



3<sup>rd</sup> ANNUAL  
LONDON & REGION  
FASD CONFERENCE 2022

BRIDGING CLINICAL, RESEARCH, AND LIVED EXPERIENCE

NEURODIVERSITY, INCLUSIVITY, AND HEALTH EQUITY:  
UNCOVERING AND REDISCOVERING  
FETAL ALCOHOL SPECTRUM DISORDER

26.OCT.2022

VIRTUAL MEETING

8:00AM - 5:00PM



# PROGRAM

AGENDA

LIVED EXPERIENCE SPEAKERS

NEURODIVERSE ARTISTS

PLENARY SPEAKERS

WORKSHOP SPEAKERS

RESEARCH E-POSTER & ORAL RESEARCH POSTER PRESENTERS

FASD CONFERENCE 2022 COMMITTEE

CPRI'S EDUCATION AND LEARNING SERVICES (ELS) DEPARTMENT



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## EVENT DAY AT A GLANCE

<b>8:00 – 8:30</b>	<b>Sign into Conference via Zoom</b> • Test your technology			
<b>8:30 – 8:40</b>	<b>CPRI Host</b> • Overview of the Day – Tech, COI Readings, & Agenda/Structure			
<b>8:40 – 8:50</b>	<b>CPRI Host &amp; Dr. Clare Mitchell</b> • Welcome, Opening Remarks, Introductions, & Land Acknowledgement			
<b>8:50 – 8:55</b>	<b>Lived Experience Speaker #1 – Cindy Quinlan-Morrone</b>			
<b>8:55 – 9:00</b>	<b>Dr. Clare Mitchell &amp; Christine Davison</b> • Honouring and Celebrating the Life of Natalie Davison / Dedication of Plenary Speaker Session			
<b>9:00 – 9:55</b>	<b>Plenary Speaker #1 / The Natalie Davison Honourary Lecture – Dr. Jocelynn Cook</b> • Building Capacity for Prevention, Diagnosis, and Interventions			
<b>9:55 – 10:05</b>	<b>Break</b>			
<b>10:05 – 11:00</b>	<b>Plenary Speaker #2 – Dr. Svetlana Popova</b> • Global and Canadian Prevalence of FASD			
<b>11:00 – 11:20</b>	<b>Meet the Speakers – Dr. Jocelynn Cook &amp; Dr. Svetlana Popova</b>			
<b>11:20 – 11:30</b>	<b>Break</b>			
<b>11:30 – 12:30</b>	<b>Workshop (Main Room) – Denise Kollee &amp; Sue Brooks</b> • Supporting System Change Through Community Partnerships	<b>Workshop (Breakout Room 1) – Jessie Jones</b> • The Social Prescription: Recreation Therapy as the Future of Holistic Healthcare	<b>Workshop (Breakout Room 2) – Dr. Ashley Bildfell &amp; Dr. Morgan Kleiber</b> • Understanding ‘Brain Domains’ Impacted by FASD and their Role in Learning: Evidence-Based Strategies for Supporting Neurodiversity in the Classroom	<b>Workshop (Breakout Room 3) – Elder Noel Milliea &amp; Dr. Nicole LeBlanc</b> • Cross-Cultural Competencies in Medicine: Partnering with First Nations for Better Health

<b>12:30 – 1:30</b>	<b>Lunch</b> <b>Research E-Poster Presenters</b> available from <b>12:45 – 1:25</b> by accessing presenters' ZOOM links			
<b>1:30 – 1:35</b>	<b>CPRI Host</b> • Welcome Back to the Main Room & Conference			
<b>1:35 – 1:40</b>	<b>Lived Experience Speaker #2 – Shannon Butt</b>			
<b>1:40 – 2:10</b>	<b>Oral Research Poster Presentations</b>			
<b>2:10 – 3:05</b>	<b>Plenary Speaker #3 – Changemakers</b> <b>CJ Lutke, Emily Hargrove, Maggie May, &amp; Justin Mitchell</b> • Field of Dreams: Building Equitable Access to FASD Diagnosis and Services in Your Community			
<b>3:05 – 3:25</b>	<b>Meet the Speakers – Changemakers</b>			
<b>3:25 – 3:35</b>	<b>Break</b>			
<b>3:35 – 3:40</b>	<b>Lived Experience Speaker #3 – Nancy Lockwood</b>			
<b>3:40 – 4:40</b>	<b>Workshop (Main Room) – Dr. Preeti Kar</b> • Brain and Behavioural Development in Young Children with Prenatal Alcohol Exposure	<b>Workshop (Breakout Room 1) – Dominique-Michelle Legacy &amp; Karin Stockwell</b> • Viewing FASD Through an Indigenous Lens	<b>Workshop (Breakout Room 2) – Dr. Charlis Raineke</b> • Links Between Immune System Dysregulation and Health Problems Following Prenatal Alcohol Exposure: A Translational Approach	<b>Workshop (Breakout Room 3) – Angela Geddes &amp; Dr. Brianne Redquest</b> • Supporting Caregivers and People Affected by FASD Through Acceptance and Commitment Therapy (ACT)
<b>4:40 – 4:45</b>	<b>Winners Announcement – CPRI Host</b> • Art Contest, Research E-Poster Presentation, & Oral Research Poster Presentation			
<b>4:45 – 5:00</b>	<b>Dr. Clare Mitchell</b> • Closing Remarks • Online Evaluations			

\*\*\* Please note that non-shaded segments in the day are non-accredited. The shaded segments (i.e., Plenary Speakers, Meet the Speakers, and Workshops) are accredited.

# THANK-YOU TO OUR LIVED EXPERIENCE SPEAKERS

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Every year, we are grateful to those who choose to share their own personal lived experiences with FASD at this conference. Not only do these speakers bring a unique perspective to our important discussions about care and support, but they also inspire conversations about hope and potential. Despite stigma and other barriers, they know how important it is for personal stories to be told and held with respect.

This year, we are privileged to hear from Cindy Quinlan-Morrone, Shannon Butt, and Nancy Lockwood. We thank them for being vulnerable and courageous and sharing their stories with all of us at this conference. We are all better for it.

## NEURODIVERSE ARTISTS

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### Virtual Art Exhibition and Competition for Neurodiverse Artists, Their Families and Caregivers

The London and Regional FASD Conference, sponsored by The Volunteer Organization of CPRI (VOCPRI) recognizes is able to showcase the remarkable artistic talent of individuals that identify as neurodiverse. For inspiration, participants were reminded that the theme of this year's London & Region FASD Conference is "Neurodiversity, Inclusivity, and Health Equity: Uncovering and Rediscovering Fetal Alcohol Spectrum Disorder. They were encouraged to consider the following:

- What does neurodiversity mean to you?
- What kind of art could you make that represents inclusivity?

### Art Competition

The competition awards a winning submission a \$150 prize, with two runner-up prizes of \$50 each, decided by a committee comprised of volunteers and local professional artists.

## PLENARY SPEAKERS

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THE NATALIE DAVISON HONOURARY LECTURE  
9:00 AM – 9:55 AM • MAIN ROOM

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### BUILDING CAPACITY FOR PREVENTION, DIAGNOSIS, AND INTERVENTIONS

JOCELYNN COOK PHD, MBA

Substance use during pregnancy continues to increase globally, and data about the impacts of in utero exposure on physical and mental health continues to emerge. Prenatal alcohol exposure (PAE) is associated with a range of neurodevelopmental and behavioural needs which, without standardized mechanisms for identification and diagnosis, can remain unaddressed. When needs are not recognized, individuals with PAE

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can experience challenges, and, as a result, opportunities for interventions to improve outcomes for individuals and families may be missed.

Canada's National FASD Database provides information on ~4,000 individuals with PAE and includes demographic, diagnostic, social, physical, mental health, and social factors. Data provides important evidence, not only about brain function and behaviour associated with PAE, but also about pre- and post-natal factors that influence how we should think about prevention, diagnosis, and interventions.

#### LEARNING OBJECTIVES

- Recognize the complexity of alcohol use during pregnancy
- Describe how those with FASD differ from those without FASD, according to current diagnostic criteria
- Explore how evidence can impact prevention, diagnostic systems, and map intervention

#### ABOUT THE SPEAKER

Dr. Jocelynn Cook graduated with a PhD in Reproductive Physiology from the Medical University of South Carolina and spent 10 years in an academic setting as a graduate student, a post-doctoral fellow, and an Assistant Professor. Wanting to expand her skillset beyond the basic science laboratory, she graduated from the University of Saskatchewan with an MBA, specializing in Economics and Health Policy. Dr. Cook's professional career has focused on issues related to maternal-fetal medicine; specifically, substance abuse during pregnancy, preterm birth, Fetal Alcohol Spectrum Disorder (FASD), Assisted Human Reproduction, and Maternal Mortality.

After holding the positions of Executive Director of the Strategy for Patient Oriented Research at the Canadian Institutes for Health Research, then Executive Director of the Canada FASD Research Network, Dr. Cook joined the Society of Obstetricians and Gynecologists of Canada as its first Chief Scientific Officer in 2014. Dr. Cook oversees all work related to public health and surveillance, research and knowledge translation, Clinical Practice Guidelines, academic programs, and education. In addition, Dr. Cook oversees national projects, including perinatal mental health and prevention of maternal morbidity and mortality.

Dr. Cook has been an Adjunct Professor to the Department of Obstetrics and Gynecology at the University of Ottawa since 2002. Dr. Cook continues to be active in her own research and in research partnerships and collaborations. In her spare time, Dr. Cook loves laughing, hugging, spending time watching her amazing daughters navigate their science courses, and beating her own score on the Peloton.

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#### INVITED PLENARY LECTURE

10:05 AM – 11:00 AM • MAIN ROOM

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### GLOBAL AND CANADIAN PREVALENCE OF FASD

SVETLANA POPOVA MD, PHDs, MPH

The World Health Organization (WHO) global strategy to reduce the harmful use of alcohol, endorsed by the 63<sup>rd</sup> World Health Assembly in May 2010, highlights the importance of the prevention and identification of the harmful use of alcohol among pregnant women and women of child-bearing age, as well as of treatment and care for individuals and families affected by Fetal Alcohol Spectrum Disorder (FASD).

FASD has a huge economic and societal impact as it affects both individuals and their families and requires lifelong assistance from a wide range of services, including health, community, remedial education, and many others. As the first step towards understanding the severity and impact of FASD in different parts of the world, required for planning adequate policy and program responses, it is essential to determine the prevalence of these conditions in different countries.

This workshop will present the prevalence of alcohol use and binge drinking by countries, WHO regions, and globally among a) women of childbearing age and b) pregnant women. It will also present the prevalence of FASD by countries (including Canada), WHO regions, and globally among a) general populations and b) specific sub-populations (i.e., children in care, correctional populations, special education populations, and specialized clinical populations).

### LEARNING OBJECTIVES

- Gain knowledge on the prevalence of alcohol use and binge drinking by countries, WHO regions, and globally among women of childbearing age and pregnant women
- Gain knowledge on the prevalence of FASD by countries (including Canada), WHO regions, and globally among general populations and specific sub-populations (i.e., children in care, correctional populations, special education populations, and specialized clinical populations)

### ABOUT THE SPEAKER

Dr. Svetlana (Lana) Popova, MD, PhDs, MPH, is a Senior Scientist at the Centre for Addiction and Mental Health, World Health Organization/Pan-American Health Organization Collaborating Centre, Toronto, Canada. She is also an Associate Professor at the Dalla Lana School of Public Health, Epidemiology Division and Factor Inwentash Faculty of Social Work, University of Toronto.

Dr. Popova's research focuses on substance abuse and disease burden and evidence-based policy development. She has a particular interest in the epidemiology, comorbidities, economic cost, prevention, and intervention strategies related to FASD.

Dr. Popova is leading one of the largest studies, guided by the World Health Organization, on determining the global prevalence of FASD among children in low- and middle-income countries of Eastern and Central Europe and Africa, as well as Canada. She was also a principal investigator of the study on Surveillance of FASD and prenatal alcohol exposure as well as on estimating the burden and economic cost associated with FASD in Canada, supported by the Public Health Agency of Canada. Dr. Popova's research in high-impact journals is widely read and cited.

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INVITED PLENARY LECTURE  
2:10 PM – 3:05 PM • MAIN ROOM

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## FIELD OF DREAMS: BUILDING EQUITABLE ACCESS TO FASD DIAGNOSIS AND SERVICES IN YOUR COMMUNITY

ADULT LEADERSHIP COLLABORATIVE OF FASD CHANGEMAKERS:  
CJ LUTKE, EMILY HARGROVE, MAGGIE MAY, & JUSTIN MITCHELL

FASD is not just a diagnosis in or for childhood, but one with life-long implications requiring understanding and accommodation, particularly as children with FASD enter adolescence and adulthood. As such, it is

imperative that the diagnosis is made at any age, as it is never too late to create the changes needed for more positive outcomes, as the Adult Leadership Collaborative (ALC) of FASD Changemakers can attest to. Equity and access are key components, both to diagnosis and to developing services that work for individuals with FASD at all ages and developmental levels, as most individuals are not intellectually disabled. This is particularly critical for those individuals with FASD who are, or, if diagnosed, would be considered “high functioning” (a term we do NOT like). This is the group for whom the correct diagnosis of FASD is most often missed, for whom service eligibility does not occur, for whom outcomes are often the poorest, but are those for whom correct diagnosis and equitable services can make the most difference.

## LEARNING OBJECTIVES

- Recognize equity as it applies to FASD and essential quality of life
- Identify the need for diagnostic processes at all ages
- Examine and explore what FASD support services need to include across the lifespan to maximize potential

## ABOUT THE SPEAKERS

The Adult Leadership Collaborative (ALC) of FASD Changemakers is a well-known group of citizen researchers and experts who each have diagnosed FASD and range in age from 26 to 44. It is made up of CJ Lutke, Myles Himmelreich, Katrina Griffin, Justin Mitchell, Anique Lutke, Emily Hargrove, and Maggie May, a group who have experienced all the events commonly associated with FASD but have learned how to overcome obstacles, maximize potential, and re-define success. They use their combined lived experience to work together as consultants, advisors, trainers, presenters, mentors, group moderators, bloggers, and as various university research project team members. As well, they develop and lead their own survey research, which has received wide interest by institutions, agencies, organizations, government bodies, and the FASD community. Their first survey has been published by Routledge, and their second is currently being written. Both research surveys have been widely presented, including internationally, and are currently being used to help focus research directions and questions.

# BREAKOUT WORKSHOP SESSIONS

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## MORNING SESSIONS

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11:30 AM – 12:30 PM • MAIN ROOM

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## SUPPORTING SYSTEM CHANGE THROUGH COMMUNITY PARTNERSHIPS

DENISE KOLLEE & SUE BROOKS

This workshop will trace the partnership journey of the Halton FASD Collaborative and the Halton Catholic District School Board in creating a model of support for students at HCDSB. Pivotal moments will be highlighted and strategies for implementing FASD informed supports in a school system will be shared. An interactive format using scenarios, polls, and discussion questions will be used to promote engagement and learning.

## LEARNING OBJECTIVES

- Recognize key ingredients that supported sustainable community collaborations in Halton
- Describe how a regional community of practice was used to create organizational champions
- Identify ways the implementation of FASD-informed supports in a district school board was operationalized

## ABOUT THE PRESENTERS

Denise Kollee has worked as a speech language pathologist for over 20 years. She is currently the Chief SLP and the FASD Lead at Halton Catholic District School Board. She began her journey learning about FASD in 2015 when she became co-chair of the Halton FASD Resource Team and has been passionate about supporting children and adolescents in a school setting ever since. She has led the creation and implementation of a tiered model of support for students with FASD at her school board. She has a leadership role in the Halton FASD Collaborative and co-chairs the Halton FASD Advisory Committee. Denise continues to facilitate FASD training and case conferences as well as supporting system change across community agencies.

Sue Brooks is a Child and Youth Worker with over 25 years of experience in a broad range of environments that includes residential, community-based, and school settings. She has worked extensively with children, youth, and their families with complex needs and has a strong passion for creating change through community partnerships. For the past 8 years, she has supported and led the Halton FASD Community Collaborative. She is currently the Manager of Specialized Consultation at Reach Out Centre for Kids (ROCK), providing leadership to the FASD Assessment & Diagnostic Clinic, FASD Consultants, Psychology Team, and Caroline Families First Program. Sue is the Co-chair of the Halton Advisory Committee and Halton FASD Resource Team (Community of Practice).

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11:30 AM – 12:30 PM • BREAKOUT ROOM 1

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## THE SOCIAL PRESCRIPTION: RECREATION THERAPY AS THE FUTURE OF HOLISTIC HEALTHCARE

JESSIE JONES

Join Jessie Jones to learn about the importance of therapeutic recreation (TR) as the future of holistic health care. Jessie will guide participants through the benefits of recreation and leisure interventions through evidence- and strength-based approaches and share how TR contributes to a salutogenic orientation to health and well-being.

## LEARNING OBJECTIVES

- Learners will be able to identify three benefits to using therapeutic recreation and leisure to support children with intellectual and developmental disabilities and mental health
- Learners will have a strong understanding of therapeutic recreation fundamentals; for example, “what is therapeutic recreation and how does one recognize the difference between recreation and therapeutic recreation?”

- Learners will be able to identify at least three basic therapeutic recreation interventions, methods, and models and how they contribute to health and wellbeing of children with intellectual and developmental disabilities and mental health

#### ABOUT THE PRESENTER

Jessie Jones is the founder and CEO of Jess Jones Recreation Therapy Inc., a social services company that provides therapeutic recreation, leisure education, and counselling to humans of all ages and abilities, with a particular emphasis on children with developmental and intellectual disabilities and mental health through connection, creativity, and curiosity.

Jessie Jones has a 2-year Recreation Therapy diploma from Canadore College, a 2-year Culinary Management diploma from Fanshawe College, and is currently a 3rd year research student obtaining an honours degree in Recreation and Leisure Studies with a concentration in Therapeutic Recreation and Psychology from Brock University. Jessie's educational objective is to become a Certified Therapeutic Recreation Specialist and continue with her master's degree in Psychology to become a Registered Psychotherapist.

As a writer, storyteller, musician, artist, caregiver, and mother, it is important to Jessie to bring people together through connection, creativity, and curiosity and honour the individual through their life story.

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11:30 AM – 12:30 PM • BREAKOUT ROOM 2

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### **UNDERSTANDING 'BRAIN DOMAINS' IMPACTED BY FASD AND THEIR ROLE IN LEARNING: EVIDENCE-BASED STRATEGIES FOR SUPPORTING NEURODIVERSITY IN THE CLASSROOM**

ASHLEY BILDFELL PHD, C. PSYCH (SUPERVISED PRACTICE) & MORGAN KLEIBER PHD

Neurodiversity – the range of differences in brain function and behaviour between individuals – is heavily determined by the interplay between biological variation and environmental influences. Differences in specific brain functions or “domains” (such as cognition, attention, memory, executive function, adaptive behaviour, or affect regulation) can impact a student's specific learning needs in a classroom setting. Evidence-based educational interventions that benefit children with Fetal Alcohol Spectrum Disorder (FASD) tend to benefit neurodiverse and neurotypical children alike, which maximizes educator efforts and student learning.

In this workshop, brain domains relevant to learning that are impacted by FASD will be explored, as well as how understanding interindividual differences in these domains (biologically and functionally) can inform practical strategies for classroom-based interventions. This workshop will examine how individual variation in brain domains impact learning, explore the neuroscience of why kids learn differently and introduce clinical classroom-based interventions specific to each brain domain. This workshop will highlight easy-to-implement, evidence-based teaching strategies that are critical for neurodiverse students with learning challenges (such as those with FASD) and that can benefit the academic achievement of all students. Workshop participants will develop an understanding of specific strategies they can implement to facilitate learning for students with specific brain-based challenges. The application of the Universal Design for Learning (UDL) model in classrooms could inform training programs that effectively address learning needs in neurodiverse students.

In sum, this workshop will discuss the potential of a classroom-based learning model sensitive to the educational needs of neurodiverse students while maximizing overall student success, and address the critical role of educators, clinicians, and parents in achieving an effective learning environment that supports neurodiversity.

#### LEARNING OBJECTIVES

- Gain a fundamental understanding of how various “brain domain” functions impact learning, with a focus on neurodiversity, in a classroom setting
- Recognize how genetics and neurobiology contribute to brain diversity and brain domain functions
- Distinguish evidence-based clinical interventions (specific to each “brain domain”) that support neuro-atypical as well as neuro-typical students in the classroom

#### ABOUT THE PRESENTERS

Dr. Ashley Bildfell is a clinical psychologist in supervised practice. Her research focused on self-regulation in early learners, specifically while writing. Dr. Bildfell has trained and worked in school, community mental health, primary care, and forensic settings. Dr. Bildfell provides clinical assessments and psychotherapy for children, adolescents, adults, and families. She has a clinical interest in supporting individuals with neurodevelopmental disorders (e.g., Learning Disabilities, Attention-Deficit/Hyperactivity Disorder, Intellectual Disabilities, Autism Spectrum Disorder, and Fetal Alcohol Spectrum Disorder), mental health problems, behaviour problems, and those involved in the justice system. Dr. Bildfell facilitates a social skills group for adolescents with Fetal Alcohol Spectrum Disorder.

Dr. Morgan Kleiber’s research examines the developmental origins of psychiatric disorders – specifically, how the genome and environment interact to shape genetic and epigenetic patterning, brain development, and ultimately behaviour. She completed her PhD at the University of Western Ontario in Cell and Molecular Genetics, focusing on how prenatal alcohol exposure can create a lifelong “footprint” on biological brain function that contributes to persistent behaviours observed in individuals with FASD. She has also trained at the University of California, San Diego (Departments of Psychiatry and Cell and Molecular Medicine) as a CIHR Postdoctoral Fellow where her research examined the contributions of rare genetic variants to Autism Spectrum Disorder (ASD). Dr. Kleiber is also a strong advocate for science education and mentorship and has won several departmental and faculty teaching awards.

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11:30 AM – 12:30 PM • BREAKOUT ROOM 3

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### **CROSS-CULTURAL COMPETENCIES IN MEDICINE: PARTNERING WITH FIRST NATIONS FOR BETTER HEALTH**

ELDER NOEL MILLIEA & DR. NICOLE LEBLANC MD, F.R.C.P.(C)

This session will discuss the steppingstones to developing cultural competencies. It will bring us to reflect on how our traditional medical model can learn from First Nation’s medicine. Drawing from the knowledge of our First Nation’s Elders, we will explore how understanding the fundamentals of relationship building with our First Nation’s communities and developing cultural competencies can lead us to better health care delivery and healthier population outcomes.

## LEARNING OBJECTIVES

- Identify challenges in providing culturally safe health care for First Nations communities
- Develop cultural competencies to improve the quality of health care provided
- Identify personal and collective future learning needs as they relate to cultural competencies in a continuous quality improvement perspective

## ABOUT THE PRESENTERS

Elder Noel Milliea is a Mic-Mac Native from the Elsipogtog First Nation's Community in New Brunswick Canada. He has been working with the Parole Board of Canada for the past 25 years in Aboriginal initiatives and Aboriginal offender reintegration. Noel has been teaching at the University of PEI for over 20 years to 4<sup>th</sup> year B.E.D. students entitled, "Indigenous Education." Noel has developed and delivered numerous courses based on cultural diversity and awareness. He developed a healing model of the medicine wheel and has been delivering this course to mainstream society as a tool to guide one's self on their journey of healing. Noel also serves as the National Elder for the Parole Board of Canada and has also presented as a keynote speaker at numerous national and international justice conferences and education conferences. Along with living a spiritual way of life, Noel is a well respected elder in his community, and is a pipe carrier/sweat lodge conductor for the people of his community. He has lived an alcohol and drug-free life for over 35 years.

Dr. Nicole LeBlanc is a Pediatrician and Chief of Staff at Vitalité Health Network. She is an associate clinical professor at the Université de Sherbrooke and Université de Moncton and an examiner for the Royal College of Physicians and Surgeons of Canada. Dr. LeBlanc is a founding member and the Medical Director of the NB FASD (fetal alcohol spectrum disorder) Centre of Excellence, where she continues to actively advocate for FASD individuals and their families in Eastern Canada. She served as a member of the National Consultant Committee to the Canadian Minister of Health on FASD, participated in the Canadian Consensus Statement on addressing legal issues of FASD, has multiple publications to her name, and is one of the co-authors of the 2005 and 2016 FASD "Canadian Guidelines for Diagnosis." As a mother of three teenaged boys, Dr. LeBlanc is a strong believer in community involvement and is passionate about developing quality interdisciplinary programs centred on the needs of the children, their family, and their community. In her quest to continuously improve quality of care given to her patients, Dr. LeBlanc has led the development of integrated and culturally safe service delivery models of care that have been awarded national recognition for both exemplary practices and innovation. She recently received the Order of Merit given by the Université de Moncton to recognize her exceptional leadership, her community engagement, and her remarkable contribution to her profession.

## AFTERNOON SESSIONS

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3:40 PM – 4:40 PM • MAIN ROOM

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### **BRAIN AND BEHAVIOURAL DEVELOPMENT IN YOUNG CHILDREN WITH PRENATAL ALCOHOL EXPOSURE**

PREETI KAR PHD

Prenatal alcohol exposure (PAE) can lead to cognitive and behavioural challenges, which stem from differences in brain development. In early childhood, neurodevelopmental differences associated with PAE may become apparent; however, prior brain research has focused on children with PAE older than 7 years.

Our team led the first brain imaging study in young children (2-7 years) with prenatal alcohol exposure. This workshop will highlight innovative methods to recognize other prenatal and postnatal exposures alongside PAE and to collect brain imaging data in young children with PAE. We will also discuss brain differences in children with PAE and how they may be linked to cognitive, language, motor, and mental health challenges during preschool years. This work may support earlier identification and intervention strategies for challenges associated with PAE.

#### LEARNING OBJECTIVES

- Name commonly co-occurring prenatal and postnatal exposures
- Describe techniques to complete neuroimaging in young children
- Differentiate brain development in young children with prenatal alcohol exposure and unexposed, typically developing, children
- Identify how brain development relates to cognitive, language, motor, and mental health in young children with prenatal alcohol exposure

#### ABOUT THE PRESENTER

Preeti Kar completed her PhD at the University of Calgary, a postdoctoral fellowship at the University of British Columbia, and is currently a medical student. Her research interests include understanding how prenatal and postnatal experiences (e.g., prenatal alcohol or substance exposure, prenatal maternal depression) impact brain and behavioural development in infants and children. Preeti is involved with the Calgary Fetal Alcohol Network and the Calgary Perinatal Collective to shape community education around alcohol and substance use in pregnancy. She strongly values knowledge translation and mobilization, and engaging family and community partners in research to optimize outcomes for children and their caregiver.

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3:40 PM – 4:40 PM • BREAKOUT ROOM 1

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### VIEWING FASD THROUGH AN INDIGENOUS LENS

DOMINIQUE-MICHELLE LEGACY & KARIN STOCKWELL

As professionals, supporting clients and families dealing with FASD can be challenging. Establishing trust can be difficult, especially when trauma is a significant factor. Indigenous health care is complex, not only because of potentially different worldviews and cultural approaches, but also because of the personal and generational, present-day, and historical trauma that Indigenous clients may have experienced.

Research has shown that relationship-building mediates trauma. To build strong relationships with Indigenous clients, professionals can benefit from an appreciation of Indigenous history, cultural practices, and lived experiences. This workshop will present a history of Indigenous experiences that can shed light on why professionals may encounter challenges while supporting their Indigenous clients, as well as help to identify obstacles and solutions to address them. The content will also include ways that practitioners can incorporate traditional values, as well as dispel myths and misconceptions regarding FASD and Indigenous communities. The overall goal is to create a safe space for Indigenous clients with FASD and their families to access services by starting the conversation on how to incorporate the unique needs of Indigenous clients into professional practice.

## LEARNING OBJECTIVES

- Participants will be able to connect key events in Indigenous history with the Truth & Reconciliation Calls to Action regarding FASD
- Participants will be able to recognize common myths around alcoholism, FASD, and Indigenous communities to challenge unconscious bias
- Participants will be able to identify common triggers and potential barriers in their professional practice that impacts the provision of cultural safe FASD care
- Participants will be able to incorporate new knowledge of cultural safety practice to support and advocate for Indigenous People living with FASD

## ABOUT THE PRESENTERS

Dominique-Michelle Legacy is Acadian French and a member of the Elsipogtog First Nation of New Brunswick. Her educational journey brought her to the Lake Huron shores in 2013. She holds a master's degree in Health Science from the University of Ottawa and a bachelor's degree in Psychology from the University of Moncton. Dominique has been part of the Southwest Ontario Aboriginal Health Access Centre Owen Sound site team since September 2013. Her career at SOAHAC began as an occupational therapist under the mental health program until recently when she accepted the position of Integrated Care Manager. Dominique's career has solely focused on working alongside Indigenous communities on and off reserve. Her professional and personal experiences have created a passion for Indigenous advocacy in trauma-informed and culturally safe provision of care. Dominique invites all sectors to be part of a profound commitment in establishing new relationships with our Indigenous communities that are embedded in mutual recognition and respect that will forge a brighter future for our brothers and sisters.

Karin Stockwell holds a B.Sc. in Developmental Biology and a B.Ed from the University of Toronto, with additional qualifications in Special Education. She is also a graduate of the Practical Nursing program at Georgian College and is registered with the Ontario College of Nurses. Throughout her career, Karin has worked in education and in allied health positions, bringing her passion for developing new programs with a client-, patient- and student-centred focus. Karin stepped into the position of FASD Coordinator with SOAHAC in 2021 with the goal to provide local FASD assessment, diagnosis, and programming using the best of traditional healing and western biomedical practices. Karin works alongside an amazing multidisciplinary team who are committed to the vision of providing client- and family-centred, culturally safe, FASD-informed, trauma-informed, evidence-based, best-practice driven FASD assessment, diagnosis, and ongoing support.

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3:40 PM – 4:40 PM • BREAKOUT ROOM 2

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## **LINKS BETWEEN IMMUNE SYSTEM DYSREGULATION AND HEALTH PROBLEMS FOLLOWING PRENATAL ALCOHOL EXPOSURE: A TRANSLATIONAL APPROACH**

CHARLIS RAINEKI PHD

During this workshop, Dr. Raineki will integrate data from both basic science and clinical research on the effects of prenatal alcohol exposure across multiple neurobehavioural domains. He will provide an overview of the complex and interactive effects of alcohol consumption during pregnancy and early-life adversity on neuroimmune development, and how these exposures can affect long-term health outcomes in the offspring.

## LEARNING OBJECTIVES

- Gain an understanding of how early-life adversity shapes individuals' neurobehavioural developmental trajectories, specially in the context of prenatal alcohol exposure
- Summarize emerging evidence for the wide-ranging effects of alcohol consumption during pregnancy and/or early adversity on offspring mental health
- Describe how disturbances in early immune system development can have long-lasting consequences for immune function and neurobehavioural development

## ABOUT THE PRESENTER

Dr. Charlis Raineke is an Assistant Professor in the Department of Psychology at Brock University. The overarching theme of Dr. Raineke's work is to understand how prenatal alcohol exposure influences development and produces long-term changes in immune, brain, hormonal, and behavioural systems. He is particularly interested in understanding the underlying mechanisms mediating the increased rates of mental health problems observed in individuals with FASD. The immune system is increasingly recognized as playing an important part in typical brain development and function, and depression and anxiety are often associated with immune dysregulation. Accordingly, Dr. Raineke's current research is investigating the immune system and its contribution to the underlying mechanisms of the increased vulnerability to mental health problems following prenatal alcohol exposure.

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3:40 PM – 4:40 PM • BREAKOUT ROOM 3

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## **SUPPORTING CAREGIVERS AND PEOPLE AFFECTED BY FASD THROUGH ACCEPTANCE AND COMMITMENT THERAPY (ACT)**

ANGELA GEDDES & BRIANNE REDQUEST PHD

Caregivers of individuals with fetal alcohol spectrum disorder (FASD) report high levels of stress, yet are often excluded from typical mental health and support services. This has been recognized by the Ontario Government's FASD provincial initiatives of which investment in Family/Caregiver Support Group Project is one priority. In response to this, our team has worked with the FASD community to support the development and delivery of various supports aimed to enhance the overall wellbeing of caregivers of people with FASD. Subsequent work in this area is finding that Acceptance and Commitment (ACT) can be very helpful for individuals with FASD as well, so we will explore some examples.

Part One of this presentation will review existing research regarding the experiences and the mental health of caregivers of people with FASD. Part Two will describe various supports for this population, highlighting an initiative led by our team of scientists and researchers from the Centre for Addiction and Mental Health and the University Health Network, caregiver advisors, and an FASD expert. Our team co-delivered a brief ACT intervention/workshop to caregivers of people with FASD that aimed to improve their mental health and wellbeing. In addition to presenting the results of this work, we will describe the importance of FASD-informed facilitation, mitigating risks, addressing barriers, and providing recommendations for future research/supports. Throughout this presentation, participants will be invited to engage in an ACT exercise. We will also explore examples of exercises that have been found to be helpful with people with FASD.

## LEARNING OBJECTIVES

- Describe the overall mental health of caregivers of people with FASD and associated impacts
- Understand the impact of Acceptance and Commitment Therapy (ACT) on caregivers of people with FASD and for people with FASD
- Identify key elements within support groups for caregivers of people with FASD that promote overall effectiveness
- Discover the core processes of Acceptance Commitment Therapy/Training (ACT) and relevant application within FASD support group activities, as well as their personal lives

## ABOUT THE PRESENTERS

Angela Geddes is a Social Worker with over 25 years of experience supporting individuals in a variety of settings. She is currently in private practice providing education, advocacy, and direct support for individuals and families experiencing complex issues, including the impact of PAE/FASD. Angela is also an active member of the FASD ONE Diagnostic Action Group and involves herself in many different projects aimed at building a more inclusive service delivery system. She has recently authored a book titled, “A Complicated & Beautiful Brain: A Guide to Understanding the Effects of Prenatal Alcohol Exposure (PAE) and what Fetal Alcohol Spectrum Disorder (FASD) Looks Like Across the Lifespan.”

Dr. Brianne Redquest is a postdoctoral associate at the University of Calgary with the ENHANCE lab. Dr. Redquest’s program of research involves co-creating innovative, accessible, and patient-informed supports for improving the mental health of people with disabilities and their caregivers.

# RESEARCH E-POSTER & ORAL RESEARCH POSTER PRESENTATIONS

The London & Region FASD Conference Committee invited established and up-and-coming FASD researchers and experts from across Canada to present their latest work at this year’s meeting. The E-Posters and Oral presentations reflect important and interdisciplinary topics, such as current FASD research, improving support and delivery models, including within Indigenous communities, and reframing how we approach understanding FASD and neurodiversity.

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## RESEARCH E-POSTER PRESENTERS

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12:45-1:25 PM • PRESENTERS’ ZOOM LINKS ON CONFERENCE WEBSITE

E-Posters will be available for preview beginning October 24 and throughout event day. Authors will be present to answer questions and discuss their work from 12:45 – 1:25pm EST by accessing presenters’ Zoom links. We hope you take the opportunity to speak to the presenters about their engaging work.

Full details and up-to-date information are available on the conference website.

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## FASD and Mental Health

Matthew Sinclair

All Relations Consulting

### **ABSTRACT**

**FASD:** FASD is a biological psychology caused when the mother is pregnant and is drinking alcohol during early development of the brain and cell growth. As a result, we see sensory behaviors that can challenge a person with FASD, possibly causing an information-sensory overload, causing behaviors, such as some form of aggression, not intended towards other people but self-directed due to difficulty in expressing emotions.

The human being with FASD is based on structure, routine, and concrete approaches to adapt to their goals and dreams. Western Medical model is based on diagnoses/labels; the Indigenous model is based on balance of a medicine wheel with a person then family and community most importantly as one within ourselves: emotional, mental, spiritual, and psychical aspects of everyday life.

**Psychosis:** “Psychosis” is a psychiatry term and can refer to “Triune”, meaning 3 into 1, which are auditory, visual hallucinations, and aggressive behaviors in the form of delusion and paranoia in active addiction. We must understand the complex hidden nature of looking at Triune as original trauma which the brain is exposed to in active addiction. Misunderstanding happens due to the nature of Triune psychology because a human being's crisis of survival is based in a state of poverty and is centered on the unnatural trauma of homelessness. We see acts of violence in the form of “co-characters” of human beings when under the influence of active addiction psychosis, taken out on others instead of self, where a parallel can be seen in relation to challenges a person faces in the frontlines of addiction.

To remain teachable allows for positive development in the form of overcoming psychosis: “Thought is not real, Action is real” Acceptance Commitment Therapy.

When we see self-talk as a form of mental illness, we criminalize the human being. Yet when someone does it to think aloud about a problem or just remember something they forgot, they do not look ill. This is where we hear our clients using different metaphors while in a state of trauma, exposed on the street in what is an unnatural exosphere, where it is important to understand that the nature of the Micro, Mezzo, Macro, and Exo are not different than Indigenous Teaching of Awareness in the form of medicine wheel aspects of Mental, Emotional, Spiritual, Psychical.

### **Understanding Trauma in Active Addiction**

Indigenous Culture is wandering and exploring our environment. Adjusting focus around mental wellness instead of the Western view of mental illness - “I” is not in Wellness. The hook of the “I am” statement, the “but it is true!” hook, the “Past” hook, the “1000 reasons” hook, the “Right vs Wrong” hook, the “Judge” hook, the “I Can’t Until” hook, the “Always and Never” hook, the “Should, Must, Have To” hook is what psychosis can look like when framed by psychology. Trauma can be a blitz of such “I am” Statements, a result perhaps of when our psychology is not designed to handle repetitive trauma day after day. The other conclusion is the avoidance of getting a diagnosis with the stigma associated with psychiatry. These external factors of addictions are not in Indigenous Culture pre-colonization - it was only after post-colonization was it seen from the West as Mental Illness.

When we look at the many advancements in the field of addiction in the understanding that human beings may be in some type of crisis and are forced to survive and adapt to stressors, we understand humans release cortisol, which can numb expression, confuse speech and behaviors, causing frustration in forms of Triune psychology. This holds true when you look at patterns of harm from untrained community members and opinion-driven ideas on how to help someone in active addiction that are based on emotion instead of reward. Someone can be incriminated for using substances by their own means, with judgements on their emotional state and not optimum state of mental health.

Would a person in crisis be looking for support? With much support around recovery-based preventions, we fail to see the most important part of the human being that is struggling and in many senses their own value as a human being.

## **PRESENTER BIOSKETCH**

Matthew Sinclair's home community is Peter Ballantyne Cree Nation in Saskatchewan. He resides in London, Ontario. His educational background is a combination of lived experience and academic, as he graduated from the Sault College Graduate Program FASD (Fetal Alcohol Spectrum Disorder) class of 2021. He is a professional speaker and advocate in the field of Fetal Alcohol Spectrum Disorder/Addictions working in the field of education and non-profit organization. A milestone in his professional career was co-creating and designing a community program designed to help others living with Fetal Alcohol Spectrum Disorder as the FASD Worker for Algoma and Northern Ontario, with partnerships with Er Consulting, Sault Ste Marie Indigenous Friendship Centre. Matthew is currently the CEO of All Relations Consulting. Additionally, he volunteers with Native Canadian Toastmaster in Toronto.

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## Assessment Team Training for existing and emerging FASD assessment clinics in Ontario

Angela Geddes<sup>1</sup>, Kimberly Harris, Mohamed Oshalla, Janet Caruibu, Louise Scott, and Clare Mitchell

<sup>1</sup>Angela Geddes Integrative Support and Wellness

### **ABSTRACT**

**Background and Research Objectives:** News: March 10th, 2021. Toronto - the Ontario government is investing 2.8 million annually to expand fetal alcohol spectrum disorder (FASD) diagnostic services by funding 12 new FASD clinics for a total of 21 funded FASD diagnostic clinics across the province. with this additional funding the government is investing 10.1 million dollars in annual funding towards FASD programs and services and diagnostic services for people impacted by FASD.

**Methods:** This training aims to assist existing and emerging diagnostic clinics in their efforts to operationalize the FASD Canadian guidelines for diagnosis and the overall multidisciplinary assessment team process. We have put together 4 modules that address the main components of an FASD assessment and all the domains that need assessment as per the Canadian Guidelines for diagnosis.

**Results:** Assessment training is currently completed, and online participation has begun. Our first session has been filled, as is our second round, and we have a wait list beyond what our online platform will allow. Clearly there is a need and an interest in building assessment skills.

**Conclusions:** This project is early in the implementation phase but the feedback so far has been very positive. Some few tech glitches, that are being resolved, and the content is seen as helpful and necessary. Up to date details will be available in early October in time for the conference.

## **PRESENTER BIOSKETCH**

**Angela Geddes** is an author and advocate, as well as a Social Worker in private practice providing direct assessment and support services to individuals with complicated mental health and developmental challenges, and also for those who love and support them.

**Dr. Kimberly Harris** is the Executive Director at Navigating Onward, a division of the London Family Court Clinic in London ON. As a licensed forensic psychologist, she maintains an active caseload including assessments for the court and has been declared an expert witness in FASD.

**Mohamed (Mo) Oshalla** is a speech and language pathologist who became involved with the FASD virtual clinic as part of his work with CPRI. He now practices privately and is the owner of Ontario Speech & Language Services, a practice with several clinics across southern Ontario.

**Janet Carioni** is an occupational therapist embedded in the education sector where she provides assessment and intervention for students with complex needs. She has provided comprehensive assessment services within a variety of FASD multidisciplinary teams.

**Dr. Louise Scott** is a pediatric neuropsychologist with over 40 years of special interest in FASD and TBI. She is also a co-author of several research articles and currently works on more than one community FASD diagnostic team while providing training and assessments within and outside of Ontario and internationally.

**Dr. Clare Mitchell** is a Developmental Pediatrician in London ON. Her clinical focus is assessment of children and adolescents with developmental delays and or mental health problems especially those with complex neurodevelopmental disorders.

## **ADDITIONAL CONTRIBUTORS**

**Tanya** is of Ojibwe descent and from the 60s scoop. She is an accomplished artist, an inspirational speaker, peer advocate, FASD consultant and certified FASD Educator.

**Ashley Rovers** is a member of the Pine Creek First Nation and is of Ojibway descent. She is currently working in construction while parenting her young son she has spent the last few years getting a better understanding of the implications of FASD and Appreciates opportunities to help increase awareness.

**Darlene Durand** is a registered Early Childhood Educator in a part time professor at Fanshawe College. Her interest in FASD was sparked when they began their foster parent journey. They have been blessed by adoption and their 14-year-old daughter who has FAS T is reason for Darlene's ongoing passion for FASD.

**Tracy Grant** has been a member of the special education advisory committee (SEAC) of the Thames Valley district school board since 2006 she currently serves on the FASD 1 education Action Group and is the founding member of the FASD Elgin London Middlesex and Oxford network.

**Rainier de Smit** is a 63-year-old fella who's had, some would say, a colourful life. With talents for music and visual imaging as well as a trained "life counselor" using the art of communication in whatever form that might entail he's paid his rent for the last 30 years plus with his creativity at 56 years of age Rainier finally received a diagnosis of adult FASD.

After a lifetime of slipping through the cracks of our healthcare system **Shannon Butt** finally received support for living with the impact of Prenatal Alcohol Exposure/FASD at age 33. Shannon believes in storytelling as a way of sharing perspective; she has created a life around sharing hers to empower others to discover, and perhaps share their own.

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## Complex Brains and Behaviour - What You Wish You Knew

Jolene Osztian and Angela Taylor

Inspire Community Outreach (Winnipeg, Manitoba)

### **ABSTRACT**

The proposed topic of this presentation will be around Neurodiversity, which includes individuals with autism, ADHD, FASD, C-PTSD, etc. and understanding the lived experience of someone who is neurodivergent; what it feels like, what it looks like, common co-occurring disabilities, and how to increase stabilization and success. Our focus will be on building strengths, sharing strategies, tools and resources to support continued growth and learning to those who are neurodivergent. We will also touch on understanding the hidden reality of families that include children with disabilities, including complex needs, and how to best work within limited resources to maximize connection and well-being for families. As well as, reframing neurological, cognitive, and psychological disabilities to invite understanding and celebration of neurodiversity and differences.

### **PRESENTER BIOSKETCH**

**Jolene Osztian** completed her Bachelor of Arts Honours degree from Brandon University with a major in Psychology. She is currently completing her Master of Social Work at the University of Manitoba with a clinical focus, conducting her field placement at Inspire Community Outreach under the supervision of Angela Taylor. Jolene has been working in social services for one year and has volunteer and professional experience working with neurodiverse children and families in care. Jolene is also an award-winning photographer.

**Angela Taylor** is the Founder and CEO of Inspire Community Outreach, a charity supporting families that include children with disabilities. Angela is a mental health and accessibility expert, specializing in complex neurology and behaviour with 23 years of experience supporting the community. She takes an eclectic therapeutic approach that includes attachment, cognitive behaviour therapy, positive psychology and CPS model (Collaborative & Proactive Solutions) supports. She is a first voice, living with multiple neurodivergences, and is currently completing her PhD focusing on effective care of individuals who live with complex neurology and behaviour. She is the author to 3 books, including Forever on Fire, A Love Letter to Never Fitting In, and supports multiple clinical teams throughout Canada.

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## Missing Pieces: Supporting Older Caregivers of Adults with FASD

Nancy Lockwood<sup>1,2</sup>

<sup>1</sup> Adopt4Life-Ontario's Association for Kin, Customary Care and Adoptive Parents

<sup>2</sup> Health Nexus

### **ABSTRACT**

**Background and Research Objectives:** Ontario benefits from numerous FASD initiatives, with the majority focused on supporting children / youth. Early intervention is key to improving outcomes, but today's older

caregivers did not have these programs when raising their children with FASD and lack targeted supports for themselves and their adult children now. This poster presentation will highlight two Ontario support / education groups designed to address the unique needs of older caregivers. Survey results will highlight common challenges including stress, PTSD, lack of respite, aggression in the home, and need for assistance with finances, lifetime planning and daily life skills.

**Methods:** In 2021, three FASD advocates received a Health Nexus grant and launched the Ontario Senior Caregiver Action Network for FASD (OSCAN), co-facilitated by a Registered Social Worker and FASD Educator. Goals were to provide support / education and develop a provincial resource guide. When funding ended, Adopt4Life asked OSCAN's facilitator to continue the group under their umbrella, extending it to their community. Meetings for both groups have focused on nurturing peer support, guest presenters on key topics, and preparing for loved ones' futures after caregivers are gone.

**Results:** Participants expressed immense relief having their needs heard and being with others who "get it". National researchers have attended meetings to learn about the needs of this demographic. The OSCAN Resource Guide has been shared / used widely across Ontario.

**Conclusions:** FASD has lifelong implications for families. Assisting older caregivers with lifetime planning will deter loved ones ending up in poverty, homeless, or isolated, while reducing caregiver stress.

## PRESENTER BIOSKETCH

Nancy Lockwood is Practice Lead of Adopt4Life's new AFCCA (Aggression Toward Family / Caregivers in Childhood & Adolescence) Family Supports Program, a provincially funded demonstration project she assisted to develop and launch. Nancy has over 25 years of work and lived experience supporting individuals of all ages with FASD as a consultant, educator, and past Manager of ABLE2's Fetal Alcohol Resource Program, a program she helped to design and build in collaboration with Kids Brain Health Network. Nancy is a passionate advocate for FASD supports *across the lifespan*, not only for individuals with FASD, but also for their families.

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## Visual-motor integration, visual perception and fine motor coordination abilities in children being assessed for fetal alcohol spectrum disorder

Danielle Johnston<sup>1,2</sup>, Lesley Pritchard<sup>1</sup>, Erin Branton<sup>1,2</sup>, Douglas P. Gross<sup>1</sup>, and Sandy Thompson-Hodgetts<sup>1</sup>

<sup>1</sup>University of Alberta

<sup>2</sup>Alberta Health Services

## ABSTRACT

**Background & Research Objectives:** Children with prenatal alcohol exposure often have different profiles of learning and abilities than children without. The aims of this study are to describe the visual-motor integration, visual perception and motor coordination pattern of abilities in children with prenatal alcohol exposure being assessed for fetal alcohol spectrum disorder (FASD).

**Methods:** This cross-sectional study included 91 children (65 males; mean age: 10 years, 6 months; SD=2 years, 10 months; age range 6–17 years) undergoing assessment for FASD. Friedman and Wilcoxon statistics

were used to compare mean visual-motor integration, visual perception and fine motor coordination percentiles from the Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery-6).

**Results:** Children being assessed for FASD (n=91) performed highest in visual perception followed by visual motor integration and then fine motor coordination ( $\bar{x}$  percentiles (SD): 35.9 (24.9), 20.6 (18.3) and 13.8 (15.5) respectively). Differences in assessment scores across the tests were statistically significant ( $\chi^2(2) = 46.909, p \leq 0.001$ ).

**Conclusions:** Results provide evidence that children being assessed for FASD experience more challenges with motor coordination compared to visual-motor integration and visual perception tasks. This pattern differs from the pattern established for the general population. These results suggest that motor coordination should be included in FASD diagnostic assessments and be considered for intervention.

### PRESENTER BIOSKETCH

Danielle Johnston is an Occupational Therapist who has worked with Alberta Health Services for 19 years. For 14 of those years she has worked on the Camrose Pediatric Specialty Clinic, a diagnostic clinic which assesses children for a variety of conditions including fetal alcohol spectrum disorder. She is currently pursuing a PhD at the University of Alberta in Rehabilitation Sciences focusing on diagnostic accuracy of motor assessment tools used during fetal alcohol spectrum disorder evaluations with children.

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## ORAL RESEARCH POSTER PRESENTERS

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1:40 PM – 2:10 PM • MAIN ROOM

Three oral presentations were selected from the abstracts submitted based on their diversity, timeliness, and significance to the FASD community. These presentations are condensed, 10-minute overviews of the critical work being conducted by the authors. Oral presentations will be held in the Main Room from 1:40 pm – 2:10 pm EST.

Full details and up-to-date information are available on the conference website.

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### Conference MAIN ROOM

1:40 – 1:50 PM

“The system is not set up for individuals with FASD”: Lived and Caregiver Perspectives Regarding Current and Ideal Housing Supports for Canadian Adults with Fetal Alcohol Spectrum Disorder

Siann Gault<sup>1</sup> and Melody Morton Ninomiya<sup>2</sup>

<sup>1</sup> Memorial University of Newfoundland

<sup>2</sup> Wilfrid Laurier University

### ABSTRACT

**Background & Research Objectives:** Adults with FASD often require lifelong support with daily activities. However, little is understood regarding daily supports for adults with FASD, and current research has heavily

relied on proxy-reports rather than lived experiences. This study highlights both the perspectives of Canadian adults with FASD living in a variety of arrangements as well as caregivers who support adults with FASD to examine: 1) current ways adults with FASD are supported with daily life activities, and 2) ideal future living arrangements and supports for adults with FASD.

**Methods:** Adults with FASD who live in housing with supportive services ( $n = 4$ ) or at home with caregivers ( $n = 7$ ), and caregivers of adults with FASD who live at home ( $n = 11$ ) participated in semi-structured interviews over video calls. The framework method was used to thematically analyze the responses of adults with FASD and caregivers, separately.

**Results:** Analyses revealed themes organized by: 1) ways adults with FASD are supported in their daily life activities, 2) perspectives of adults with FASD regarding positive and negative aspects of their living arrangement, and 3) ideal living arrangements and daily supports, including caregiver concerns regarding future living arrangements for the adults with FASD they support.

**Conclusions:** This study offers insight into the perspectives of adults with FASD regarding their daily living support, which is critical to inform future supported housing and support self-determination. Findings highlight a pressing need for policy change directed towards developing FASD-informed, affordable, available, and appropriate housing supports.

## PRESENTER BIOSKETCH

Siann Gault is a Clinical Psychology doctoral (PsyD) student at Memorial University of Newfoundland. Siann completed a Master of Arts in Community Psychology at Wilfrid Laurier University, and a Bachelor of Arts and Business in Psychology at the University of Waterloo. Siann's presented research is from her Master's thesis project, which was supervised by Dr. Melody Morton Ninomiya and developed in response to pressing questions posed by members of the Waterloo Region FASD Action Group.

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## Conference MAIN ROOM

1:50 – 2:00 PM

Supporting Healthy Pregnancies: Understanding Pregnant Women and New Mothers' Perspectives Regarding Fetal Alcohol Spectrum Disorder Prevention Campaigns in Northeastern Ontario

Taylor Watkins<sup>1</sup>, Kelly Harding<sup>1,2,3</sup>, Shelley Watson<sup>1</sup>, and Celisse Bibr<sup>1</sup>

<sup>1</sup>School of Rural and Northern Health, Laurentian University

<sup>2</sup>Department of Psychology, Laurentian University

<sup>3</sup>Canada FASD Research Network

## ABSTRACT

**Background:** Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe the lifelong impacts on fetal development from prenatal alcohol exposure. Although FASD impacts approximately 4% of the Canadian population, prevalence rates are suggested to be higher in rural, remote, and northern communities. As FASD prevention efforts have been heavily criticized for their stigmatizing nature, women may be reluctant to disclose information about alcohol use during pregnancy.

**Research Objectives:** The objectives of this study include: (1) to explore pregnant and postpartum women's attitudes about alcohol use during pregnancy, and their perspectives on existing FASD prevention campaigns; and (2) to generate recommendations for non-stigmatizing FASD prevention campaigns for Northeastern Ontario.

**Methods:** Approximately 30 pregnant women and new mothers (aged 17-45) across the Sudbury and Manitoulin Districts are being recruited to participate in online focus groups. Messaging and imagery from 10 existing prevention campaigns are employed to facilitate focus group discussions. Data from this study will be analyzed using Bengtsson's (2016) qualitative content analysis to generate salient themes.

**Results:** At the time of this submission, data collection is in the initial stages. To date, 3 women have participated in 2 focus groups. Preliminary findings indicate that current FASD prevention initiatives are lacking and require enhanced accessibility and messages of support.

**Conclusions:** The current study will contribute to the growing discourse on informing non-stigmatizing FASD prevention initiatives for Northeastern Ontario.

### **PRESENTER BIOSKETCH**

My name is Taylor Watkins, and I was born and raised in Sudbury, Ontario; thus, Laurentian University was a natural choice for my post-secondary education. My post-secondary educational journey began in 2017 when I decided to pursue my Bachelor of Science in Psychology. During the duration of my undergraduate degree, my passion for public health and developmental disabilities emerged. In 2021, I graduated with my Bachelor of Science (Honours) in Psychology and decided to continue my educational endeavours. Currently, I am a Canadian Institute of Health Research (CIHR) funded graduate student in the Master of Arts in Interdisciplinary Health Program at Laurentian University. I am researching the stigmatization around existing Fetal Alcohol Spectrum Disorder prevention campaigns to inform effective and non-stigmatizing approaches in Northeastern Ontario. After completing my master's degree, I aspire to continue my research focusing on FASD in northern Ontario while completing a Ph.D.

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### Conference MAIN ROOM

2:00 – 2:10 PM

**Weathering the Storm: Addressing the Complex Issue of Aggression Toward Families / Caregivers in Childhood and Adolescence (AFCCA) Through Holistic Family-Directed Circles of Support**

Nancy Lockwood<sup>1,2</sup> and Tracy Moisan<sup>1</sup>

<sup>1</sup>National Consortium on Aggression Toward Families and Caregivers in Childhood & Adolescence (AFCCA) - Adopt4Life

<sup>2</sup>Health Nexus

### **ABSTRACT**

**Background & Research Objectives:** Aggression toward Family / Caregivers in Childhood & Adolescence (AFCCA) describes a pattern of behaviour characterized by aggressive behaviour toward family members /other caregivers, causing significant harm (physical and/or psychological) to the child/adolescent, those the

behaviour is directed toward, and witnessing family members. While many know of its existence, AFCCA is frequently unreported and misunderstood. Two promising Canadian initiatives have been developed to improve outcomes for families, including those raising children/youth with FASD.

**Methods:** In 2021, Kids Brain Health Network and Adopt4Life, Ontario's Association for Kin, Customary Care, and Adoptive Parents, spearheaded the **National Consortium on AFCCA**, bringing together researchers, practitioners, and policymakers alongside 100+ parents/caregivers, young adults, and siblings who shared their lived expertise to shape key learnings, co-develop recommendations, and validate conclusions.

**Results:** The Consortium findings, including operational definitions, policy framework, and strategic recommendations, are detailed here: [www.afcca-apfea.ca](http://www.afcca-apfea.ca). Noteworthy is the opportunity to better support families through holistic, family-directed circles of support. Adopt4Life's new **AFCCA Family**

**Supports Program** provides parents/caregivers with access to specialized supports / services that are responsive to a family's individual needs. This is Canada's first publicly funded support program specifically for AFCCA, via a 3-year demonstration project supported by Ontario's MCCSS.

**Conclusions:** An understanding peer community can provide immense relief for families experiencing AFCCA, and additional access to a highly skilled clinical team can help to promote family safety, stability, and preservation. Presenters will further explain how evaluation data collected will be shared to encourage ongoing capacity building.

## **PRESENTER BIOSKETCH**

**Nancy Lockwood** is Practice Lead of Adopt4Life's new AFCCA (Aggression Toward Family / Caregivers in Childhood & Adolescence) Family Supports Program, a provincially funded demonstration project she assisted to develop and launch. Nancy has over 25 years of work and lived experience supporting individuals of all ages with FASD as a consultant, educator, and past Manager of ABLE2's Fetal Alcohol Resource Program, a program she helped to design and build in collaboration with Kids Brain Health Network. Nancy is a passionate advocate for FASD supports *across the lifespan*, not only for individuals with FASD, but also for their families.

**Tracy Moisan** is Program Director for the National Consortium on Aggression toward Family/Caregivers in Childhood and Adolescence (AFCCA). With Adopt4Life, Tracy leads marketing / community engagement strategies that develop understanding of adoptive families' needs. She is an advocate for deepening family engagement in research, partnering on multiple research studies, and is a founding director of two FASD parent peer support networks. Tracy's 25+ years' experience in marketing and communications leadership spans the technology and non-profit sectors.

# FASD CONFERENCE 2022 COMMITTEE

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Lived Experience Presentations Lead & Workshop Host

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