing the Seed: A journey to infant mental health and wellness**

**Chaya Kulkarni**, BAA, M.Ed, Ed.D, Director of Infant Mental Health Promotion (IMHP) at The Hospital for Sick Children in Toronto.

**Ronda Guenette**, Child Care Site Supervisor, Keepers of the Circle

**Roberta Oshkawbewisens**, Nookamis/Grandmother and Traditional Facilitator, Temiskaming Native Women's Centre-Keepers of the Circle

##### **Social ABCs: A parent-mediated intervention for toddlers with early signs of Autism Spectrum Disorder**

**Jessica Brian**, PhD Psychologist and Clinician-Investigator at Holland Bloorview Kids Rehabilitation Hospital and Assistant Professor, Department of Pediatrics, University of Toronto

**Irene Drmic**, Ron Joyce Children's Health Centre in the Autism Spectrum Disorder (ASD) Program and Child and Youth Mental Health Program

##### **Moving from research to social action: Navigation support for families of children with neurodisabilities**

**Lucy Lach**, PhD, Associate Professor in the School of Social Work and Associate Member of the Departments of Paediatrics and Neurology/Neurosurgery in the Faculty of Medicine, McGill University

**Angela Clancy**, BA, Executive Director, Family Support Institute of BC



3:30 pm

#### Closing Remarks

➤ Governor General Ballroom

Speakers

**Nicky Lewis**, Chief Executive Officer, Kids Brain Health Network

**James Reynolds**, PhD, Chief Scientific Officer, Kids Brain Health Network

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### DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>

**12:00 pm Lunch** ➤ **Governor General Ballroom foyer**  
Open to all registered KBHN Conference delegates

**12:00 pm “Meet the Experts” Trainee Lunch**  
➤ **Governor General Ballroom**

Conference trainees can network and gain valuable insight from leaders in the field during lunch on December 10<sup>th</sup>. Join us for the opportunity to visit with conference dignitaries and invited experts to discuss translational and clinical research and implementation topics. “Expert” table hosts will guide the discussions and share personal insights into neurodevelopmental research, community engagement, and career development for young researchers.

**1:00 pm Opening Remarks**  
By the Hon. Senator Colin Deacon  
➤ **Governor General Ballroom**

Hon. Senator Colin Deacon will give welcoming remarks to officially open the 2019 Kids Brain Health Conference. Senator Deacon served as a KBHN Board Director from 2016-2018 and assumed Vice Chair to the Board in 2017 prior to serving on the Senate.



**Senator Colin Deacon**

The Honourable Colin Deacon’s entrepreneurial background provides a unique perspective in Canada’s Upper Chamber. He has spent much of his career turning ideas into products and services sold globally. During his career, Sen. Deacon worked as a broker, helped found one of the largest life science venture funds in Canada, and commercialized technology that led to the creation of new job opportunities for Atlantic Canadians. In 2009, he founded BlueLight Analytics, a company that improved the quality of restorative dentistry using innovative technologies. As a newly appointed Independent Senator, Sen. Deacon aims to continue his focus on knowledge

mobilization and data-driven decision-making to strengthen Canada’s ability to compete in our digital world. Right now, this involves focusing on the importance of #OpeningBanking to improve our productivity and competitiveness, and to protect Canadian consumers.

**CONFERENCE PROGRAM****DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>****1:10 pm****Plenary Session: What the Science of Implementation can tell us about Changing Health Practice**

By Melanie Barwick, PhD followed by a discussion led by Kathryn Graham, PhD

► **Governor General Ballroom***Sponsored by Title Sponsor Simon Fraser University*

This presentation will introduce implementation science, describe why we fail at implementing evidence, and how implementation science can help us do better at practice change.

**Melanie Barwick**

Dr. Barwick is a Registered Psychologist and Senior Scientist in the Child Health Evaluative Sciences program of the SickKids' Research Institute. She is Full Professor in the Department of Psychiatry, Faculty of Medicine and in the Dalla Lana School of Public Health at the University of Toronto. Her focus is in implementation science, studying innovative knowledge translation and implementation strategies to facilitate the effectiveness of how research evidence is used in practice across various contexts, including health, mental health, global health, and education. Her program of research explores empirically supported approaches, measures, and tools to facilitate the implementation of evidence-based practices across these multiple contexts. Her work in education and professional development includes the development of the Specialist Knowledge Translation Training program (SKTT), the Knowledge Translation Professional Certificate (KTPC), the Knowledge Translation Planning Template, The KT Game, The Implementation Game, and The Knowledge Translation Plan Appraisal Tool.

**Kathryn Graham**

Dr. Kathryn Graham is the Executive Director of Performance Management and Evaluation at Alberta Innovates, a Canadian-based publicly-funded provincial health research and innovation organization. She is a Fellow of the Canadian Academy of Health Sciences (CAHS), co-founder of the International School on Research Impact Assessment, and Director of the School during its time in Banff in 2014. She has over 25 years of strategic evaluation experience in health care, and health research and innovation. Her expertise is in developing performance management, evaluation, impact strategies, and implementing assessment frameworks for complex systems and organizations. She successfully implemented the CAHS (2009) health research and impact framework and was instrumental in its application nationally and internationally. Kathryn is a social scientist, bridge builder and advisor on numerous expert committees that focus on the assessment of research and innovation. She is frequently presents nationally and internationally.

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### DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>

**2:30 pm** **Trainee Lightning Talks**  
 Facilitated by Douglas Swanson, PhD  
 ► **Governor General Ballroom**  
*Sponsored by AIDE Canada and CHEO*



Lightning Talks are short (3 mins, 1 slide) presentations that highlight key research findings and outcomes that will have an impact in an area of study. During these sessions, trainees and young professionals will have the opportunity to take the stage to showcase their cutting-edge research, stimulate discussion, and attract traffic to their posters.

**Analyssa Cardenas, HBSc, Master's Student**

(Rehabilitation Sciences Institute, University of Toronto)

**Poster #36: Inpatient Rehabilitation Exergames for Children with Cerebral Palsy after Lower Limb Orthopedic Surgery: A Feasibility Study**

**Summary:** How can interactive video games play a role in pediatric rehab? Analyssa Cardenas will discuss implementing exergames for children with Cerebral Palsy after lower limb orthopedic surgery.

**Sarah Raza, BSc, MSc, Doctoral Student**

(Department of Pediatrics, University of Alberta)

**Poster #22: A Novel Approach to Modeling Emotion Regulation in Autism Spectrum Disorder**

**Summary:** Emotions may play an important role in the development of autism spectrum disorder in at-risk infants. We can use both behavior and physiology to help us dig deeper and understand why.

**Emily Collis, HBSc, Master's Student**

(Centre for Neuroscience Studies, Queen's University)

**Poster #4: Nurturing the Seed: A collaborative journey to infant mental health and wellness**

**Summary:** The Nurturing the Seed resource developed by Infant Mental Health Promotion and key stakeholders melds worldviews and practices distinct to Indigenous communities with evidence-based assessment tools and customized developmental support planning.

**Christiane Rohr, PhD, Postdoctoral Fellow**

(Child and Adolescent Imaging Research Program, The University of Calgary)

**Poster #28: White Matter Tract Signatures of ADHD and Emotional Lability Traits in Young Children**

**Summary:** Many children with ADHD present with high levels of emotional lability, which associates with poorer outcomes. We assess the brain basis of this relationship in two white matter tracts that are crucial for attention and emotion.

**Heather Shearer, DC, MSc, Doctoral Student**

(Institute of Health Policy, Management and Evaluation, University of Toronto)

**Poster #33: Short-term pain trajectories and well-being in children and youth with cerebral palsy: A feasibility study**

**Summary:** How does pain intensity change in children/youth with cerebral palsy? This talk suggests a cohort study to describe short-term pain trajectories and their association with well-being in this population.

## CONFERENCE PROGRAM

### DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>

**3:00 pm**
**Health Break** ➤ Governor General Ballroom foyer

Refreshments will be served in the Governor General Ballroom foyer for all registered KBHN Conference delegates

**3:30 pm**
**Fraser Mustard Lecture -  
From Evidence to Influence: Making a Difference for  
Children and Families Through Health Research**

➤ Governor General Ballroom

*Sponsored by Children's Healthcare Canada*


Scientific research will only help children and families if it can be effectively disseminated and implemented. Unfortunately, the public is generally unaware of the value of health research and best available evidence is often not used in clinical practice. In the Fraser Mustard presentation, Dr. Christine Chambers will provide an overview of the practice of dissemination and the science of implementation in health research, highlighting how one must consider the application of scientific discoveries to different types of knowledge users and settings, the value of partnerships, the importance of patient engagement, and the role of evolving communication technologies.


**Christine Chambers**

Dr. Christine Chambers is a clinical psychologist, Canada Research Chair (Tier 1) in Children's Pain and Killam Professor of Pediatrics and Psychology & Neuroscience at Dalhousie University. She is also the Scientific Director of a national knowledge mobilization network, Solutions for Kids in Pain (SKIP). SKIP's mission is to improve children's pain management by mobilizing evidence-based solutions through coordination and collaboration. Dr. Chambers' research, based in the Centre for Pediatric Pain Research at the IWK Health Centre, aims at improving the assessment and management of children's pain. Chambers has published over 150 articles in peer-reviewed scientific journals. She is also one of the top 10 most productive women clinical psychology professors in Canada. Her award-winning #ItDoesntHaveToHurt initiative for parents generated 150 million views worldwide, trended on social media, and appeared in national and international media. She is a leader and innovator in patient engagement, partnerships, and the mobilization of health research.

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### DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>

4:30 pm

#### Trainee Lightning Talks

Facilitated by Douglas Swanson, PhD

➤ **Governor General Ballroom**

*Sponsored by AIDE Canada and CHEO*



Lightning Talks are short (3 mins, 1 slide) presentations that highlight key research findings and outcomes that will have an impact in the area of study. During these sessions, trainees and young professionals will have the opportunity to take the stage to showcase their cutting-edge research, stimulate discussion, and attract traffic to their posters.

#### **Brittany Finlay, MPP, Research Associate**

(Health Policy, School of Public Policy, University of Calgary)

##### **Poster #38: Parent and Youth Experiences Accessing Government Disability Programs Across Canada: A Mixed-Method Analysis**

**Summary:** Survey and interview data from youth with disabilities and their parents/caregivers highlight the significant barriers these individuals face when accessing government-funded disability programs across Canada.

#### **Ayesha Siddiqua, MSc, Doctoral Student**

(Offord Centre for Child Studies, McMaster University)

##### **Poster #32: Association between neighbourhood socioeconomic status and development of kindergarten children with Autism Spectrum Disorder: A pan-Canadian study**

**Summary:** Children with Autism Spectrum Disorder living in neighbourhoods with higher socioeconomic status are less likely to demonstrate developmental vulnerability, regardless of their province of residence.

#### **Sarah Hutchison, PhD, Postdoctoral Fellow**

(Department of Pediatrics, University of British Columbia)

##### **Poster #27: Everyday executive function associated with adaptive functioning in children and adolescents with prenatal alcohol exposure**

**Summary:** We explored how everyday mental and behavioural skills are related in children and adolescents with prenatal alcohol exposure and show important implications for intervention.

#### **Gabrielle López-Arango, MSc, Doctoral Student**

(Centre de recherche du CHU Saint-Justine, Université de Montréal)

##### **Poster #24: Repetition suppression as an electrophysiological correlate of habituation is associated with adaptive skills during the first year of life**

**Summary:** Simple forms of learning can be measured in infants during the first year of life. Our studies show stable and age-related brain activities that are important building blocks in intellectual function and can serve as valuable early markers of neurodevelopment.

#### **Kinga Pozniak, PhD, Postdoctoral Fellow**

(CanChild and Department of Pediatrics, McMaster University)

##### **Poster #7: ENVISAGE: A workshop for parents, by parents.**

**Summary:** Envisage is a workshop series for parents new to the journey of disability, co-designed by parents and researchers, that builds confidence and empowers parents to communicate more effectively with service providers.

## CONFERENCE PROGRAM

### DAY 1 TUESDAY, DECEMBER 10<sup>th</sup>

5:00 pm

#### Poster Session and Networking Reception

Open to all registered conference delegates

► **Governor General Ballroom III**

*Sponsored by The Azrieli Foundation*



This early evening reception is open and complimentary for all meeting attendees. Poster presenters will share research study results, community engagement activities, and knowledge mobilization initiatives. Presenters and attendees can learn what is happening across the KBHN community space and have the chance to network with old and new friends. Refreshments and hors d'oeuvres will be served.

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### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

7:00 am

**Breakfast** ➤ Governor General Ballroom foyer

8:00 am

### Policy Forum: Breaking down barriers: Informing policy through research

Facilitated by Jennifer Zwicker, PhD

➤ Governor General Ballroom

Communicating research findings is critical in development of policies that impact the lives of children with developmental disabilities and their families. In this panel, decision makers and community stakeholders will discuss their perspectives on the role of researchers in informing policy development, including practical approaches for communicating evidence to decision makers. The session will explore approaches for communicating findings, showcasing KBHN work as examples, and reflect on the role of researchers and stakeholders in the policy development process.



#### Julia Hanigsberg

Julia Hanigsberg is President and CEO of Holland Bloorview Kids Rehabilitation Hospital, Canada's largest paediatric rehabilitation hospital and an academic health science centre fully affiliated with the University of Toronto. Julia has spent her career in government, post-secondary education and healthcare as a champion for cultural transformation, innovation, excellence and social justice. She is a two-time Women's Executive Network Most Powerful Women Top 100 honouree. She honed her expertise in public policy during her time with the Ontario government including roles as Counsel to the Deputy Attorney General, Counsel and Special Advisor to two Secretaries of Cabinet

and Chief of Staff to the Attorney General of Ontario. Julia has degrees from McGill University and the Columbia Law School and following graduation from law school clerked at the Supreme Court of Canada. She has held Social Sciences, Humanities Research Council of Canada, and Fulbright Fellowships.



#### Heather Lacey

Heather Lacey completed a Bachelor of Arts degree majoring in Psychology and Law. After completing her studies, she worked for 12 years with children with special needs and developed an expertise working with children and youth living with autism. This interest was cultivated when her oldest child was diagnosed with autism and developmental delays at the age of four. By 2007, she was working with the Ontario government (Ministry of Children and Youth Services) in Aboriginal Child Welfare and Mental Health. Here, she gained valuable insights in to the history of the Aboriginal people's experiences within Canada that would shape her perspective and practice

going forward. In 2012, Heather accepted the challenge to work as the Executive Director for a Delegated Aboriginal Child and Family Service Agency in British Columbia. Heather is now working as the Executive Director of Citizen Advocacy Ottawa.



#### Krista Wilcox

As the Director General of the Office for Disability Issues in the Accessibility Task Team at Employment and Social Development Canada, Krista leads a team of dedicated policy professionals working as the focal point in the Government of Canada to advance the full inclusion of people with disabilities in Canadian society and the economy. Prior to this, Krista has held various executive positions within Employment and Social Development Canada in the areas of communications, family and children's policy and social finance/social innovation. She attended Carleton University and Wilfrid Laurier University where she obtained a Master's of Arts and a Bachelor's of Arts in

Political Science respectively. Outside of work, Krista is a married mom of three boys, a basset hound and a cat.



## CONFERENCE PROGRAM

### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

9:30 am

#### Part 1: Implementation Team Talks

Facilitated by James Reynolds, PhD

► **Governor General Ballroom**

*Sponsored by School of Medicine, Queen's University*



In this series of presentations, KBHN researchers and key partners will tell their stories that focus on the implementation of research innovations aimed at improving outcomes for children and families.

#### **Better Nights Better Days - an eHealth intervention for children with neurodevelopmental disorders and insomnia; from a parent and researcher's perspective**



##### **Shelly Weiss**

Shelly Weiss, MD, FRCPC, is a pediatric neurologist; sleep physician, and clinical researcher at the Hospital for Sick Children where she directs the Sleep Neurology Clinic. She is a Professor in the Department of Pediatrics, University of Toronto. Currently, her primary research focuses on pediatric insomnia (in children who are typically developing or have neurodevelopmental disabilities). She is a co-principal investigator with Dr. Penny Corkum on the study Better Nights Better Days for Children with Neurodevelopmental Disabilities funded by KBHN. In addition to research publications, she has authored a self-help book for parents: "Better Sleep for your Baby

& Child" (2006). Dr. Weiss is the previous President (2011-2014) of the Canadian Sleep Society. Currently, she is the North American representative on the Governing Council of the World Sleep Society. She is also involved in national sleep education as the Vice-Chair of the training program in Sleep Disorder Medicine at the Royal College of Physicians and Surgeons of Canada.



##### **Ben Seligman**

Ben Seligman was born in the U.K. He immigrated to Canada at the age of twelve and, other than during a seven-year sabbatical in South East Asia, has lived here for more than fifty years. He holds a college diploma and three degrees from Western University. He spent his working life in diverse roles including retail management and ownership, reporting and news editing, commercial copy writing, teaching high school and, in his later years, in Human Resource Development both in Canada and internationally. He has spent the past eight years focusing on being the single Dad of a now ten-year old son with A.D.H.D.

**CONFERENCE PROGRAM**

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**SFU**SIMON FRASER  
UNIVERSITY**DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>**

9:30 am

**Part 1: Implementation Team Talks *continued***

Facilitated by James Reynolds, PhD

► **Governor General Ballroom***Sponsored by School of Medicine, Queen's University*

In this series of presentations, KBHN researchers and key partners will tell their stories that focus on the implementation of research innovations aimed at improving outcomes for children and families.

### **Dino Island: A novel university-community partnership to improve executive functioning in children with neurodevelopmental disorders**

**Sarah Macoun**

Dr. Sarah Macoun is a Registered Psychologist and Assistant Professor in Psychology (Clinical Neuropsychology, Pediatrics) at the University of Victoria (UVic). Dr. Macoun has over 15 years of experience as a practicing clinical neuropsychologist and applied researcher within communities, hospitals and school settings, where she has worked with children and youth with a range of neurodevelopmental disorders (NDDs) including ASD, ADHD, FASD, LD, etc. Her professional expertise includes neuropsychological/educational assessment, development and evaluation of educational/cognitive interventions, and program planning/policy development for children with special needs. Dr. Macoun has research expertise in the area of child cognitive development, attention and EF deficits, and cognitive rehabilitation. She leads a large research team of trainees that range from undergraduate honors students who are interested in pursuing career in psychology to upper level PhD students in clinical neuropsychology. Dr. Macoun's recent achievements include development and validation of the Dino Island 'serious' game' for children with neurodevelopmental disorders.

**Brian Katz**

Dr. Brian Katz is a Registered Psychologist and the Vice President of Child and Youth Services at The Centre for Child Development in Surrey, BC. The Centre is the largest child development centre in the province. The Centre's team of 160+ staff provide direct therapeutic services each year to more than 3,100 children through 30,000 service sessions annually throughout the lower mainland. At The Centre, Dr. Katz leads a team of psychologists, social workers, key workers, and mental health clinicians providing services to children with special needs throughout the Lower Mainland of BC. Dr. Katz has research and clinical experience working with children with an array of neurodevelopmental and physical disorders. His research interests include cognitive development in children and youth with neurodevelopmental disorders, the role of stress on the development of psychopathology in urban children and youth, and specifically the role of neighbourhood factors on developmental trajectories in children and youth living in urban areas. Dr. Katz also has extensive community connections in BC. Dr. Katz is currently collaborating with Dr. Macoun in the design and implementation of clinical validation work pertaining to the Dino Island intervention.

## CONFERENCE PROGRAM

### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

9:30 am

#### Part 1: Implementation Team Talks *continued*

Facilitated by James Reynolds, PhD

➤ **Governor General Ballroom**

*Sponsored by School of Medicine, Queen's University*



In this series of presentations, KBHN researchers and key partners will tell their stories that focus on the implementation of research innovations aimed at improving outcomes for children and families.

### Physical Activity Programs for children with neurodevelopmental disabilities and their families: Community partnerships to implement a new physical activity coaching intervention



#### Mojgan Gitimoghaddam

Dr. Mojgan Gitimoghaddam is a family physician by background and currently a PhD candidate at University of British Columbia in BC., under supervision of Dr. Jean-Paul Collet. Mojgan's research is focused on learning and development of children with neurodevelopmental disabilities through maximizing the effect of community-based physical activity programs. She has also been actively involved in research studies regarding the patients' care for children with complex chronic conditions and various types of disabilities through the support of child-centred approaches and the use of modern communication technologies. Mojgan is presently working on several projects

to implement the new physical activity coaching intervention in Special Olympics BC sites, as well as, rural and Indigenous communities, funded by Kids Brain Health Network, BC Ministry of Health, and Michael Smith Foundation for Health Research. Mojgan acts as a co-PI in these studies. She is also responsible for the overall management and field implementation.



#### Chelsea Rogers

Chelsea Rogers is the Community Development Coordinator for the Lower Mainland at Special Olympics BC. After obtaining a Bachelor's Degree in Recreation Management at Langara in Vancouver, 2017, Chelsea sought to pursue a career in sport, and came across Special Olympics BC. Since then, she has worked closely with volunteer coaches, and athletes of all ages, abilities, and competition levels including international competition. In 2018, Chelsea was named Mission Staff for Team BC in the National Winter Games in Thunder Bay, Ontario, 2020. Chelsea has also worked in partnership with the University of British Columbia, in Knowledge Translation & Implementation

Science Research, connecting them with programs, coaches and youth athletes, under the age of 12, and continuing to work towards positive change for youth with intellectual disabilities through sport.

10:30 am

#### Health Break

➤ **Governor General Ballroom foyer**

Refreshments will be served in the Governor General Ballroom foyer for all registered KBHN Conference delegates

## CONFERENCE PROGRAM

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### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

11:00 am

#### Family Engagement in Research Workshop

Facilitated by Andrea Cross, Donna Thomson, Connie Putterman, Rachel Martens, Kirsti Mardell, Crystal Shannon

► **Governor General Ballroom**

*Sponsored by Child-Bright Network*



The KBHN Family Engagement in Research Certificate Program brings together families and researchers who have an interest in child neurodevelopmental research in a 10-week online course. Co-developed and co-instructed by parents and researchers, the course aims to develop the next generation of leaders in the field of family engagement. In this presentation, instructors and students will share evidence and experiences of researchers and families in this national online training program.



**Andrea Cross**

Andrea is a postdoctoral fellow at CanChild. She graduated in 2011 from Wilfrid Laurier University with a Master’s of Science in Kinesiology, and in 2018, with a PhD in Rehabilitation Science from McMaster University. Andrea’s doctoral research aimed to disseminate the ‘F-words’ in Childhood Disability directly to families and service providers, and to explore the uptake of a holistic and health affirming approach to childhood disability. Andrea’s postdoctoral research focuses on training in family engagement in research and implementation science. Andrea is the co-developer and co-instructor of the KBHN funded Family Engagement in Research Certificate of Completion Program at CanChild and McMaster University.



**Donna Thomson**

Donna is the author of “The Four Walls of My Freedom: Lessons I’ve Learned From a Life of Caregiving” (The House of Anansi Press, 2014), and is the co-author of “The Unexpected Journey of Caring: The Transformation of Loved One to Caregiver” (Rowman and Littlefield, June 2019). She is a past board director of Kids Brain Health Network and is the co-designer and co-instructor of the KBHN Family Engagement in Research Certificate Program at CanChild, McMaster University. Donna is also a member of the steering and citizen engagement committees of the CHILD-BRIGHT SPOR.



**Connie Putterman**

Connie is a long-time parent partner, advisor and advocate for engagement in neurodevelopmental and autism research and inclusion initiatives. Connie recently became a “research trainee” after completing her MHSc in Translational Research at the University of Toronto’s Faculty of Medicine. Connie is the co-developer, co-designer, and co-instructor of the KBHN Family Engagement in Research Certificate Program at CanChild and McMaster University. She speaks publicly about research engagement both internationally and in Canada. Her 2016 Ted Talk-“Finding your Waze” reflects her perspectives and philosophies on parent engagement in research. In 2014, she founded the Canada/Israel Autism Research Initiative, which fosters international collaborations in autism research. Connie is a co-lead of the Knowledge Translation committee of the CHILD-BRIGHT SPOR and a long-time member of the PAC of OBI’s POND Network. Connie lives in Toronto.

**CONFERENCE PROGRAM**

**DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>**

**11:00 am** **Family Engagement in Research Workshop**  
*continued*

Facilitated by Andrea Cross, Donna Thomson, Connie Putterman, Rachel Martens, Kirsti Mardell, Crystal Shannon

➤ **Governor General Ballroom**

*Sponsored by Child-Bright Network*



**Rachel Martens**

Rachel Martens is a parent partner with both Kids Brain Health Network and CHILD-BRIGHT Network. She currently works as an Engagement Officer for the KBHN Family Engagement in Research Certificate Program.



**Kirsti Mardell**

Kirsti is a parent of three children and lives in Fort McMurray, Alberta. She is involved in a number of research projects with KBHN and Child-Bright and is a graduate of the Fall 2018 KBHN Family Engagement in Research Course.



**Crystal Shannon**

Crystal Shannon has BSc and MSc in Nursing and is presently a PhD student (UBC Okanagan). Her masters' thesis focused on parent's experiences promoting safe and active recreation for children living with autism spectrum disorders (ADS) in rural settings. She is a KBHN Research Trainee and a recent graduate in the KBHN Family Engagement in Research Certificate program.

**12:30 pm** **Lunch Break** ➤ **Governor General Ballroom foyer**

A lunch buffet will be served in the Governor General Ballroom foyer for all registered KBHN Conference delegates

## CONFERENCE PROGRAM

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### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

1:00 pm

#### Plenary: The Changing World of Human Genomics

Facilitated by Francois Bolduc, MD, FRCPC, PhD

Presentation by Peter Goodhand

➤ **Governor General Ballroom**

An overview of current global initiatives in the responsible sharing of genomic and related health data. The Global Alliance for Genomics and Health (GA4GH) was launched in 2013 and works to enable sharing across the research to healthcare continuum.



#### Peter Goodhand

Peter Goodhand is the Chief Executive Officer of the Global Alliance for Genomics and Health (GA4GH), as well as a leader in the global health sector as a senior executive and board member. Additionally, he has fifteen years of experience as a patient advocate, caregiver, and navigator throughout his family's battle with a rare cancer. Goodhand is currently a member of the Occupational Cancer Research Centre Steering Committee, Co-Chair of the Medical and Scientific Advisory Board of Global Genes, Co-Chair of the International 100K+ Cohorts Consortium (IHCC), and a member of the Global Genomic Medicine Collaboration (G2MC) Steering Committee.

2:00 pm

#### Part 2: Implementation Team Talks

Facilitated by James Reynolds, PhD

➤ **Governor General Ballroom**

*Sponsored by School of Medicine, Queen's University*



In this series of presentations, KBHN researchers and key partners will tell their stories that focus on the implementation of research innovations aimed at improving outcomes for children and families.

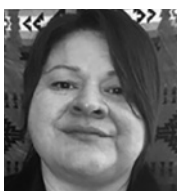
#### Development of a genomic assessment tool for early identification of children at-risk for FASD in Manitoba



#### Geoff Hicks

Geoff Hicks is the Director of Regenerative Medicine Program and Professor of Biochemistry & Medical Genetics at the University of Manitoba. Hicks' lab studies mouse models to understand genetic determinants of cancer, neurodegenerative disease (ALS) and neurodevelopmental disorders (Fetal Alcohol Spectrum Disorder). Hicks is co-founder of the Canada Israel International FASD Consortium (CIIFAC), Team member of the CIHR Canadian Epigenetics, Environment and Health Research Consortium (CEEHRC) in FASD, and a PI of the Kid's Brain Health Network. Recently he developed a novel mouse model of FASD that identifies Vitamin A as a potential preventative

treatment for FASD. Dr. Hicks has presented this work at over 25 presentations internationally, and he and his collaborators have organized and presented eight research sessions at International Symposia.



#### Daphne Lafreniere

Daphne Lafreniere is a Metis/Cree treaty indigenous woman from the Opaskwayak Cree Nation in Manitoba. In 2005, she obtained a Bachelor of Arts degree from the University of Manitoba with a major in Native Studies and a minor in Psychology. For five years, Daphne was honoured for supporting Survivors in 150 Indian Residential School IAP Hearings during her employment with the Aboriginal & Wellness Centre in Winnipeg, MB. *(continued on next page)*

## CONFERENCE PROGRAM

### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

#### **Daphne Lafreniere** *(continued)*

She spent an additional five years working as a Mentor for the STAR FASD Prevention Program at the Cree Nation Tribal Health Centre in The Pas, MB. Daphne's education and ten years as a front-line worker has provided her with extensive insights into the behaviours surrounding indigenous peoples as a result of colonization and genocide in Canada. Her challenge lies in working at de-colonizing the emotional, mental and spiritual pitfalls experienced by Indigenous peoples of Manitoba by practicing living the good life. Most recently, Daphne became the STAR Program Coordinator for Cree Nation Tribal Health Centre and was also appointed to sit on the Manitoba First Nations Child Advisory Committee. Finally, she takes pride for the opportunity of coordinating the Translating to the Communities: A Socio-Epigenetic Study on FASD through the University of Manitoba.

### **Nurturing the Seed: A journey to infant mental health and wellness**



#### **Chaya Kulkarni**

Chaya Kulkarni is Director of Infant Mental Health Promotion (IMHP) at The Hospital for Sick Children, a national organization focused on promoting and influencing practice, policy and knowledge in areas related to infant mental health. In her role with IMHP Chaya is currently leading advocacy and training initiatives in areas such as child welfare including family courts, and community-based programs supporting families in their neighborhoods. Prior to joining IMHP Chaya held positions as Vice President of Parent and Professional Education at Invest in Kids and as a Senior Policy Advisor at the Legislative Assembly of Ontario. Chaya has also sat on the Prime

Ministers Committee for the Award of Excellence, and currently sits on a number of committees within the health and social services sectors. She is also the co-author of a book, *Your Guide to Nurturing Parent Child Relationships*.



#### **Roberta Oshkawbewisens**

Roberta Oshkawbewisens works at Temiskaming Native Women's Centre - Keepers Of The Circle - Wisdom Keepers in Kirkland Lake as a Nookamis/Grandmother and a Traditional Facilitator. She has been in connection with T.N.W.S.G. & K.O.T.C for the past 10 year in facilitating Traditional and Cultural Support for both organization and community, Assembly of First Nations, Union Ontario Indians, Early Childhood Education students as well as other First Nations as Nookamis when requested. Roberta enjoys supporting and working with her community and other programs and agencies as resource. "I am a mother, grandmother, proud of my sons and grandchildren. Proud to share what I have learned and experienced with my grandmothers and grandfathers and family members."



#### **Ronda Guenette**

Ronda Guenette is a Child Care Site Supervisor with Keepers of the Circle. In this role, Ronda leads a team of educators providing Indigenous-based early learning and childcare for families in the community of Kirkland Lake. Ronda has more than 12 years' experience working in a variety of early learning and child care centres and is passionate about the positive influence child care can provide to the children, families and community she serves. As a Registered Early Childhood Educator, Ronda recognizes the value of culturally appropriate early interventions that address the mental health of infants and children.

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### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

2:00 pm

#### Part 2: Implementation Team Talks *continued*

Facilitated by James Reynolds, PhD

► **Governor General Ballroom**

*Sponsored by School of Medicine, Queen's University*



In this series of presentations, KBHN researchers and key partners will tell their stories that focus on the implementation of research innovations aimed at improving outcomes for children and families.

#### **Social ABCs: A parent-mediated intervention for toddlers with early signs of Autism Spectrum Disorder**



##### **Jessica Brian**

Jessica Brian is a Psychologist and Clinician-Investigator at Holland Bloorview Kids Rehabilitation Hospital and Assistant Professor at the University of Toronto in the department of Paediatrics. She also co-leads the Autism Research Centre at Holland Bloorview. Dr. Brian received her Ph.D. from the clinical-developmental program at York University and received intensive training in Applied Behaviour Analysis during a full-year internship at the Princeton Child Development Institute in New Jersey. Jessica has been heavily involved in a range of multi-site research programs aimed at understanding the emergence of ASD, the behavioural phenotype, and genetic markers of ASD

and related disorders. For over a decade, Dr. Brian has been involved in the Canadian Infant Siblings Study, and is a member of the international Baby Siblings Research Consortium. Jessica co-developed and led the evaluation of the Social ABCs, a very early parent-mediated intervention for infants and toddlers with emerging ASD or related social-communication challenges.



##### **Irene Drmic**

Dr. Irene Drmic is a Psychologist at the Ron Joyce Children's Health Centre in the Autism Spectrum Disorder (ASD) Program and Child and Youth Mental Health Program. Her clinical and research interests include mental health in individuals with neurodevelopmental disabilities, phenotypic and genetic overlap of ASD and other neurodevelopmental disorders, predictors of treatment response and outcome, and program development and evaluation.



## CONFERENCE PROGRAM

### DAY 2 WEDNESDAY, DECEMBER 11<sup>th</sup>

2:00 pm

#### Part 2: Implementation Team Talks *continued*

Facilitated by James Reynolds, PhD

► **Governor General Ballroom**

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In this series of presentations, KBHN researchers and key partners will tell their stories that focus on the implementation of research innovations aimed at improving outcomes for children and families.

#### **Moving from research to social action: Navigation support for families of children with neurodisabilities**



##### **Lucyna Lach**

Lucyna Lach is an Associate Professor in the School of Social Work, McGill University and an Associate Member of the Departments of Pediatrics and Neurology/Neurosurgery in the Faculty of Medicine, McGill University. Her program of research focusses on the quality of life of children with neurodisabilities and their caregiver (i.e. caregiver health, and parenting). Dr. Lach's current projects address social determinants of health of children with neurodisabilities. She is co-leading a team of researchers and trainees who are using population-based as well as administrative and clinical databases to document determinants such as income, service use, and educational

outcomes. She is part of a recently funded Strategic Patient-Oriented Research (SPOR) Team entitled CHILDBRIGHT, as co-lead of one of three themes that is evaluating five intervention/prevention approaches to supporting children with neurodisabilities and their families. Dr. Lach is currently the Co-PI of a KBHN funded project on System and Resource Navigation to which she will be speaking.



##### **Angela Clancy**

Angela Clancy has been the Executive Director of the Family Support Institute (FSIBC) for 18 years. In her role at FSI, she has been able to maximize her long history of experience and education with families who face the extraordinary challenges that come with having a family member with a disability. Angela's brother, Alan, requires ongoing supports throughout his life due to disability challenges and continues to inspire her both personally and professionally. Angela's education and life experience have led her to form a strong value system based on equal rights, equal opportunities, and community inclusion for all people. Angela has three daughters who have all

individually taught her lessons about herself, her dedication to family, how to maximize every opportunity in your life and to cherish every minute and every experience.

3:30 pm

#### **Closing Remarks**

► **Governor General Ballroom**

*Speakers* **Nicky Lewis**, Chief Executive Officer, Kids Brain Health Network  
**James Reynolds**, PhD, Chief Scientific Officer, Kids Brain Health Network

## CONFERENCE PROGRAM COMMITTEE

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### **James Reynolds, PhD**

Dr. James Reynolds is a Professor in the Department of Biomedical and Molecular Sciences and the Centre for Neuroscience Studies, and an Associate Dean in the School of Graduate Studies, at Queen's University in Kingston, Ontario. Dr. Reynolds has been involved in research on Fetal Alcohol Spectrum Disorder (FASD) for over 25 years, and over that time his research program grew to encompass both basic and clinical investigations. Dr. Reynolds has served the Network in a number of roles, including leading the FASD Research Program in the Kids Brain Health Network since 2010, serving as the investigator representative on the Board of Directors, and as the Deputy Scientific Director (2015-18). In March, 2019 Dr. Reynolds was appointed as the Chief Scientific Officer of the Kids Brain Health Network.

### **Francois Bolduc, MD, FRCPC, PhD**

Dr. Francois Bolduc completed his medical school in Sherbrooke, Quebec, Canada. He moved to Montreal to study pediatrics at Hôpital Ste Justine (Université de Montreal) and then pediatric neurology at McGill University's Montreal Children Hospital. He obtained his PhD from Cold Spring Harbor Laboratory, NY, USA in neurogenetics. Dr. Bolduc is a clinician-scientist in pediatric neuroscience and pursues his work on cognition in human using next-generation sequencing in individuals with neurodevelopmental disability (NDD) and his exploration of the mechanisms linking memory and NDD using *Drosophila* at the University of Alberta. More recently, his work has also included exploration of navigation and coaching for families, educators and health professionals interacting with individuals with NDD using artificial intelligence. Dr. Bolduc is passionate about bridging basic and clinical sciences to improve quality of life for individuals with NDD and their families.

### **Sara Raza, MSc, PhD candidate**

Sarah Raza is a PhD student in the Department of Pediatrics at the University of Alberta. She previously completed her MSc in neuroscience at the University of Lethbridge, where she investigated the role of early experiences on brain development and subsequent behavioral outcomes. Currently working on her PhD under the supervision of Dr. Lonnie Zwaigenbaum, Sarah's doctoral research is part of the Canadian Infant Sibling Study. Her work focuses on understanding the developmental pathways and risk factors leading to the emergence of autism spectrum disorder in at-risk infants, with particular emphasis on the role of emotion regulation (using a behavioral-physiological approach). Sarah has been a KBHN trainee since 2015, and is actively involved on the Trainee Advisory Committee and the Trainee Policy and Advocacy Committee.

## CONFERENCE PROGRAM COMMITTEE

### **Christiane Rohr, PhD**

Christiane Rohr is an Alberta Innovates Postdoctoral Fellow with Dr. Signe Bray at the University of Calgary, and based at the Alberta Children's Hospital Research Institute. She earned her PhD at the Max Planck Institute for Human Cognitive and Brain Sciences in Berlin and Leipzig, Germany, where she conducted research into how individual differences in brain function associate with behaviour. She has since expanded this approach to assess potential brain-based markers of behaviours that are affected in children with ADHD or autism, in a variety of ways, and with the view that relevant predictors may ultimately be used to improve outcomes. Christiane is active on KBHN's Trainee Policy and Advocacy Committee.

### **Doug Swanson, PhD**

Doug Swanson has been a part of Kids Brain Health Network from its inception back in 2010. He took on the role of Research and Training Manager to help oversee the implementation and growth of the nation-wide Training Program. He received his PhD in Neuroscience from the University of Florida and continued his postdoctoral training at Oregon Health Sciences University and the University of Tennessee Health Science Center. His work as a developmental neuroscientist has taken him from his early work in animal models of FASD to studies of the genetic underpinnings of normal and abnormal brain development. His work with KBHN now focuses on maximizing the efforts of Network researchers and trainees and developing innovative ways of training young researchers to become the "next generation" of leaders in neurodevelopmental disorder research.

### **Jennifer Zwicker, PhD, MPP**

Jennifer Zwicker, MPP, PhD, is Director of Health Policy at the School of Public Policy and an assistant professor in the Faculty of Kinesiology, University of Calgary. With broad interests in the impact of health and social policy on health outcomes, Dr. Zwicker's recent research utilizes economic evaluation and policy analysis to assess interventions and inform policy around the allocation of funding, services and supports for children and youth with developmental disabilities and their families. Utilizing longitudinal analysis of the national and administrative data sets, Dr. Zwicker's research is aimed at improving outcomes for children with developmental disabilities and their families from a life course perspective, important for both our evaluation studies and informing policy development to address unmet needs.

## Poster Number / Presenter / Title

### Theme 1 - Community Engaged Research

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- |            |                                    |   |
|------------|------------------------------------|---|
| <b>#1</b>  | Erin Dempsey                       | <b>Moral Foundations Theory in Autism Spectrum Disorder: A Qualitative Investigation</b>  |
| <b>#2</b>  | Isabelle Darveau                   | <b>Community-Based Concussion Prevention and Management Program for Children and Adolescents in Schools</b>                                       |
| <b>#3</b>  | Mojgan Gitimoghaddam               | <b>The Impacts of Physical Activity Programs on Development of Children with Neurodevelopmental Disabilities: Parents' Perceptions</b>            |
| <b>#4</b>  | Emily Collis                       | <b>Nurturing the Seed: A collaborative journey to infant mental health and wellness</b>   |
| <b>#5</b>  | Tracy Moisan                       | <b>FASD &amp; Me: Strengthening My Community</b>  |
| <b>#6</b>  | Andrea Cross                       | <b>Building capacity for families as partners in research: A national online training program for families and researchers</b>                    |
| <b>#7</b>  | Kinga Pozniak                      | <b>ENVISAGE: A workshop for parents, by parents. Report of a new research program.</b>  |
| <b>#8</b>  | David Nicholas                     | <b>Unveiling the service delivery landscape for individuals with neurodevelopmental disabilities: Parents' and service providers' experiences</b> |
| <b>#9</b>  | Wendy Mitchell                     | <b>Service Access and Navigation Needs of Children with Neurodevelopmental Disabilities in Rural Communities in Alberta</b>                       |
| <b>#10</b> | Lucy Lach                          | <b>Examining and Building Systems Capacity in Health: The Example of Navigation Service Advancement for Families in which a Child has a NDD</b>   |
| <b>#11</b> | Hannah Randolph                    | <b>Listening to the community: recommendations for optimal service provision to polyimpaired children and their families</b>                      |
| <b>#12</b> | Kirsti Mardell and Crystal Shannon | <b>Family engagement in child health research needed</b>  |

## Poster Number / Presenter / Title

### Theme 2 - Knowledge Translation Initiative

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- |            |                     |  |
|------------|---------------------|--|
| <b>#13</b> | Crystal Shannon     | <b>“There’s nothing here”:</b> perspectives from rural parents promoting safe active recreation for children living with autism spectrum disorders                 |
| <b>#14</b> | Monika Novak Pavlic | <b>Grandparents of Children with Disabilities: A Scoping Review</b>  |
| <b>#15</b> | Saeideh Shahin      | <b>Examining the environmental factors that have an impact on workplace participation of transition-aged youths and young adults with brain-based disabilities</b> |
| <b>#16</b> | Annie Taskiran      | <b>Would diagnosing adhd from li differentially allow for more effective intervention strategies to be implemented academically?</b>                               |
| <b>#17</b> | Meaghan Reitzel     | <b>Describing discharge policies in paediatric rehabilitation— Does policy impact access to services?</b>  |
| <b>#18</b> | Suzanne Jorisch     | <b>Research Unlocked:<br/>Making research publications accessible to clients and families</b>  |
| <b>#19</b> | Arbella Yonadam     | <b>Best Practices for Communicating Mental Health in Paediatric Healthcare Settings: A Scoping Review</b>  |
| <b>#20</b> | Anton Miller        | <b>How does service adequacy influence the relation between child behavior problems and negative impact among families of children with neurodisability?</b>       |
| <b>#21</b> | N/A                 | This poster has been withdrawn   |

## Poster Number / Presenter / Title

### Theme 3 - Basic Research

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- #22** Sarah Raza **A Novel Approach to Modeling Emotion Regulation in Autism Spectrum Disorder**
- #23** Lori Sacrey **Physiological Measurement of Emotion from Infancy to Preschool**
- #24** Gabriela López-Arango **Repetition suppression as an electrophysiological correlate of habituation is associated with adaptive skills during the first year of life**
- #25** Camille Noiseux-Lush **The impact of increased head circumference on the repetition suppression mechanism during the first year of life: An EEG study**
- #26** Behnaz Bahmei and John Yang **Exploring the nature of auditory hypersensitivity in Autism Spectrum Disorder**
- #27** Sarah Hutchinson **Everyday Executive Function Associated with Adaptive Functioning in Children and Adolescents with Prenatal Alcohol Exposure**
- #28** Christiane Rohr **White Matter Tract Signatures of ADHD and Emotional Lability Traits in Young Children**
- #29** Zeenat Ladak **A Therapy to Prevent Neurodevelopmental Disabilities: Protection of Brain Cells by Sulforaphane**

**Poster Number / Presenter / Title**

## Theme 4 - Clinical/Community Research

- #30** Meghan Ford "It's hard to find support": Utilization, barriers and future needs of therapeutic interventions for parents of children with early brain injury
- #31** Jael Bootsma Assessing language comprehension in children with speech and motor impairments
- #32** Ayesha Siddiqua Association between neighbourhood socioeconomic status and development of kindergarten children with Autism Spectrum Disorder: A pan-Canadian study
- #33** Heather Shearer Short-term pain trajectories and well-being in children and youth with cerebral palsy: A feasibility study
- #34** Trish Domi Radiographic Patterns of Injury and Risk Factors in Children with Hemiplegic Cerebral Palsy
- #35** Daniela Chan-Viquez Movement-tracking video game for upper limb home rehabilitation for children with cerebral palsy
- #36** Analyssa Cardenas Inpatient Rehabilitation Exergames in Children with Cerebral Palsy after Lower Extremity Orthopedic Surgery: A Feasibility Study
- #37** Abhishek Dhankar Natural Language Processing Based Automated Website Vetting for Neurodevelopmental Disability
- #38** Brittany Finlay Parent and Youth Experiences Accessing Government Disability Programs Across Canada: A Mixed-Method Analysis
- #39** Matthew Russell Administrative data analysis of family disability service use among families with young children with disabilities
- #40** Patrick Berrigan The Cost-effectiveness of screening tools used in the diagnosis of fetal alcohol spectrum disorder: A modelled analysis
- #41** Jessica Lewis Combining Cognitive Rehabilitation with Reading Intervention for Children with Learning Disabilities
- #42** Elizabeth Keys Transdiagnostic eHealth Sleep Intervention for Parents of Children with Neurodevelopmental Disorders
- #43** Linda Nguyen Understanding the essential components and experiences of youth with autism spectrum disorder in peer mentorship programs
- #44** Annie Richard Pragmatic language difficulties in people with epilepsy reflect shared biological mechanisms causing both epilepsy and autism spectrum disorder

## Theme 1 - Community Engaged Research

## Poster # 1

**Moral Foundations Theory in Autism Spectrum Disorder: A Qualitative Investigation**Presenter **Erin Dempsey****Author(s):** E. E. Dempsey<sup>1</sup>, C. Moore<sup>1</sup>, I. M. Smith<sup>1,2,3</sup>**Organization(s):** <sup>1</sup>Department of Psychology and Neuroscience, Dalhousie University;<sup>2</sup>Department of Pediatrics, Dalhousie University; <sup>3</sup>Autism Research Centre, IWK Health Centre**Abstract:**

Moral thinking is integral to how humans treat each other and non-human animals. Subtle differences in moral reasoning have been found between autistic and neurotypical individuals. Research in this area has been framed by theories of moral psychology that suggest that hierarchical moral principles develop from the ability to take the perspectives of others, i.e., perspective taking. Yet, even autistic individuals, who sometimes differ in their ability to automatically consider the perspectives of others, show moral judgements similar to neurotypical individuals. Moral foundations theory is a psychological theory that presents a non-hierarchical account of moral principles. These principles address five domains of moral judgements: care/harm, fairness/reciprocity, in-group/loyalty, authority/respect, and purity/sanctity. An individual's thoughts or actions reflecting the relative importance of each domain depends on such factors as culture, socioeconomic status, and political orientation. This theory relies less on perspective-taking ability than do rationalist accounts, emphasizing the role of emotions in moral decision making instead. As such, moral foundations theory could help make sense of similarity in moral judgements made by autistic and neurotypical individuals. Moral foundations theory has not yet been investigated among autistic research participants.

The current qualitative study used critical incident interviews and thematic analysis as an initial foray into understanding first-person autistic moral thinking through a strengths-based lens. We sought to investigate whether each of the moral foundations was represented in autistic moral thinking, and the degree to which emotions influenced the moral decision-making process.

We found that each of Haidt's five moral foundations was represented in the interviews. However, emotions posited to be related to moral decision making did not feature prominently among autistic individuals' reasoning about whether certain transgressions were immoral. We discuss implications for theory and future research.

**Funded by:**

E.E. Dempsey is supported by the Maritime SPOR Support Unit (MSSU), which receives financial support from the Canadian Institutes of Health Research (CIHR), the Nova Scotia Department of Health and Wellness, the New Brunswick Department of Health, the Nova Scotia Health Research Foundation (NSHRF), and the New Brunswick Health Research Foundation (NBHRF). The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources. No endorsement by the MSSU or the named funding partners is intended or should be inferred.

I.M. Smith is supported by the Joan & Jack Craig Chair in Autism Research

**Keywords:**

Autism spectrum disorder, moral psychology, moral foundations theory, social cognition, ethics



## Theme 1 - Community Engaged Research

## Poster # 2

## Community-Based Concussion Prevention and Management Program for Children and Adolescents in Schools

Presenter **Isabelle Darveau**

**Author(s):** I. Darveau<sup>3</sup>, N. LeBlanc<sup>1,2</sup>, M. S. Doucet<sup>2</sup>

**Organization(s):** <sup>1</sup>Vitalité Health Network; <sup>2</sup>Université de Sherbrooke; <sup>3</sup>New Brunswick Public Health

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**Abstract:**

Concussions are common amongst children and adolescents, and while they potentially result in severe and permanent brain damage, symptoms are often neglected. Similarly, programs involving the collaboration of the education and health sectors, and the community to address this gap are deficient. Hence, it is imperative to address this discrepancy by implementing a community-based program, bridging the health and education sectors, to foster appropriate and timely concussion intervention. Here, we describe an evidence-based concussion prevention and management program that aims to minimize and prevent the impact of brain injuries among children and adolescents, and reduce associated risk factors.

Consensus-based policies and procedures were developed based on existing guidelines and were applied to the concussion program. The program established a sustainable data acquisition infrastructure to provide recommendations from acquired actionable data and was applied in 37 schools totaling over 16,000 students in the Francophone South School District (New Brunswick, Canada). This multisector collaboration facilitated health and education data sharing and enabled highly personalized continuous improvement regarding concussion prevention (e.g., age, location, sport).

Collectively, the health, education and community sectors developed clear and uniform evidence-based concussion management policies and procedures to foster appropriate and timely intervention, and adequate management for children and adolescents by assembling a relevant and versatile team of individuals (e.g., parents, physicians, health professionals, school personnel, community members).

This study explores how a concussion prevention and management program based on data improves health outcomes. Data such as program compliance, school attendance and grades, location, sex and concussion history is collected and will be essential in improving prevention and intervention. Furthermore, these outcomes will be critical to evaluate the impact of the program on the students' health and education.

This study exhibits a sustainable and adaptable program based on data that addresses the gap relating to prevention and management of concussions for children and adolescents in the community by collaborating with the education and health sector.

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**Funded by:**

Vitalité Health Network, Francophone South School District of New Brunswick, New Brunswick Trauma Program

**Keywords:**

Concussion, Prevention, Community, Education, Big data

## Theme 1 - Community Engaged Research

## Poster # 3

## The Impacts of Physical Activity Programs on Development of Children with Neurodevelopmental Disabilities: Parents' Perceptions

Presenter **Mojgan Gitimoghaddam**

**Author(s):** M. Gitimoghaddam<sup>1</sup>, W. H. McKellin<sup>1</sup>, A. R. Miller<sup>1</sup>, J. P. Collet<sup>1</sup>

**Organization(s):** <sup>1</sup>University of British Columbia

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**Abstract:**

**Introduction:** Children with neurodevelopmental disabilities/disorders (NDD/D) often have lower levels of participation in physical activities than typically developing children. Consequently, they miss important opportunities for physical and psychosocial development. Community-based physical activity programs (PAPs) offer a context for personalized, adapted activities to enhance the child's motor skills and social development. Formal documentation of the effects of PAPs on the development of children with NDD/D remains limited, however.

**Objectives:** To explore parents' perception of changes in their child's physical, psychological and social functioning following attendance at PAPs.

**Methods:** 85 parents of children with NDD/D were recruited from 23 PAPs. Baseline and 3 monthly structured interviews were conducted with each parent over the course of one year. In the follow-up interviews, we asked parents to indicate their perception of changes in their child during the previous 3 months. If a change was reported, parents were asked to indicate their perception regarding the reason for the change and the contribution of attending the PAP. In order to prevent the bias in our report, we report data from 43 parents from multiple sites (the other 42 parents all belong to the same single site): 3 interviews with 18 parents, 2 with another 18 and 1 with 7 parents.

**Results:** The sample comprised predominantly male children (77%) with mean age 9.5 years. The most common reported improvements were in physical function with 41% of parents reporting improvements in the first follow up interview and 52% in the second. When the reported improvements related to physical, cognitive or mental functions, 50-60% of parents indicated that attending the PAP was the most important contribution to the change. For improvements in behavioural or social functions, parents reported other important social activities, such as attending other social groups or school as responsible for the change. Finally, parents perceived that the initial change in physical and psychosocial functioning led to other improvements such as self-confidence, motivation, and the development of friendships.

**Conclusions:** These findings highlight the specific contributions of PAP participation to the complex dynamics of learning and development by children with NDD/D.

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**Funded by:**

Kids Brain Health Network

**Keywords:**

Children, Disability, Physical activity, Parent, Development, Learning

## Theme 1 - Community Engaged Research

## Poster # 4

**Nurturing the Seed: A collaborative journey to infant mental health and wellness**Presenter **Emily Collis****Author(s):** E. Collis<sup>1</sup>, J. Reynolds<sup>1</sup>, C. Kulkarni<sup>2</sup>, A. Ramos<sup>1</sup>, J. Robertson<sup>2</sup>, K. Peterson-Katz<sup>1</sup>, N. Tuzi<sup>2</sup>, N. Khambati<sup>2</sup>**Organization(s):** <sup>1</sup>Center for Neuroscience Studies, Queen's University; <sup>2</sup>The Hospital for Sick Children, Infant Mental Health Promotion**Abstract:**

Despite the known value of culturally meaningful practice in supporting mental health in Indigenous communities, there lacks culturally informed developmental screening tools and interventions to serve the specific needs of this population. Nurturing the Seed (NTS) addresses this gap, and was designed to support the work of all frontline practitioners in addressing the developmental needs of young Indigenous children. These children are at a greater risk for poor outcomes due to generational familial trauma. Developed by Infant Mental Health Promotion in consultation with key stakeholders, NTS melds worldviews and practices distinct to Indigenous communities with evidence-based assessment tools and customized developmental support planning. The program utilizes a relational approach to addressing physical, social, and emotional development in young children. The aims of the project are to: (1) train non-Indigenous service workers to adopt a culturally informed approach to supporting Indigenous children and families; (2) evaluate the efficacy of NTS by examining child development scores, as well as global measures of parental wellbeing and stress; and (3) strengthen the knowledge of all participants about early mental health and their importance in supporting healthy brain development.

To-date, we have engaged six Canadian communities, in which the following work plan is taking place:

- **Initial Advisory Community Meeting:** Indigenous community representatives and Elders provide cultural consultation on program design, methodology, and feasibility of implementation in the community.
- **Training:** A 3-day training workshop equip practitioners with infant mental health knowledge; the ability to administer the developmental screening tool, and create individualized developmental support plans using NTS.
- **Evaluation:** Developmental assessment will occur at 3-4-month intervals utilizing the Ages and Stages Questionnaires.
- **Coaching:** Staff in all communities will participate in coaching sessions using a blended model of face-to-face and online sessions.

Preliminary data supports the notion that this screening and intervention model can alter the developmental trajectory of at-risk children such that they achieve developmental milestones. The research team will establish proof of principle for scaling the use of an early screening and intervention model to Indigenous populations across Canada, and improving the sensitivity, aptitude and skill set of frontline service agencies that work with Indigenous communities.

**Funded by:**

Kids Brain Health Network, Infant Mental Health Promotion

Theme 1 - Community Engaged Research

Poster # 5

## FASD & Me: Strengthening My Community

Presenter **Tracy Moisan**

**Author(s):** T. Moisan  
**Organization(s):** Adopt4Life

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**Abstract:**

Adopt4Life provides support, advocacy and resources to families formed through adoption, kinship, and customary care. Our mission is to strengthen and empower parents and caregivers to create permanency within a family for children, so they can reach their full potential. While FASD prevalence in Canada is currently understood to be ~4% of the population, it's widely acknowledged that there is a significant over-representation of children with FASD in Canada's child welfare systems—as much as 15x higher. Within Adopt4Life's community of more than 1500 community parents, hundreds have identified they are raising children living with FASD, and countless more seek our support as they work tirelessly to navigate the path to accurate diagnosis, applicable services and interventions, and long-term success strategies for their children.

Earlier this year, Adopt4Life developed a project to aid parents and caregivers in helping their children understand FASD; building understanding of, and support within, their communities; and develop personalized understanding of their children's unique needs and characteristics.

Delivered as an interactive workshop, the project leverages the workbook **"FASD and Me, Strengthening My Community"**, which has been developed and published by Adopt4Life with support from Health Nexus. The booklet is a tool for children, that also empowers parents and caregivers to understand and apply leading FASD research and recognized Canadian resources, in a way that's actionable for their families and support networks.

The workbook covers topics such as:

- Helping children and families understand FASD, the diagnosis, and recognizing behaviours as symptoms;
- Navigating how children can take ownership of their challenges and strengths, and end misconceptions about FASD;
- The importance of teaching our children to have a voice and learning to self-advocate;
- Enabling ongoing conversations and learnings from educators, community members, and support professionals
- How parents can help their child to embrace FASD in their community.

Parents and caregivers can purchase the workbook as a standalone resource, whereas professionals/organizations can engage Adopt4Life for workshops with larger groups of parents/caregivers, or simply provide their clients/families with workbooks to use on their own.

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**Funded by:**  
Adopt4Life

**Keywords:**  
FASD, Community, Children & Youth, Adoption, School, Education

## Theme 1 - Community Engaged Research

## Poster # 6

## Building capacity for families as partners in research: A national online training program for families and researchers

Presenter **Andrea Cross**

**Author(s):** A. Cross<sup>1,2,3</sup>, D. Thomson<sup>1,2,4</sup>, C. Putterman<sup>1,2,4,5</sup>, and K. Pozniak<sup>1,2,3</sup>

**Organization(s):** <sup>1</sup>CanChild Centre for Childhood Disability Research; <sup>2</sup>Kids Brain Health Network; <sup>3</sup>McMaster University; <sup>4</sup>CHILD-BRIGHT; <sup>5</sup>University of Toronto

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**Abstract:**

**Background:** Internationally, it is recognized that research benefits from meaningful stakeholder involvement. However, **how** stakeholders are engaged in research is not self-evident and the demand for such roles has not kept pace with the need for appropriate training. In this poster, we will share evidence and experiences of researchers and families in a national online training program: 'Family Engagement in Research Certificate of Completion Program', run in partnership by Kids Brain Health Network, CanChild, and McMaster Centre for Continuing Education.

**Methods:** To date, 36 students (19 research trainees; 17 family members) have graduated from the program. Using a before-after follow-up study design, we conducted a pilot evaluation to explore the feasibility of the program, and the impact of the program on participants' knowledge, attitudes, and self-confidence in family engagement in research. Data collection includes: i) surveys completed pre- and post- the program; ii) semi-structured interviews completed following the course; and iii) focus groups completed 9-months post-intervention to explore longer term impacts.

**Results:** Our target recruitment/retention was 20 participants completing the program in Year 1. We accepted 40 participants in total and had four dropouts (1 trainee and 3 parents). A total of 36 participants completed the program (90% retention rate). All dropouts occurred during the first few weeks after recognizing they did not have the time to fully commit to the course. Overall, the course was highly rated amongst students with a mean of 8.7/10 (N= 21) in regards to participant satisfaction. Both graduate student research trainees and families expressed that they gained confidence and competence in family engagement in research.

**Conclusion:** This program is unique in that it brings families together with trainees in order to enhance knowledge and skills surrounding family engagement in research and to build a trusted community for leadership, mentorship and collaboration. We believe that this work will have wide generalizability to other training initiatives and that many of the families and graduate student research trainees will go on to be leaders in the field of family engagement in research and will have a transformative impact on the way childhood disability research is conducted in Canada and internationally.

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**Funded by:**

Kids Brain Health Network

**Keywords:**

family engagement in research; family-researcher partnerships, training

Theme 1 - Community Engaged Research

**Poster # 7**

**ENVISAGE: A workshop for parents, by parents.  
Report of a new research program.**

Presenter **Kinga Pozniak**

**Author(s):** R. Martens, K. Pozniak, M. Novak Pavlic, A. Cross, P. Rosenbaum

**Organization(s):** McMaster University and CanChild

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**Abstract:**

'Early intervention' in pediatric research has traditionally focused on children's development in many spheres of function. With the increased embrace of family-centred models we are seeing a growing emphasis on supporting parents and caregivers. A second important development has been the priority to engage with patients and caregivers, and to develop research questions and approaches to implementation in close collaboration with parents. These paradigm shifts underpin the development of ENVISAGE, an integrated research program in which parents and researchers are working in partnership to develop a parent-focused online 'early intervention' program for families.

The '**ENVISAGE: ENabling VISions And Growing Expectations**' program is an intervention developed for parents, by parents and researchers together. It is an online, interactive workshop series designed to empower parents of children with disabilities to build confidence and competence and to connect and communicate effectively with service providers to improve parent and family outcomes. The content offered reflects contemporary concepts in child and family development, childhood disability, and parent-professional collaboration.

ENVISAGE is being undertaken as a research study that has been built over five phases, and is currently in its fourth phase. We have developed and beta-tested the content of the ENVISAGE workshops and are now entering the pilot trial. The pilot study will be conducted in Canada and Australia with parents who have children under six years of age. We will assess the program's impact on parents' well-being and their sense of confidence, family functioning, and empowerment.

In this poster presentation we will outline the development path of ENVISAGE, and describe in particular the process of parent-researcher partnership and how it has shaped the content and format of the program in many important ways. We will share our early findings about the major issues faced by caregivers in their journey into childhood disability, and outline strategies for supporting parents in making life-course choices. Finally, we will outline next steps and future directions for evolving the ENVISAGE program in light of parents' needs and feedback.

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**Funded by:**

CIHR, Pedal for Peter through the American Academy for Cerebral Palsy and Developmental Medicine

**Keywords:**

parent-researcher partnership; parent engagement in research; family well-being; family-centered service; 'early intervention' for parents; impact on parents of intervention programs

## Theme 1 - Community Engaged Research

## Poster # 8

## Unveiling the service delivery landscape for individuals with neurodevelopmental disabilities: Parents' and service providers' experiences

Presenter

**David Nicholas****Author(s):** D. Nicholas<sup>1</sup>, R. Zulla<sup>2</sup>, W. Mitchell<sup>1</sup>**Organization(s):** <sup>1</sup>University of Calgary; <sup>2</sup>University of Alberta**Abstract:**

Across their developmental trajectory, children with neurodevelopmental disabilities (NDD) will have multiple needs and thus require finding services from a variety of different sectors. In this mixed methods study, survey as well as individual and group interview data were collected from 17 youth with NDD, 93 parents and 31 service providers in Alberta.

Findings demonstrate that the search for services across health, education, disability and the social care sectors is fraught with multiple gaps. Parents describe the service delivery landscape as a 'maze' comprised of 'multiple hoops' that involve lengthy paperwork, engaging with multiple people, enduring long waiting times for services, and tirelessly advocating for services that the child with NDD is qualified for and needs. This landscape is further complicated with frequent changes in program and funding eligibility, and parental gaps in awareness of services, and a lack of knowledgeable service providers regarding service access pathways. This has resulted in parents feeling "burnt out" and distrustful of services, and parental worry about whether or not services will be available for their child in the future. To buffer these stressful experiences, parents have relied extensively on their personal skills/resourcefulness (e.g., being proactive) and their social networks accrued throughout their journey of navigating services.

Service providers emphasized the need to create an integrated service approach that is premised on proactive principles and relationship-building across sectors, including ongoing professional and family development opportunities as well as attention to how service providers relate to one another and reach out to families. Implications of these findings suggest that facilitating the experience of searching for services for parents must move beyond individual capacity-building initiatives. Systemic processes need to be developed, with continual updating to ensure ongoing and equitable access. These findings and implications will be presented, as well as recommendations for moving forward.

**Funded by:**

KBHN, The Azrieli Foundation, Private Donor

**Keywords:**

Navigation, Neurodevelopmental disability, Families, Service Providers

Theme 1 - Community Engaged Research

**Poster # 9**

**Service Access and Navigation Needs of Children with Neurodevelopmental Disabilities in Rural Communities in Alberta**

Presenter **Wendy Mitchell**

**Author(s):** W. Mitchell<sup>1</sup>, D. Nicholas<sup>1</sup>, R. Zulla<sup>2</sup>  
**Organization(s):** <sup>1</sup>University of Calgary; <sup>2</sup>University of Alberta

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**Abstract:**

Children with neurodevelopmental disabilities require services across sectors including health, education and mental health. Unfortunately, the system of care is often fragmented, suboptimal, and difficult to navigate. As part of a larger project exploring service navigation needs, group interviews were conducted with 15 parents and 18 service providers in rural communities in Alberta to identify local needs and build on existing strengths.

Data were analyzed using Interpretive Description. Participants identified a lack of awareness about access to and availability of services as well as quantity/quality of services. They described sometimes not knowing what to ask of service providers/systems. Concerns were raised about key transitions such as youth to adulthood, given markedly fewer service options as youth aged. Wait times and limited availability of services were compounded by extended travel distances. Services were described as ill-equipped to address the breadth of child needs, and restrictive eligibility criteria reportedly limited access. Parents identified rural schools as community 'hubs' for connecting with services; however, schools were seen as insufficiently equipped to meet the breadth of child/youth needs. Coordination of care was identified as a major gap, warranting navigators and centralized services. Care access was limited by a lack of information-sharing across services. Staff vacancy and turnover was a key concern, with extensive delays in filling vacant positions. Conversely, a sense of community/solidarity was noted in some rural locales whereby parents reportedly supported one another, exchanged ideas, and sought to organize supportive collectives. Rural service providers noted strength in local partnerships and the importance of relationships with stakeholders, including engagement with families.

Implications and recommendations will be provided. We will identify considerations and strategies for developing rural capacity and leveraging community strengths and optimizing technology utilization.

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**Funded by:**

KBHN, The Azrieli Foundation, Private Donor, Alberta Health Services and PolicyWise

**Keywords:**

Navigation, Rural Communities, Neurodevelopmental Disabilities



## Theme 1 - Community Engaged Research

## Poster # 10

## Examining and Building Systems Capacity in Health: The Example of Navigation Service Advancement for Families in which a Child has a NDD

Presenter

**Lucy Lach****Author(s):** L. Lach<sup>1</sup>, D. Nicholas<sup>2</sup>, W. Mitchell<sup>2</sup>**Organization(s):** <sup>1</sup>McGill University; <sup>2</sup>University of Calgary**Abstract:**

This study has examined and advanced health and disability service access and navigational processes in three Canadian regions (Alberta, British Columbia and the Yukon) for families in which a child has a neurodevelopmental disability. We have sought 'Collective Impact' aims, based on tenets of Participatory Action Research (PAR). Regional teams from each province/territory identified key partners in disability and health sectors, who collectively determined system gaps and priorities for proactive change.

To date innovative changes have been implemented to navigation systems based on evidence that has been collected. As an example, based on feedback received from families in Vancouver, navigation support offered to children who have neurologic, psychiatric, and developmental pediatric service needs have been transformed. Preliminary findings indicate that families are very satisfied with this change as navigation is focused on supporting social determinants of health such as family overload, monetary issues, travel needs, and community supports that go beyond (and include) coordinating numerous appointments for families. In the Yukon, the implementation of a navigator in a remote community has positively influenced family trust and engagement with service providers, heightened cross-ministerial collaboration, and resulted in more timely access to services. In Alberta, greater understanding of multiple service systems/resources has been developed, including gaps and approaches for moving forward.

Based on PAR, regions have collectively developed and shared learnings, with key regional (and cross-regional) relationships being nurtured for both inquiry/learning aims and systems innovation. Backbone support by university partners has facilitated project evaluation, inter-regional communication and project coordination. Strategies linking research to action at a systems level, include the early integration of families, service providers and policy makers in the inquiry process, and the implementation and evaluation of 'pilots' as a driver to innovation. Data collection processes (interviews, focus groups, instruments, process evaluation) and findings will be conveyed, as will PAR considerations for systems-level capacity building. Implications and recommendations will be offered.

**Funded by:**

KBHN, The Azrieli Foundation, Private Donor

**Keywords:**

Navigation, Participatory Action Research, Systems change, Collective Impact

## Theme 1 - Community Engaged Research

## Poster # 11

**Listening to the community: recommendations for optimal service provision to polyimpaired children and their families**Presenter **Hannah Randolph****Author(s):** H. Randolph<sup>1,2</sup>, D. Chênevert<sup>2</sup>, A. Lajoie<sup>2,3</sup>, and A. Tsimicalis<sup>1,4</sup>**Organization(s):** <sup>1</sup>McGill University; <sup>2</sup>Centre Philou; <sup>3</sup>Université de Montreal; <sup>4</sup>Shriners Hospitals for Children®-Canada**Abstract:**

**Question we sought to answer:** Children with severe physical and intellectual disabilities (sometimes referred to as having profound intellectual and multiple disabilities, here referred to as polyimpaired) present complex, unique needs compared to children with less severe disabilities. Organizing and providing care for these children is a substantial task for family members. Despite this, the growing body of knowledge specific to polyimpaired children and their families largely focuses on characteristics, assessment, and intervention. A paucity of research has been conducted to understand their particular needs navigating health, social, educational, and community service networks. Our newly established community partnership sought to answer, *“What key recommendations can be made to improve service provision rendered to polyimpaired children and their families in and around Montreal, Quebec?”*.

**How we addressed our question:** A partnership was established between a community organization offering respite and developmental programs to polyimpaired children and a university-affiliated, pediatric orthopedic hospital. Together, they reached out to their networks of family members, community workers, administrative workers, and healthcare professionals to gain insight into their experiences navigating, providing, or coordinating services to polyimpaired children. These audio-recorded interviews were transcribed, analyzed, and synthesized into recommendations. An iterative review of the empirical literature was simultaneously conducted for added insight into the recommendations.

**What we want our audience to learn:** In-depth stakeholder interviews and iterative review of the empirical literature revealed different perspectives on the strengths and weaknesses of the current service provision systems. Seven recommendations were proposed: (1) Adopt a formal definition of polyimpairment at a policy level; (2) Teach the essentials of polyimpairment to all professionals who may encounter polyimpaired clients; (3) Ensure the availability of specialists where appropriate; (4) Ensure the presence of knowledgeable coordinating bodies; (5) Prioritize collaboration between professionals, disciplines, and service sectors; (6) Value small improvements in the child’s capacities while communicating openly about the child’s prognosis; and (7) Practice family-centered care and strive for individualized service provision. This preliminary work will inform a larger-scale study to understand the experiences of service provision to polyimpaired children and their families. This study integrated community and institutional expertise to identify ways to improve this reality for everyone involved.

**Funded by:**

Centre Philou and Shriners Hospitals for Children®-Canada Summer Bursary (H. Randolph)

**Keywords:**

polyimpairment; polyhandicap; profound intellectual and multiple disabilities; cerebral palsy; community; service provision

Theme 1 - Community Engaged Research

Poster # 12

**Family engagement in child health research needed**Presenters **Kirsti Mardell and Crystal Shannon****Author(s):** K. Mardell<sup>1,2</sup>, and C. Shannon<sup>1,3</sup>**Organization(s):** <sup>1</sup>Kids Brain Health Network; <sup>2</sup>McMaster University; <sup>3</sup>University of British Columbia, Okanagan**Abstract:**

**Issues addressed:** Family engagement in research is needed in order to bring communities such as parents of children living with neurodevelopmental disabilities a collaborative voice. Researchers and families may have different reasons for wanting to participate in pediatric research; however, their goals may still align when the commitment to foster better outcomes and positive change for child health is present. The authors formed a researcher-family partnership during the first cohort of the Family Engagement in Research (FER) Certificate of Completion, sponsored by Kids Brain Health Network in partnership with McMaster University. Together, Kirsti and Crystal, developed a knowledge translation (KT) tool in the form of an infographic to heighten awareness of the importance of integrated research teams.

**Context:** The authors met online during the FER course designed for graduate students and family members who share a joint interest for neurodevelopmental research. Their completed project is intended to illustrate the importance of family engagement in research for child health in a visually appealing manner that can be easily understood. The infographic is user-friendly and can be widely distributed to a variety of stakeholders using several platforms including: Facebook groups and organizations or can be posted on related websites.

**Project question and how this will be addressed:** Using an evidence-based approach, this KT project focused on providing insight to the question of what family engagement in research is, while outlining the reasons for researchers and benefits to parents in partnering together in child health research. The project's question was addressed by providing an operational definition that established the concept of family engagement being interchangeably with the terms 'patient engagement'; as the latter was more evident in the review of literature. The partners goal was to provide a family-centred explanation to the target populations at hand.

**Learning outcomes:** Audiences will gain awareness about how more inclusive representation in research can impact children living with neurodevelopmental disabilities when researchers and families set priorities together. The authors will present their KT project as an example of why this work is important for all parties involved.

**Funded by:**

Kids Brain Health Network

**Keywords:**

Family engagement, patient engagement, parents, child health, pediatrics, research

**“There’s nothing here”:  
perspectives from rural parents promoting safe active  
recreation for children living with autism spectrum disorders**

Presenter **Crystal Shannon**

**Author(s):** C. Shannon<sup>1,2</sup>, L. Olsen<sup>1,2</sup>, R. Hole<sup>1,2</sup>, K. Rush<sup>1</sup>

**Organization(s):** <sup>1</sup>University of British Columbia, Okanagan; <sup>2</sup>Canadian Institute for Inclusion and Citizenship

**Abstract:**

**Issues addressed:** Participation in recreational physical activity by children with Autism Spectrum Disorder (ASD) is important for improving health, fitness, and quality of life; however, these children and their families experience challenges and barriers at multiple levels that influence their participation levels. Barriers in access to opportunities for engaging in recreation may also be greater for families living in rural communities.

**Context:** The study was conducted in rural communities in the Okanagan region of British Columbia and focused on gathering information from parents in smaller, more remote communities in relation to safe physical activity needs, barriers and supports for children ages 3 to 12 years living with ASD.

**Study questions and how these will be addressed:** This masters thesis project focused on questions of how families and caregivers can promote safe, active, and inclusive recreation for their children with ASD and how rural communities can provide supportive and inclusive environments. The study questions were addressed using a qualitative methodology that involved in-depth interviews with parents; both mothers and fathers. Methods were also informed by a scoping review of literature and environmental scan of current recreational opportunities in the Okanagan region.

**Learning outcomes:** Participants will gain knowledge about study findings that showed how specific barriers and supportive factors played a role in rural families’ and communities’ efforts to promote safe, active, and inclusive recreation for children with ASD. Audiences will gain awareness about how parents’ child safety concerns were heightened in rural settings due to outdoor hazards, child bolting/wandering, concerns linked to child’s individual interests, contact with strangers and bullying. Additionally, a lack of local community programs, safe spaces/ facilities and trained facilitators were identified as significant barriers. Supports included parent involvement with recreational activities and perceptions of enhanced safety for their children in rural communities. Participants will learn how these results were directly informed by exploring the parents’ viewpoints in order to further understand how services and policies can be tailored to meet family needs across rural settings.

**Funded by:**

Social Sciences and Humanities Research Council (SSHRC)

**Keywords:**

Autism spectrum disorders, recreation, physical activity, parents, safety, rural

## Theme 2 - Knowledge Translation Initiative

## Poster # 14

## Grandparents of Children with Disabilities: A Scoping Review

Presenter **Monika Novak Pavlic**

**Author(s):** M. Novak Pavlic<sup>1,2</sup>, P. Rosenbaum<sup>1,2</sup>, L. Macedo<sup>1</sup>, B. DiRezze<sup>1,2</sup>, S. Abdel Malek<sup>1,2</sup>

**Organization(s):** <sup>1</sup>McMaster University; <sup>2</sup>CanChild Centre for Childhood Disability Research

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**Abstract:**

**Background:** The primary aim of the study was to summarize and describe the published evidence on non-custodial grandparents of children with physical, intellectual or developmental disabilities.

**Methods:** We utilized Arksey and O'Malley's five-stage scoping review methodology to explore grandparents' experiences, perceptions, and roles, with a specific focus on their grandchild(ren) with disabilities and their families. Four databases were searched: Medline, CINAHL, Embase, and PsycINFO. References were only included if they were reports of a primary study on non-custodial grandparents of children with disabilities.

**Results:** A total of 31 primary studies were selected and analyzed. The included studies were not limited by research design. The majority of the studies were qualitative in nature (n=22). The findings were organized into four key themes: 1) adjustment to grandchild's disability, 2) roles, 3) perceptions, and 4) experiences. Grandparents share unique challenges in their adjustments to their grandchild's disability. They play an important part in families of children with disabilities, a role that is often neglected by professionals. The grandparental roles, perceptions, and experiences are influenced by numerous factors, which were shown to have an impact not just on the grandparents' well-being, but also on the functioning of other family members and the family as a unit. Grandparents of children with disabilities have increased needs for education and support for themselves, but their access to services is extremely limited.

**Conclusion:** Grandparents' position in the family needs to be acknowledged by health, education and social services professionals. Services should include all significant family members and be delivered in a family-centred manner. Considerations for future experimental study designs are provided.

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**Keywords:**

grandparents, family-centred service, intergenerational relationships

## Theme 2 - Knowledge Translation Initiative

## Poster # 15

**Examining the environmental factors that have an impact on workplace participation of transition-aged youths and young adults with brain-based disabilities**

Presenter

**Saeideh Shahin****Author(s):**S, Shahin<sup>1,2</sup>, M, Reitzel<sup>3,4</sup>, B, DiRezze<sup>3,4</sup>, S, Ahmed<sup>1,2</sup>, D, Anaby<sup>1,2,4</sup>**Organization(s):**<sup>1</sup>McGill University; <sup>2</sup>CRIR; <sup>3</sup>McMaster University;<sup>4</sup>CanChild Centre for Childhood Disability Research**Abstract:**

**Introduction:** Transition-aged youth with brain-based disabilities experience poorer employment outcomes when compared to peers without a disability. Gaining knowledge on environmental factors is imperative to our understanding of the challenges in an understudied area that youth and young adults with brain-based disabilities face in the workplace.

**Purpose:** To synthesize existing knowledge on the impact of the environment on workplace participation of transition-age youths and young adults with brain-based disabilities.

**Methods:** A scoping review of peer-reviewed studies, published between January 1995 and June 2018, was conducted by searching OVID MEDLINE, EMBASE, PsychINFO, PubMed and CINHALL. Two independent reviewers systematically selected studies that explored the environmental impact on work participation in transition-aged youths aged 18-35 years old, that were written in English. Results were categorized into the four environmental domains of the International Classification of Functioning, Disability and Health (ICF); Products and technology & natural environment, supports and relationships, attitudes, and services, systems and policies.

**Results:** Thirty-one articles, both qualitative and quantitative, met the inclusion criteria. All aspects of the ICF environmental domains had an impact on the workplace participation of transition-aged youths with a variety of brain-based disabilities (e.g., spina bifida, cerebral palsy, epilepsy, intellectual disability, traumatic brain injury). The majority of the studies, 77%, highlighted the importance of services and supports at the institutional and organizational levels of the workplace, including policies, in the employment and inclusion of transition-aged youths and young adults with disabilities in the workplace. Sixty-eight percent of the studies explored the impact of social support from family, friends, employers and colleagues, 55% discussed the importance of a physically accessible workspace and assistive technology, and 11% focused on attitudes of colleagues and employers on workplace participation. Distinct findings demonstrated that educational level and socioeconomic status of the family influence the workplace participation of this population.

**Conclusion:** Findings support the need for interventions at the organization and institutional level. Partnering with stakeholders (i.e., clinicians, policymakers, employers) is key to jointly reduce barriers and reinforce supports, identified in this review, to improve participation and employment outcomes among transition-aged youths with brain-based disabilities.

**Keywords:**

Transition-aged youth, young adults, Brain-based disabilities, workplace participation, employment

## Theme 2 - Knowledge Translation Initiative

## Poster # 16

**Would diagnosing ADHD from LI differentially allow for more effective intervention strategies to be implemented academically?**

Presenter

**Annie Taskiran****Author(s):**

A. Taskiran

**Organization(s):**

McGill University, Department of Education

**Abstract:**

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neuropsychiatric disorders in children, with an estimated 5.29% prevalence in youth (Green, Johnson, & Bretherton, 2014), of which 3-7% are affected well into adulthood. Similarly, reading disorders and language impairments (LI) occur in approximately 5% of this population, too (Germanò et al., 2010). However, it is still unclear how LI can be correctly identified in ADHD, thus causing underdiagnoses within the ADHD population (Chan & Fugard, 2018). To complicate matters further, ADHD additionally co-occurs with conditions such as oppositional defiant disorder, anxiety, social problems, and crucially for this literature review, low academic achievement (AA) (Alloway & Stein, 2014; Gremillion & Martel, 2012). Furthermore, the mechanism responsible for the latter association still remains unclear, on top of having a significant gap between research findings about the matter and the course of action that is being implemented in education. In order to correct the misidentification of LI diagnoses, and in light of LI's co-occurrence with ADHD and low AA, this research paper uses a descriptive approach to uncover whether posing a differential diagnosis between the two disorders would allow for more effective intervention strategies to be implemented academically, in the hopes of bettering AA. The research conducted thus far suggests that diagnosing and subsequently treating these comorbid conditions separately could help improve AA in the long term. Conversely, failing to distinguish these concomitant disorders can affect treatment efficiency, which is why establishing a standardized diagnosis process would be capital in future considerations.

**Keywords:**

ADHD, LI, academic achievement, differential diagnosis

## Theme 2 - Knowledge Translation Initiative

## Poster # 17

**Describing discharge policies in paediatric rehabilitation—  
Does policy impact access to services?**Presenter **Meaghan Reitzel****Author(s):** M. Reitzel<sup>1</sup>, B. Di Rezze<sup>1,2</sup>, L. Letts<sup>1</sup> and M. Pheonix<sup>1,2</sup>**Organization(s):** <sup>1</sup>McMaster University; <sup>2</sup>CanChild Centre for Childhood Disability Research**Abstract:**

**Broad context:** Approximately 74,000 children and youth with disabilities receive publicly funded rehabilitation services from children's treatment centres (CTCs) in Ontario annually. Many families face barriers, such as travel, that limit service use and CTCs may manage missed appointments and client non-contact through discharge policies and procedures. The impact of discharge practices on families' access to rehabilitation services and potential effects on child outcomes are unknown.

**Research aims and methods:** This critical discourse analysis will investigate (i) what are the trends in discharge policy for how missed appointments are managed in Ontario's CTCs and (ii) how does the text of policy documents reveal common discourse(s) around missed appointments and potentially impact access to services. An intersectionality lens will be applied to critically explore potential social inequalities and imbalances in power relationships within current discharge practices to facilitate organizational change.

**Results:** 74 policy documents were collected from 18 CTC's in Ontario. 38 documents met inclusion criteria including: 19 formal policies and/or procedures, 3 documents created to support clinicians in sharing information with families about the policy, and 16 documents sent directly to families with information about a missed appointment. The following descriptive data was extracted: date of policy creation and revision, methods used to contact family, methods to support family attendance, procedures for management of missed visits, number of missed visits required before discharge, time to discharge after missed visits, and exceptions to the policies.

**Why is this important?** Information presented from initial phases of this qualitative study will support conference attendees' learning about trends in the management of non-attendance related discharge at Ontario CTCs and obtain information regarding the targeted outcomes of this study. In the next phase of analysis, use of a critical lens will uncover potential inequities and power imbalances within current discharge practices to guide recommendations for ethical and inclusive policies. These future results may strengthen the relationship between CTCs and the families they serve to support equitable access to service and improve developmental outcomes.

**Keywords:**

paediatric rehabilitation, policy, discharge, non-attendance, missed appointments, non-contact



## Theme 2 - Knowledge Translation Initiative

## Poster # 18

**Research Unlocked:  
Making research publications accessible to clients and families**Presenter **Suzanne Jorisch****Author(s):** S. Jorisch<sup>3</sup>, C. Provvienza<sup>1,2</sup>, N. Tanel<sup>2</sup>, R. Nesdale-Tucker<sup>3</sup>, K. Davis<sup>3</sup>, S. Babakhanova<sup>2</sup>, S. Kingsnorth<sup>1,2</sup>, S. Scratch<sup>2</sup> & A. McPherson<sup>2</sup>**Organization(s):** <sup>1</sup>Evidence to Care, Holland Bloorview Kids Rehabilitation Hospital; <sup>2</sup>Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital; <sup>3</sup>Research Family Engagement Committee, Holland Bloorview Kids Rehabilitation Hospital**Abstract:**

Clients and their families face many barriers when trying to access and use research findings that are published in academic journals. Published research is written for scientific audiences, and is often not available or tailored to meet the needs of clients and families. Lay summaries are one strategy to make research easy to understand and available to clients and families. While researchers often create lay summaries to share their information, these summaries are typically written using language that is difficult to understand and are shared with a small number of individuals. Scientists do not have the time, resources or training to write lay summaries that meet the needs of and target a broader family audience.

To address these barriers and make research findings accessible to clients and families within the childhood disability context, including neurodevelopmental disabilities, the Research Family Engagement Committee at Holland Bloorview Kids Rehabilitation Hospital worked with knowledge translation specialists and scientists to answer the following questions: 1. What information should be included in a family-focused lay summary?; and 2. What is an effective process for creating and sharing lay summaries? The team used a co-creation process involving a needs assessment and workshop activities to gather scientist and family perspectives. These activities informed the development of criteria for selecting the appropriate publications and a unique lay summary template. A 10 step process, called *Research Unlocked*, was developed to create the lay summaries to ensure the research summarized is scientifically accurate and relevant to clients, families and the broader community. Eleven summaries have gone through the *Research Unlocked* process. These summaries were launched in June 2019 and have been shared broadly through Twitter, family-focused Facebook groups and within Holland Bloorview.

*Research Unlocked* enhances access to childhood disability research findings. With improved access to research findings, clients and families are able to bring information that impacts them to the attention of others (e.g. clinicians, teachers), and use this information to request personalized care based on current research. Through this presentation we will share the selection criteria, lay summary template and the development process created through this work.

**Funded by:**

Centre for Leadership, Holland Bloorview Kids Rehabilitation Hospital

**Keywords:**

lay summaries, childhood disability, accessibility, knowledge mobilization

## **Best Practices for Communicating Mental Health in Paediatric Healthcare Settings: A Scoping Review**

Presenter **Arbella Yonadam**

**Author(s):** A. Yonadam<sup>1</sup>, A. McPherson<sup>1,2</sup>, and A. Snider<sup>2</sup>

**Organization(s):** <sup>1</sup>University of Toronto; <sup>2</sup>Holland Bloorview Kids Rehabilitation Hospital

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**Abstract:**

Young people with disabilities have been noted to experience higher rates of mental health issues, namely depression, anxiety, and social isolation, compared to their peers without disabilities. In particular, young people with spina bifida (SB), a congenital physical disability, have been shown to experience challenges related to their mental wellbeing. Despite this concern, literature regarding the mental health of this population is scarce, indicating the significance of exploring the mental health of young people living with disabilities, specifically individuals with SB.

The aim of this scoping review is to *identify, chart, and synthesize the existing knowledge about the most effective ways to communicate about mental health in a paediatric health care setting*. The scoping review will employ Arskey and O'Malley's six-stage scoping review framework, with updated recommendations from Levac, Colquhoun, and O'Brien. Additionally, the World Health Organization's rapid review guidelines will also be consulted throughout the review process.

Findings from the review will be presented to stakeholders (parents and young adults with SB) to obtain their perspectives and opinions on how study findings might be tailored and applied to i) a rehabilitation setting; and ii) for children with SB.

The long-term objective of this study is to develop clinical guiding principles/best practices that will assist in better equipping youth to cope with their mental health concerns in paediatric health care settings. Moreover, we hope to broaden the understanding of conference attendees about the significance of incorporating evidence-informed best practices of mental health communication in paediatric health care settings.

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**Funded by:**

CIHR

**Keywords:**

spina bifida, mental health, communication, paediatric health care

## Theme 2 - Knowledge Translation Initiative

## Poster # 20

## How does service adequacy influence the relation between child behavior problems and negative impact among families of children with neurodisability?

Presenter

**Anton Miller****Author(s):**E. Gardiner<sup>1,2</sup>, A. R. Miller<sup>1,2</sup>, and L. M. Lach<sup>3,4</sup>**Organization(s):**<sup>1</sup>BC Children's Hospital Research Institute; <sup>2</sup>Department of Pediatrics, University of British Columbia; <sup>3</sup>School of Social Work, McGill University; <sup>4</sup>Department of Pediatrics, McGill University**Abstract:**

**Background:** Raising a child with a neurodevelopmental disorder or disability (NDD/D) presents unique challenges to the family, and presence of behaviour problems has been identified as a critical risk factor for a broad range of adverse family outcomes.

**Aims:** This study aims to examine the role of access to services in the established relation between child behavioural difficulties and negative family impact. Previous research has suggested that services for those with NDD/D should go beyond being only child-focused; the current research examines both child- and family-focused supports and services. To this end, we asked:

1. Is the relationship between child behaviour problems and perceived negative family impact explained (i.e., mediated) by caregiver perceptions of child and family service adequacy?
2. Is the relationship between child behaviour problems and perceived negative family impact moderated by caregiver perceptions of child and family service adequacy?

**Methods and Procedures:** Caregivers provided data for 215 children with NDD/D (M=8.16 years), completing measures of child behavior problems (Strengths and Difficulties Questionnaire), perceived child and family service inadequacy (Supports and Services Questionnaire), and family impact (Family Impact of Childhood Disability Scale). Two mediation and two moderation analyses were conducted following Hayes' (2014) PROCESS macro procedures for SPSS.

**Outcomes and Results:** Both child and family service inadequacy partially mediated, but did not moderate the association between child behaviour problems and perceived negative family impact.

**Conclusions and Implications:** The finding that service inadequacy partially mediates but does not moderate the association between child behaviour problems and negative family impact highlights the need for adequate services and supports for families, and not just children. Furthermore, that this need exists across levels of behavior problems, and not just the most severe. Access to a range of supports serving both the child and family may be critical to ameliorating negative perceptions regarding the impact of a child's disability on family life.

**Funded by:**

Sunny Hill Foundation for Children. Canadian Institutes of Health Research Emerging Team Grant

**Keywords:**

Neurodevelopmental disorder/disability; Supports and Services; Family Impact; Behaviour Problems

## Theme 3 - Basic Research

## Poster # 22

**A Novel Approach to Modeling Emotion Regulation in Autism Spectrum Disorder**Presenter **Sarah Raza****Author(s):** S. Raza<sup>1</sup>, L. R. Sacrey<sup>1</sup>, V. Armstrong<sup>2</sup>, A. Kushki<sup>3,4</sup>, L. Zwaigenbaum<sup>1</sup>, S. Bryson<sup>2</sup>, J. Brian<sup>3,4</sup>, I. M. Smith<sup>2</sup>, P. Szatmari<sup>4,5</sup>, T. Vaillancourt<sup>6</sup>, & L. Schmidt<sup>7</sup>**Organization(s):** <sup>1</sup>University of Alberta/Autism Research Centre; <sup>2</sup>Dalhousie University/IWK Health Centre; <sup>3</sup>Bloorview Research Institute; <sup>4</sup>University of Toronto; <sup>5</sup>Centre for Addiction and Mental Health; <sup>6</sup>University of Ottawa; <sup>7</sup>McMaster University**Abstract:****Broad Context and Issue:** Autism spectrum disorder (ASD) is associated with impaired emotion regulation (ER), the ability to maintain homeostasis in response to positive and negative events. Infants at risk for ASD have difficulty regulating their emotional states by 12 months of age, and this ability is critical to the development of later social-communicative skills and may affect the onset of ASD. We propose a unique, novel model of ASD symptom development by focusing on ER as an early risk marker that may predict ASD diagnoses. Given that ER is a multicomponent process, a behavioral-physiological approach is warranted.**Purpose:** Can behavioral affect and/or heart-rate predict ASD symptom expression in infant siblings of children diagnosed with ASD (i.e., high-risk (HR) infants)?**Methodology:** 35 HR infants were assessed at 12 months on an ER task, comprised of activities designed to elicit positive (bubbles, toy play) and negative (toy removal, masks, grooming) emotions. Behavioral affect was coded for valence (positive, negative, or neutral) and intensity (to differentiate mild/moderate displays from intense displays of affect). Raw heart-rate was recorded and extracted from an electrocardiogram signal. The Autism Observation Scale for Infants (AOSI) was used to measure early signs of ASD. Relationships between behavioral affect, heart-rate, and AOSI were explored using Spearman rank-order correlations.**Results and Significance:** There was modest congruence between behavioral affect and heart-rate in 12-month-old HR infants. Behavioral affect, but not heart-rate, was correlated with concurrent ASD symptom expression in HR infants. This research has the potential to identify infants likely to develop ASD in the first year. First, by examining ER using a behavioral-physiological approach, early risk markers of ASD can be identified. This could not only lower the age of initial detection and diagnosis, but also identify new treatments and intervention programs to reduce/prevent disability associated with ASD. Second, this project may inform parents, clinicians, and service providers, as well as guide practice and public policy related to ASD diagnosis and treatment.**Funded by:**

KBHN, WCHRI, Alberta Innovates – Health Solutions, Brain Canada, CIHR, Azrieli Foundation, Stollery Children's Hospital Foundation Chair in Autism

**Keywords:**

Autism spectrum disorders, emotion regulation, high-risk infants, early identification

## Theme 3 - Basic Research

## Poster # 23

**Physiological Measurement of Emotion from Infancy to Preschool**Presenter **Lori Sacrey****Author(s):** L. R. Sacrey<sup>1</sup>, S. Raza<sup>1</sup>, V. Armstrong<sup>2</sup>, A. Kushki<sup>3</sup>, J. Brian<sup>3</sup>, I. M. Smith<sup>2</sup>, & L. Zwaigenbaum<sup>1</sup>**Organization(s):** <sup>1</sup>University of Alberta/Autism Research Centre, Glenrose Rehabilitation Hospital; <sup>2</sup>Dalhousie University/Autism Research Centre, IWK Health Centre; <sup>3</sup>University of Toronto/Autism Research Centre, Bloorview Research Institute**Abstract:**

**Broad Context and Issue:** Emotional regulation, the ability to regulate emotional responses to environmental stimuli, develops in the first years of life and plays an important role in the development of social competence, personality, and problematic behaviours. Responses to positive and negative stimuli may be difficult to assess in young children who do not yet have the ability to communicate verbally. As such, physiological measurement is a method that can allow us to better understand age-related changes and individual differences in response to environmental challenges. Unfortunately, there are currently no standards practices for measuring cardiac physiology for very young children.

**Purpose:** We completed a review of the literature to provide an in-depth examination of research that has measured physiology during emotion-evoking tasks in neurotypical preschool children to provide recommendations for (1) normative values of respiratory sinus arrhythmia (RSA) for baseline and emotion-evoking tasks, and (2) variability in responses to positive and negative tasks.

**Methodology:** A systematic literature review was completed in accordance with the PRISMA checklist. Searches were performed in PsycINFO, Web of Science, CINAHL Plus, and Ovid MEDLINE(R) using the following terms: emotion, physiology, and preschooler. Of the 2,598 articles found, 64 were included in the in-depth analyses of the various methodologies.

**Significance:** Having a good understanding of age-related changes of neurotypical children, for both baseline and emotion-evoking tasks, as well as the different methodologies used to assess and analyze responding, is vital when examining emotional regulation in populations of children who are at-risk or diagnosed with developmental disorders.

**Funded by:**

Canadian Institutes of Health Research (CIHR), Brain Canada, and the Azrieli Foundation for their support

**Keywords:**

physiology; heart rate; RSA; heart period; preschool; typically developing children

## Theme 3 - Basic Research

## Poster # 24

**Repetition suppression as an electrophysiological correlate of habituation is associated with adaptive skills during the first year of life**

Presenter

**Gabriela López-Arango****Author(s):**G. López-Arango<sup>1,2</sup>, I. S. Knoth<sup>1</sup>, F. Barlaam<sup>1</sup>, V. Côté<sup>1,3</sup>, C. Dupont<sup>3</sup>, K. Agbogba<sup>1</sup>, S. Lippé<sup>1,3</sup>**Organization(s):**<sup>1</sup>Research Center, Sainte-Justine Hospital; <sup>2</sup>Neurosciences Department, Montreal University; <sup>3</sup>Psychology Department, Montreal University**Abstract:**

Intellectual disability is highly comorbid with autism. An important focus of neurodevelopmental research aims at identifying such disorders as early as possible in order to act favourably on development within the time window of highest brain plasticity. Habituation, the simplest form of learning, can be measured very early on behavioral paradigms. It has been shown to be moderately correlated with cognitive development (Bornstein & Sigman, 1986; Kavsek, 2013). The electrophysiological correlate of habituation, described as repetition suppression (Snyder & Keil, 2008), has been shown to be associated with intellectual disability (Knoth et al., 2018) and sensorial hypersensitivity (Ethridge et al., 2016), traits that can be found in autism spectrum disorders. Repetition suppression evolution with maturation and link with early behavioural development still need to be determined.

The purpose of our study is to investigate the relationship between repetition suppression and adaptive skills, an early surrogate of intellectual functioning, during the first year of life. We recorded high density EEG in 59 healthy infants (23 females) age between 3 and 9 months at the CHU Sainte Justine hospital. The experimental design consisted of a sequence of three times the vowel A (AAA) presented 64 times. Auditory presentations were supported by visual images (faces pronouncing the syllables) in order to attract infant's attention (Basirat, 2014). Adaptive skills were measured using the GAC score obtained through the parent form of the Adaptive Behavior Assessment System Second Edition (ABAS-II). A time-frequency analysis and a linear mixed model were performed to investigate changes in spectral power with regards to stimulus repetition. Age and GAC score were tested as potential predictors for the model.

Our results show a stable repetition suppression effect in low frequency oscillations such as theta. Importantly, maturation and adaptive skills modulated repetition effects in higher frequencies. Age modulation was observed in low gamma oscillations (30-40Hz), and adaptive skills modulation was evidenced in low beta (10-20Hz) and high gamma oscillations (80-120Hz).

These results suggest that repetition suppression can be interpreted as an important building bloc in cognitive development and as a valuable electrophysiological marker of neurodevelopment during the first year of life.

**Funded by:**

Canadian Institutes of Health Research (CIHR) Grant (DCO150GP). G.L.A was supported by a scholarship from Fonds de recherche du Québec-Nature et technologies (FRQNT)

**Keywords:**

adaptive skills, habituation, infants, repetition suppression, time-frequency analysis

## Theme 3 - Basic Research

## Poster # 25

**The impact of increased head circumference on the repetition suppression mechanism during the first year of life: An EEG study**

Presenter

**Camille Noiseux-Lush****Author(s):**C. Noiseux-Lush<sup>1,2</sup>, G. Lopez<sup>1</sup>, I. Sophia Knoth<sup>1</sup>, F. Deguire<sup>1,2</sup>, F. Barlam<sup>1</sup>, A. Dampousse<sup>3</sup>, M. Meloche<sup>3</sup>, S. Lippé<sup>1,2</sup>**Organization(s):**<sup>1</sup>Laboratoire Neurosciences of Early Development; <sup>2</sup>Université de Montréal; <sup>3</sup>CHU Sainte-Justine**Abstract:**

**Introduction and Hypotheses:** Macrocephaly is defined by an head circumference (HC) of more than two SD above the mean. It is thought to be a biomarker of ASD and some ADHD symptomatology (Courchesne, Carper, & Akshoomoff, 2003; Rommelse & al., 2011). Noteworthy, increased HC has been associated with greater conduction delays of neural responses (Changizi & Shimojo, 2005). The purpose of this study is to examine how abnormal variations of HC affect brain responses of the repetition suppression (RS) phenomenon during the first year of life (reduction of neural response following the presentation of a repeated stimulus). We posit that the RS mechanism is altered in infants with macrocephaly in the first year of life as it linked to a typical neurodevelopment.

**Methods:** A sample of 100 babies (6-10 months) has been recruited (50 controls, 50 macrocephalics). The stimuli presented during EEG recordings (128 electrodes EEG-system) is four frames of a male and female face during the articulation of vowel /a/ (3 presentations) who is normally supposed to trigger the RS response. We analysed RS on the P2 and N2 components by looking at the latency and the amplitude of the EEG signal. Using the data of 20 babies (10 macrocephalics), the non-parametric Friedman test has been performed on the event-related potentials data in order to analyse the brain responses.

**Preliminary results:** In the control group, we observed a statistically significant (SS) decrease in latency for all of the components ( $p = .001$  (P2),  $p = .004$  (N2)). For the amplitude, P2 decrease is SS ( $p = .001$ ), but the N2 did not show significant changes ( $p = .692$ ). In the macrocephalic group, N2 showed a repetition enhancement instead of a RS ( $p = .002$  (amplitude),  $p = .004$  (latency)). However, P2 revealed a normal RS with a diminution of latency ( $p = .002$ ) and amplitude ( $p = .034$ ).

**Conclusions:** The results of this research suggest RS is atypical in macrocephalic infants. It seems pertinent to pursue our research in order to determine precisely how atypical brain growth impacts on development. It would be important to follow the evolution of the macrocephalic children to see if their atypical RS is linked to their cognitives abilities.

**Funded by:**

Canadian Institute of Health Research

**Keywords:**

Electroencephalography, neurodevelopment, brain activity, learning mechanism, infant study

## Theme 3 - Basic Research

## Poster # 26

**Exploring the nature of auditory hypersensitivity in Autism Spectrum Disorder**Presenters **Behnaz Bahmei and John Yang****Author(s):** B. Bahmei<sup>1</sup>, J. Yang<sup>1</sup>, S. Arzanpour<sup>1</sup>, T. Herdman<sup>2</sup>, G. Iarocci<sup>1</sup>, and E. Birmingham<sup>1</sup>**Organization(s):** <sup>1</sup>Simon Fraser University; <sup>2</sup>University of British Columbia**Abstract:****Aim:** Many children with Autism Spectrum Disorders (ASD) experience auditory hypersensitivity. The goal of the current study was to 1) determine how auditory hypersensitivity influences the everyday lives and behaviors of individuals with ASD, and 2) explore the nature of responses to specific sounds including loudness comfort levels.**Background:** Auditory hypersensitivity to specific stimuli is demonstrated in children with ASD [1], and interferes with participation in social, educational and recreational activities. However, more research is needed on the nature of children's responses to sounds in their environments.**Method:** Adolescents with ASD (aged 13-18 years) and their parents were recruited to complete 3 sessions in the lab. Inclusion in the full study required full-scale IQ>85 (Wechsler Abbreviated Scale of Intelligence) and normal hearing thresholds ( $\leq 25$ db) confirmed by pure-tone audiometry for each ear. Session 1 included interviews, questionnaires (e.g., the Child Sensory Profile 2 [CSP2; 2], Adolescent/Adult Sensory Profile [ASP; 3], and the Auditory Sensitivity and Child Safety Questionnaire [ASCSQ; 4]). In Sessions 2 and 3, youth were presented with sounds that they reported to be pleasant (Session 2) or aversive (Session 3). Participants were asked to manually adjust the volume and/or pitch of sounds to a comfortable listening level, and to rate the sounds on valence and arousal using a Likert scale.**Results:** Preliminary results from Session 1 (n = 5 families, mean age of child 15.4 years) confirmed that all children experienced negative reactions to sound in the last 6 months. Frequency of negative reactions: every day (1/5), a few times/month (2/5), once/month (2/5). Specific reactions to aversive sounds included being anxious (4/5), irritable (3/5), not responding to name (3/5), yelling and screaming at other children/adult (2/5), and being unaware of surroundings (2/5). Sounds that provoked negative reactions included loud (4/5), sudden (4/5), shrill (3/5), high-pitched (2/5), and repetitive (2/5). Data collection for Session 2 and 3 is in progress and will be available for the poster.**Conclusion:** Auditory hypersensitivity is an important challenge in ASD. The results of this study will shed new light on the nature of this issue and how it affects families.**References:**

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**Funded by:**

Kids Brain Health Network

**Keywords:**

Autism spectrum disorders, auditory hypersensitivity, sensory sensitivity



## Theme 3 - Basic Research

## Poster # 27

## Everyday Executive Function Associated with Adaptive Functioning in Children and Adolescents with Prenatal Alcohol Exposure

Presenter

**Sarah Hutchinson****Author(s):**S. M. Hutchison<sup>1</sup>, E. Gardiner<sup>1</sup>, K. McLachlan<sup>2</sup>, L. C. Mâsse<sup>3</sup>, T. F. Oberlander<sup>1,3</sup>, C. Rasmussen<sup>4</sup>, J. Pei<sup>5</sup>, and J. N. Reynolds<sup>6</sup>**Organization(s):**<sup>1</sup>Department of Pediatrics, University of British Columbia; <sup>2</sup>Department of Psychology, University of Guelph; <sup>3</sup>School of Population and Public Health, University of British Columbia; <sup>4</sup>Department of Pediatrics, University of Alberta; <sup>5</sup>Department of Educational Psychology, University of Alberta; <sup>6</sup>Centre for Neuroscience Studies, Queens University**Abstract:**

Children with Prenatal Alcohol Exposure (PAE) have a range of adverse outcomes that impact multiple domains of functioning, including cognitive, physical, mental health, behavioural, social-emotional, communication, and learning. To inform tailored clinical intervention, the current study examined the relation between cognitive skills (executive function; EF) and adaptive functioning. Specifically, this study tested the following hypotheses:

1. Composite measures of EF skills (Behavior Regulation, Metacognition) are associated with adaptive functioning skills (practical, conceptual, social) in children with a history of PAE.
2. Individual measures of EF skills (Inhibit, Shift, Emotional Control, Initiate, Working Memory, Plan/ Organize, Organization of Materials, Monitor) are associated with adaptive functioning skills (practical, conceptual, social) in children with a history of PAE.

Caregivers of 87 children and adolescents (aged 5 to 18 years) reported on EF (Behavior Rating Inventory of Executive Function; Gioia et al., 2000) and adaptive function (Adaptive Behavior Assessment System, 2nd Edition; Harrison & Oakland, 2003) skills.

Results showed that caregivers reported significantly poorer EF and adaptive functioning skills for children with PAE compared to the normative sample. Poorer behavior regulation skills were associated with all aspects of adaptive functioning (practical, conceptual, and social skills). Specifically, poorer shifting skills emerged as the best predictor of poorer adaptive functioning in children with a history of PAE. These results suggest that targeting particular EF domains among individuals with PAE may have direct benefit for behavior regulation, which may also extend to adaptive skills. Implications for the development of interventions for children and adolescents with PAE will be presented.

**Funded by:**

Kids Brain Health Network, Women and Children's Health Research Institute, Sunnyhill Health Centre for Children Foundation, BC Children's Hospital Research Institute, Brain Canada, University of British Columbia

**Keywords:**

Prenatal Alcohol Exposure (PAE), Fetal Alcohol Spectrum Disorder (FASD), Cognition, Adaptive skills, Parent ratings

## White Matter Tract Signatures of ADHD and Emotional Lability Traits in Young Children

Presenter **Christiane Rohr**

**Author(s):** C. S. Rohr, D. Dimond, A. Ip, D. M. Dewey, S. L. Bray

**Organization(s):** The University of Calgary

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**Abstract:**

**Background:** 40-50% of children with ADHD present with high levels of emotional lability, which associates with poorer outcomes for these children. This means that characterizing the interplay between core ADHD traits and emotional lability is critical for effective treatment. Here, we assess the brain basis of this relationship in two white matter tracts: the superior longitudinal fasciculus (SLF, crucial for attention) and uncinate fasciculus (UF, crucial for emotion).

**Methods:** Diffusion-weighted images (b-value=0/2000, 45 directions) were acquired in 58 typically developing children aged 4-7 years, and preprocessed using motion and signal-dropout correction (FSL/MRTrix). Emotional lability was assessed with the Emotion Regulation Checklist; inattention and hyperactivity were assessed with the SNAP-IV Parent Questionnaire. In a voxel-based analysis, we investigated linear associations between the interaction of emotional lability and ADHD traits, and fractional anisotropy (FA) and mean diffusivity (MD) in the SLF and UF (controlling for main effects, handedness and motion).

**Results:** Emotional lability, inattention and hyperactivity scores all correlated ( $r's > .63$ ). The interaction between hyperactivity and emotional lability negatively correlated with FA in bilateral UF, and negatively with MD in left anterior SLF. MD in left anterior SLF also negatively correlated with the interaction between inattention and hyperactivity, and with the interaction between inattention and emotional lability at trend-level.

**Conclusions:** Our findings suggest that UF and SLF diffusion properties underlie the interplay between emotional lability and ADHD traits in early childhood, and demonstrate the utility of behavioral assessments to elucidate the brain basis of potential vulnerabilities in young children.

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## Theme 3 - Basic Research

## Poster # 29

## A Therapy to Prevent Neurodevelopmental Disabilities: Protection of Brain Cells by Sulforaphane

Presenter **Zeenat Ladak**

**Author(s):** Z. Ladak, E. Garcia, E. A. Armstrong, J. Yoon, S. Persad, J. Y. Yager

**Organization(s):** Department of Pediatrics, University of Alberta

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**Abstract:**

Perinatal brain injury results in neurodevelopmental disabilities (NDDs) including cerebral palsy, autism, and attention deficit disorder among others. Many factors contribute to perinatal brain injury, one major factor being placental insufficiency which causes a hypoxic-ischemic environment in-utero. Over 80% of perinatal brain injuries lead to NDDs prior to birth. Therefore, preventive approaches are needed, as opposed to 'rescue' therapies which take place after the injury has already occurred. Sulforaphane (SFA), a natural health product derived from cruciferous vegetables such as broccoli sprouts, indirectly enhances the production of anti-oxidant enzymes and has shown promise as a neuro-protective agent.

The aim of this study is to explore how SFA affects different brain cell types and the dosing range of SFA for protection and toxicity in normal and oxygen/glucose deprived (OGD) cell cultures. OGD simulates in-vitro, the conditions of in-vivo hypoxia-ischemia. We developed a newborn rodent primary cortical neuronal, astrocyte, and combined cell culture (co-culture). Cell culture purity is evaluated using western blot and immunofluorescence (IF). Cultures are exposed to an OGD environment for different durations of time to achieve 50% cell death (LD50). Using the LD50, cultures are exposed to varying doses of SFA. Control cultures are not exposed to OGD. Cell viability is assessed by a Live/Dead assay using IF/high content and cytotoxicity by Alamar blue.

One Way ANOVA and Dunette's Multiple Comparison are used for statistics. Primary cortical neuronal, astrocyte, and co-cultures have been established. We determined the LD50 to be 2 hours for neurons, 4 hours for astrocytes, and 10 hours for co-cultures. At the previously determined LD50, SFA was protective at 2.5uM ( $p < 0.05$ ) in both neurons and co-cultures, and at 5uM ( $p < 0.001$ ) in astrocytes. Significant toxicity of SFA in control cultures was seen at doses  $\geq 100\text{uM}$  ( $p < 0.01$ ) for neurons, and  $\geq 50\text{uM}$  ( $p < 0.05$ ) for both astrocytes and co-cultures.

These findings suggest that SFA shows promise as a preventative agent for fetal ischemic brain injury and that dosing parameters are required for safety. Future studies include determining the safety and efficacy of SFA in a rodent animal model of placental insufficiency.

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**Funded by:**

Women and Children Health Institute (WCHRI), Innovation Grant Maternal and Child Health (MatCH) Scholarship Program

**Keywords:**

Sulforaphane, neurodevelopmental disabilities, perinatal brain injury, prevention, protection

## Theme 4 - Clinical/Community Research

## Poster # 30

**“It’s hard to find support”: Utilization, barriers and future needs of therapeutic interventions for parents of children with early brain injury**Presenter **Meghan Ford****Author(s):** M. K. Ford, S. Vyas, B. Burek, & T. S. Williams**Organization(s):** The Hospital for Sick Children**Abstract:**

**Objective:** Parents experience intense distress learning that their ‘healthy’ infant has suffered a brain injury or has a life-threatening illness. High levels of parental psychological distress have been shown to be associated with negative impact on the adaptive functioning and quality of life of children and families. One effective way to lessen parent distress is by providing support through therapeutic services. However, there may be critical systematic differences in parents’ abilities to access necessary support services. This study examined current access to therapeutic intervention, related barriers and future service needs among parents of children with early brain injury.

**Method:** 111 parents of children diagnosed with neonatal hypoxic-ischemic encephalopathy (HIE), stroke, or congenital heart disease (CHD) between the ages of 1 to 9 years ( $M = 3y1m$ ,  $SD = 2y0m$ ) completed the Parent Experiences Questionnaire (PEQ), a 24-item descriptive survey including forced-choice and open commentary questions regarding parental perception of therapeutic support following their child’s early brain injury. Therapeutic support was defined as psychological services, parent groups, and web-based programs/forums. A thematic analysis was conducted to examine patterns in the data.

**Results:** Parents reported engaging in psychological interventions (27%; i.e., individual counsellor, psychiatrist, psychologist, therapist, or social worker), web-based programs/forums such as Facebook exclusive groups (26%), and in-person parent groups (6%) as a way of supporting themselves as a result of their experience as a parent of a child with early brain injury. 32% of parents reported accessing no services to help navigate their child’s diagnosis. Three unique categories were identified as barriers for parents to access therapeutic services: (1) lack of availability of information and resources, (2) inaccessibility (e.g., distance, waitlists, time, childcare), and (3) socioeconomic status. Parents reported they would benefit from more support groups (34%), education (33%), and outpatient support (28%).

**Conclusions:** Findings highlight the many barriers parents experience in accessing supports for themselves, following their child’s early brain injury. This study offers future direction for the development and implementation of services that could support and facilitate child outcomes through better addressing parenting distress.

**Funded by:**

Medical Psychiatry Alliance

**Keywords:**

Parent experiences; support; brain injury; mental health; needs assessment; qualitative evaluation

## Theme 4 - Clinical/Community Research

## Poster # 31

**Assessing language comprehension in children with speech and motor impairments**Presenter **Jael Bootsma****Author(s):** J. N. Bootsma<sup>1,2</sup>, S. Hopmans<sup>1</sup>, D. McCauley<sup>1</sup>, J. J. Geytenbeek<sup>3</sup>, O. Kraus de Camargo<sup>1,4</sup>, and J. W. Gorter<sup>1,2,4</sup>**Organization(s):** <sup>1</sup>CanChild Centre for Childhood Disability Research, McMaster University; <sup>2</sup>School of Rehabilitation Science, McMaster University; <sup>3</sup>Amsterdam University Medical Centre; <sup>4</sup>McMaster Children's Hospital, Hamilton**Abstract:****Background:** Many children with cerebral palsy (CP) have difficulties speaking. Together with their motor impairments, this can make it quite challenging to test their language and cognitive skills. Regular tests usually require the participant to say or point at the answers, which are things these children cannot do.

In this presentation, we present a new accessible language test. This test helps to find out what somebody understands from spoken language. This information can be very helpful to determine the best way to support the child's communication and development. Children with CP can participate in the test using an access method that suits their abilities. They can for instance use a sensitive touchscreen, or an eye-tracker to respond to the items. We will also present and explain the research we are currently doing to make sure the test is of good quality. We are comparing the results that this tool provides, to the results of other tools that are already well-established. We will share some results of these comparisons and explain what they mean. Finally, we will outline the future steps we have planned to make sure all Canadian children with CP and communication difficulties can have access to this new tool.

This presentation will be interesting for families, educators, clinicians, and researchers. While the test was originally developed for children with CP, we encourage people who are personally or professionally interested in other brain-based disabilities to explore how this test can be used in other populations.

**Funded by:**

This project was funded by a HASHO Innovation Grant.

**Keywords:**

cerebral palsy, assessment, language comprehension, alternative and augmentative communication

## Theme 4 - Clinical/Community Research

Poster # 32

**Association between neighbourhood socioeconomic status and development of kindergarten children with Autism Spectrum Disorder: A pan-Canadian study**

Presenter

**Ayesha Siddiqua****Author(s):**A. Siddiqua<sup>1,2</sup>, E. Duku<sup>2</sup>, and M. Janus<sup>2</sup>**Organization(s):**<sup>1</sup>Department of Health Research Methods, Evidence, and Impact, McMaster University;<sup>2</sup>Offord Centre for Child Studies, Department of Psychiatry and Behavioural Neurosciences, McMaster University**Abstract:**

**Purpose:** To examine the association between neighbourhood socioeconomic status (SES) and developmental vulnerability at the individual level, while controlling for neighbourhood clustering and individual SES, among kindergarten children with Autism Spectrum Disorder (ASD).

**Methods:** This study used data from a population-level database of child development in kindergarten, collected with the Early Development Instrument (EDI). The EDI is completed by kindergarten teachers, includes records of medical diagnoses, and has been administered at the population level in most Canadian provinces and territories. The EDI data provide information on children's developmental status in 5 domains: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communication skills and general knowledge. Scores below a baseline 10th percent cut-off on any of the 5 domains indicate vulnerability and overall vulnerability is indicated by vulnerability on one or more domains. Neighbourhood SES was assessed using an SES index created using 10 variables from the 2011 Canadian Census and 2010 Taxfiler data. Individual SES was assessed using 4 variables from the 2016 Canadian Census data. Multilevel logistic regression analyses were used to examine the association between neighbourhood SES and developmental vulnerability of the child, while controlling for individual SES, demographic characteristics, province of residence, as well as clustering of children in neighbourhoods.

**Results:** After controlling for individual SES, demographic characteristics, province of residence, and neighbourhood clustering, there was a negative association between neighbourhood SES with overall vulnerability (OR: -0.12, 95% CI: -0.22, -0.02;  $p < 0.05$ ), with vulnerability on the physical health and well-being domain (OR: -0.09, 95% CI: -0.16 to -0.03;  $p < 0.01$ ), with vulnerability on the emotional maturity domain (OR: -0.09, 95% CI: -0.16 to -0.02;  $p < 0.05$ ), and with vulnerability on the communication skills and general knowledge domain (OR: -0.10, 95% CI: -0.18 to -0.03;  $p < 0.01$ ).

**Conclusions:** Regardless of the province of residence and sociodemographic characteristics of children with ASD, neighbourhood SES has an independent effect on development of children with this disorder. Children with ASD living in neighbourhoods with higher SES are less likely to demonstrate developmental vulnerability, which emphasizes the importance of addressing neighbourhood deprivation to support their development.

**Funded by:**

Brain Canada-Kids Brain Health Pre-Doctoral Fellowship, CIHR Project Grant

**Keywords:**

ASD, kindergarten, developmental disabilities, behaviour, Early Development Instrument, neighbourhood

## Theme 4 - Clinical/Community Research

## Poster # 33

## Short-term pain trajectories and well-being in children and youth with cerebral palsy: A feasibility study

Presenter **Heather Shearer**

**Author(s):** H. M. Shearer<sup>1,2</sup>, P. Côté<sup>1,3</sup>, S. Hogg-Johnson<sup>1,4</sup>, P. McKeever<sup>1</sup>, and D. Fehlings<sup>1,2</sup>

**Organization(s):** <sup>1</sup>University of Toronto; <sup>2</sup>Holland Bloorview Kids Rehabilitation Hospital; <sup>3</sup>University of Ontario Institute of Technology; <sup>4</sup>Canadian Memorial Chiropractic College

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**Abstract:**

**Introduction:** Chronic pain is common in children with cerebral palsy (CP). However, we lack knowledge about short-term pain fluctuations and their impact on these children's well-being. Objective: Conduct a feasibility study to identify methodological and logistical issues aimed to inform the development of a multi-site cohort study measuring short-term pain trajectories and their association with well-being in children and youth with CP.

**Patients and methods:** A pilot cohort study of 10 children/youth who: 1) were 8-18 years old; 2) have CP; 3) attended children's rehabilitation centers in the Greater Toronto Area; 4) successfully completed a validated sorting task; and 5) self-reported pain and well-being. We collected sleep characteristics, preceding months' interventions, age, sex, type of CP, Gross Motor Functional Classification System (GMFCS) level, comorbidities, self-report physical and psychological well-being (KIDSCREEN-27), weekly pain intensity over four weeks (Faces Pain Scale-Revised, Numeric Rating Scale), and pain location by phone or electronic survey link. Participants were followed once weekly for five weeks.

**Results:** Pilot study recruitment occurred between March-May, 2019. We had 40% (n=10/25) recruitment and 100% participation rates. Follow-up rates varied by site. Participants were 8-17 years-old, an equal number of females:males, GMFCS levels of I-III, mean (SD) baseline pain intensity=2.3/10 (2.5), pain intensity range of 0-8/10, with 80% reporting pain experienced within the prior week. There was an overall increase in mean pain intensity from baseline to follow-up 4 by 0.9. Identified barriers prompted changes in recruitment strategies (adding snowballing technique and networking with family groups) and enhanced staff training. Successful recruitment and data collection was related to: 1) the use of client call lists; 2) flexible appointment hours (evenings/weekends); 3) the use of electronic follow-up questionnaires (chosen by 90% of participants); and 4) close monitoring of questionnaire completion (6/9 participants required reminders).

**Conclusion:** Alongside stakeholder consultation, this novel pilot study identified potential challenges with recruitment and data collection leading to methodological modifications of our larger cohort study. This study suggests conducting the first cohort study to describe short-term pain trajectories and measure their association with self-reported short-term well-being in children and youth with CP is feasible.

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**Funded by:**

Brain Canada-Kids Brain Health Network Doctoral Fellowship Award, CIHR Frederick Banting and Charles Best Canada Graduate Scholarships Doctoral Award

**Keywords:**

cerebral palsy, children, pain, well-being, pilot study

## Radiographic Patterns of Injury and Risk Factors in Children with Hemiplegic Cerebral Palsy

Presenter **Trish Domi**

**Author(s):** T. Domi<sup>1,2</sup>, M. Slim<sup>1</sup>, N. Dlamini<sup>1</sup>, P. Krishnan<sup>1</sup>, D. Fehling<sup>3,4</sup>, G. A. deVeber<sup>1</sup>, and the CP-Net Group<sup>3</sup>

**Organization(s):** <sup>1</sup>Institute of Medical Science, University of Toronto; <sup>2</sup>The Hospital for Sick Children, Toronto, Canada; <sup>3</sup>Holland Bloorview Kids Rehabilitation Hospital; <sup>4</sup>Department of Developmental Paediatrics

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**Abstract:**

The timing of injury to the brain differentiates the mechanisms that lead to cerebral palsy. Radiographic characteristics of the injury to the brain are one of the determinants that clinicians rely on to diagnose cerebral palsy.

**Objective:** To describe radiographic characteristics of perinatal arterial ischemic stroke (PAIS) and periventricular injury (PVI) and the associated clinical risk factors in each group.

**Methods:** Patients were identified through the Childhood Hemiplegic Cerebral Palsy Integrated Neuroscience Discovery Network (CP Hemi-NET) from nine clinical centres across Ontario, Canada. Lesion characteristics were determined by 2 blinded pediatric neuroradiologists.

**Results:** A total of 211 children with hemiplegic cerebral palsy were included (median age at diagnosis 12 months; 62% males). Cerebrovascular lesions were classified as PAIS in 101 and PVI in 110 patients (36% with periventricular venous infarction). Males and females were equally represented (males: 60% in PAIS, 64% in PVI,  $p=0.5$ ). Children with PAIS were diagnosed younger (median 9 months vs. 13 months,  $p<0.01$ ), weighed more at birth ( $3237\pm 801$  vs  $2688\pm 1114$  grams,  $p<0.01$ ), and more likely to have seizures within 24 hours after birth (58% vs 25.7%,  $p<0.001$ ). Children with PVI were more likely to be premature (40% vs 18%,  $p<0.001$ ) and require resuscitation at birth (39% vs 25%,  $p=0.04$ ). Univariate analysis revealed higher odds for PAIS diagnosis with a maternal history of blood clots (OR=4.9; 95% confidence interval [CI]:1.01-23.5) or smoking (OR=2.4; 95%CI:1-5.9). Premature placental rupture and use of fertility treatments increased the odds of PVI diagnosis (OR=9; 95%CI:1.1-71 and OR=4.1; 95%CI:1.3-12.7, respectively).

**Conclusion:** PAIS and PVI imaging characteristics were determined by blinded neuroradiologists. In PAIS, the increased odds of maternal history of blood clots and smoking, and in PVI prematurity, birth following premature placental rupture, and fertility treatments are novel findings.

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**Funded by:**

Stroke Imaging Lab for Children, CP-NET

**Keywords:**

cerebral palsy, perinatal stroke, radiography, clinical risk factors



## Theme 4 - Clinical/Community Research

## Poster # 35

**Movement-tracking video game for upper limb home rehabilitation for children with cerebral palsy**Presenter **Daniela Chan-Viquez****Author(s):** D. Chan-Viquez<sup>1,2</sup>, A. Khan<sup>1</sup>, D. Fehlings<sup>1,3</sup>, V. Wright<sup>1,2</sup>, E. Biddiss<sup>1,4</sup>**Organization(s):** <sup>1</sup>Bloorview Research Institute; <sup>2</sup>Rehabilitation Sciences Institute, University of Toronto; <sup>3</sup>Faculty of Medicine, University of Toronto; <sup>4</sup>Institute of Biomaterials and Biomedical Engineering, University of Toronto**Abstract:**

Novel home rehabilitation programs are needed to improve therapy engagement and adherence in children with Cerebral Palsy (CP). Bootle Blast (BB) is a low-cost, movement-tracking rehabilitation video game for practice of hand/arm exercises. BB is customizable to each child's physical abilities and therapy goals.

This pilot study investigates a 12-week home intervention with BB. Our **aims** are to: 1) *determine the feasibility of BB for sustaining play motivation and adherence*, 2) *measure changes in hand/arm motor outcomes*, and 3) *explore participants' experiences of using BB for home rehabilitation*. **Feasibility** criteria are: 80% of children will achieve their play-time goal in at least 10/12 weeks, and 80% of children will complete the 12-week intervention. This intervention was designed with a patient-family centred approach, where participants identified meaningful and achievable therapy and play time goals (minutes, days) based on their family dynamics.

Three participants (10-13 yrs, high-functioning hand/arm) have been enrolled in the study\*. Study assessments were performed pre and post-intervention, and at 4 weeks follow up. Measures targeted hand/arm quality of movement, bilateral hand function, and performance/satisfaction on self-identified hand/arm therapy goals (**aim 2**). A post-intervention interview explored factors influencing play motivation and adherence (**aim 3**). Computer game-logs which provided active play time and game progress data were collected at week 12 (**aim 1**).

Two children completed the intervention. Play time goal was achieved in 90-100% of the weeks. Both children improved in active wrist extension ( $+12.5^{\circ} \pm 10.6^{\circ}$ ), ability to grasp/release objects ( $+5.5 \pm 3.5$  pts, Box and Blocks test), bilateral hand function ( $+4.5 \pm 0.7$  pts, Assisting Hand Assessment) and in self-reported performance/satisfaction on hand/arm therapy goals (performance:  $+3 \pm 0.8$  pts, satisfaction:  $+3,8 \pm 2.1$  pts, Canadian Occupational Performance Measure). Post-intervention interviews suggested that BB was "fun" to play and kept the children motivated. It was considered an acceptable media and perceived as useful for hand/arm home rehabilitation.

Video games like BB provide children with CP an engaging option to practice therapy at home in a more frequent and accessible way. Family support remains an important enabler. Results from this study will improve our understanding of how these innovative approaches can best be deployed for home rehabilitation.

*\*Ongoing study. Results from at least two more participants will be presented by the time of the conference.*

**Funded by:**

NSERC, CIHR, Bloorview Research Institute

**Keywords:**

Cerebral Palsy, Hemiplegia, rehabilitation technology, movement-tracking video game

## Inpatient Rehabilitation Exergames in Children with Cerebral Palsy after Lower Extremity Orthopedic Surgery: A Feasibility Study

Presenter

**Analyssa Cardenas****Author(s):**A. Cardenas<sup>1,2</sup>, D. Warner<sup>2</sup>, L. Switzer<sup>2</sup>, N. Golubovich<sup>3</sup>, T. C. N. Graham<sup>3</sup>, D. Fehlings<sup>1,2</sup>**Organization(s):**<sup>1</sup>Rehabilitation Sciences Institute, University of Toronto; <sup>2</sup>Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital; <sup>3</sup>School of Computing, Queen's University**Abstract:**

**Background:** When children with CP grow, they often need lower limb surgery due to changes that occur in their muscles and bones. During the recovery period, pain is commonly experienced as well as fewer opportunities for fitness and social interaction. Exercise video games, or 'exergames' are a new approach to engaging these children with fitness and social interaction following lower limb surgery. Our team developed the Liberi Exergames, a multiplayer exergame designed for children with CP, powered by pedaling a stationary bicycle and using game-controllers. Opportunities for youth with CP to cycle on the exergames after surgery may activate and stretch their muscles, therefore decreasing pain, and promote social interaction to enhance wellbeing.

**Objectives:**

- 1) Assess the feasibility of incorporating the Liberi Exergames for inpatient children with CP recovering from lower limb surgery. Key feasibility indicators assessed recruitment, outcome completion, and intervention compliance.
- 2) Explore the effectiveness of the exergames to decrease pain and enhance wellbeing

**Methods:** Ten children with CP recovering from lower limb surgery in a hospital's inpatient unit were recruited; the first 5 received physiotherapy ("comparison group"), and the next 5 received 15 exergame sessions over 3 weeks and physiotherapy ("case group"). Questionnaires evaluating pain were administered. The case group completed interviews exploring their experiences playing the exergames.

**Results:** All key feasibility indicators were met. 100% of participants who qualified for the study enrolled, 100% of participants completed all pain questionnaires, and all case group participants completed at least 12/15 exergame sessions. Although there were no statistically significant differences in pain between groups, in the comparison group 2 participants experienced increasing, 2 experienced decreasing, none experienced persisting, and 1 experienced no pain; and in the case group, none experienced increasing, 2 experienced decreasing, 1 experienced persisting, and 2 experienced no pain. Interviews revealed that participants enjoyed playing the exergames.

**Impact:** Incorporating the Liberi Exergames into inpatient rehabilitation following lower limb surgery is feasible and indicates a trend toward pain reduction in the case group. This project provides the basis for developing larger studies in evaluating the benefits of cycling in pediatric populations using novel and interactive technology.

**Funded by:**

Holland Bloorview Kids Rehabilitation Hospital's Centre for Leadership Program and the 2019-2020 Frederick Banting and Charles Best - Canada Graduate Scholarship - Master's (CGS-M CIHR) Award

**Keywords:**

Cerebral palsy, exergames, pain, neurotechnology

## Theme 4 - Clinical/Community Research

## Poster # 37

## Natural Language Processing Based Automated Website Vetting for Neurodevelopmental Disability

Presenter **Abhishek Dhankar**

**Author(s):** A. Dhankar<sup>1</sup>, B. James<sup>1</sup>, F. Bolduc<sup>1</sup>, and Z. Osmar<sup>1</sup>

**Organization(s):** <sup>1</sup>University of Alberta

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**Abstract:**

**Background:** Our team is developing a chatbot to assist children with Neurodevelopmental Disabilities (NDD) by helping their parents, healthcare workers and educational specialists find websites with high-quality resources and authentic information. At the moment, these websites are drawn from a database provided by NDD experts. We are also developing a web portal to allow the general public, parents and other end-users to provide more websites, and a tool to verify the authenticity of information provided. Considering the potentially large number of sites, an alternative to human expert evaluation would help manage such large data. We are creating an automated vetting system to deal with the large number of websites, known as MedFact, which will determine an authenticity and readability score for each website, thus distinguishing authoritative from fake NDD related websites.

**Method:** In collaboration with KBHN, we conducted a survey to identify the degree of agreement between experts and MedFact in rating websites related to NDD. In addition, we used an existing automated resource vetting system and identified an optimization for resources specific to NDD by using Natural Language Processing (NLP). This optimization involves creating a vector representation of words trained on a general corpus find better representations of the vocabulary of a relatively smaller, domain-specific corpus, such as an NDD corpus. To train our NLP algorithm, we are also creating a database of accurate and “fake information” websites.

**Results:** We identified variation between MedFact and experts in the evaluation of the websites’ extracts. We present the corpus of “fake resources” and ways for parents and experts in NDD to provide further information.

**Relevance:** A previous nationwide survey from KBHN has shown that families need a source of accurate NDD-related information. Human-only vetting of information is not scalable. Our NLP powered tool will allow the chatbot to access a wide range of resources and include parents in information sharing.

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**Funded by:**

CIHR, NSERC, SSHRC Collaborative AI grant, KBHN team building grant

**Keywords:**

chatbot, Kids Brain Health Network, Natural Language Processing, Neurodevelopmental Disabilities

## Theme 4 - Clinical/Community Research

## Poster # 38

**Parent and Youth Experiences Accessing Government Disability Programs Across Canada: A Mixed-Method Analysis**Presenter **Brittany Finlay****Author(s):** B. Finlay<sup>1</sup>, D. Materula<sup>1</sup>, K. Wittevrongel<sup>1</sup>, L. Lach<sup>2</sup>, D. Nicholas<sup>3</sup>, J. Zwicker<sup>1,4</sup>**Organization(s):** <sup>1</sup>University of Calgary; <sup>2</sup>McGill University; <sup>3</sup>University of Calgary; <sup>4</sup>University of Calgary**Abstract:**

**Background:** Government disability programs provide support to individuals with disabilities to address the economic, educational, and social barriers they face. Previous work shows that uptake of one such program, the Disability Tax Credit (DTC), is relatively low across Canada. This is problematic, as the DTC not only reduces tax liability of individuals with disabilities, but is also a prerequisite for accessing many other government programs, suggesting that these programs are likely also underutilized.

**Aim:** Identifying the underlying reasons for low uptake of disability programs is of key importance to determine policy changes needed to ensure individuals with disabilities receive adequate support. As such, the aim of this project is to understand how Canadian youth with disabilities and their families experience the process of accessing government disability programs.

**Methods:** This study uses a mixed methods approach with an online survey and follow-up interviews with youth (18-30 years) with disabilities and parents/caregivers of youth (0-30 years) with disabilities. The survey asked demographic questions, questions about disability and activity limitations, and questions about accessing government programs. At the conclusion of the survey, participants indicated their interest in participating in a follow-up interview. Maximum variation sampling was used among those interested to select participants for a 30-minute, semi-structured interview, during which participants elaborated on their survey responses and overall experiences accessing government programs. Data from both phases were analyzed using Microsoft Excel and NVivo.

**Results:** 395 individuals completed the online survey and 47 individuals participated in a follow-up interview. Participants varied with respect to many demographic factors, including province of residence, income, disability diagnosis, and community size. A quantitative analysis of survey responses indicated that 77% of participants have some or a lot of difficulty applying for disability programs. Qualitative analysis of interviews revealed facilitators and barriers to accessing government disability programs.

**Conclusion:** This study has revealed the challenges associated with accessing government disability programs from the perspective of youth with disabilities and their parents/caregivers. Future work must examine how these findings translate into policy changes that can improve support for this population.

**Funded by:**

Sinnave Family Foundation, SSHRC, Kids Brain Health Network

**Keywords:**

Survey, interviews, disability programs, access

## Theme 4 - Clinical/Community Research

## Poster # 39

## Administrative data analysis of family disability service use among families with young children with disabilities

Presenter **Matthew Russell**

**Author(s):** M. Russell<sup>1,2,3</sup>, Y. Zhang<sup>1</sup>, X. Cui<sup>1</sup>, S. Tough<sup>2,4\*</sup>, and J. D. Zwicker<sup>3,5\*</sup>

**Organization(s):** <sup>1</sup>PolicyWise for Children & Families; University of Calgary; <sup>2</sup>Community Health Sciences, Cumming School of Medicine; <sup>3</sup>School of Public Policy; <sup>4</sup>Paediatrics, Cumming School of Medicine; <sup>5</sup>Department of Kinesiology  
\* shared senior authorship

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**Abstract:**

**Aim:** This study provides information on use of disability services for families with young children with disabilities.

**Method:** We used linked administrative data from different ministries in Alberta to describe families' use of disability services when their children were between the ages of 3 and 8. Disability was investigated based on the presence of a severe special education code for children, and level of special education support. The outcome was the use of family disability services through the Family Support for Children with Disabilities (FSCD) program.

**Results:** Of 31,319 children, 25,589 (81.7%) children had no special education code, 3,154 (10.1%) had a mild code, and 2,603 (8.3%) had a severe code. Level of special education support use was associated with child characteristics and service use. More severe disability codes were generally related to more service use. Of note, only 26% of children with severe codes used family disability services. In addition, among children with severe codes, many years of severe special education coding (compared to less) had the strongest association with family disability service use (*Prevalence Ratio* 5.50; *Confidence Interval* 4.10-7.37). Associations with family disability support use were seen with mental health, health care, and educational achievement. Interactions between child characteristics and service use were observed.

**Interpretation:** This study provides information on how families use disability services. Such information is important as we plan to support families with children with disabilities early on.

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**Funded by:**

Kids Brain Health Network and the Canadian Institutes of Health Research (CIHR), through the Health System Impact Fellowship program

**Keywords:**

administrative data, health outcomes, special education, disability, neurodevelopmental disorders, disability support

## The Cost-effectiveness of screening tools used in the diagnosis of fetal alcohol spectrum disorder: A modelled analysis

Presenter **Patrick Berrigan**

**Author(s):** P. Berrigan<sup>1</sup>, G. Andrew<sup>2,3</sup>, J. N. Reynolds<sup>4</sup>, J. D. Zwicker<sup>1,5</sup>

**Organization(s):** <sup>1</sup>University of Calgary; <sup>2</sup>University of Alberta; <sup>3</sup>Glenrose FASD Clinic, Alberta Health Services; <sup>4</sup>Queen's University; <sup>5</sup>University of Calgary

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**Abstract:**

**Background:** Fetal Alcohol Spectrum Disorder (FASD) is characterized by physical and neurological abnormalities resulting from prenatal alcohol exposure. Though diagnosis may help improve patient outcomes, the diagnostic process can be costly. Subsequently, screening children suspected of FASD prior to diagnostic testing has been suggested, to avoid administering testing to children who are unlikely to receive a diagnosis. The present study set out to assess the cost-effectiveness of currently recommended FASD screening tools.

**Methods:** The screenings tools evaluated were chosen from Children's Healthcare Canada's National Screening Toolkit for Children and Youth Identified and Potentially Affected by FASD and include meconium testing of fatty acid ethyl esters (meconium testing) and the neurobehavioral screening tool (NST). An economic model was constructed to assess cost-effectiveness. One-way and probabilistic sensitivity analyses were conducted to assess the robustness of findings. Costs reflect 2017 Canadian dollars and the perspective is the public healthcare system.

**Results:** Both screening tools evaluated resulted in reduced costs and fewer diagnosed years of life than a no screening strategy in which all children suspected of FASD receive diagnostic testing. The model predicts that screening newborns with meconium testing results in a reduced cost of \$89,186 per 100 individuals screened and 38 fewer diagnosed years of life by age 18, corresponding to an incremental cost-effectiveness ratio (ICER) of \$2,359. Screening children with the NST resulted in a reduced cost of \$183,895 per 100 individuals screened and 77 fewer diagnosed years of life by age 18, corresponding to an ICER of \$2,390.

**Conclusion:** Findings suggest that screening is associated with less use of healthcare recourses but also fewer years of life with an FASD diagnosis over a no screening strategy. Since diagnosis can be key to children receiving timely and appropriate health and educational services, cost-savings must be weighed against the fewer years of life with a diagnosis associated with screening.

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**Funded by:**

Kids Brain Health Network

**Keywords:**

cost-effectiveness analysis, fetal alcohol spectrum disorder, screening

Theme 4 - Clinical/Community Research

Poster # 41

## Combining Cognitive Rehabilitation with Reading Intervention for Children with Learning Disabilities

Presenter **Jessica Lewis****Author(s):** J. Lewis<sup>1</sup>, S. Macoun<sup>1</sup>, and G. Harrison<sup>2</sup>**Organization(s):** <sup>1</sup>University of Victoria; <sup>2</sup>University of Victoria**Abstract:**

**Objective:** Reading difficulties (RDs) place 7% of school-age children at risk of negative life outcomes. Reading is a complex multi-componential process involving integration of various cognitive processes. Attention and EFs are important cognitive contributors to reading outcomes, even beyond other well-known predictors (e.g., language, phonological abilities, etc.). A host of academic interventions have been developed to remediate RDs yet failure to address their underlying cognitive deficits may limit outcomes. There is recent interest in combining neuroscientific and educational approaches to address academic difficulties and their cognitive causes, yet extremely limited efficacy data on such approaches. This feasibility study investigated a 12-week intervention program (Word Up!) that combined an innovative Attention and EF intervention (Dino Island) with a validated academic intervention in reading (RAVE-O).

**Participants and Methods:** Participants included 11 children with diagnosed reading disabilities ages 6.5-11 years (M = 9.42, SD = 1.28). Children completed 12 hours of DI and 12 hours of Rave-O intervention delivered twice a week in a group format at a community centre for children with Learning Disorders (24 hours of total intervention). Pre-post cognitive and academic outcome measures included tasks of attention, working memory, word knowledge, reading fluency, and reading comprehension.

**Results:** Pre-post test results indicated trends for improvements in visual attention, switching, and working memory. Significant gains were seen in word reading ability and trends for improvements were seen in reading comprehension. Exit interviews with tutor interventionists indicated improvements in focus and self-regulation as well as increased implementation of metacognitive strategies. Overall, the intervention was enjoyed by children and was feasible as delivered as an integrated intervention by tutors in a group format.

**Conclusions:** These findings provide preliminary support for the feasibility and efficacy of combining cognitive intervention (Dino Island) with reading intervention (RAVE-O) to improve academic outcomes. We will expand on our results and will discuss recommendations for implementation of such interventions in community settings and for concurrent implementation of interventions to boost intervention outcomes.

**Funded by:**

Kids Brain Health Network, University of Victoria Centre for Outreach Education (CORE), Learning Disabilities Association

**Keywords:**

cognitive rehabilitation, reading interventions, engagement

## Transdiagnostic eHealth Sleep Intervention for Parents of Children with Neurodevelopmental Disorders

Presenter **Elizabeth Keys**

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**Organization(s):** <sup>1</sup>University of Toronto; <sup>2</sup>Dalhousie University; <sup>3</sup>University of Alberta; <sup>4</sup>McGill University; <sup>5</sup>Université de Montréal; <sup>6</sup>University of Manitoba; <sup>7</sup>University of British Columbia; <sup>8</sup>Western University; <sup>9</sup>Central Queensland University

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**Abstract:**

The majority (up to 90%) of children with neurodevelopmental disorders (NDD) experience sleep problems, particularly insomnia (i.e., difficulties falling asleep, staying asleep, and problems with morning awakenings). Despite clear evidence that sleep problems can have significant consequences for children's physical and psychosocial health, as well as for their parents' well-being, less than 15% of these children receive evidence-based treatments (i.e., behavioural interventions). Key access barriers include limited training for health care providers (HCP) and few available intervention programs that are accessible to parents and targeted to children with NDD. To determine if an eHealth transdiagnostic intervention would address these access barriers, we conducted four foundational studies. The first two studies, a Systematic Review and a Delphi study, gathered information from stakeholders—researchers and content experts. The second two studies, a Focus Group study and a Usability study, gathered evidence from consumers of sleep interventions—parents and HCPs. All four studies provide evidence for the feasibility of a transdiagnostic eHealth intervention. The results of these four studies were used to inform the development of Better Nights, Better Days for Parents of Children with Neurodevelopmental Disorders. A Canada-wide Randomized Controlled Trial is now underway recruiting parents of children ages 4 to 12 years of age with a diagnosis of Attention-Deficit/Hyperactivity Disorder, Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, and Cerebral Palsy who also evidence symptoms of insomnia.

**Learning Objectives:**

- 1) Increase knowledge about sleep problems in children with NDD
  - 2) Learn about the four foundational research studies informing a transdiagnostic eHealth intervention
  - 3) Become familiar with Better Nights, Better Days for Children with NDD
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**Funded by:**

Kids Brain Health Network

**Keywords:**

Neurodevelopmental Disorders, Insomnia, Intervention, eHealth



## Theme 4 - Clinical/Community Research

## Poster # 43

## Understanding the essential components and experiences of youth with autism spectrum disorder in peer mentorship programs

Presenter

**Linda Nguyen**

**Author(s):**L. Nguyen<sup>1,2,3</sup>, S. Jack<sup>4,5</sup>, M. Ketelaar<sup>1,6</sup>, B. Di Rezze<sup>1,2,3</sup>, A. K. Soper<sup>1,7</sup>, and J. W. Gorter<sup>1,3,7</sup>**Organization(s):**

<sup>1</sup>CanChild Centre for Childhood Disability Research; <sup>2</sup>McMaster Autism Research Team; <sup>3</sup>McMaster University; <sup>4</sup>McMaster University; <sup>5</sup>Offord Centre for Child Studies; <sup>6</sup>Centre of Excellence for Rehabilitation Medicine; <sup>7</sup>McMaster University

**Abstract:**

**Background:** Youth with autism spectrum disorder (ASD) often require additional supports during the period of transition to from high school to post-secondary education or career paths. Peer mentorship programs create opportunities to support youth with ASD in identifying their personal, academic, and career goals after graduating from high school, however there is limited insight about the components of these programs that are valued by both participants and peer mentors and that are perceived to contribute to the overall success of a program in achieving their goals. Our objective was to identify, describe and synthesize the components of peer mentorship programs valued by youth with ASD and their peer mentors, as well as to document their experiences in these transitional support services.

**Methods:** A meta-ethnography was conducted to synthesize qualitative and mixed methods studies of PM programs for youth with ASD. A systematic search of seven databases yielded 142 non-duplicate articles. Data analysis and synthesis involved: 1) extraction of raw data; 2) extraction of study authors' interpretations, followed by inductive coding; 3) synthesis of key themes; and 4) schematic diagram development to illustrate the relationship of themes.

**Results:** 10 studies of PM programs from Canada (2), United States (4), Australia (3), and United Kingdom (1) were included. Extracted data reflected experiences of 131 mentees and 82 mentors. The essential program components identified were: 1) mentorship; 2) skill building; 3) peer group; and 4) facilitating transition.

**Significance:** Peer mentorship characterized by clear communication and connection between mentors and mentees was valuable to the success of the program. Peer mentors played an essential role to facilitate the positive experiences that mentees had with program components, including interactions with peer groups. Successful PM programs created a safe environment for mentees to practice skills, and help mentees gain confidence to expand their roles to take leadership in their learning.

**Keywords:**

Autism Spectrum Disorder, Mentorship, Post-secondary Education, Qualitative Synthesis, Meta-ethnography, Peer

Theme 4 - Clinical/Community Research

Poster # 44

## Pragmatic language difficulties in people with epilepsy reflect shared biological mechanisms causing both epilepsy and autism spectrum disorder

Presenter

**Annie Richard****Author(s):**A. E. Richard<sup>1</sup>, I. E. Scheffer<sup>2</sup>, and S. J. Wilson<sup>1</sup>**Organization(s):**<sup>1</sup>The University of Melbourne; <sup>2</sup>The University of Melbourne, Austin Health and Royal Children's Hospital, Florey and Murdoch Children's Research Institutes**Abstract:**

Epilepsy and autism spectrum disorder (ASD) share causal mechanisms. Supporting this, people with epilepsy (PWE) have an increased rate of the broader autism phenotype (BAP), which comprises mild autism traits and is seen in 20% of relatives of individuals with ASD. We hypothesized that these traits may underpin difficulties faced by children and adults with epilepsy, including poor pragmatic language, which constitutes difficulties adapting language to social contexts.

To characterise pragmatic language in PWE we profiled their pragmatic skills compared to other language abilities including verbal fluency and confrontation naming. Then, we examined their association with these language abilities, IQ, social abilities (i.e., theory of mind), epilepsy variables (e.g., age at seizure onset), and the BAP. Language skills were evaluated using the Pragmatic Rating Scale, Boston Naming Test-2, and Controlled Oral Word Association Test in 103 adults (55 females) with epilepsy whose seizures were not secondary to acquired brain injury or another neurological condition (Mean age=37.4 years; Mean IQ=104.0; 51 temporal lobe epilepsy, 40 genetic generalized epilepsy, 12 other) and 58 local community members (Mean age=39.6 years; Mean IQ=113.0; 38 females). Theory of mind was evaluated using the Faux Pas Task. The BAP was assessed using the Broader Autism Phenotype Questionnaire and Autism Endophenotype Interview.

PWE had more severe pragmatic language difficulties than controls ( $p < .001$ ) and these were more common (45%) than other language difficulties (1-18%,  $p < .05$ ). Using cluster analysis, we identified three distinct pragmatic language profiles in PWE: reduced verbal output ( $n = 59$ ), overly talkative ( $n = 30$ ), and confusing communication ( $n = 14$ ). These profiles were not associated with the BAP, social abilities or epilepsy variables. Lower IQ and confrontation naming were associated with more severe pragmatic language difficulties in the reduced verbal output group ( $r = -.41$ ,  $p = .001$ ;  $r = -.39$ ,  $p = .002$ ). Taken together, a lack of association of pragmatic language with epilepsy variables and similar pragmatic language in PWE with and without the BAP suggest that shared mechanisms of epilepsy and ASD may underpin poor pragmatic language in PWE. Thus, interventions that improve pragmatic language in ASD may also be effective for PWE.

**Funded by:**

The National Health and Medical Research Council of Australia Project grants APP1044175, 2013-2016 and App1098255, 2016-2021, and Practitioner Fellowship (App1104831), and an Australian Postgraduate Award

**Keywords:**

Epilepsy, Autism, Broader autism phenotype, Pragmatic language



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