9th International Research Conference on
ADOLESCENTS AND ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDERS

Review, Respond, and Relate
Integrating Research, Policy, and Practice
Around the World

Hyatt Regency, Seattle, WA

APRIL 11-14 2024
www.FASDUnited.org
Despite thousands of published articles on FASD, limited research focuses specifically on adolescents and adults with FASD. As individuals diagnosed with FASD age, the “need to know” across a broad spectrum of areas continues to be critically important for identifying clinically relevant research questions and directions that will impact their day-to-day function and health outcomes.

Building on the work of eight previous conferences*, we aim to examine relevant global research, programs, and policies. What can we learn from practice-based evidence? What does existing or emerging research tell us? Are the results transferable from country to country and/or from laboratory and clinical studies to real life? Are there clinical implications of results from any of these areas of which we should be aware? What are the changes in our thinking, practice, and directions that will be required to improve outcomes? What are the implications for the future?

We hope you can join us at this interactive conference and be at the forefront of addressing these relevant global issues.

*This conference, previously held in Vancouver and hosted by University of British Columbia’s Interprofessional Continuing Education, has been moved to Seattle, the birthplace of the FASD diagnosis in North America. FASD United has taken on the task of putting on this unique global FASD conference in consultation with the International Adult Leadership Collaborative (ALC) of FASD Changemakers, a group of talented and dedicated individuals with FASD who are leaders in the community.
Register before/on February 14, 2024 to save up to $100 on registration. The tuition fee includes conference materials, refreshment breaks, and three lunches. We encourage you to register online (the most secure method) at the conference website. Please visit the website as well as cancellation/refund/transfer guidelines. If you need assistance in registering, please contact registration@fasdunited.org.

### BEFORE/ON FEBRUARY 14, 2024

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<tr>
<td>Full Conference (April 11-14)</td>
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<td>Pre-conference (April 11)</td>
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<td>Main Conference (April 12 - 14)</td>
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### AFTER FEBRUARY 14, 2024

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<td>Main Conference (April 12 - 14)</td>
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**SPECIAL RATES**

- Individual with FASD: $0
- *Parent Pre-conference (April 11)*: $100
- *Parent Main-conference (April 12-14)*: $400
- **Student Pre-conference (April 11)**: $100
- **Student Main conference (April 12-14)**: $400

**Notes:**
- All rates are quoted in USD.
- *Available only for parents/guardians of individuals with FASD who do not work in the area of FASD.
- **Available only for full-time students. A copy of valid student photo ID must be sent with your registration. Please email a copy to registration@fasdunited.org after registering to qualify for this rate.

### PROGRAM AT-A-GLANCE

**APRIL 11**

8:00 - 10:00
Pre-conference: PC1 or PC2

10:00 - 10:30 Break (April 12, 13: exhibits, posters)

10:30 - 12:00
PC 1 or PC2 continues

12:00 - 1:00
Lunch (on your own)

1:00 - 2:30
PC 1 or PC2 continues

2:30 - 3:00 Break (April 12, 13: exhibits, posters)

3:00 - 4:30
PC 1 or PC2 continues

8:30 - 10:00
Remarks, Plenary

10:10 - 11:40
Breakout Session E

11:40 - 12:40
Lunch (provided)
Exhibits, posters

12:40 - 2:30
Remarks, Plenary,
Starfish Award &
Closing Ceremonies

3:30
Adjourn
Safe travels!

**APRIL 12**

8:00 - 10:00
Welcome Remarks, Plenary

10:00 - 10:30 Break (April 12, 13: exhibits, posters)

10:30 - 12:00
Breakout Session A

12:00 - 1:00
Lunch (provided), exhibits, posters

1:00 - 2:30
Breakout Session B

2:30 - 3:00 Break (April 12, 13: exhibits, posters)

3:00 - 4:30
Remarks, Plenary

**APRIL 13**

8:30 - 10:00
Remarks, Plenary

10:00 - 10:30 Break (April 12, 13: exhibits, posters)

10:30 - 12:00
Breakout Session C

12:00 - 1:30
Lunch (provided), exhibits, posters

1:30 - 3:00
Breakout Session D

3:00 - 3:30 Break, exhibits, posters

3:30 - 5:10
Remarks, Plenary

**APRIL 14**

12 - 14: MAIN CONFERENCE

As in years past, there will be an official adults and teens track at the 2024 conference. Designed, planned, and led by the International Adult Leadership Collaborative (ALC), FASD Changemakers, this track is free to teens and adults with FASD. Please visit [here](#) to view the teen & adult stream program.
CONFERENCE COMMITTEES

PROGRAM PLANNING COMMITTEE

Jan Lutke, Conference Chair, Vancouver, BC
Jo Votolato, Conference Director, FASD United, Washington, DC
Heather Carmichael Olson, Ph.D., Clinical Professor, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, WA
Michael Charness, MD, Chief of Staff, VA Boston Healthcare System; Faculty Associate Dean, Professor of Neurology, Harvard Medical School; Associate Dean, Professor of Neurology, Boston University School of Medicine, West Roxbury, MA
Peter W. Choate, RCSW, Ph.D., Clinical Social Worker, Professor, Social Work Mount Royal University, Calgary AB
Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA
Bill Dunty, Ph.D., FASD Research Coordinator and Program Director, Division of Metabolism and Health Effects, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, MD
Brenda Knight, Registered Psychologist, Private Practice, Vancouver, BC
Christine Loock, MD, FRCPC, FAAP, Developmental and Social Pediatrician, Associate Professor, Department of Pediatrics, University of British Columbia, BC Children's Hospital & Sunny Hill Health Centre for Children, Vancouver, BC
Rajesh Miranda, Ph.D., Professor, Department of Neuroscience and Experimental Therapeutics, College of Medicine, Texas A&M University Health Science Center, Bryan, TX
Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, New York, NY
Edward Riley, Ph.D., Distinguished Research Professor, Center for Behavioral Teratology, San Diego State University, San Diego, CA
Joanne Weinberg, Ph.D., Professor and Distinguished University Scholar, Emerita, Department of Cellular & Physiological Sciences, University of British Columbia, Vancouver, BC

LOCAL PLANNING COMMITTEE

Jan Lutke, Conference Chair, Vancouver, BC
Jo Votolato, Conference Director, FASD United, Washington, DC
Jennifer Wisdahl, Chief Operating Officer, FASD United, Washington, DC
Allison D. Brooks, Ph.D., Licensed Psychologist, University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network; Clinic Director, Brooks Powers Group, Seattle, WA
Paul Connor, Ph.D., Clinical Neuropsychologist/Licensed Psychologist Private Practice, Des Moines, WA; Courtesy Clinical Assistant Professor, University of Washington, Psychiatry and Behavioral Sciences, Fetal Alcohol and Drug Unit, Seattle, WA
Carolyn Hartness, Fetal Alcohol Spectrum Disorders/Reentry Consultant/Trainer, Seattle, WA
Susan (Astley) Hemingway, Ph.D., Professor of Epidemiology and Pediatrics, Schools of Public Health and Medicine, University of Washington, Director WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network, Seattle WA
Tracy Jirikowic, Ph.D., OTR/L, FAOTA, Professor | Department of Rehabilitation Medicine; Program Director, Division of Occupational Therapy; Co-Director, Program in Rehabilitation Science, UW Medicine, University of Washington, Seattle, WA
Kay Kelly, Project Director, FASD Legal Issues Resource Center; Research Coordinator, Multisite Study of Prenatal Alcohol Exposure: Effects of Inflammation and Endocrine Dysfunction in Adulthood, Brain Maturation in Adults with FASD, Addictions, Drug & Alcohol Institute (ADAI)/Fetal Alcohol and Drug Unit (FADU), University of Washington/ School of Medicine/Psychiatry, Seattle, WA
Michelle Kuhn, Ph.D., Assistant Professor of Psychiatry and Behavioral Sciences, University of Washington Medical School; Attending Psychologist, Seattle Children’s Hospital, Seattle, WA
Annette Kunzman, MBA, President, FASD Network of Southern California, member of FASDNow! Alliance Member, Manhattan Beach, CA
Natalie Novick Brown, Ph.D., Clinical Assistant Professor, University of Washington, Seattle, WA
Erin Olson, Ph.D., Clinical Associate Professor, Psychiatry & Behavioral Sciences, University of Washington School of Medicine; Psychologist, Fetal Alcohol Syndrome Diagnostic & Prevention Network, Institute on Human Development and Disability University of Washington; Attending Psychologist, Autism Center, Seattle Children's Hospital, Seattle, WA
Joanne Sparrow, Ph.D., Licensed Clinical Psychologist in Private Practice (Redmond, WA) and Special Projects Coordinator – Families Moving Forward Program (Seattle Childrens Research Institute), Seattle, WA
Karen A Steele, Attorney, Salem, OR
Susan Stoner, Ph.D., Research Associate Professor, Ann Streissguth Ph.D. Professor of Fetal Alcohol Spectrum Disorders: Addictions, Drug & Alcohol Institute; Department of Psychiatry & Behavioral Sciences; University of Washington School of Medicine, Seattle, WA
CONFERENCE COMMITTEES

INTERNATIONAL ADVISORY COMMITTEE

Sabrina Agnihotri, Trainee Representative; MD/Ph.D., PGY-5, Department of Psychiatry, University of Toronto, Toronto, ON

Dorothy Badry, Ph.D., RSW, Professor, Faculty of Social Work, University of Calgary, Calgary, AB

Tatiana Balachova, Ph.D., Health Scientist Administrator/Program Director, Division of Epidemiology and Prevention Research (DEPR); Scientific Coordinator and Executive Secretary, Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD), National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, MD

Claire Coles, Ph.D., Professor, Department of Psychiatry and Behavioral Sciences; Director, Maternal Substance Abuse and Child Development Program (MSACD), Emory University, Atlanta, GA

Paul Connor, Ph.D., Clinical Neuropsychologist/Licensed Psychologist Private Practice, Des Moines, WA; Courtesy Clinical Assistant Professor, University of Washington, Psychiatry and Behavioral Sciences, Fetal Alcohol and Drug Unit, Seattle, WA

Lori Vitale Cox, Ph.D., Director Elsipogtog Eastern Door Centre; Adjunct Professor UBC Faculty of Medicine, Department of Pediatrics, Rexton, NB

Julian Davies, MD, Clinical Professor of Pediatrics, University of Washington, Fetal Alcohol Syndrome Diagnostic and Prevention Network, Seattle, WA

Elizabeth Elliott, Professor, Discipline of Child and Adolescent Health, Faculty of Medicine and Health Science, University of Sydney; and Consultant Paediatrician, The Sydney Children’s Hospitals Network, Westmead, Australia

Carmen Enache, MD, Ph.D., Senior Consultant, Obstetrics and Gynecology, Emergency Clinical Hospital, Bucharest, Romania

Erikson Furtado, MD, Ph.D., University of Sao Paulo, School of Medicine of Ribeirao Preto, Department of Neurosciences and Behavior, Division of Psychiatry, Child & Adolescent Psychiatry and Mental Health, Alcohol & Drugs Program – PAI-PAD Ribeirao Preto, Brazil

Mary Kate Harvie, Judge, Provincial Court of Manitoba, Winnipeg, MB

Susan (Astley) Hemingway, Ph.D., Professor of Epidemiology and Pediatrics, Schools of Public Health and Medicine, University of Washington, Director WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network, Seattle WA

Heike Hoff-Emden, Dr.med, Leader, FASD Centre, Central Germany/Leipzig Leipzig, Germany

Parker Holman, Senior Lab Demonstrator, Anatomy, Department of Kinesiology; Adjunct Professor, Department of Psychology, Brock University, St. Catharines, ON

Hon. Michael I. Jeffery, Utqiagvik (Barrow), Alaska. Superior Court Judge (Ret.) Alaska Court System; Board member, Alaska Center for FASD, Barrow, AK

Kay Kelly, Project Director, FASD Legal Issues Resource Center; Research Coordinator, Multisite Study of Prenatal Alcohol Exposure: Effects of Inflammation and Endocrine Dysfunction in Adulthood, Brain Maturation in Adults with FASD, Addictions, Drug & Alcohol Institute (ADAI)/Fetal Alcohol and Drug Unit (FADU), University of Washington / School of Medicine/Psychiatry, Seattle, WA

Denis Lamblin, MD, Developmental Pediatrician, President SAF FRANCE; President and Delegate Director, Local & Regional Networks, International SAFTHON (FASTHON), Reunion Island, France

Philip May, Ph.D., Research Professor, Gillings School of Global Public Health, University of North Carolina at Chapel Hill-Nutrition Research Institute, Kannapolis, NC

Valerie McGinn, Ph.D., Clinical Neuropsychologist, Department of Population Health, University of Auckland, Auckland, New Zealand

Kathleen Mitchell, Senior Vice President of FASD Prevention and Recovery Services, FASD United, Washington, DC

Raja Mukherjee, MBE, MBBS, FRCPsych, PGDIP EPP, PhD, Consultant Psychiatrist, Clinical Lead Adult Neurodevelopmental Services, FASD Specialist Clinic and Adult Autism Diagnostic Services, SABP NHS Foundation Trust, Surrey, UK

Leon Olivier, Chief Executive Officer, Foundation for Alcohol Related Research (FARR), Cape Town, South Africa

Moira Plant, Professor Emeritus, Alcohol & Health Research Unit, University of the West of England, Bristol, UK; Adjunct Professor, Curtin University, Edinburgh, UK

Svetlana (Lana) Popova, Senior Scientist, Institute for Mental Health Policy Research, Centre for Addiction and Mental Health; Associate Professor, Epidemiology Division, Dalla Lana School of Public Health, University of Toronto; Associate Professor, Factor-Inwentash Faculty of Social Work, University of Toronto; Graduate Faculty Associate Member, Institute of Medical Science, University of Toronto, Toronto, ON

Jon Skranes, Professor, Child Neurology and Rehabilitation, Department of Clinical and Molecular Medicine, Faculty of Medicine and Health Sciences, Norwegian University of Science and Technology (NTNU), Trondheim; Head of Child Habilitation Unit and Senior Consultant, Regional Competence Center for Children with Prenatal Alcohol/Drug Exposure, Dept. of Pediatrics, Sørlandet Hospital, Lillesand, Norway

Paula Stanghetta, Facilitator, Coach, Trainer, Paula Stanghetta & Associates Inc., Kitchener, ON
CONFERENCE COMMITTEES

**FASD LEADERSHIP COMMITTEE: INTERNATIONAL ADULT LEADERSHIP COLLABORATIVE (ALC), FASD CHANGEMAKERS**

**Myles Himmelreich**, ALC FASD Changemakers, Nanaimo, BC

**CJ Lutke**, ALC FASD Changemakers, Vancouver, BC

**Katrina Griffin**, ALC FASD Changemakers, Vancouver, BC

**Emily Hargrove**, ALC FASD Changemakers, Paducah, KY

**Justin Mitchell**, ALC FASD Changemakers, Vancouver, BC

**Anique Lutke**, ALC FASD Changemakers, Vancouver, BC

**Maggie May**, ALC FASD Changemakers, Ireland

**Jacob Dedman**, ALC FASD Changemakers, Australia

**Jessica Birch**, ALC FASD Changemakers, Australia

**Nury van Beers**, ALC FASD Changemakers, Netherlands

**Kim Dokter**, ALC FASD Changemakers, Netherlands

**Byron Jones**, ALC FASD Changemakers, New Zealand

**Gina Schumaker**, ALC FASD Changemakers, AK

**Shannon Butt**, ALC FASD Changemakers, Ottawa, ON

**Justin Shepherd**, ALC FASD Changemakers

Remember that no one is born a **CHANGEMAKER**. It is something you become when you see a problem, then dare to become part of the **SOLUTION**.

**Melinda Gates**
Despite concerning FASD prevalence numbers, there is a persistent lack of understanding regarding how to effectively accommodate individuals with FASD when they have justice encounters. Recent strides in scientific research and collaborative efforts involving judges, lawyers, probation officers, social workers, researchers, and other professionals have challenged legal principles and fostered a growing recognition of the pressing ethical and moral imperatives to identify FASD and respond accordingly.

Please join us in this interactive session with justice and non-justice professionals to foster dialogue, share strategies and tools, and disseminate recent research into accessible information for use in courts and community. The lack of accommodation, for individuals with a recognized disability, raises social justice concerns as their access to justice (at all levels) is severely impacted which can lead to unjust outcomes including loss of personal freedom, loss of parental rights, and/or prolonged justice engagement. From sensory challenges to delayed processing, FASD can present myriad challenges to individuals. The over-representation of individuals with FASD in the criminal justice system as well as family and child welfare courts presents an important issue with the potential for intergenerational impacts.

To advance access to justice, this workshop will be organized around three key questions:

- How can the different judicial systems better respond with heightened awareness and effectiveness regarding all parties, including victims, defendants, and witnesses in the criminal court, and the children and families with FASD in the family court?
- How can justice professionals and those disciplines which intersect within the criminal justice system better share practice-based evidence to further our collective understanding of the complexities of FASD and appropriate accommodations to more effectively support individuals to stay in community?
- How can the family courts, child welfare, and intersecting systems better support parents with FASD who become involved in the child protection system, to successfully parent or be involved with the parenting of their children?

This one-day workshop will bring together leading justice, community and research voices to explore proven, promising and innovative practices for an interdisciplinary audience. We will share information across sectors to build overall capacity to support individuals with FASD inside and outside the courtroom.

After this insightful one-day session, participants will be able to:

- Explain the ways in which FASD can present particular challenges for individuals with FASD and justice professionals in different courtroom settings
- Describe barriers to justice as they present in criminal, family, and child welfare courtroom settings
- Demonstrate new language and understanding of how to implement proven practices to better support individuals with FASD in community and justice settings
- Describe the best practices showcased in this session and apply them in diverse court settings in your own communities

For the detailed schedule for this day, please see the next two pages.

Please note that there will be a follow-up breakout session scheduled in the main conference, A3 (Friday, April 12, 10:30 - 12:00) in which some of the presenters from this day will be available for a Q&A format type of session in which parents/caregivers of individuals with FASD can discuss how the courts function and how they can work effectively on behalf of their children and adult children who are involved with the courts.

Continuing Legal Credits

We have applied for continuing legal education (CLE) credits through University of Washington and are also looking into CLE credits from British Columbia. Please check our website for updates.
The VERDICT IS IN YOUR COURT:
ADVANCING JUSTICE FOR INDIVIDUALS WITH FASD ACROSS JUDICIAL SYSTEMS

7:00 - 8:00  Registration
8:00 - 9:00  FASD 101 (optional*)
           "This session is an opportunity to refresh attendees' understanding of FASD or provide the basics of FASD to those new to the disability.

Julian Davies, MD, Clinical Professor of Pediatrics, University of Washington, Fetal Alcohol Syndrome Diagnostic and Prevention Network, Seattle, WA

9:00 - 9:30  Welcome & Blessing

Julian Davies, MD, Clinical Professor of Pediatrics, University of Washington, Fetal Alcohol Syndrome Diagnostic and Prevention Network, Seattle, WA
Kay Kelly, Project Director, FASD Legal Issues Resource Center; Research Coordinator, Multisite Study of Prenatal Alcohol Exposure: Effects of Inflammation and Endocrine Dysfunction in Adulthood, Brain Maturation in Adults with FASD, Addictions, Drug & Alcohol Institute (ADAI)/Fetal Alcohol and Drug Unit (FADU), University of Washington / School of Medicine/Psychiatry, Seattle, WA
Frances Gordon, JD, Former Crown Counsel/Prosecutor, British Columbia
Senator Manka Dhingra, WA., State Senate, Deputy Majority Leader, Chair of Behavioral Health Committee, King County Prosecuting Attorney from 2000-2017, working in the Mental Health Court, Seattle, WA
Carolyn Hartness, Fetal Alcohol Spectrum Disorders/Reentry Consultant/Trainer, Seattle, WA

9:30 - 10:30  PANEL #1:
FASD-INFORMED INNOVATIONS IN COURT PRACTICES: JUDGES’ PERSPECTIVE

Moderators: Peter W. Choate, RCSW, Ph.D., Clinical Social Worker Professor, Social Work, Mount Royal University, Calgary, AB & Anthony P. (Tony) Wartnik, King County (Washington) Superior Court Judge (Retired) and Adjunct Professor, Human Services Department, Concordia University, St. Paul, MN

Hon. Michael Jeffery, Alaska Superior Court, Barrow (ret.), Alaska Center for FASD
Justice Todd LaRochelle, Alberta Court of Justice, Family and Youth Division, Calgary, AB
Justice Larry Anderson, Adult Criminal Division, Alberta Court of Justice

10:30 - 10:45  Refreshment break (coffee/tea provided)

10:45 - 11:45  PANEL #2:
FASD-INFORMED POLICING

Moderator: Corey La Berge, Member of the Law Society of Manitoba, Community Living British Columbia, BC

FASD-Informed Approach to Justice
Patricia Yuzwenko, Legal and Strategic Policy Counsel, Office of the Representative for Children and Youth, British Columbia

An Innovative Approach to Justice
Chris Andrade, FASD Justice Program, Lethbridge Police Service, Lethbridge, AB
Sabrina Hacker, FASD Justice Program Coordinator, FASD Adults Justice Program, Lethbridge, AB

FASD-Informed Alternatives for Misdemeanor Offenders
Malika Lamont, Director, Law Enforcement Assisted Diversion (LEAD) Washington State Technical Support Team and VOCAL-WA, Seattle, WA
Brandie Flood, MSW, Director of Community Justice, Evergreen Treatment Services--REACH, Law Enforcement Assisted Diversion (LEAD), Seattle, WA

11:45 - 1:00 Lunch (delegates on their own)
The Verdict is in Your Court: Advancing Justice for Individuals with FASD Across Judicial Systems

1:00 - 2:30
PANEL #3:
EFFECTIVE ACCESS TO JUSTICE AND REPRESENTATION FOR INDIVIDUALS WITH FASD AS DEFENDANTS, WITNESSES, AND VICTIMS

Moderator: Frances Gordon, JD, Former Crown Counsel/Prosecutor, British Columbia

Findings from the FASD Changemakers Lay of the Land Survey #2: Implications for Judicial Systems
Justin Shepherd, ALC FASD Changemakers

Red Flags
Natalie Novick Brown, Ph.D., Clinical Assistant Professor, University of Washington, Seattle, WA

Diagnostics, Provisional Assessments and Services in the Child Welfare System
Anthony P. (Tony) Wartnik, King County (Washington) Superior Court Judge (Retired) and Adjunct Professor, Human Services Department, Concordia University, St. Paul, MN

Social Cognition Deficits that Make Defendants with FASD Incompetent
Stephen Greenspan, Ph.D., Department of Educational Psychology, University of Connecticut, Storrs, CT

Accommodating Clients with FASD: A Canadian Lawyer’s Perspective
Corey La Berge, Member of the Law Society of Manitoba, Community Living British Columbia, BC

2:30 - 2:45
Refreshment Break

2:45 - 3:45
PANEL #4:
INNOVATIONS AND CHALLENGES IN THE JUVENILE COURT

Moderator: Patricia Yuzwenko, Legal and Strategic Policy Counsel, Office of the Representative for Children and Youth, BC

FASD in the Juvenile Court - Screening, Diagnosis & Intervention - A Model Approach

Implementing an FASD Screening and Strengths and Strategies Approach in a Juvenile Probation Office
Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA

Interrogative Suggestibility and Frontal Lobe Paradox: Implications for the Juvenile Courts
David Junior Gilbert, Ph.D., School of Health and Society, Salford University, Manchester, United Kingdom

Innovative Juvenile Court Practices in San Diego
Hon. Marian Gaston, California Superior Court, San Diego

3:45 - 5:15
PANEL #5:
LIFE COURSE SOLUTIONS–NOT EPISODIC APPROACHES–IN CHILD WELFARE AND FAMILY COURTS

Peter W. Choate, RCSW, Ph.D., Clinical Social Worker Professor, Social Work, Mount Royal University, Calgary, AB
Justice Todd LaRochelle, Alberta Court of Justice, Family and Youth Division, Calgary, AB
Christina Tortorelli, Assistant Professor, Social Work, Mount Royal University, Calgary, AB
Kim Spicer, MSW, RSW - Director, Investigations and Legal Representation for Children and Youth at Office of the Child and Youth Advocate, Edmonton, AB

5:15 - 5:30
Closing Remarks
Julian Davies, MD, Clinical Professor of Pediatrics, University of Washington, Fetal Alcohol Syndrome Diagnostic and Prevention Network, Seattle, WA
FASD was first clinically identified over 50 years ago, and international research continues to provide a very large, growing and diverse body of scientific evidence about the impact of prenatal alcohol exposure on the brain and body. Of particular importance, however, to teens and adults with FASD and those who live and work with them is the impact of alcohol on the area of memory. Memory is the critical building block or cornerstone of cognition, thinking, learning and the application of accumulated knowledge which has been retained – when it is required, where it is required, for whom it is required, how it is required, as it is required, and why it is required, on demand over time. The practical use of knowledge is always memory-based, and when memory is impaired, the ability to function effectively in real life in a fast-paced world is impaired. No one can function well in a vacuum of information. So, how is what science knows translated into use and how can this usage benefit teens and adults with FASD and their parents/caregivers?

Using the expertise of research clinicians, Adult Leadership Collaborative (ALC) members and the wisdom in the room, delegates will discuss how the science of memory, its assessment, test interpretation and use in everyday life can be better understood. Can it be better assessed in an ecologically valid manner and what are the implications for function going forward?

Learning Objectives
- Review the theory and science behind memory, specifically in relation to memory in adolescents and adults with FASD
- Consider how impaired memory relates to everyday activities in expected function in those with FASD
- Examine roles in understanding and supporting memory functioning
- Explore the concept of an “interautonomous approach” to effectively communicate about memory in different environments and systems
- Discuss the gap between formal memory assessment and real life demands
- Consider meaningful and realistic strategies and functional support by everyone involved, including parents and caregivers

The session will begin at 8:15AM with the following breaks:
- 10:30 - 10:45 Morning Break
- 11:40 - 1:00 Lunch (not provided)
- 2:45 - 3:00 Afternoon Break

FACILITATOR:

PAULA STANGHETTA
Facilitator, Coach, Trainer, Paula Stanghetta & Associates, Kitchener, ON

WELCOME REMARKS:

JAN LUTKE
Conference Chair, Vancouver, BC

OPENING & CLOSING REMARKS: NOTHING ABOUT US WITHOUT US...

CJ LUTKE
International Adult Leadership Collaborative (ALC), Vancouver, BC

EMILY HARGROVE
International Adult Leadership Collaborative (ALC), Paducah, KY

EXPERT SPEAKERS:

JULIE KABLE
Ph.D., Associate Professor, Department of Psychiatry and Behavioural Sciences and Pediatrics, School of Medicine, Emory University, Atlanta, GA

JACQUELINE PEI
Ph.D., RPsych, Professor, Department of Educational Psychology, Assistant Clinical Professor, Department of Pediatrics, University of Alberta, Edmonton, AB
7:30 - 8:30  Registration

8:30 - 9:10  Conference Welcome & Opening Remarks

& Senator Manka Dhingra, WA., State Senate, Deputy Majority Leader, Chair of Behavioral Health Committee, King County Prosecuting Attorney from 2000-2017, working in the Mental Health Court, Seattle, WA

& International Adult Leadership Collaborative (ALC), FASD Changemakers

Remarks: Nothing About Us Without Us - Life as I Live It

Myles Himmelreich, International Adult Leadership Collaborative (ALC), FASD Changemakers, Nanaimo, BC

CJ Lutke, International Adult Leadership Collaborative (ALC), FASD Changemakers, Vancouver, BC

Katrina Griffin, International Adult Leadership Collaborative (ALC), FASD Changemakers, Vancouver, BC

Emily Hargrove, International Adult Leadership Collaborative (ALC), FASD Changemakers, Paducah, KY

Anique Lutke, International Adult Leadership Collaborative (ALC), FASD Changemakers, Vancouver, BC

9:10 - 10:00

MORNING PLENARY

RESULTS FROM FASD CHANGEMAKERS LAY OF THE LAND SURVEY #2:
QUALITY OF LIFE—WHAT REALLY MATTERS?
LIFE AS WE LIVE IT

Myles Himmelreich, International Adult Leadership Collaborative (ALC), FASD Changemakers, Nanaimo, BC

CJ Lutke, International Adult Leadership Collaborative (ALC), FASD Changemakers, Vancouver, BC

Katrina Griffin, International Adult Leadership Collaborative (ALC), FASD Changemakers, Vancouver, BC

Emily Hargrove, International Adult Leadership Collaborative (ALC), FASD Changemakers, Paducah, KY

Anique Lutke, International Adult Leadership Collaborative (ALC), FASD Changemakers, Vancouver, BC

- Discuss why this survey was developed
- Identify key findings from the survey
- Consider the implications of the survey results and areas requiring further research

10:00 - 10:30  Break: exhibits open and poster viewing

"Coming together is a BEGINNING. Keeping together is PROGRESS. Working together is SUCCESS." — Henry Ford
MAI N CONFERENCE
FRIDAY, APRIL

10:30 - 12:00 BREAKOUT SESSION A

Each session will have a 25% interactive component.

A1
4 oral papers (15 minutes & Q&A)

A1a Electroencephalographic Results in Children with FASD
Katarzyna Dyląg, MD, Physician, Faculty of Medicine, Jagiellonian University, St. Louis Children Hospital, Krakow, Poland

A1b Disruption of Circadian Clocks in Children with FASD
Dipak Sarkar, Ph.D., DPhil, Board of Governors Professor, Director, Endocrinology Program; Distinguished Professor, Department of Animal Science, The State University of New Jersey, Rutgers, New Brunswick, NJ

A1c Sex Differences in Cognitive and Behavioral Effects of Prenatal Alcohol Exposure in a Rat Model
Shameena Bake, Ph.D., Assistant Professor, Department of Neuroscience and Experimental Therapeutics, Texas A&M Health Science Center, Bryan, Texas

A1d Prenatal alcohol exposure impairs spatial learning in transgenic F344-AD in middle-aged rats
Nadia Samiya, MS, Graduate Student, Texas A&M University Health Science Center, Bryan, TX

A2
2 x 45-minute sessions & Q&A

A2a Diversity, Equity and Belonging: Inclusive Strengths-based Approaches to Address FASD in Urban Indigenous Communities
Emily Fisher, MD, MSc, FRCP, Clinical Assistant Professor, Division of Developmental Pediatrics, Department of Pediatrics, Faculty of Medicine, University of British Columbia, Vancouver, BC
Christine Loock, MD, Developmental & Social Pediatrician, Associate Professor, University of British Columbia; Responsive Intersectoral Community Health, Education, and Research (RICHER) Initiative, Vancouver, BC
Kristina Pikksalu, BA, BScN, MScN, NP (F) (Primary Care), RICHER Social Pediatrics Program, BC Children's & Women's Health Centre
Eva Moore, MD, MSPH, FAAP, Clinical Associate Professor, Division of Adolescent Medicine, Department of Pediatrics, Faculty of Medicine, University of British Columbia, Vancouver, BC
Gaxlagexelax Jenelle McMillan, Indigenous Chemical Addictions Specialist III, BGS, BEd with a Specialization in Indigenous Education, FASD and Addiction counsellor; Board Member, Métis Family Services, Owner/Operator of Wolf Song Healing Farm; K - 12 Culture and Nłeʔkepmxcn Language Teacher, Mother and Grandmother, Papsilqua IR2, BC

A2b Accessible Strategies for Training Pediatric and Adult Primary Care Providers in FASD Diagnosis and Care
Lynn L. Cole, DNP, Clinical Associate Professor, University of Rochester School of Nursing, University of Rochester, New York, NY
Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, New York, NY

A3
90-minute session, only open to delegates who attended the pre-conference session #1 (page 8)

Follow-up to PC1: The Verdict in in Your Court: Advancing Justice for Individuals with FASD Across Judicial Systems
Peter W. Choate, RCSW, Ph.D., Clinical Social Worker Professor, Social Work, Mount Royal University, Calgary, AB
Judge Marian Gaston, San Diego Superior Court, San Diego, CA
Corey La Berge, Member of the Law Society of Manitoba, Community Living British Columbia, BC

For those who attended PC1, this breakout session will focus on issues specifically of interest to parents and/or caregivers of individuals with FASD as it relates to the judicial systems, or those interested in child welfare and family courts. Please only select this session if you attended PC1.

A4
90-minute session

Implementing an FASD Assessment and Strengths and Strategies Approach in a Substance Use Treatment Agency and a Behavioral Health Agency
Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA
Summer Krochta, LCSW, Vice President of Programs, Children's Service Center, Wilkes-Barre, PA

- Describe a process of identifying individuals who likely have FASD
- Discuss a strengths and strategies approach for supporting these individuals
- Examine barriers to implementing screening and modifications in treatment settings
- Identify benefits of this screening and strategies approach

Angela Geddes, CYC, MSW, RSW, YTT, Researcher, Social Worker, Private Practice, Elgin County, ON
Shannon Butt, International Adult Leadership Collaborative (ALC), FASD Changemakers, Ottawa, ON

- Demonstrate the importance of working alongside individuals with FASD and their caregivers to develop and deliver supports tailored to their needs
- Collaborate and develop partnerships with community agencies, sharing expertise and resources, while building skills and capacity
- Identify the unique and key elements of support groups that are considered effective in addressing the wellbeing of individuals with FASD and their caregivers
- Practice and further discover the benefit of Acceptance Commitment Therapy/Training (ACT) for all: facilitators, group and individual participants

Interrogative Suggestibility, Confabulation and Compliance: Findings from an Experimental Study

David Junior Gilbert, Ph.D., School of Health and Society, Salford University, Manchester, United Kingdom

- Present the research on interrogative suggestibility in adolescents with FASD (compared to a control) as measured immediately and after one week
- Present findings on the unique patterns of confabulation observed in adolescents with FASD as measured immediately and after one week
- Expand on the types of responses of adolescents with FASD in comparison to controls during interrogative questioning with the implications of the findings

12:00 - 1:00 Lunch (provided), exhibits, and posters

Parent Lunch: In past conferences, parents have appreciated the opportunity to come together at these events to connect with other parents who are raising a child, youth, or adult with FASD. For those parents who have children/adults living with FASD and are registered to attend the main conference, we are happy to announce that this lunch is arranged for you. If you are interested in attending, please sign up when registering for the conference. You will receive more information closer to the conference about this lunch.

1:00 - 2:30 BREAKOUT SESSION B

Each session will have a 25% interactive component.

B1

4 oral papers (15 minutes & Q&A)

B1a Examination of Epigenetic Profiles Associated with Prenatal Exposure to Alcohol
Aileen Baldwin, Ph.D., MPH, Assistant Laboratory Director for Research, United States Drug Testing Laboratories, Des Plaines, IL

B1b Ultrasound imaging of ciliary arterial blood flow as a potential ocular biomarker for brain effects in adult offspring prenatally exposed to alcohol
Marisa Pinson, BS, Graduate Assistant Researcher, Neuroscience and Experimental Therapeutics, Texas A&M Health Science Center, Bryan, TX

B1c Metabolic and Cardiovascular Diseases in a Retrospective Cohort of Adults with FASD
Olivia Weeks, Postdoctoral Research Fellow, Division of Cardiology, Boston Children’s Hospital, Harvard Medical School, and Brigham and Women’s Hospital, Boston, MA

B1d Embryonic Alcohol Exposure in Zebrafish Predisposes Adults to Cardiomyopathy and Diastolic Dysfunction
Olivia Weeks, Postdoctoral Research Fellow, Division of Cardiology, Boston Children’s Hospital, Harvard Medical School, and Brigham and Women’s Hospital, Boston, MA

B2

4 oral papers (15 minutes & Q&A)

B2a Planning Healthy Outcomes with Caregivers of Individuals with FASD: Caregiver Perceptions and Beliefs
Vannesa Joly, BA, Graduate Research Assistant, Department of Educational Psychology, University of Alberta, Edmonton, AB

B2b Weaving Indigenous and Western Worldviews within the Assessment and Diagnosis of FASD

B2c Results from the Randomized Controlled Efficacy Trial of the Families Moving Forward Connect App for Caregivers Raising Children with FASD
Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, New York, NY

B2d Rural and Remote Programming: Changing Pathways for Youth Living with FASD
Wanda Beland, BEd, Executive Director, NWR FASD Society-Mackenzie Network, High Level, AB
FASD as a Brain/Body Disorder: A Social Determinants of Health Perspective

Peter W. Choate, RCSW, Ph.D., Clinical Social Worker Professor, Social Work, Mount Royal University, Calgary AB
Dorothy Badry, Ph.D., RSW, Professor, Faculty of Social Work, University of Calgary, Calgary, AB
Christina Tortorelli, Assistant Professor, Social Work, Mount Royal University, Calgary, AB

- Use the proposed FASD Social Determinants framework for policy and clinical practice development
- Develop language and positions to engage colleagues in changing to strengths and capacity perspectives
- Integrate social determinants and human rights creating foundational advocacy positions that can be used in various forums intersecting with people with FASD
- Locate capacity building in case plans developed with clients

Parenting Children and Adults with FASD: Recognizing the Joys and Adjusting to What You Can and Cannot Change

Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA
Brenda Knight, Registered Psychologist, Private Practice, Vancouver, BC

- Identify positive aspects of raising your child
- Describe challenges of meeting the needs of the child or adult
- Increase your coping skills
- Recognize the need to reduce your isolation
EXPLORING HEALTH OUTCOMES IN ADULTS WITH FASD

Evidence from the Atlanta and Seattle Research Study Sites

- Provide an overview of the impact of prenatal alcohol exposure on adult health and immune function
- Identify areas of risk and resilience
- Discuss the implications of the results for improving medical care and treatment options

Evidence from the Canadian Research Study Site

- Provide an overview of the impact of prenatal alcohol exposure on adult health and immune function
- Identify areas of risk and resilience
- Discuss the implications of the results for improving medical care and treatment options

The Potential for Severe Cerebrovascular Outcomes in Adulthood Due to Prenatal Alcohol

- Recognize that prenatal alcohol exposure (PAE) is a risk factor for adult cardiovascular diseases
- Recognize sex differences in stroke outcomes in PAE adults

Preliminary Results on the Study of the Cardiovascular Risk in Adults with a History of Prenatal Alcohol Exposure

- Identify relative risk for cardiovascular disease in adults with FASD
- Discuss the role that lifestyle and environmental factors play in mediating cardiovascular outcomes in adults with FASD
- Review the importance of early screening for cardiovascular disease and vascular functioning in individuals with FASD
MORNING PLENARY

A SYSTEMATIC AND PERSON-CENTERED HARMONIZING FRAMEWORK FOR HOUSING INDIVIDUALS WITH FASD: EXPERIENCES AND TRANSLATIONAL RESOURCES

FACILITATOR:

BRENDA KNIGHT
Registered Psychologist, Private Practice, Vancouver, BC

JACQUELINE PEI
Ph.D., RPsych, Professor, Department of Educational Psychology; Assistant Clinical Professor, Department of Pediatrics, University of Alberta, Edmonton, AB

ELIZABETH CARLSON
MA, Doctoral Student, School and Clinical Child Psychology Program, University of Alberta, Edmonton, AB

- Apply a harmonizing housing framework and use accompanying translational resources to support individuals with FASD in meaningful ways. These actionable resources are intended to aid service providers, caregivers, and individuals with FASD by promoting understanding and facilitating meaningful goal attainment
- Recognize current housing provision practices, identify current successes, and demonstrate knowledge on how to adapt programming to better meet the needs of individuals with FASD

REPORT

PROGRESS REPORT FROM THE INTERNATIONAL CONSENSUS COMMITTEE ON THE RESEARCH CLASSIFICATION OF FASD

FACILITATOR:

MICHAEL CHARNESS
MD, Chief of Staff, VA Boston Healthcare System; Faculty Associate Dean, Professor of Neurology, Harvard Medical School; Associate Dean, Professor of Neurology, Boston University School of Medicine, West Roxbury, MA

- Understand the basic clinical elements that contribute to a diagnosis of FASD
- Identify the similarities and differences in the three principal diagnostic systems that are used most widely to diagnose FASD
- Recognize the challenges for the field in working with different diagnostic systems

10:00 - 10:30 Break, exhibits, and posters
**BREAKOUT SESSION C**

**C1**

4 oral papers (15 minutes & Q&A)

- **C1a** Recommendations Towards Neuropsychological Assessment, Therapy and Post-Diagnostic Activities Based on Proposition of Polish Diagnostic Guidelines of FASD
  
  **Magdalena Borkowska**, MSc, Researcher, The National Center for Prevention of Addictions (KCPU) Department of Prevention and Public Education, Warsaw, Poland

- **C1b** Can Dysmorphology Examinations at Midlife Detect Physical Differences Between Adults With and Without Prenatal Alcohol Exposure?
  
  **Susan Stoner**, Ph.D., Research Associate Professor, Ann Streissguth Ph.D. Professor of Fetal Alcohol Spectrum Disorders; Addictions, Drug & Alcohol Institute; Department of Psychiatry & Behavioral Sciences; University of Washington School of Medicine, Seattle, WA

- **C1c** Caregiver perspectives on the stressors and successes of life transitions among adolescents and adults with FASD
  
  **Katherine Flannigan**, Ph.D., RPsych, Research Associate, Canada FASD Research Network, Edmonton, AB
  
  **Dorothy Reid**, MA, Parent/Family Member, Family Advisory Committee, CanFASD Research Network, Abbotsford, BC

- **C1d** Healthcare Utilization and Characteristics of Individuals with FAS: A descriptive population-based cohort study in Ontario
  
  **Daniela Dozet**, MPH, Research Analyst, Institute for Mental Health Policy Research, Centre For Addiction And Mental Health; Ph.D. Student, Institute of Medical Science, Faculty of Medicine, University of Toronto; Toronto, ON

**C3**

- FASD and Justice

  **Andrea Kotlar**, Executive Director, FASD Network of Saskatchewan, Saskatoon, SK
  
  **Shana Mohr**, Training and Programs Manager, FASD Network of Saskatchewan, Saskatoon, SK

  - Explore how harm reduction can work in the justice system
  - Review trauma-informed care and the role FASD plays in criminal occurrences
  - Discuss how to work with lawyers to create an FASD-informed approach to representing their clients

**C4**

90-minute session (Film showing with Q&A)

- (Film showing) ‘8 Keys for Adults with FASD’: Seven adults with fetal alcohol spectrum disorders telling their stories, challenges, strengths, and strategies for success
  
  **Presented by the Alaska Center for Fetal Alcohol Spectrum Disorders**

  **Teri Tibbett**, M.F.A., President, Board of Directors, Alaska Center for FASD; Coordinator, Alaska Prenatal Alcohol Partnership, Juneau, AK
  
  **Gina Schumaker**, (film cast member) Vice-President, Board of Directors, Alaska Center for FASD; Self-Advocate, Anchorage, AK
  
  **Marilyn Pierce-Bulger**, A.P.R.N., (film co-producer) Retired Family Nurse Practitioner/Certified Nurse Midwife; Founder, Alaska Center for FASD, Anchorage, AK
  
  **Karen Arnalquar’ Lomack**, Board Member, Alaska Center for FASD; Parent/Parent Navigator, Anchorage, AK
  
  **Mary Katasse**, Board Member, Alaska Center for FASD; Parent Advocate, Juneau, AK
  
  **Mike Jeffery**, J.D., Board Member, Alaska Center for FASD; Retired Superior Court Judge, Utqiagvik/Barrow, AK
  
  **Janice Weiss**, M.F.A., Executive Director, Alaska Center for FASD; Disability Advocate, Palmer, AK

  - Identify a broad range of impacts & challenges that are associated with prenatal alcohol exposure and FASD
  - Describe a range of strategies that can be helpful to those who experience an FASD
  - Explore their own reaction to the stories shared by the adults in the film, from the panel, and questions from audience members

**C2**

Open only to mental health clinicians

90-minute session

- Integrating Knowledge, Experience and Approaches to Mental Health Treatment for Individuals and Families Living with FASD

  **Dan Dubovsky**, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA
  
  **Brenda Knight**, Registered Psychologist, Private Practice, Vancouver, BC

  - Examine underlying issues that contribute to mental health concerns
  - Review issues related to the utilization of evidence-based practices in mental health treatment
  - Reflect on your standards of practice
  - Discuss the importance of professional self-care
C5 90-minute session

Holistic Support for Adolescents with FASD: From Disability Processing to Relationship-Building to Adaptive Living Skills

Janis Yue, OTD, OTR/L, Assistant Professor of Clinical Occupational Therapy, University of Southern California, Los Angeles, CA

Jessica Frausto, OTR/L, Occupational Therapy Doctoral Resident, University of Southern California, Los Angeles, CA

- Identify challenges with self-efficacy that adolescents with FASD often experience
- Describe how challenges with self-efficacy can result in poor outcomes for adolescents with FASD
- Apply sensory and arts-based strategies to support self-efficacy for adolescents with FASD

C6 90-minute session (Two parts: I & II)

Susan (Astley) Hemingway, Ph.D., Professor of Epidemiology and Pediatrics, Schools of Public Health and Medicine, University of Washington, Director WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN), Seattle, WA

(Part I) Comparison of The 4-Digit Code 2004, Canadian 2015, Australian 2016 and Hoyme 2016 FASD Diagnostic Guidelines When Applied to the Records of 1,392 Patients

- Recognize the key contrasts and similarities in the diagnostic criteria between the 4-Digit Code, Canadian 2015, Australian 2016 and Hoyme 2016 FASD diagnostic guidelines
- Recognize the key contrasts and similarities between the measurement tools (Lip-Philtrum Guides; direct versus photographic measurement of facial features; palpebral fissure length normal growth charts) utilized by the 4 systems
- Discuss the magnitude of discordance in diagnoses generated by the 4 systems
- Identify the ethical and clinical implications of the diagnostic nomenclature

(Part II) FASD in Washington State: A 50-Year Reflection

- Showcase the accomplishments of WA State in the 50 years since the University of Washington coined the term FAS in 1973
- Demonstrate how legislative support, interagency collaboration, centralized data collection, and use of an evidence-based FASD diagnostic system (4-Digit Code) has been key to the 30-year success of the FASDPN
- Demonstrate the value of adopting a single diagnostic system: we can now compare the WA and AK 4-Digit Code FASD diagnostic outcomes and prenatal exposures of thousands of patients diagnosed across both states over 3 decades
- Demonstrate how the FASDPN diagnostic model/tools has been adopted in 35 countries, most recently through the Polish Instytut of FASD

12:00 - 1:30 Lunch (provided), exhibits, and posters

1:30 - 3:00 BREAKOUT SESSION D

Each session will have a 25% interactive component.

D1 4 oral papers (15 minutes & Q&A)

D1a A Thematic Analysis of Strengths and Protective Factors in Youth with FASD and Criminal Legal System Involvement

Chantel Ritter, MSc, Ph.D. Student, Clinical Child and Adolescent Psychology, University of Guelph, Guelph, ON

D1b FASD in Canadian Criminal Cases: A Case Law Review

Kaitlyn McLachlan, MA, Ph.D., Assistant Professor, Department of Psychology, University of Guelph, Guelph, ON

D1c Nothing About Us Without Us: Research Participants Speak Back and Outline What is Needed for Ethical Collaborations

Dorothy Reid, MA, Parent/Family Member, Family Advisory Committee, CanFASD Research Network, Abbotsford, BC

D1d Unpacking the narrative of the child and family experience: When FASD and Child welfare Intersect

Christina Tortorelli, Assistant Professor, Social Work, Mount Royal University, Calgary, AB

D2 90-minute session

Implementing a Screening Assessment, and Intervention Protocol to Identify Youth with FASD Within Michigan’s Department of Health and Human Services

Katherine Fitzpatrick, MA, Coordinator, SED and Neurodevelopmental Disorders, Michigan Department of Health and Human Services, Lansing, MI

Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA

- Describe the screening, assessment, and implementation process to identify youth with FASD
- Discuss the importance of utilizing a strengths assessment for youth and their family members
- Identify barriers to implementing the protocol
A Community Initiative to Increase Well-being and Reduce Recidivism in Youth Offenders with FASD

Sam Galloway, Practice Manager, START Taranaki, Kaponga, Taranaki, New Zealand
Judge Maria Pecotić, District Court, New Zealand
Valerie McGinn, Ph.D., Clinical Neuropsychologist, Department of Population Health, University of Auckland, Auckland, New Zealand

- Identify what leads to increased well-being and better outcomes for recidivist youth offenders with FASD
- Apply this type of community initiative in your own community to build productive crime free lives and achieve success for youth with FASD

FASD Across the Lifespan Research Including a Report on Adolescent Deaths and Serious Injuries with Prenatal Substance Exposure/FASD in Child Advocate Reports in Canada: A Systematic Review

Dorothy Badry, Ph.D., RSW, Educator, Faculty Of Social Work, University of Calgary, Calgary, AB

- Review current research evidence and literature on the state of practice issues for adolescents with FASD
- Consider the issues of child deaths and serious injuries as reported by child advocates across Canada, contributing to a recognition of the serious need for FASD informed practice in child protection

My Health Coach: A community-engaged partnership to develop a scalable mobile health tool for adults to aid with FASD self-management

Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, New York, NY
Christiano Tapparello, Research Associate Professor, Department of Electrical and Computer Engineering, University of Rochester, New York, NY
Emily Speybroeck, Graduate Student, Clinical Psychology, University of Rochester, New York, NY

& available members of the ALC who contributed to this project (Myles Himmelreich, CJ Lutke, Anique Lutke, Katrina Griffin, Maggie May, and Emily Hargrove)

- Describe the user-centered design approach used in initial development and evaluation of the My Health Coach app for adults with FASD
- Describe feasibility trial results including user acceptability, recommendations for future refinements, and lessons learned

New Directions for FASD: Perspectives from Australia, USA, and Canada

Elizabeth Elliott, AM, MD, MPhil, MBBS, FRACP, FRCPCH, FRCP, Child and Adolescent Health, Sydney Medical School, University of Sydney; and The Sydney Children’s, Hospitals Network, Westmead, Sydney, Australia
Claire Coles, Ph.D., Professor, Department of Psychiatry and Behavioral Sciences; Director, Maternal Substance Abuse and Child Development Program (MSACD), Emory University, Atlanta, GA
Christine Loock, MD, FRCPC, FAAP, Developmental and Social Pediatrician, Associate Professor, Department of Pediatrics, University of British Columbia, BC Children’s Hospital & Sunny Hill Health Centre for Children, Vancouver, BC

The session will include information about FASD from national databases, on adult outcomes, on FASD in racialized and other equity seeking populations, on the challenges we encounter in addressing FASD, and on innovations developed to facilitate the diagnosis of FASD and support for individuals and their families.

- Overall objective: To provide updated information on prevalence, contexts, and current state of play regarding FASD in Australia, Canada and USA, the challenges we face in each country, and solutions that have been developed to address these challenges.
3:30 - 3:40  Remarks: Nothing About Us Without Us - Life with FASD in the Rest of the World – Don’t Forget About Us

3:40 - 4:40  AFTERNOON PLENARY

LIFE EXPERIENCE OF INDIVIDUALS WITH FASD IN A RURAL SOUTH AFRICAN CONTEXT

LEANA OLIVIER
Ph.D., Chief Executive Officer, Foundation for Alcohol Related Research (FARR), Cape Town, South Africa

- Review results from follow-up on a cohort of South African individuals diagnosed with FASD and matched controls 16 years after diagnosis
- Reflect on professionals’ perceptions about the life outcomes of people living with FASD in developed versus developing countries
- Consider the implication of the difference in perceived independence between individuals with FASD and that reported by their parents/caregivers

4:40 - 5:10  AFTERNOON PLENARY

THE LASTING LEGACY OF DR. ANN STREISSGUTH: WIDE-RANGING WORK ON FASD

SUSAN STONER
Ph.D., Research Associate Professor, Ann Streissguth Ph.D. Professor of Fetal Alcohol Spectrum Disorders, Addictions, Drug & Alcohol Institute; Department of Psychiatry & Behavioral Sciences; University of Washington School of Medicine, Seattle, WA

- Provide an overview of studies of FASD by Dr. Streissguth from 1974-2004
- Recognize the significance of Dr. Streissguth’s work
- Describe emergent findings from longitudinal studies with the Streissguth research cohort

5:10  Adjourn
Registration

Remarks: Nothing About Us Without Us - Epigenetics in FASD: What We Want to Know; What We Need to Know

Gina Schumaker
International Adult Leadership Collaborative (IALC) FASD Changemakers, AK

8:40 - 9:40

MORNING PLENARY

THE CHANGING WORLD OF EPIGENETICS:
EXPERIENCE IS WRITTEN IN OUR GENES, BUT DOES IT HAVE TO STAY THERE?

Epigenetic Signatures of Developmental Adversity: Implications for Risk and Resilience in FASD

Alexandre Lussier
Ph.D., Instructor in Psychology, Harvard Medical School, Massachusetts General Hospital, Boston, MA

- Discuss the epigenetic mechanisms that might underlie the effects of early life adversity during sensitive periods
- Compare and contrast findings from animal models and human epigenetic studies of prenatal alcohol exposure and FASD
- Assess evidence of epigenetics as a mechanism for risk and resilience for physical and mental health outcomes

Thomas Reynolds
Ph.D., Chief Scientific Officer, Kids Brain Health Network; Professor, Department of Biomedical and Molecular Sciences, Queen’s University, Kingston, ON

- Describe the impact of early life adversity on brain development and long-term health outcomes
- Recommend tools for assessing child development and developmental support planning to improve long-term outcomes

Break, exhibits, posters

9:40 - 10:10

10:10 - 11:40 BREAKOUT SESSION E

Each session will have a 25% interactive component.

E1 90-minute session

Essential Lessons from Medical Assessments at one of the two British Columbia Adult FASD Diagnostic Clinics: What I Needed to Learn to Understand Symptoms and Improve Patient Outcomes

Roderick Densmore, MD, Physician, Adult FASD Diagnostic Clinic, Independent Living Vernon, Vernon, BC

- Identify questions that screen for common—but often undiagnosed—FASD-related sensory "invisible disabilities"
- One example: safety in traffic is at risk if the patient has difficulties predicting where a moving object (such as a car) will be in a few seconds time; this issue is often not recognized.
- Effectively advocate for patients when imminent risk of suicide seems to be underestimated by other professionals
- Review a series of 20 templates that describe our clinic’s approaches to common clinical issues that affect youth and adults with FASD
- Identify additional strategies and tools that can save time and increase accuracy of assessments

E2 90-minute session

Capacity to Stand Trial issues and Ensuring Effective Participation for Defendants with FASD: an International Perspective

Valerie McGinn, Ph.D., Clinical Neuropsychologist, Department of Population Health, University of Auckland, Auckland, New Zealand
Mansfield Mela, MBBS, FWACP, FRC Psych, MSc, FRCP, Professor and Forensic Psychiatrist, Department of Psychiatry, University of Saskatchewan, Saskatoon, SK
Maria Pecotić, Judge, District Court, New Zealand
Stephen Greenspan, Ph.D., Department of Educational Psychology, University of Connecticut, Storrs, CT
David Junior Gilbert, Ph.D., School of Health and Society, Salford University, Manchester, United Kingdom

- Identify factors that impact on capacity to stand trial in defendants with FASD
- Consider how to respond to these identified factors at all stages of the legal process to ensure a fair process
The SAFTHON, an International Movement
Denis Lamblin, MD, Developmental Pediatrician, President SAF
FRANCE; President and Delegate Director, Local & Regional
Networks, International SAFTHON (FASTHON), National &
International Relations, FASD Resource Center, Père Favron
Foundation, Reunion Island, France
Sarah Lamblin, MA, Communication Consultant, SAF FRANCE;
SAFTHON, Paris, France

Recognize the importance of a global advocacy strategy for a
better recognition of FASD by public health actors,
institutions and systems in their own countries
Exemplify or consider SAFTHON as a cost effective strategy
and communication support that builds on the combined
commitment of many countries in the prevention of FASD
Initiate a SAFTHON awareness campaign in your own
country to influence stakeholders utilizing tools and
strategies provided by SAF France professionals

Closing the FASD Health Service Gap in the Eastern Doorway—
Taking Action on Canada’s Truth and Reconciliation
Commission (TRC)’s Calls to Action— Participant Action
Research in Wabanaki
Lori Vitale Cox, Ph.D., Director Elsipogtog Eastern Door Centre;
Adjunct Professor UBC Faculty of Medicine, Department of
Pediatrics, Elsipogtog FN, NB Canada

- Discuss FASD in relation to generational trauma and the
  colonial process
- Discuss Two Eyed Seeing approach to FASD service delivery
  and the Eastern Door Centre model and its challenges and
  successes
- Discuss the findings of Indigenous Community Based
  Participant Action Research regarding FASD health service
delivery in the Eastern Doorway (Atlantic Canada)
- Engage session participants in a discussion regarding both
  successes and gaps in delivering culturally safe FASD
  services in other communities and regions of Turtle Island

The FASD United Family Navigator: Support and Resources for
the FASD Community and Resources from CDC and Partners
Jennifer Wisdahl, Chief Operating Officer, FASD United,
Washington, DC
Laura Bousquet, Family Navigator, FASD United, Washington, DC
Elizabeth Dang, MPH, Behavioral Scientist, National Center on
Birth Defects and Developmental Disabilities, Centers for Disease
Control and Prevention, Atlanta, GA

- Describe the navigator support, services, and referrals
  available to individuals living with FASD and their caregivers
- Recognize through the experiences of users how the
  navigator can help improve outcomes and opportunities for
  adolescents and adults with FASD
- Overcome reluctance to identify with FASD and be self-
  confident in communicating with professionals about FASD
  and your needs
- Describe resources available from the Centers for Disease
  Control and Prevention (CDC) and its partners to help
  prevent alcohol use during pregnancy and provide care for
  individuals with FASD and their families across the lifespan

11:40 - 12:40 Lunch (provided), exhibits, and posters
12:40 - 12:50  Remarks: Nothing About Us Without Us - The Plight for What is Right

JESSICA BIRCH
International Adult Leadership Collaborative (ALC), FASD Changemakers, Australia

12:50 - 1:50  FETAL ALCOHOL SPECTRUM DISORDERS: A RIGHTS PERSPECTIVE VERSUS BEST INTEREST

PETER W. CHOATE
RCSW, Ph.D., Clinical Social Worker Professor, Social Work, Mount Royal University, Calgary AB

MOIRA PLANT
Professor Emeritus Alcohol & Health Research Unit, University of the West of England, Bristol, UK; Adjunct Professor, Curtin University, Edinburgh, UK

Integrate an understanding of human rights as having a higher importance in the lives of people with FASD as opposed to best interest
Assess and utilize human rights in program development, case planning and service delivery
Acquire knowledge for the application of human rights advocacy

TERRI PELTON
BSW, RSW, Child and Youth Advocate (Alberta), Edmonton, AB

1:50 - 3:30  STARFISH AWARD PRESENTATIONS & CLOSING CEREMONY: WE ARE THE FUTURE

3:30  Adjourn. Have a safe journey home!

STARFISH - every life form seems to reach out to its own kind in order to, not just survive, but to FLOURISH.

LINDA MAXWELL