10th International Conference on

Adolescents and Adults with Fetal Alcohol Spectrum Disorders:

Integrating Research, Practice, and Policy Around the World

Research

Real Life

of adolescents & adults with FASD

Practice & Policy

April 19-21
2026

Main Conference Syllabus

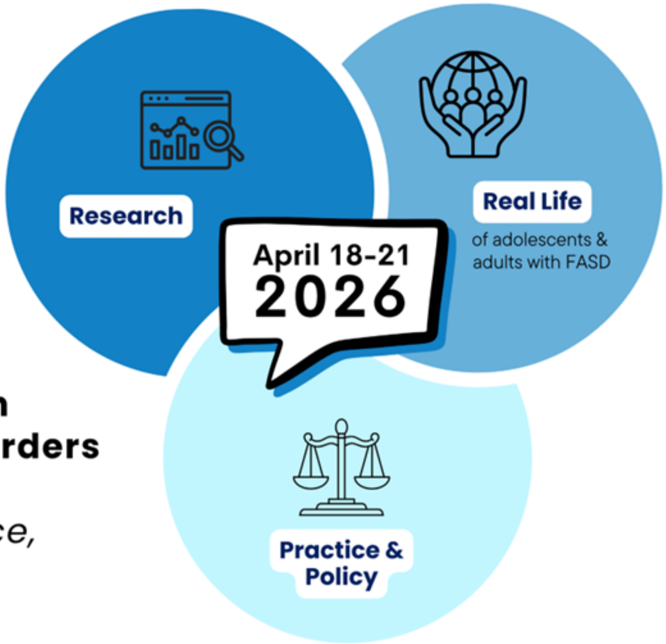
Seattle, WA

Welcome

10th International Conference on

Adolescents and Adults with Fetal Alcohol Spectrum Disorders

Integrating Research, Practice, and Policy Around the World



SUNDAY, APRIL 19

Session #	Session Title
Plenary	Through the Looking Glass, and What Individuals with FASD Found There: Experiences and Choices in Parenting
A1i	Identifying the Brain Areas and Neural Circuits Regulating Learning Memory in a Mouse Model of FASD
A1ii	Discovery and Characterization of Epileptiform Discharges in Essential Memory Circuits in a Mouse Model of FASD
A1iii	Prenatal Alcohol Exposure Disrupts Synapse Maturation and Heightens Vulnerability to Substance Use Through Accumbens Circuit Mechanisms
A1iv	New Imaging Approach to Evaluate the Effects of Developmental Alcohol Exposure on Brain Grey and White Matter Intervention Outcomes
A1v	Comparing Stressor and Resource Domains Across Prenatal Alcohol Exposure Groups: Implications for Intervention
A2i	The Neurowise Model – Integrating Research, Therapeutic Coaching, and Lived Experience in a Brain-Based, Dual Track Approach to Supporting FASD Caregivers, Practitioners, and Young People

MONDAY, APRIL 20

C1i	Early Indicators of Comorbidities in Children and Adolescents with Prenatal Alcohol Exposure
C1ii	Social Engagement and Challenging Behaviors in Children with FASD
C1iii	Learning With FASD: Evaluation of a Research Translation Initiative to Disseminate Evidence-Based Resources on FASD for Secondary School Teaching and Support Staff
C1iv	Enhancing Educators' Capacity to Support Students with FASD: A Participatory Program Evaluation
C1v	Taking FASD-Informed Care from Research to the Real World: Disseminating, Implementing and Expanding the Families Moving Forward Program
C2i	Bridging Care Models: Exploring an FASD-Informed Therapeutic Assessment Model in Inpatient Psychiatric Care
C2ii	From Awareness to Action: Immersive Community-Based FASD Training for Pediatric Care Teams
C2iii	Advancing Pediatric Care: Successful Strategies for Supporting Children with FASD
C2iv	Australian Occupational Therapists' Awareness, Knowledge and Practice of FASD
C2v	Building Better Pathways to FASD Care: National Insights on Clinician Readiness, Cultural Safety and Barriers to Early Identification in Canada
C3	Seeing the Unseen: How Social Workers Can Transform FASD Identification and Support
C4	FASD and Autism Across Development: Distinguishing Social Profiles From Childhood to Adolescence — A Conversational Roundtable
C5	Three Generations of FASD: Unmasking Lived Experiences, Trauma, and the Healing Power of Culture
C6	FASD Across the Lifespan: Bridging Research, Community Supports for Lifelong Well-Being
C7	Implementing a Process to Support Youth and Families within a Behavioral Health Treatment Modality
C8 & D8	Ability Mapping: A Powerful Tool for Increasing Understanding, Education and Advocacy about FASD
D1i	A Neurodevelopmentally Informed Probation Framework: The Collaborative Support Supervision Triad (CSS-T) Model for Individuals with FASD
D1ii	Reflecting on Prenatal Marijuana Exposure: Why Monitoring for Prenatal Ethanol Exposure Is Essential
D1iii	Stronger Than Stigma: What People with Living Experience Have Told Researchers Over the Past 20 Years
D2i	Association Between Paternal Alcoholism and Adverse Outcomes Observed in Individuals with PAE Receiving an FASD Diagnostic Evaluation
D2ii	Impacts of Prenatal Alcohol Exposure on Neurobiological, Psychopathological, Behavioural, and Cognitive Outcomes Across Adolescence
D2iii	Prenatal Alcohol Exposure and Nailfold Capillary Morphology in Children Aged 3–17 Years
D3	Celebrating Families!: A Community-Based, Trauma-Informed Whole-Family Approach to Healing Intergenerational Substance Use
D5	The Animation Curriculum: Acceptability, Feasibility and Engagement of a Specifically Designed FASD Educational Intervention
D6	Breaking the Myth of Independence – Making Invisible Supports Visible
D7	Integrated Care for Adolescents with FASD: A Community Clinic Model in Los Angeles
Plenary	The Power of Knowledge: Insights from Birth Moms
Plenary	Paternal Alcohol Use: "Half the Equation: Why Fathers Matter in FASD Risk"
Plenary	Expanding FASD Prevention: Combined Parental Alcohol Use Shapes Offspring Aging and Chronic Disease Risk

TUESDAY, APRIL 21

Plenary	Addressing Mental Health in Teens with FASD: Building Accessible and Community-Informed Treatment Approaches
E1i	Navigating Young Adulthood with FASD: Goals, Challenges, and Role of Social Support Networks
E1ii	Cardiovascular Disease in a Retrospective Cohort of Adults with FASD
E1iii	Prenatal Alcohol-Exposure and Perinatal Alcohol-Use by Mothers Enrolled in the Parent-Child Assistance Program in Washington State
E2i	The Changing Presentation of Neurodevelopmental Impairments With Age in Australian Adolescents Living With FASD
E2ii	Early-Life Exposures, Lasting Imprints: Gut Microbiota-Metabolite Alterations Linking Prenatal Alcohol and Cannabinoids to Adult Addiction Risk
E2iii	Predictors and Opportunities for Prevention of Mental Health Disorders in Remote-Dwelling Australian Aboriginal Adolescents With FASD
E3	Stress in Life and in Work: What Causes It and How to Cope
E4	Seeing the Invisible: Prioritizing FASD in Adolescent Education
E5	Enhancing Attachment, Regulation, and Family Stability in FASD: Outcomes of a TBRI-Integrated Clinical Approach
E7	Translating Brain Science into Practice: Neurobehavioral Interventions for FASD
E8	Designing Dignity: Self-Advocates on Successful Housing for Adults with FASD
F1i	Prenatal Alcohol and Cannabinoid Exposures Disrupt Acetylcholine Receptor Subunit Expression in Adult Mouse Offspring
F1ii	Bridging the Gap: Behavior Parent Training for Caregivers with Children with Childhood Adversities
F1iii	Adaptive Function Outcomes in FASD: Comparing Facial Phenotype and Associated Risk Factors
F2i	Supporting the Mental Health of Students with FASD: POPFASD On-Demand Course FASD 103
F2ii	From Clinic to Classroom: Investigating IEPs and Diagnostic Clinical Evaluation Recommendations for Students with a FASD Diagnosis
F2iii	FASD, Faith, and Spirituality – Sharing Our Testimonies
F3	Tribal Therapeutic and Problem-Solving Courts: A Collaborative Team-Building Approach to Responding with Care for Individuals with FASD
F5	Hope Rising Clinic, A Model for Therapeutic Intervention for Children and Families Affected by FASD and Prenatal Substance Exposure
F6	Prevent Sexual Exploitation and Human Trafficking for Clients with FASD
F7	Trauma-Informed, Family-Centered Care for Children with Polysubstance Exposure and FASDs
F8	Affirming and Supporting FASD—Improved Outcomes with the FASCETS Neurobehavioral Approach
F9	Not Your Typical Growing Up Guide
Plenary	From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

POSTER LISTING

2	FASD: Ireland's Silent Epidemic
3	Fetal Alcohol Spectrum Disorder: An Exploration of Causes, Prevention, and Supports
13	Elevating FASD Across the Association of University Centers on Disabilities (AUCD) Network: Building Visibility, Capacity, and Comm 13 1415 1617 1819 2021unity to Strengthen National Systems of Support
15	Mini-ICF-APP : Discrepancy Between Self-and Other-Perception of People with FASD – A Clue for Further Research
23	The impact of epileptiform discharges on memory circuits following third-trimester alcohol exposure
35	Long-term retention of motor learning is impaired by prenatal alcohol exposure
51	Preclinical Development of FASD-Specific Nasal Peptide Medications Targeting Root Causes of Neurocognitive Challenges
58	Transitioning to Adulthood with FASD: Family Members' Perspectives on Wellbeing and Access to Supports
64	Lifelong Impacts of PAE on Stem Cell Health: Implications for Healthy Aging in FASD
65	microRNA Biomarkers in Maternal–Child Pairs Provide New Insights Into Risk for Atypical Neurodevelopment
70	FASDPlay© - An Evidence Based Holistic Trauma Therapy for Individuals with FASD Across the Lifespan
76	FASD and Youth Justice: A Prevalence Study Among Young People Sentenced to Detention in Reunion Island (France)115.
80	Exploring spatial navigation in children and adolescents with FASD 98. *Courtney Farrow-Lawrence*
83	A Virtual Interprofessional Collaborative to Improve FASD: Recognition and Management in Child Welfare Populations
86	My Health Coach 2.0: A Scalable Mobile Health Tool for Adults to Aid With FAS Self-Management
93	FASD State Needs and Services Assessment
98	From the Land Translations: Understanding the Whole Person and Unveiling Gifts
103	Prenatal Alcohol Exposure Increases the Likelihood of Adaptive Functioning Difficulties in the Proposed ND-PAE Diagnosis in Children With ADHD
113	Teratogenic Effects of Ethanol in Monoaminergic Neurogenesis in Zebrafish Larvae
115	The Gifts you Carry: The Story of the Sacred Child and FASD
119	Assessing Long-Term Social Consequences in Adult Zebrafish Embryonically Exposed to Ethanol
122	Taking FASD-Informed Care from Research to the Real World: Disseminating, Implementing and Expanding the Families Moving Forward Program

CONFERENCE DESCRIPTION AND OBJECTIVES

While research on fetal alcohol spectrum disorders (FASD) has increased over the years, the unique needs of adolescents and adults are still too often overlooked. This conference will be a global gathering of people with FASD and their families, as well as researchers, professionals, and policy makers who seek to improve the health and lives of adolescents and adults with FASD.

Building on the work of the nine previous conferences, this conference will examine research, programs, and policies to reduce stigma, strengthen collaboration, and create meaningful change for individuals with FASD and those who support them.

Together, we will explore questions such as:

- How can practice and policy inform research, and how can research inform practice and policy?
- Can findings be shared across countries or from the lab and clinic to impact everyday life?
- What clinical issues should we be paying attention to?
- What changes in practice and thinking are needed to reduce stigma and improve outcomes?
- What are the most important directions for the future?

The learning objectives for this conference are:

- Learn how research can better address the real needs of individuals with FASD and their families, communities, and professionals in the field.
- Discover new research and ideas that can guide fair policies, practical supports, emerging approaches to treatment, and stronger collaboration across systems
- Examine practice-based evidence and programs to spark opportunities for research collaboration and potential long-term studies
- Share and exchange knowledge across different perspectives to create synergistic solutions
- Learn directly from individuals with FASD and their families, ensuring their voices are at the forefront of efforts to reduce stigma and impact research and practice

PROGRAM COMMITTEE MEMBERS

Laura Bousquet, FASD Self-Advocate, Parent to a Young Adult with FASD, LEND Alumni, Texas FASD Network Board Member, IACP Consortium Member, FASD United Family Navigator, USA

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

R. Colin Carter, M.D., M.M.Sc., Associate Professor of Pediatrics in Nutrition and Emergency Medicine, Departments of Pediatrics and Emergency Medicine and the Institute of Human Nutrition, Columbia University Vagelos College of Physicians and Surgeons, New York, NY, USA

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, USA

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, USA

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

Elizabeth Elliott, Professor of Paediatrics and Child Health; Consultant Paediatrician, Sydney Children's Hospital Network; Leadership Fellow, National Health and Medical Research Council of Australia, Australia

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

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, Canada

Rajesh C. Miranda, Ph.D., Professor, Department of Neuroscience and Experimental Therapeutics, College of Medicine, Texas A&M University Health Science Center, Bryan, TX, USA

Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, Rochester, NY, USA

Siara K. Rouzer, Ph.D., Postdoctoral Research Fellow, Department of Neuroscience & Experimental Therapeutics, Naresh K. Vashisht College of Medicine, Texas A&M University

Susan Shepard Carlson, JD, Chair, FASD United, FASD justice trainer, writer and speaker; former Hennepin County District Court Judicial Officer, Minneapolis, MN, USA; member of ICCFASD Justice Work Group, DC, USA

Jo Votolato, Conference Director, FASD United, Los Angeles, CA, USA

Joanne Weinberg, Ph.D., Professor and Distinguished University Scholar, Emerita, Department of Cellular & Physiological Sciences, University of British Columbia, Vancouver, BC, Canada

SPONSOR ACKNOWLEDGMENTS

We would like to extend our sincere appreciation for the generous financial support provided by our sponsors.

abmrf
THE FOUNDATION FOR
ALCOHOL RESEARCH

NIH
National Institute on Alcohol
Abuse and Alcoholism

Kate Boyce Reeder

*Funding for this conference was made possible (in part) by **5R13AA028176-05** from the National Institute on Alcohol Abuse and Alcoholism (NIAAA)**.** The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention by trade names, commercial practices, or organizations imply endorsement by the U.S. Government.*

EXHIBITOR LISTING

Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD)
The purpose of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) consortium is to inform and develop effective interventions and treatment approaches for FASD through multidisciplinary research involving basic, behavioral, and clinical investigators and projects. CIFASD is funded by grants from NIAAA.

Dream Acres
Dream Acres' purpose is to provide a safe supported living environment for individuals living with an FASD (Fetal Alcohol Spectrum Disorder) through on-site living units and added employment opportunities with support staff providing supervision and oversight.

FASCETS Center for Neurodiversity
FASCETS is a non-profit organization that provides information, training and consultation on the FASCETS Neurobehavioral Approach for individuals, families, and community partners (including educators, clinicians, social services, and justice system) who live or work with individuals with FASD and other brain-based differences. Our approach links brain with behaviors, leading to supports work make a difference for everyone involved.

FASD Coaches
FASD Coaches brings together the lived experience, brain science, and practical wisdom of FASD Mosaic and FASD Elephant. Led by Barb Clark and Michael Harris, we provide coaching, training, curriculum writing and tools that translate complex neurodevelopmental differences into real-world strategies for caregivers, professionals, and systems supporting individuals with FASD.

FASD Focus Northwest (NW)

FASD Focus Northwest (NW) provides peer-led support groups for caregivers and families impacted by Fetal Alcohol Spectrum Disorders across Washington State. In collaboration with FASD United and the Washington State Health Care Authority, these groups offer connection, practical strategies, and trusted resources that reduce isolation and strengthen families navigating FASD. www.fasdfocusnw.org

FASD Research Booth

Visit to learn about ongoing FASD research in Canada (University of Calgary) and the United States (University of Washington), including studies on health and aging and immune function. Meet our team, explore current projects, and learn how to participate, collaborate, or sign up to stay informed about future research opportunities.

FASD United

FASD United is the US national nonprofit dedicated to preventing prenatal alcohol exposure and supporting individuals and families affected by fetal alcohol spectrum disorders. Through policy advocacy, education, research support, and community programs, FASD United advances awareness, improves systems of care, and works to ensure lifelong support and opportunities for people with FASD.

Hope Rising Clinic
(a division of Wonderland Child & Family Services)

Hope Rising Clinic is Washington's first clinic dedicated exclusively to children with prenatal substance exposure. As part of Wonderland Child & Family Services, the clinic offers trauma informed, neurobehavioral care, providing specialized therapy, mental health support, caregiver education, and advocacy to help children build skills, regulate emotions, and thrive.

James Bell Associates

JBA's legacy is built on delivering excellence in evaluation and capacity building to improve the health and well-being of children, families, and communities. Headquartered in Arlington, Virginia, we provide actionable findings and evaluation technical assistance to inform policy and management in health and human services. Our projects cross disciplines, with an emphasis on child and family development, child welfare, tribal evaluation, and health care. Our clients include federal, state, tribal, and local governments as well as universities, foundations, and nonprofits. Our mission is to improve the lives of children, families, and communities through evaluation.

The Florida Center for Early Childhood, Inc.
(The Florida Center Training Institute)

The Florida Center Training Institute, in partnership with Seattle Children's, serves as the primary training location for Families Moving Forward Foundations Specialist Training, equipping master's-level professionals worldwide to deliver a scientifically validated intervention for families affected by prenatal alcohol exposure and FASD. Recognized as a promising practice and recommended by the CDC, this internationally expanding program integrates positive behavior support, motivational interviewing, and cognitive behavioral therapy to strengthen families and improve long-term outcomes.

The Florida Center for Early Childhood is a recognized leader in FASD, operating Florida's only FASD clinics and providing multidisciplinary evaluations for individuals of all ages with suspected prenatal alcohol exposure. For 47 years, The Florida Center has advanced healthy development for children and families in Florida through integrated education and therapeutic services. The Florida Center's programs support children at risk academically, socially, economically, or developmentally, changing life trajectories through early intervention. The Florida Center provides developmental therapies, mental health counseling, Healthy Families home visiting, and operates Starfish Academy, an inclusive preschool with integrated supports.

Willow Winds Support Network and Love 146
Willow Winds Support Network is an FASD and Brain Domain Challenge organization supporting Edmonton, Alberta, and western Canada; ElevateHer supports the Atlantic provinces. Love 146 supports the prevention of sexual exploitation and human trafficking in the USA. Together they train facilitators to offer the prevention program Not a Number on Sexual Exploitation and Human Trafficking for vulnerable populations and connect organizations wanting the program with trained professionals to deliver it.

PRESENTER LISTING

Adler, Richard	Forensic & Clinical Psychiatrist, University of Washington, Seattle, WA, USA
Anderson-Feldman, Brie	Hope Rising Clinic, Bothell, WA, USA
Anunziata, Florencia	Postdoctoral Researcher, University of California San Diego, San Diego, CA, USA
Arvizu, Rosa	Public Health Professional, American Academy of Pediatrics, Itasca, Illinois, USA
Attaalla, Moheb	Clinical Counsellor & FASD Key Worker, City University of Seattle, Virtual, Alberta, Canada
Barett, Hope	Public Health Professional, American Academy of Pediatrics, Itasca, Illinois, USA
Barrett, Jasmin	Clinical Psychology Graduate Student, Seattle Pacific University, Seattle, Washington, USA
Barton, Hannah	Doctoral Candidate, University of Washington, Seattle, WA, USA
Bodnar, Tamara	Researcher, University of Calgary, Calgary, Alberta, Canada
Boome, Peter	Judge, University of Washington, Seattle, WA, USA
Bothe, Denise	Developmental Pediatrician, University Hospitals Rainbow Babies & Children's Hospital, Cleveland, OH, USA
Borkowska, Magdalena	FASD Specialist, Warsaw, Poland
Bouillard, Margaux	Master’s Student, York University, Toronto, Ontario, Canada
Brassard, Nathalie	Executive Director, FASCETS Center for Neurodiversity, Albany, OR, USA
Brown, Tenisha	Educator, Love146, Houston, Texas, USA
Brown-Kivi, Kayla	Registered Social Worker, Willow Winds Support Network, Edmonton, Alberta, Canada
Burkhart, Kimberly	Psychologist, University Hospitals Rainbow Babies & Children's Hospital, Cleveland, OH, USA
Byrnes, Mary	Founder and Executive Director, Harrison’s Hope, Stouffville, Ontario, Canada
Candelaria-Cook, Felicha	The Mind Research Network, Albuquerque, NM, USA

Cappella, Maggy	Clinician, Community County Services, DuBois, Pennsylvania, USA
Cardenas Rolon, Ana	Clinical Social Worker, Violence Intervention Program, Los Angeles, CA, USA
Carmichael Olson, Heather	Researcher, Psychologist, Seattle Children's Research Institute, Seattle, WA, USA; University of Washington School of Medicine, Seattle, WA, USA
Casson-Rennie, Jacob	Person Living with FASD/Student, FASD Ireland, Ennis, Clare, Ireland
Casson-Rennie, Tristan	Chief Executive Officer, FASD Ireland, Ennis, Clare, Ireland
Chambers, Christina	Department of Pediatrics, University of California San Diego, La Jolla, CA, USA
Chang, Roxanne	Pediatrician, David Geffen School of Medicine at UCLA, Los Angeles, CA, USA
Clark, Barb	FASD Trainer, FASD Mosaic, Homosassa, FL, USA
Cleveland, Elizabeth	Assistant Professor, University of Arkansas for Medical Sciences, Little Rock, AR, USA
Coles, Claire	Professor, Emory University School of Medicine, Atlanta, Georgia, USA
Collin, Kelly Rain	Educational Consultant/Advocate and Child Mental Health Specialist, Healthy Minds Consulting, Tustin, CA, USA
Collins, Mary Beth	Administrator/Trainer/Developer, National Association for Children of Addiction - NACoA, Bel Air, MD, USA
Conkel Ziebell, Julia	Pediatric Psychologist, Proof Alliance, St. Paul, MN, USA
Conley, Ryan	Hope Rising Clinic, Bothell, WA, USA
Connor, Paul	Clinical Neuropsychologist, University of Washington, Seattle, WA, USA
Cox, Lori Vitale	Clinician Researcher, Elsipogtog Eastern Door Centre, Elsipogtog First Nation, New Brunswick, Canada
Crockett, Shanna	FASD Specialist/Parent Advocate, The Papillion Center, Paducah, KY, USA
Davuluri, Harshini	Research Assistant, Texas A&M University, College Station, Texas, USA
Delage, Madeline	Doctoral Candidate, University of Rochester, Rochester, NY, USA

Devine, Emma	Research Fellow, The Matilda Centre for Research in Mental Health and Substance Use, The University of Sydney, Sydney, NSW, Australia
Dickerson, Jody	Colorado Department of Education, Denver, Co, USA
Dodge, Neil	Research Associate, Wayne State University, Detroit, MI, USA
Drafton, Kaitlyn	Clinical Psychology Postdoctoral Fellow, Seattle Children's Hospital, Seattle, Washington, USA
Dubosky, Dan	Social Work, Philadelphia, PA, USA
Eller, Tami	Lead Behavioral Health Training Coordinator, UAA Center for Human Development, Family Services Training Center, Anchorage, AK, USA. Licensed Professional Counselor, University of Alaska Anchorage, Anchorage, AK, USA. Clinician, Alaska Impact Alliance, Fairbanks, Alaska, USA
Elligson, Melissa	Program Director and Counselor, FASCETS Center For Neurodiversity, Albany, OR, USA
Elliott, Elizabeth	Paediatrician, University of Sydney and Children’s Hospital Westmead, Sydney, NSW, Australia. The University of Sydney, Sydney, NSW, Australia
Emery, Suzanne	Program Director, Family Nurse Practitioner, FASCETS Center For Neurodiversity, Albany, OR, USA
Esralew, Lucy	Clinical Neuropsychologist, Department of Developmental Services, Sacramento, CA, USA
Farrow-Lawrence, Courtney	Founder, FASD Institute, Vancouver, BC, Canada
Felicicchia, Riley	Clinical Psychology Graduate Student, San Diego State University, San Diego, CA, USA
Flake, Eric	Clinical Researcher, USUHS, Dupont, WA, USA
Geddes, Angela	Social Worker, Geddes Specialized Supports and Integrative Wellness, St. Thomas, ON, Canada
Gelo, Julie	WA, USA
Gharehptian, Stephani	Assistant Professor and Clinician, Violence Intervention Program, Los Angeles, CA, USA
Gludt, Kendra	Director of National Programs, Proof Alliance, St. Paul, MN, USA
Golding, Michael	Professor, Texas A&M University, College Station, Texas, USA
Goodman, Erin	Licensed Clinical Social Worker, The Papillion Center, Paducah, KY, USA

Hamilton-Smith, Kaye	Family Member/Caregiver, Toronto, ON, Canada
Hargrove, Emily	Advocate, ALC FASD Changemakers, Paducah, KY, USA
Harris, Michael	MA, LP, Licensed Psychologist, FASD Elephant, Minneapolis, MN, USA
Hartness, Carolyn	Consultant, Seventh Generation, Indianola, WA, USA
Hashimoto-Torii, Kazue	Co-founder/CEO, Thyntra Therapeutics, Brookeville, Maryland, USA
Hemingway, Susan (Astley)	Professor of Epidemiology/Pediatrics, University of Washington, Institute on Human Development & Disability, Seattle, Washington, USA
Hilly, Catherine	Occupational Therapy Lecturer and PhD Candidate, Australian Catholic University, Watson, ACT, Australia
Hudnall, Monica	Speech Language Pathologist, Department of Developmental Services, Sacramento, CA, USA
Iacobacci, Shannon	Non-Attorney Educational Advocate, Embracing the Brain, La Verne, CA, USA
Ibrahim, Marwa	Master’s Student, York University, Toronto, Ontario, Canada
Ipsiroglu, Osman I	Clinical Associate Professor, University of British Columbia, Vancouver Sleep Medicine, Dept. of Pediatrics, Faculty of Medicine, University of British Columbia Investigator, Sleep/Wake-Behaviours Research Lab, BC Children's Hospital Research Institute Lecturer/Associate Professor, Medical University of Vienna Fellow, Sleep/Wake-Research Institute, Vienna
Jirikowic, Tracy	Researcher – Occupational Therapy, University of Washington, Seattle, WA, USA
Jolly, Ryan	Psychiatric Mental Health Nurse Practitioner and DNP, CEO and C Brain First Family Center, Lenexa, KS, USA
Kable, Julie	Researcher/Clinician, Emory University School of Medicine, Atlanta, Georgia, USA
Kelsh, Stacey	Provincial Program Lead and Educator, Provincial Outreach Program Fetal Alcohol Spectrum Disorder, Prince George, BC, Canada
Kittrell, Reuben	FASD Services Coordinator, Institute for Health and Recovery, Watertown, Massachusetts, USA
Klintsova, Anna	Professor, Department of Psychological and Brain Sciences, University of Delaware, Newark, DE, USA

Kover, Sara	Professor, University of Washington, Seattle, WA, USA
Kuerschner, Suzie	Consultant, S.P.I.R.I.T.S., Rhodedendron, OR, USA
Kunath, Kathleen	Social Worker, FASD-Center, Berlin, Berlin, Germany
Law, Julie	Developmental-Behavioral Pediatrics, UC Davis Health MIND Institute, Sacramento, CA, USA
Lawrence, Fatima Natascha	Clinical Director and Counsellor, FASD Institute, Vancouver, BC, Canada
Lee, Hyuna	Associate Professor, Biola University, La Mirada, CA, USA
Legg, Joshua	Mental Health Coach & Pastoral Care, Papillion Center for FASD, Gallatin, Tennessee, USA
Lesic, Ursula	Parent/Fearless Advocate/Status Quo Disruptor, Pittsburgh, PA, USA
Lewis, Brandon	AUCD Project Manager, Association of University Centers on Disabilities, Silver Spring, MD, USA
Linsenbardt, David	Assistant Professor, University of New Mexico, Albuquerque, NM, USA
Lipman, Catherine	Developmental Pediatrician, Cleveland Clinic Children's Hospital, Cleveland, OH, USA
Loock, Christine	Social Pediatrics, UBC, Vancouver, BC, Canada
Lundy, Alex	Hope Rising Clinic, Bothell, WA, USA
Lutke, CJ	Self-Advocate, ALC FASD Changemakers, Maple Ridge, BC, Canada
Ma, Yao-Ying	Neuroscientist, Indiana University School of Medicine, Indianapolis, IN, USA
Mahnke, Amanda	Researcher, Texas A&M University, Bryan, Texas, USA
Manley, Emma Esteve	University of Washington, Seattle, WA, USA
Mattson, Sarah	Neuropsychologist, Center for Behavioral Teratology and Department of Psychology, San Diego, California, USA
May, Maggie	ALC FASD Changemakers, County Clare, Munster, Ireland
McMillan, Jenelle	Cultural Educator, Wolf Song Healing Farm, Papsilqua IR2, BC, Canada
Meinhardt, Kathryn	Dream Acres, Topeka, KS, USA

Miranda-Sohrabji, Darius	Texas A&M University Naresh K. Vashisht College of Medicine, Bryan, TX, USA
Mitchell, Emalise	Graduate Student, University of Washington, Seattle, WA, USA
Moehlig, Kathie	Advocate and Caregiver, San Diego, CA, USA
Moehlig, Sam	San Diego, CA, USA
Moore, Caroline	Undergraduate Researcher, Biola University, La Mirada, CA, USA
Myers, Julianne	Clinical Psychologist and Clinical Psychology Postdoctoral Fellow, University of Rochester, Departments of Psychology and Pediatrics, Mt. Hope Family Center, Rochester, NY, USA
Myrick, Abbey	Researcher, University of New Mexico, Albuquerque, NM, USA
Nolla Hernández, Esteban	Fundación de Investigaciones Sociales, A.C.I, Mexico, Mexico City, Mexico
Novick Brown, Natalie	Forensic & Clinical Psychologist, University of Washington, Seattle, WA, USA
Nussbaum, Olga "Alex"	Dream Acres, Topeka, KS, USA
O'Connell, Robert	Training & Research Coordinator, FASD Ireland, Ennis, Clare, Ireland
O'Halloran, Aine	FASD Hub Coordinator, FASD Ireland, Ennis, Clare, Ireland
Olivier, Leana	FASD Specialist, Foundation for Alcohol Related Research, Cape Town, South AfricaOK that's perfect
Olson, Erin	Researcher/Manager, University of Washington, Seattle, WA, USA
Ormstrup, Danna	Executive Director, Foorhills Fetal Alcohol Society, Foothills Fetal Alcohol Society, High River, Alberta, Canada
Ostermann, Javan	Undergraduate Researcher, Biola University, La Mirada, CA, USA
Pandey, Tia	Graduate Student, Department of Public Health, School of Public Health, Texas A&M University,, College Station, Texas, USA
Pang, Priscilla	The George Washington University, Washington, DC, USA
Perea Caballero, Aranza Lilian	Fundación de Investigaciones Sociales, A.C.I, Mexico, Mexico City, Mexico
Perez, Alexandra	Psychologist, Emory University School of Medicine, Atlanta, GA, USA
Perovsek, Lauren	Clinical Psychology Graduate Student, Seattle Pacific University, Seattle, Washington, USA

Petrenko, Christie L.M.	Research Associate Professor, University of Rochester, Departments of Psychology and Pediatrics, Mt. Hope Family Center, Rochester, NY, USA
Pierce-Bulger, Marilyn	Clinician, Consultant and Captain US Public Health Service-Ret, Anchorage, Alaska, USA
Pruner, Misty	Occupational Therapist, University of Washington, Seattle, WA, USA
Riches, Julia	The Matilda Centre for Research in Mental Health and Substance Use, the University of Sydney, Sydney, NSW, Australia
Roach, Taniyah	Seattle Pacific University, Seattle, Washington, USA
Ross, Yolanda	LMSW, LCD, TX, USA
Rouzer, Siara	Research Scientist, Department of Neuroscience & Experimental Therapeutics Naresh K. Vashisht College of Medicine, Texas A&M University, College Station, TX, USA
Roy-Doray, Berenice	Medical Practioner, Laboratory CEPOI University of Reunion Island, Saint-Pierre, Reunion Island, France
Rutherford, Jessica	Research Fellow, University of Salford, Salford, England, United Kingdom
Schalk, Mary	FASD Program Coordinator, Alpena, Michigan, USA
Schumaker, Gina	Self-Advocate and Board Member, Alaska Center for FASD, Anchorage, AK, USA
Senturias, Yasmin	Developmental-Behavioral Pediatrician, Atrium Health-Levine Children's, Charlotte, NC, USA
Shah, Prachi	Developmental Behavioral Pediatrician, American Academy of Pediatrics, Itasca, IL, USA
Shulman, Rosemary	Education Navigation/Intake Coordinator, The Florida Center for Early Childhood FASD Clinic (Diagnostics), Sarasota, FL, USA
Sing, Rachel	Advocate and Caregiver, Berkeley, California, USA
Smith, Cindy	Judge, Suquamish Tribal Court, Suquamish, WA, USA
Soja, Jacqueline	Doctoral Student, Center for Behavioral Teratology, San Diego State University, San Diego, CA, USA
Sparrow, Joanne	Psychologist and Clinician, FASD Focus NW, Seattle, WA, USA. Seattle Children's Research Institute, Seattle, WA, USA

Speybroeck, Emily	Clinical Psychology Doctoral Student, University of Rochester, Department of Psychology, Mt. Hope Family Center, Rochester, NY, USA
Spiller, Vanessa	Clinical Psychologist, JumpStart Psychology, FASD Training Australia, Brisbane, QLD, Australia
Steele, Domenica	Illuminate Colorado, Denver, Colorado, USA
Steele, Karen	Attorney, Karen A Steele, Esq., Salem, OR, USA
Stockwell, Ephraim	Therapist, Community County Services, DuBois, Pennsylvania, USA
Stoner, Susan	Researcher, University of Washington, Seattle, WA, USA
Tapparello, Cristiano	University of Rochester, Rochester, NY, USA
Thorne, John	Associate Teaching Professor, University of Washington, Seattle, WA, USA
Trancik, Anika	Psychologist, The Florida Center Training Institute, Sarasota, FL, USA
Troutt, Chris	Marriage & Family Therapist, Papillion Center for FASD, Gallatin, Tennessee, USA
Tsuda-Nguyen, Keilana	Undergraduate Researcher, Biola University, La Mirada, CA, USA
Turner, Haylee	Pediatrician, LA General Medical Center, Department of Pediatrics, Los Angeles, CA, USA
Upreti, Deepa	Department of Neuroscience and Experimental Therapeutics, Texas A&M University, Naresh K. Vashisht School of Medicine, Bryan, Texas, USA
Veziris, Christina	SDSU/UCSD, San Diego, CA, USA
Walker-Bauer, Michele	Clinical Psychologist, Violence Intervention Program, Los Angeles, CA, USA
Webster, Anna	Coaching Psychologist, Neurowise Coaching and Training, Manchester, Greater Manchester, United Kingdom. University of Salford, Salford, North West England, United Kingdom
Weeks, Olivia	Boston Children's Hospital, Boston, MA, USA
White, Kathy	Certified Facilitator of the FASCETS Neurobehavioral Model Archdiocese of Kansas City; Foster Ministry Coordinator of the Archdiocese of Kansas City, Kansas City, Kansas, USA
Whitney, Nancy	Psychiatric Evaluation Specialist, Seattle-King County Public Health, Seattle, WA, USA

Wilaisakditipakorn, Tanaporn Jasmine	Developmental and Behavioral Pediatrician Department of Pediatrics, UC Davis MIND Institute, Sacramento, CA, USA
Wilhelm, Alison	Research Scientist, University of Washington, Seattle, WA, USA
Wisdahl, Jennifer	Advocate, FASD United, Seattle, WA, USA
Young, Carl	Author and Advocate, Embracing Neurodiversity LLC, Blaine, MN, USA
Yue, Janis	Assistant Professor and Clinician, Violence Intervention Program, Los Angeles, CA, USA

PLENARY

Through the Looking Glass, and What Individuals with FASD Found There: Experiences and Choices in Parenting

Emily Travis Hargrove, CJ Lutke, Maggie May, Gina Schumaker, Carl Young

BREAKOUT SESSION A

A1i: Identifying the Brain Areas and Neural Circuits Regulating Learning Memory in a Mouse Model of FASD

David Linsenbardt

Exposure to alcohol during development has an impact on brain function that can lead to lifelong alterations in learning and memory. For this reason, one of our goals as neuroscientists is to discover where brain function has been altered, so that we can target those areas to improve memory in those with FASD. Because to date the field has only a limited understanding of which brain areas are impacted by developmental alcohol exposure, we conducted an exploratory experiment in a mouse model of FASD (and non-alcohol-exposed controls) to permanently label all neurons in the brain participating in the same memory. We then captured images of these neurons with a high-powered microscope and evaluated them using a variety of computational tools. First, we found that alcohol-treated mice displayed a less robust memory compared to control subjects. We then found that while alcohol exposure led to increases in activity of the CA1 and CA3 regions of the hippocampus, it also led to decreases in activity of nuclei located in the anterior portion of the thalamus. However, when we evaluated the entire brain as a functional network, we also discovered broad hyperconnectivity between all 120 regions in alcohol-exposed subjects. Thus, in addition to finding key brain areas impacted by alcohol, we also uncovered evidence of broad network inefficiency that may serve as treatment targets for FASD.

A1ii: Discovery and Characterization of Epileptiform Discharges in Essential Memory Circuits in a Mouse Model of FASD

Abbey Myrick

Memory differences are a commonly cited difficulty for individuals living with FASD, though the causes are poorly understood. The current study investigated changes to the hippocampal-retrosplenial cortex circuit - two regions essential to learning and memory known to be impacted by prenatal alcohol exposure. We were specifically interested in high frequency oscillations (HFO), which are thought to support the transfer of newly formed memories to the cortex for long-term storage.

Using a mouse model of FASD and surgically implanted neural electrodes, we quickly discovered epileptiform discharges (EDs) within both regions. These large amplitude, pathological events are observed in epilepsy, as well as in Alzheimer's and Parkinson's disease patients. Importantly, our mice do not exhibit outward signs of seizure activity. Because previous work has shown that EDs negatively impact memory, we investigated the hypothesis that they do so by altering the HFOs critical for memory.

We discovered that epileptiform discharges occur most frequently during Non-Rapid Eye Movement (NREM), an important state for memory consolidation. We next discovered that EDs were often immediately followed (20-100 milliseconds) by HFOs. Unlike HFOs occurring outside this timeframe, these 'Rapid HFOs' have higher power, frequency, duration and amplitude the closer to an ED they appear. Compared to other HFOs, Rapid HFOs are generally larger in all these metrics.

The findings presented here collectively suggest that developmental alcohol exposure may lead to changes in neural development that culminate in high rates of epileptiform discharges within centers of the brain and during times critically important for memory consolidation. We are currently working towards developing a better mechanistic understanding of these alcohol exposure-induced EDs, including identifying where they originate within the brain, and which molecular systems drive them. These findings point to a potential mechanistic basis for FASD-related memory differences which represents a potentially promising target for improving memory in FASD.

BREAKOUT SESSION A

A1iii: Prenatal Alcohol Exposure Disrupts Synapse Maturation and Heightens Vulnerability to Substance Use Through Accumbens Circuit Mechanisms

Yao-Ying Ma

A1iv: New Imaging Approach to Evaluate the Effects of Developmental Alcohol Exposure on Brain Grey and White Matter Intervention Outcomes

Anna Klintsova

Background/Objectives: The teratogenic alcohol impact on growth and neurodevelopment is extensive, resulting in Fetal Alcohol Spectrum Disorders (FASD), which have lasting consequences on behavior. Recent advances in neuroimaging and biomechanics suggest that the mechanical properties of the brain, such as tissue resistance to deformation (known as stiffness and damping ratio), may provide new insights into neurodevelopmental disorders, yet this approach has not been extensively applied to FASD. Magnetic resonance elastography (MRE) is an imaging modality for measuring the mechanical properties of brain tissue *in vivo*, which sensitively reflect microstructural tissue composition and organization. Structural brain changes underlying FASD behavioral and functional abnormalities include cell loss, connectivity impairment, reduced myelination, and aberrant extracellular matrix (ECM).

Methods: In a series of studies using a rat model of FASD (third trimester-equivalent alcohol exposure (AE), postnatal days 4-9), we first tested the hypothesis that teratogenic AE dramatically increases cell death in vulnerable brain regions, resulting in reduced populations of neuron- and oligodendrocyte precursor cells and mature neurons and oligodendrocytes. We followed with the MRE to show that brain mechanical properties are reduced due to AE during the third trimester equivalent in the rat brain. Finally, we evaluated the expression of the perineuronal nets (PNNs), a component of the ECM, in the cortical regions, cerebellum and in the thalamic reticular nucleus, using immunocytochemistry and densitometry. To measure WFA staining as a proxy for PNN density in the cortex, the average integrated density of staining was quantified using ImageJ (NIH).

Results: Our study demonstrated that the number of mature oligodendrocytes and the production of myelin basic protein were reduced in the female corpus callosum following AE in a rat model of FASD. Moreover, dysregulated oligodendrocyte number and myelin basic protein production were observed in the male and female AE brain in adolescence. AE reduced forebrain stiffness in standard-housed adolescent rats as measured by MRE. Forebrain damping ratio was lowest in AE rats in adolescence ($p < 0.01$). In adulthood, AE and sham-intubated (SI) rats exhibited comparable forebrain stiffness and damping ratio ($p > 0.05$). We discovered that the density of cortical PNNs was reduced in adolescent AE rats compared to SI controls ($p < 0.05$), suggesting that the maturation of PNNs is disrupted by AE during the brain growth spurt. In a similar study, cerebellar tissue was collected from AE and SI rats in juvenility on PD 15 to investigate PNN formation. Preliminary qualitative comparison of WFA^+ staining in AE and SI tissue samples indicated that PNN density is significantly lower in AE rats, supporting frontal cortex and cerebellum as critical regions for further investigation.

Conclusions: MRE successfully captured alcohol-related changes to forebrain stiffness and damping ratio.

A1v: Comparing Stressor and Resource Domains Across Prenatal Alcohol Exposure Groups: Implications for Intervention

Alexandra Perez

Background/Objectives:

Prenatal alcohol exposure (PAE) is associated with adverse psychosocial outcomes, particularly in individuals diagnosed with Fetal Alcohol Syndrome (FAS). These individuals often face increased life stressors and diminished social resources, which can affect physical and mental health. The aim of this presentation is to compare stressor and resource profiles across three groups: non-PAE controls, PAE, and PAE Dysmorphic, using the Life Stressors and Social Resources Inventory (LISRES).

Methods:

Participants were categorized into three groups: non-PAE controls, PAE, and PAE Dysmorphic. The LISRES was administered to examine life stressors, social resources and their relationship to each other and to aspects of individual health and well-being. A one-way ANOVA was conducted to examine group differences, followed by post-hoc comparisons to identify specific contrasts.

Results:

ANOVA results indicated significant differences among groups in negative life events, home/neighborhood conditions, family stressors, family resources, and friend resources. Post-hoc analyses revealed that the PAE Dysmorphic group reported the highest levels of negative life events and family stressors and the lowest levels of family and friend resources. The PAE group demonstrated intermediate scores, while the non-PAE control group reported the least stressors and greatest resources.

Discussion/conclusion:

Findings highlight the compounded psychosocial burden experienced by individuals with FAS, characterized by elevated stressors and diminished social support. These disparities underscore the need for targeted interventions that strengthen family and peer support networks and address social and environmental challenges. Enhancing social resources may mitigate the adverse effects of life stressors in this vulnerable population.

A2i: The Neurowise Model – Integrating Research, Therapeutic Coaching, and Lived Experience in a Brain-Based, Dual Track Approach to Supporting FASD Caregivers, Practitioners, and Young People

Anna Webster

Background

Testing of SPECIFiC, a psychoeducation programme for caregivers of children and adolescents with FASD demonstrated a significant effect size in parenting self-efficacy. Co-author and facilitator Anna Webster co-led this programme at The University of Salford and has also conducted research into the wellbeing needs of FASD caregivers. This research revealed that caregivers often struggle to recognise or prioritise their own needs, and frequently experience stigma, blame, and shame when therapeutic parenting and attachment-based approaches prove ineffective. These findings, combined with Anna's therapeutic practice and lived experience as the mother of an adolescent with FASD, led to the development of the Neurowise model—an integrative, psychoeducation and therapeutic coaching approach for FASD care. This vital intervention is one of only a handful of similar programmes for FASD caregivers globally.

Methods

The Neurowise intervention for FASD caregivers is a six-week programme combining group workshops with 1:1 coaching at the start, midpoint, and end. Progressed in partnership with Clinical Psychologist Rachel Beckford, with lived experience of FASD caregiving, the programme builds skills and understanding of FASD's spiky profile, sensory and emotion regulation, executive functioning, attachment and relationships and advocacy. Building on trauma and attachment frameworks, Neurowise introduces an integrative, brain-based model that reframes pre-birth factors and brain differences as key to understanding attachment, relationships, and emotional needs. The dual-track design supports the biopsychosocial needs and wellbeing of both caregivers, practitioners and those they support. Integrating Self Determination Theory, Neuroscience, Acceptance and Commitment Therapy, and Cognitive Analytic Therapy, Neurowise builds caregiver's and practitioner's understanding and skills in specific areas where children and adolescents with FASD often struggle. These areas include expressing and meeting needs, connection with self and others, emotion regulation, awareness and easing of patterns of defence, distress and uncertainty tolerance and mindful self compassion. This creates a positive ripple effect – children and adolescents benefit from a more co-regulated and co-integrated environment and from the understanding and skills that adults can pass down in accessible, practical ways.

Results

Evaluation of the pilot indicates strong outcomes, including:
Increased understanding of the brain-based connectivity disorder and spiky profile of FASD.
Reduced stigma, shame, and isolation through peer connection and validation.
Greater caregiver wellbeing, confidence, empowerment and advocacy.

As one participant reflected:
"This programme is the best I've attended since adopting. It's the only programme with space for me to be and feel, and that considers adopters as THE MOST important people for our children and young people."

Conclusions
The Neurowise model represents an innovative and novel intervention that integrates research, therapeutic coaching practice, and lived experience. It has the potential to spark research collaboration with similar global interventions that will enhance support for the emotional and practical needs of individuals living with FASD and their families. The reduction of stigma, shame and isolation through the integration and reframing of trauma and attachment approaches for FASD offers a new paradigm for therapeutic care for FASD. This has the potential to make a transformational difference to the lives of those with FASD and their families.

A2ii: Caregiver Contributions to Development and Trial Implementation of a Relationship-Based Early Intervention for Young Children With or at Risk for FASD: Families Moving Forward Bridges

Tracy Jirikowic, Misty Pruner, Heather Carmichael-Olson

The Families Moving Forward (FMF) Bridges model, is a relationship-based, parent-child intervention for families raising children with PAE birth to 3 years of age. We describe the development of the FMF Bridges early intervention model around the six steps for development of quality interventions based on the 6SQuID framework (Wight et al., 2015) Caregiver input has contributed to each iterative step, guiding decisions related to curriculum development and the design of usable program materials. An overview of caregiver contributions at the first 5 stages of intervention development will be described. Steps 1-4 will be outlined based on: 1) a summary of outcomes from caregiver focus groups that revealed caregiver priorities and needs such as “care for the caregiver, support for transitions, and resources to meet basic needs;" 2) a description of caregiver engagement during intervention development phases; and 3) selected caregiver-focused modules that were created for the FMF Bridges intervention resulting from this formative input. Emphasis will then be placed on Step 5 through the presentation of process data from caregiver experiences with the intervention in a small community feasibility trial. Caregiver input has been fundamental to shaping the FMF Bridges model, intervention aims, logic model, curriculum, as well as intervention delivery. Feasibility outcomes will be critical and valuable for refinement of the FMF Bridges intervention and piloting the intervention in the community on a larger scale.

BREAKOUT SESSION A

A2iii: Utilizing the Behavior Dysregulation Program with Children and Adolescents Affected by FASD

Chris Troutt, Joshua Legg

This presentation is designed to help both the professional and families identify supports and create a system of felt safety for vulnerable children including those prenatally exposed to alcohol and drugs. It offers a basic outline that can be followed by therapists or other professionals. The program has shown statistical significance in reducing anxiety and depression in the children and reducing parental stress, while increasing parental resilience.

BREAKOUT SESSION A

A2iv: “Perseveration: ‘Danger Zone Cycles’” Family Interventions & Epigenetic Insights

Carl Young

Perseveration—characterized by repetitive thoughts, verbal loops, or actions with impaired set-shifting—is a common and high-risk challenge for individuals with Fetal Alcohol Spectrum Disorder (FASD). In everyday contexts, it may present as repeated questioning, fixation on a topic, or an inability to move on from a thought or concern. These behaviors are frequently misunderstood as defiance, anxiety, or poor coping. However, perseveration is best understood as a brain-based difficulty with cognitive flexibility, particularly when multiple neurodevelopmental domains are impacted.

This presentation draws from Chapter 10 of Embracing Hope and introduces perseveration as a “danger zone” in FASD—one that can amplify conflict, compromise safety, and disrupt daily functioning when supports are mismatched. Through a case illustration, participants will explore how perseveration unfolds in real-world settings. For example, a student given a routine assignment may become cognitively “stuck,” experiencing escalating worry, sleep disruption, repeated questioning, and eventual emotional dysregulation. Such patterns are not driven by willful behavior but reflect underlying neurocognitive challenges.

Perseveration is defined as the persistent repetition of thoughts, words, or actions beyond their appropriate context, associated with impaired cognitive flexibility. In individuals with FASD, this phenomenon reflects the interaction of several brain domains. Executive function contributes to difficulties with inhibition and shifting. Attention systems impact the ability to disengage and redirect focus. Affect regulation influences emotional responses during transitions, often intensifying the loop. Memory systems may reinforce perseveration by retrieving familiar patterns, even when they are no longer adaptive.

At the neurological level, perseveration involves disruptions in systems responsible for error detection, working memory, and habit formation. Once initiated, perseverative loops tend to strengthen through repetition, making them increasingly resistant to change. As a result, traditional approaches such as repeated explanations, reasoning, or behavioral correction are often ineffective and may escalate distress.

This session emphasizes a domain-informed framework that shifts the guiding question from “Why won’t they stop?” to “Which domain needs support right now?” This reframing supports more targeted, compassionate, and effective interventions.

Participants will be introduced to three practical, domain-informed strategies designed to interrupt perseveration and support regulation in adolescent and adult contexts. First, visual externalization reduces cognitive load by moving information from working memory into the environment through tools such as written schedules, checklists, and visual cues. Second, proactive routines leverage predictability to reduce uncertainty, incorporating consistent responses, scripted reassurance, and gradual transitions. Third, regulated transitions prioritize nervous system regulation through sensory supports, movement, and co-regulation before attempting redirection or task shifting.

In addition to these strategies, the presentation will address common pitfalls, including over-reliance on verbal reasoning and repeated explanations, which may inadvertently reinforce perseverative loops. Instead, participants will learn how to align supports with the individual's current neurocognitive capacity.

By the end of this session, participants will be able to define perseveration within the context of FASD, map it to affected brain domains, and apply at least three domain-informed strategies—visual externalization, proactive routines, and regulated transitions—to de-escalate perseveration in real-world settings.

Ultimately, this presentation highlights that perseveration is not a behavioral choice but a neurodevelopmental response. With appropriate, domain-aligned supports, caregivers and professionals can effectively interrupt these loops, reduce escalation, and promote more adaptive functioning across home, school, and community environments.

A2v: An Educational Intervention to Improve Healthcare Professionals’ Knowledge, Beliefs and Attitudes about FASD

Julie Law

Background:
FASD affects 1-5% of school-aged children in the United States, yet > 80% are undiagnosed. Lack of knowledge and stigma about FASD among healthcare professionals (HCPs) are important factors contributing to missed or delayed diagnosis. No prior studies have explored how HCPs’ knowledge, attitudes, and beliefs about FASD directly impact the experiences of Californians with FASD. Since timely FASD diagnosis is critical, this is an important area of research. The study aims were to explore the lived experiences of Californians with FASD to 1) identify HCP strategies to improve the healthcare of patients with FASD, and 2) develop a brief educational intervention to improve HCPs’ knowledge, attitudes, and beliefs about FASD.

Methods:
An initial qualitative study was conducted using interviews and focus groups with 14 Californian teens and adults with FASD and 15 caregivers. Findings were used to develop a 60-minute educational intervention for HCPs who work directly with pediatric and adult patients in primary and specialty care. Qualtrics pre- and post-surveys measured changes in knowledge, attitudes, and beliefs about FASD immediately before and after the intervention. Data was analysed to determine the intervention’s effectiveness using paired sample T-tests and the McNemar test.

Results:
The central qualitative theme was the importance of FASD diagnosis and awareness to strengthen family relationships and partnerships with HCPs and improve personal and health outcomes for individuals with FASD. Successful HCP strategies included compassionate curiosity (empathy combined with willingness to learn), involving caregivers, adapting to patient needs, and providing an FASD-informed medical home. 41 HCPs participated in the educational intervention including Pediatric and Internal Medicine residents and practicing physicians, Developmental-Behavioral Pediatrics fellows, psychologists, social workers, and other HCPs. Knowledge about FASD significantly improved from 29% to 69%, while attitudes and beliefs about FASD were unexpectedly positive and did not change significantly. All participants agreed that their knowledge and understanding of FASD improved, and 97% considered changing their practice to improve screening for prenatal alcohol exposure and FASD.

Conclusions:
HCP knowledge, attitudes, and beliefs about FASD significantly impact Californians with FASD. Successful HCP strategies to improve the healthcare of patients with FASD include

compassionate curiosity, involving caregivers, adapting to patient needs, and providing an FASD-informed medical home. A brief educational intervention is an effective way to improve knowledge about FASD among HCPs. Further research is needed to determine how HCP knowledge about FASD and practice change can be sustained over time.

BREAKOUT SESSION A

A3 - From Science to System: Updating the FASD Model Forensic Assessment Protocol for Justice, Clarity, and Change

Natalie Novick Brown, Richard Adler, Paul Connor, Karen Steele

"From Science to System: Updating the FASD Model Forensic Assessment Protocol for Justice, Clarity, and Change" is a 90-minute panel presentation bringing together Dr. Natalie Novick Brown, Dr. Richard Adler, and Dr. Paul Connor — the principal contributors to the 2026, peer-reviewed, recently published "An Updated Fetal Alcohol Spectrum Disorder Assessment Protocol for the Forensic Context." Moderated by attorney Karen Steele, the panel brings to life the updated protocol, which builds on over fifteen years of accumulated practice-based evidence and scientific advancement to provide a refined, interdisciplinary framework for evaluating individuals with Fetal Alcohol Spectrum Disorder (FASD) in forensic settings. Grounded in a multidisciplinary team (MDT) approach and driven by continuous quality improvement (CQI), the protocol integrates developmental psychology, neuropsychology, and forensic psychiatry, into a coherent, evidence-informed model. It also provides a tiered MDT approach for use in lesser forensic contexts or where resources are constrained. The panel will explore the evolution of best practices and their implications for justice-involved individuals with FASD, their families, and the broader FASD community.

The developmental perspective anchors the updated protocol in a biopsychosocial lifespan framework that connects early neurodevelopmental injury to later functional manifestations in thinking, behavior, and adaptive skills. The developmental psychologist's role remains pivotal throughout the assessment process. Using a whole cloth approach — meaning all findings across disciplines are integrated rather than considered in isolation — the developmental psychologist establishes consistency across the data and identifies the nexus between FASD-related impairments and the specific behavior at issue in forensic proceedings. Central to this role is the application of Forward-Thinking Intervention (FTI), a framework that connects diagnostic clarity with practical, individualized strategies oriented toward short- and long-term stabilization and the reduction of problematic behavior. Rather than treating the forensic evaluation as an endpoint, FTI positions the assessment as a foundation for meaningful intervention — bringing the legal team, including the client, onto the same page regarding the nature of the impairment and the realistic pathways available for support and change.

The medical component of the updated protocol emphasizes diagnostic clarity grounded in both traditional clinical assessment and carefully selected neuroimaging techniques. While the forensic context is rarely clearcut and evaluees may have experienced a variety of potentially harmful prenatal exposures, the updated medical lens provides greater clarity around foundational issues such as diagnostic methodology, testing procedures, differential diagnosis, and the anticipation of challenges that may arise in courtroom settings. FTI has special application in the hands of the forensic psychiatrist, with diagnosis representing a significant step in offering the beginning of an antidote to claims of future dangerousness and hopelessness. Also significant since the original protocol was published, emerging technologies offer powerful new tools for visualizing brain structure and function in individuals with FASD. Quantitative electroencephalography (qEEG) — computer-based analysis of the brain's electrical activity — is highlighted for its accuracy across multiple levels of analysis and its ability to generate compelling, court-accessible graphics. Of particular relevance to forensic proceedings is qEEG's capacity to illuminate the Frontal-Limbic Network and its relationship to cognitive and behavioral regulation, helping courts understand the brain-based underpinnings of the conduct at issue. Volumetric MRI quantification and Diffusion Tensor Imaging (DTI) are also acknowledged as valuable additions to the assessment toolkit. Rather than prescribing a fixed neuroimaging battery, the protocol reinforces professional judgment as the cornerstone of admissibility and explanatory coherence: the medical expert determines which data and visual representations have the greatest explanatory power for the specific case at hand. The presentation will candidly address the tension between the rapid advancement of neuroimaging science and the more cautious pace of evidentiary admissibility in courts, equipping practitioners to navigate that landscape thoughtfully. When applied with care and judgment, these medical diagnostic methods contribute to convergent validity — making the accuracy, reliability, and forensic relevance of the FASD diagnosis clear and defensible.

The neuropsychological evaluation component of the updated protocol has been substantially refined, and the presentation will make the case that — contrary to a widespread misperception — FASD does in fact present a distinctive functional "footprint" identifiable through rigorous neuropsychological assessment. The updated protocol expands the recommended domains of evaluation from nine to eleven empirically supported areas, adding visuospatial construction skills, processing speed, and direct assessment of adaptive functioning. This expansion reflects growing evidence about the specific cognitive profile associated with prenatal alcohol exposure and strengthens the diagnostic validity of the evaluation as a whole. The functional footprint of FASD manifests in several characteristic patterns. These include cognitive variability — test performance that fluctuates across tasks in ways inconsistent with a simple global impairment model — as well as learning disability-type patterns and a marked disconnect between IQ scores and adaptive functioning scores. This last feature is particularly significant in forensic contexts: an individual whose measured intellectual abilities appear relatively intact may nonetheless be profoundly impaired in their capacity to function independently, regulate behavior, and make sound decisions in real-world conditions. Courts and juries accustomed to equating IQ with general competence can misread this profile without careful expert guidance. The footprint also includes characteristic impairments in visuospatial perception and a pattern of declining performance as tasks become less structured and more abstract — reflecting the degree to which individuals with FASD rely on external scaffolding and concrete cues to compensate for executive functioning deficits. When that structure is removed, performance deteriorates in predictable and diagnostically meaningful ways. Two key procedural updates to the neuropsychological evaluation will also be discussed. Self-report measures are excluded from the battery, given that individuals with FASD frequently have limited insight into the nature and extent of their own deficits. Additionally, performance validity testing (PVT) is now distributed throughout the evaluation day rather than administered at a single point, ensuring that the evaluee's effort can be monitored across the full assessment — a methodological safeguard that strengthens the defensibility of findings in adversarial legal settings.

All panelists, with the assistance of the moderator, will address how the updated protocol's science and methodology translates into practical application for legal counsel and evaluators. The central message is that consistent adherence to the updated protocol not only enables but actively equips legal teams to anticipate and meet foreseeable challenges in FASD litigation. Those challenges include evidentiary admissibility questions surrounding neuroimaging and other visual materials; misunderstandings about future risk and dangerousness; and mischaracterizations of volition or culpability. The protocol's whole cloth methodology — rejecting fragmented or siloed interpretations of evidence in favor of an integrated neurodevelopmental narrative — empowers legal professionals to represent clients with integrity, accuracy, and compassion. By incorporating FTI into the legal strategy, the protocol helps demonstrate that diagnosis can be connected to concrete intervention, countering claims of intractable future risk and supporting outcomes that serve both the individual and the public interest.

Beyond its immediate forensic applications, the updated protocol carries meaningful implications for the broader FASD community. For researchers, it underscores emerging areas warranting further study — including validation of the expanded neuropsychological domains, recognition of FASD's functional footprint, the functional significance of the Frontal-Limbic Network, and the real-world impacts of FASD at the intersection of neurodevelopment and forensic involvement. For clinicians and forensic evaluators, the protocol's whole cloth methodology and emphasis on FTI provide structure that is both scientifically grounded and operationally practical, reducing fragmentation in assessments and strengthening opportunities for cross-sector collaboration. Because the protocol is structured around CQI, it is designed to evolve alongside advances in FASD science rather than becoming static. At a systemic level, the protocol's clarity and consistency in assessment — and its insistence on situating behavior within the context of neurodevelopmental impairment rather than moral judgment — contribute meaningfully to efforts to reduce stigma across medical, legal, and community settings.

For individuals with FASD and their families, the implications of the updated protocol are equally significant. By reframing behavior through the lens of neurodevelopmental injury rather than moral failure or volitional misconduct, the protocol directly counters the stigma that families and individuals regularly confront — stigma that too often leads to misinterpretation, punitive responses, and unmet needs. The integrated narrative produced by the whole cloth approach helps judges, attorneys, service providers, and the individuals and families themselves rise above stereotypes and preexisting prejudices, fostering genuine appreciation of the challenges that arise from brain-based impairment. The protocol’s emphasis on FTI offers a roadmap toward stability and safety — connecting diagnostic clarity with practical, individualized strategies that support sustained improvement rather than episodic crisis management. In doing so, it helps families feel seen, equips them with tools for advocacy, and fosters system responses that prioritize support, dignity, and long-term well-being.

Taken together, the four perspectives presented in this panel — developmental, medical, neuropsychological, and legal — illustrate how rigorous interdisciplinary assessment can meaningfully improve the justice system’s capacity to respond to FASD. The updated protocol advances not only forensic practice but the broader research, clinical, and advocacy ecosystems that support people with FASD, their families, and the communities in which they live. It signals a framework that acknowledges FASD not as a label but as a lived reality — one that, when properly understood and addressed, leads to better outcomes for individuals, families, and society alike.

A4 - The Medicine Wheel Sleepy Bear Cards: A Holistic, Culturally-Grounded Sleep Screening Tool for Youth

Lori Vitale Cox, Christine Loock, Osman S. Ipsiroglu

Sleep is a foundational biological process that underpins learning, emotional regulation, physical health, behavior, and social participation across the lifespan. For adolescents and young adults with Fetal Alcohol Spectrum Disorder (FASD) and other neurodevelopmental conditions, sleep disturbances are not a secondary concern but a core feature shaping daily functioning, mental health, and long-term outcomes. Difficulties initiating and maintaining sleep, circadian rhythm disruption, parasomnias, excessive daytime sleepiness, and sleep-related breathing problems are common in this population and are often persistent across development. Yet despite the centrality of sleep to health and wellbeing, sleep problems among neurodiverse youth remain significantly underrecognized, underassessed, and undertreated.

One major reason for this gap lies in how sleep is typically assessed. Conventional pediatric sleep screening tools are most often administered by adults, rely heavily on caregiver report, and prioritize observable medical symptoms over lived experience. These tools may be effective in identifying specific sleep disorders, but they frequently fail to capture the broader ecological realities shaping young people’s sleep—particularly for those living with poverty, housing instability, intergenerational trauma, involvement in child welfare, racism, or community violence. When the youth’s own voice is absent from the assessment process, critical information about fear, safety, routine disruption, hunger, sensory overload, or emotional distress may never be articulated. As a result, sleep difficulties are often medicalized, misunderstood, or attributed solely to behavioral noncompliance, rather than recognized as meaningful signals of unmet needs.

The Medicine Wheel Sleepy Bear Cards were developed in response to these limitations, offering a culturally grounded, youth-friendly, and holistic approach to sleep screening and dialogue. The cards were designed to honor Indigenous knowledge systems while also aligning with evidence-informed pediatric sleep medicine. Rooted in the teachings of the Medicine Wheel, the tool integrates physical, emotional, mental, and spiritual dimensions of wellbeing, recognizing that sleep does not occur in isolation from the rest of a young person’s life. Instead, sleep is understood as a relational and contextual experience shaped by environment, culture, relationships, safety, and identity.

At the same time, the Sleepy Bear Cards incorporate the structure of the well-established BEARS pediatric sleep screening framework—Bedtime issues, Excessive daytime sleepiness, Awakenings, Regularity and duration of sleep, and Snoring. By embedding BEARS concepts within a visual, narrative-based, and culturally meaningful format, the cards translate a clinically validated screening approach into a form that is accessible to adolescents, including those with cognitive, communication, or executive functioning challenges. This integration ensures that the tool remains clinically useful while expanding its relevance and reach to Indigenous, neurodiverse, and marginalized youth.

Each card in the deck invites reflection on a specific aspect of sleep or sleep disruption. Rather than relying on abstract questioning, the cards use clear language, symbolic imagery, and gentle prompts that encourage storytelling. Youth are invited to select cards that resonate with their own experiences, whether independently or alongside a trusted adult. This element of choice is critical: it positions the young person as an active participant rather than a passive subject of assessment. The process becomes a conversation rather than an interrogation, fostering trust, engagement, and psychological safety.

Importantly, the Sleepy Bear Cards intentionally extend beyond traditional sleep symptoms to explore broader influences that are often invisible in clinical encounters. Cards address issues such as inadequate housing, lack of a bed or bedding, overcrowding, nighttime noise, fear of violence, inconsistent caregiving, late-night screen use, food insecurity, and emotional distress. These factors are not framed as individual failings but as contextual realities that shape sleep opportunities and quality. By creating space for these experiences to be named, the cards help clinicians and community workers identify structural and social determinants of sleep that require responses beyond sleep hygiene advice.

This holistic approach aligns closely with contemporary understandings of sleep in the ICD-11, which introduced a dedicated chapter on sleep-wake disorders. The ICD-11 represents a significant shift from earlier diagnostic frameworks by recognizing sleep disorders as a distinct group rather than secondary symptoms of mental or physical illness. It emphasizes dimensional assessment, developmental considerations, and the interaction between biological, psychological, and environmental factors. For clinicians working with youth with FASD and other neurodevelopmental conditions, the ICD-11 framework reinforces the importance of comprehensive sleep assessment that considers comorbidity, context, and function.

The Sleepy Bear Cards complement the ICD-11 approach by providing a practical, youth-engaged entry point into this broader assessment framework. While the cards are not a diagnostic tool, they support early identification of sleep-related concerns that may warrant further evaluation under ICD-11 criteria. They also help translate diagnostic categories into meaningful lived experiences, bridging the gap between classification systems and real-world practice. In this way, the cards serve as a relational front door to evidence-based sleep assessment rather than a replacement for it.

Beyond clinical alignment, the Sleepy Bear Cards are deeply grounded in a children's rights perspective, particularly the emerging recognition of the child's right to sleep. While the United

Nations Convention on the Rights of the Child does not explicitly name sleep as a standalone right, it is embedded within the rights to health, development, protection, and participation. Adequate sleep is essential for cognitive development, emotional wellbeing, learning, and safety. When children are deprived of safe, sufficient, and restorative sleep due to structural inequities or systemic neglect, their rights are compromised.

From this perspective, sleep problems are not merely individual health issues but indicators of whether a child's basic needs are being met. The Sleepy Bear Cards help surface these rights-based concerns by making visible the conditions that prevent healthy sleep. A child who cannot sleep because they are afraid, hungry, or without a bed is not simply experiencing insomnia; they are experiencing a failure of systems to uphold their rights. By documenting these realities in the child's own words, the cards provide ethically grounded information that can inform advocacy, care planning, and policy responses.

Central to this rights-based approach is youth participation. Article 12 of the UN Convention affirms the right of children and young people to express their views in matters affecting them and to have those views taken seriously. Sleep assessments that exclude youth voices directly contradict this principle. The Sleepy Bear Cards operationalize participation by design, ensuring that young people can communicate their experiences in ways that align with their strengths and preferences. For youth with FASD, who may struggle with memory, sequencing, or verbal abstraction, the visual and tactile nature of the cards provides alternative pathways for expression.

Early pilot use of the Sleepy Bear Cards has demonstrated high levels of engagement and enthusiasm among youth. Many young people report feeling seen and understood through the process, often for the first time in relation to their sleep. Clinicians and community workers have noted that the cards facilitate richer conversations, uncover previously unrecognized barriers, and support collaborative goal-setting. Rather than prescribing solutions, helpers and youth co-create individualized wellness plans that address both sleep behaviors and the underlying conditions affecting rest.

The Medicine Wheel framework further reinforces this collaborative process by emphasizing balance and interconnectedness. Sleep is explored not only as a physical process but as something influenced by emotions, thoughts, relationships, and spiritual wellbeing. This holistic lens is particularly relevant for Indigenous youth, for whom sleep may be understood relationally rather than mechanistically. At the same time, the framework resonates with non-Indigenous youth by validating the complexity of their experiences and moving beyond reductionist models of health.

In practice, the Sleepy Bear Cards are adaptable across settings, including community programs, primary care, pediatric clinics, schools, and youth justice contexts. They can be used as a brief screening conversation or as part of a more in-depth assessment and intervention process. The tool is flexible enough to accommodate different cultural contexts while maintaining fidelity to its core principles of respect, participation, and holistic understanding.

This presentation will introduce participants to the origins, development, and structure of the Medicine Wheel Sleepy Bear Cards. Attendees will be guided through the conceptual foundations of the tool, including its integration of Indigenous teachings, the BEARS framework, and ICD-11-informed sleep assessment. Through demonstration and case examples, participants will learn practical strategies for using the cards with adolescents and young adults with FASD and other neurodevelopmental conditions.

The session will also invite critical reflection on current sleep assessment practices and the ethical implications of excluding youth voices. Participants will explore how incorporating children's rights and participation can transform sleep assessment from a diagnostic exercise into a relational and empowering process. Particular attention will be given to recognizing how sleep difficulties may signal unmet needs related to safety, housing, nutrition, and emotional support.

Ultimately, this workshop highlights the potential of the Medicine Wheel Sleepy Bear Cards to shift how we listen to young people about sleep. By centering youth experience, honoring cultural knowledge, and aligning with contemporary diagnostic frameworks, the cards model a more humane, effective, and just approach to sleep assessment. In doing so, they remind us that supporting healthy sleep is not only a clinical responsibility but a collective commitment to the wellbeing, dignity, and rights of children and young people.

A5 - Effects of Prenatal Alcohol Exposure in Midlife: The CIFASD Multisite Adult Study

Claire Coles, Julie Kable, Tamara Bodnar, Amanda Mahnke

Recent research suggests that prenatal alcohol exposure (PAE) is associated with early onset of health problems, some occurring in children and adolescents and others as individuals age leading to conditions more typical of older adults. Whether PAE leads to premature aging from the cellular level to the functional, is being explored by the Multisite Adult Health Study, part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD). The Multisite Study is being carried out at several sites in the United States and Canada, where middle-aged adults with documented prenatal exposure to alcohol or diagnoses of FASD, are compared to unexposed, age-matched controls and older individuals (>65 years), with the goal of better understanding and predicting health outcomes. In this presentation, collaborators discuss evidence from this project that PAE is associated with alterations in cognitive functioning, vascularization, immune response and in "epigenetic clocks" and biological markers of aging present in blood and will discuss the implications for affected individuals and their families.

The first speaker, Claire D. Coles, describes the project overall and details the performance of alcohol affected adults compared to age-matched unexposed controls and older adults on a computerized measure of cognition used to identify early cognitive decline, demonstrating that PAE is associated with specific cognitive deficits similar to those seen in older adults.

Julie A. Kable presents a novel technique to compare vascularization in midlife adults with and without PAE. Participant's nailbeds were imaged identifying alterations in capillary width, density and tortuosity, which reflect characteristics of vascularization throughout the body. Such changes may contribute to cardiovascular health as well as brain function. In addition, peripheral blood flow, arterial stiffness and cognitive function were measured. Results suggested that alcohol-related dysmorphology may predict lifelong alterations in microvasculature structure and functional deficits.

Tamara Bodnar, in addition to reviewing data on neurodegenerative markers, describes the immune system changes seen in those affected by alcohol exposure, including PAE-related alterations in cytokine levels and networks. The functional relevance of these changes is illustrated by the relationship between these immune system alterations and participant mental health outcomes suggesting that such alterations may be one basis for impaired health in older individuals with prenatal exposure.

Amanda H. Mahnke discusses biomarkers of aging in adults with FASD. These markers can provide insight into the relationship between an individual's age in years in comparison to their “biological” age, which may be more relevant for their health outcomes. The markers include the “epigenetic clock”, a term describing the pattern of attaching methyl groups to DNA, which is found to be disrupted in adults with FASD, as well as miRNAs, found previously to indicate risk in infants and children, and finally plasma proteins, which may indicate relative age effects across different organ systems, suggesting the degree of risk for various diseases.

In summary, the results of this Multisite collaboration provide insight into bases for health and mental health issues in individuals with fetal alcohol spectrum disorders and may offer guidance for future research and clinical care.

A7 - Co-Creating Thrive: A Person-Centered Planning Intervention for Young Adults with FASD in Partnership with Self-advocates, Caregivers, and Professionals

Julianne Myers, Emily Speybroeck, Christie L. M. Petrenko, Gina Schumaker, Kathie Moehlig, Tami Eller

---

Background:
Transitioning to young adulthood is a pivotal developmental period for individuals with fetal alcohol spectrum disorders (FASD). However, this transition is frequently accompanied by a reduction in systemic support and increased expectation for independence, which can pose significant challenges. These challenges often create barriers for goal achievement and result in lower quality of life. To address these issues, a person-centered planning intervention called Thrive was iteratively developed with community members, including adult self-advocates with FASD, caregivers of adults with FASD, and mental health providers. The primary aim of Thrive is to empower young adults with FASD by equipping them with the skills needed to identify self-determined goals, access appropriate supports, and work interdependently to make progress towards goal achievement. This presentation showcases key findings from the development process, highlighting Thrive’s iterative community-engaged research practices.

Methods:
The development of the Thrive program involved intervention working groups (IWGs), qualitative interviews, and a two-phase usability study of initial program content and materials. Monthly meetings were held with three IWGs: self-advocates, service providers, and caregivers of adults with FASD. These meetings refined program goals, content, and materials. Qualitative interviews were concurrently conducted with young adults with FASD aged 18-25 (n=17) aiming to understand the goals, barriers, and supports experienced by young adults with FASD, as well as testing of initial programmatic tools. After program material development, two rounds of usability testing (5 participants per round, total n=10 young adults) were conducted to pilot and inform needed adaptations of program materials and future randomized control trial procedures.

Results:
Feedback from IWGs led to refinements in program materials (e.g. language, visual layout) and components (e.g. session frequency, facilitator qualifications). Qualitative interviews revealed diverse goals among young adults with FASD, including physical health, relationships, and employment, as well as barriers like limited autonomy and transportation. Usability testing resulted in a flexible program structure of 9–15 sessions, each 30–45 minutes, tailored to individual needs. Thrive was completed by 75% of participants in an average of 5.8 months (range: 3.25–8.75 months), with two withdrawals due to adverse life events. Social network

members supported participants in 83% of cases, with 1–5 supporters invited (mean=2). Thrive goals ranged from topics of employment, transportation, physical health, and relationships, with all participants reporting making progress toward goal attainment. Overall, the program was acceptable to both intervention facilitators and participants.

Discussion:
Aligning with intervention development best practices, the Thrive program was developed with community input at each stage. This collaborative approach resulted in a program that accounts for the unique support needs of young adults with FASD, a group often underserved during this critical developmental period. Program content, materials, and study procedures were found to be overall acceptable by IWG members and study participants, with specific recommendations for further refinement. Through community input and subsequent program refinement, the Thrive program is now positioned for larger-scale evaluation testing the program’s efficacy.

A8 & B8 - Stop, Drop & Connect: A Deep Dive into Behavior, Brain Science & Caregiver Well-Being

Barb Clark, Michael Harris

Caregivers of individuals with Fetal Alcohol Spectrum Disorders (FASD) face blow-ups that come out of nowhere: explosive behaviors, emotional shutdowns, confabulation spirals, and patterns that escalate without warning. These moments are exhausting, bewildering and isolating, which leaves caregivers drained and confused about how to deal with their kid because traditional thinking and parenting strategies were never designed for brains shaped by prenatal alcohol exposure, trauma, loss, and chronic stress.

That is because big behaviors do not happen in a vacuum. Yes, they are rooted in the kid's unique brain, but those behaviors can also activate a caregiver's own feelings of helplessness, fatigue, and secondary trauma. This nervous system–to–nervous system dynamic then creates overwhelm and dysregulation, and the caregiver is pulled into that same brain storm. Escalation happens quickly; disconnection happens even faster; then bad outcomes feel inevitable.

In Stop, Drop & Connect, caregivers will learn to interrupt that spiral by orienting first to restore safety and connection, rather than using the same old strategies that always backfire.

The First Half: Understanding & Responding to Big Behaviors (1 hour)

This section of the workshop focuses on practical behavior techniques for caregivers from the standpoint of neurobiology, attachment, and the lived experience of individuals with FASD. Participants will learn concrete tools to:

- Recognize and work with escalation cues earlier to move from survival states to more regulated engagement
- Experience negative behaviors through a brain-based, trauma-aware lens
- Apply compassionate strategies for responding to perceived dishonesty
- Work with (not against) FASD neurobiology during crisis moments

BREAKOUT SESSION B

B1i: A Virtual Interprofessional Collaborative to Improve FASD: Recognition and Management in Child Welfare Populations

Roxanne Chang, Michele Walker-Bauer

Fetal Alcohol Spectrum Disorders (FASDs) are highly prevalent in child welfare populations yet remain widely under-recognized, leading to fragmented care and adverse life outcomes. Integrated, cross-sector care models are essential, but implementation is often hindered by provider knowledge gaps, stigma, and a lack of coordinated systems. To address these challenges, we tested the feasibility of a grassroots, interprofessional, and interagency virtual collaborative within Los Angeles County designed to increase provider knowledge, improve care coordination, and strengthen clinicians' confidence in identifying and managing FASDs.

The collaborative was structured using the COM-B behavior change model to support capability through education, opportunity through networking, and motivation through a shared relational space for case discussion. Led by a pediatrician specializing in foster/adoptive care and a psychologist directing a FASD-informed intervention clinic, the collaborative convened monthly 1.5-hour Zoom conferences. Meetings included introductions, updates, resource exchange, and case-based discussions of diagnostic complexity, clinical management, and referral pathways. Program effectiveness was assessed through a voluntary six-question survey and a facilitated focus group.

Over the 32-month period, 21 conferences were held. Attendance grew organically from an initial four participants to a consistent 15–20 per session, with 41 individuals on the listserv at the time of evaluation. Participants represented a broad array of disciplines—including medicine, psychology, social work, occupational therapy, education, behavioral health, parent partners, disability support services, and national FASD program leadership—reflecting the collaborative's cross-sector reach. Three participants identified as having lived experience with FASD.

Survey responses (n=20) demonstrated strong perceived benefits. The majority of respondents agreed or strongly agreed that participation increased their knowledge of FASD recognition, assessment, and management, and improved their understanding of the variability in FASD presentations. Most participants also reported feeling more supported and less isolated in their work and endorsed meaningful expansion of their professional networks. Respondents further indicated greater confidence in applying FASD-informed recommendations and reported implementing at least one idea from the collaborative into their clinical practice. Focus group feedback aligned with survey data, with participants describing improved understanding of FASD presentations and treatment strategies, increased confidence managing cases without immediate specialty referral, and a desire for more training in frontline screening, interagency collaboration, and advocacy. Clinical scheduling conflicts were the most commonly cited barrier to participation.

Collaborative discussions directly facilitated interagency problem-solving for 15 child-welfare–involved cases, resulting in multiple successful referral linkages, revised individualized education program (IEP) eligibility decisions, and averting two potential adoption dissolutions. One additional child was subsequently placed with a disability-trained caregiver following a disrupted prospective adoption.

These findings suggest that a lightly structured, relationship-centered, virtual interagency collaborative is both feasible and effective in increasing provider knowledge, strengthening professional networks, and supporting more coordinated care for children with FASD. This model may be generalizable to other communities. Future work should examine integrated service delivery models and measure specific patient and family outcomes using frameworks such as relational coordination

Provide relevance of findings for 1) the broader field of FASD (e.g., providers, policymakers, and communities) 2) benefiting of individuals and families living with FASD or the prevention of FASD in a way that does not further stigmatize families. Both answers must use plain language, understandable by a general, lay audience.

1) Relevance of Findings for the Broader Field of FASD

These findings matter for the wider FASD community—including providers, policymakers, and local systems—because they show that a simple, low-cost, relationship-based learning group can make a real difference in how professionals understand and support people with FASD. Many clinicians want to help but have little formal training, and agencies often work in isolation. This project demonstrates that when professionals come together regularly to share practical knowledge, discuss cases, and learn from one another, they become more confident and better equipped to recognize FASD and connect families with the right resources. For policymakers, the results highlight the need for cross-agency collaboration and consistent training opportunities. For communities, it shows that improving care does not always require major programs or funding—sometimes connection, communication, and shared understanding can change outcomes.

2) Benefits for Individuals and Families Living With FASD

This collaborative ultimately benefits individuals and families by helping professionals better understand the unique needs that come with FASD. When providers are more knowledgeable and coordinated, families experience less confusion, fewer repeated assessments, and more consistent support. Parents and caregivers—who often feel overwhelmed or misunderstood—

are more likely to be met with compassion and practical guidance rather than blame. These efforts also help create safer and more stable environments for children, reducing school struggles and preventing unnecessary placement moves. On a community level, improving awareness and coordination supports earlier identification and family-centered care, which can prevent secondary difficulties and help people with FASD thrive. Importantly, the focus is on understanding and supporting individuals rather than judging families, recognizing that all caregivers deserve respect, partnership, and access to clear information.

B1ii: A Participation-Focused Approach for Children and Adolescents With FASD: A Research and Practice Priority

Catherine Hilly

Background/objectives: Children and adolescents with fetal alcohol spectrum disorder (FASD) experience a range of neurodevelopmental impairments that impact their participation in home, school and the community. Conversely, literature indicates that they benefit from successful participation in leisure and school activities to foster skills, resilience and wellbeing. Given the importance of participation for learning, development, health, and well-being, it is considered an essential intervention outcome for children and youth with disabilities and a research priority. The Cognitive Orientation to daily Occupational Performance Approach (CO-OP) is an effective intervention to address occupational performance goals and promote participation in people of all ages. It is yet to be evaluated for people with FASD. This PhD project explores (i) literature on the effectiveness of participation-focused interventions and (ii) feasibility of the CO-OP approach for children and adolescents with FASD.

Methods: First, a systematic review was conducted of allied health and educational intervention studies on children with FASD aged 5-18 years; this covered participation-focused, body function and structures, activity and behavioural outcomes. Second, a mixed-methods case report was used to evaluate feasibility of CO-OP. Intervention consisted of ten weekly CO-OP sessions provided to three children (aged 10-12 years) with FASD in their home, addressing occupational performance goals. Preliminary evaluation measured caregiver- and child-rated goal performance using the Canadian Occupational Performance Measure (COPM). An evaluator blind to participant's intervention status rated goal performance using the Performance Quality Rating Scale (PQRS). Children and caregivers were interviewed about their experiences of participating in CO-OP. Data analysis involved comparing pre-post and follow up intervention goal outcomes, thematic analysis of interviews and triangulation of field notes and session videos.

Results: The systematic review included 25 studies with 735 participants. The mean participant age of 9.3 years. Adolescents participated in 30% of the studies. This review revealed that most interventions for FASD target outcomes at body structures and function level of the ICF, and activity and behaviour. No participation outcomes were found. For the case study, all three children completed the allocated CO-OP sessions and showed improvements in their goal attainment with varying levels of maintenance at follow-up. CO-OP was perceived as acceptable to children and caregivers. Caregivers identified that more sessions would help their child attain goals, remember strategies and apply these beyond CO-OP.

Discussion/conclusion: Identifying effective interventions for people with FASD is needed to enable their successful participation across environments. CO-OP is feasible for children with FASD to improve occupational performance goals and supports participation outcomes. Additional sessions may support children with FASD to elicit goals and attainment using CO-OP. Its application may be considered for adolescents and adults with FASD. Participation-focused practice and research for people with FASD is a priority to promote successful outcomes across environments.

BREAKOUT SESSION B

B1iii: A Practical Guide for Designing and Implementing FASD Diagnostic and Clinical Care Practices

Julia Conkel Ziebell

FASD remains underdiagnosed, due in part to complex clinical presentations and gaps in provider training. In partnership with Wilder Research, Proof Alliance conducted semi-structured interviews with experienced FASD diagnosticians and medical experts across the United States, as well as clinicians seeking to integrate FASD diagnostic services into their practices. These interviews informed the development of "A Practical Guide for Designing and Implementing Fetal Alcohol Spectrum Disorder (FASD) Diagnostic and Clinical Care Practices," published by Proof Alliance in 2025.

This presentation will review qualitative findings from these interviews, highlighting clinical best practices that support accurate and timely FASD diagnosis. Key themes include the importance of collaborative partnerships for multidisciplinary assessment, strengths-based approaches to evaluation, and strategies for engaging allied educational and healthcare providers to build robust referral networks.

Drawing on Proof Alliance's 14-year experience in establishing and sustaining an FASD diagnostic clinic, the presentation will offer actionable guidance for organizations seeking to implement or expand FASD diagnostic services. Attendees will gain practical insights into business model design, provider training, intake and assessment protocols, and the integration of ongoing support services, with a focus on lessons learned and strategies for overcoming common barriers. This session aims to empower clinicians and organizations to deliver comprehensive, person-centered FASD diagnostic care.

BREAKOUT SESSION B

B2i: Hidden in Plain Sight: The Urgent Need to Recognize and Respond to FASD in Foster Care Systems

Ryan Jolly, Kathy White

Background and Objectives

Fetal Alcohol Spectrum Disorders (FASD) remain profoundly under identified in the United States, despite prevalence estimates suggesting rates of as much as five percent of the general population. The foster care system is disproportionately impacted. Research consistently shows that children entering foster care experience elevated rates of prenatal alcohol exposure, neurodevelopmental adversity, early trauma, and environmental instability, all of which complicate accurate diagnosis and accessing support. Yet caregivers and frontline professionals often lack the tools, training, and system-level support needed to recognize brain-based differences, leading to misinterpretation of behaviors as willful, oppositional, or trauma-only in origin.

This project emerges from the collaborative perspectives of a psychiatric nurse practitioner specializing in FASD evaluation, and a foster care coordinator and foster-to-adoptive parent. The objective is to synthesize translational insight that bridges clinical realities with lived experience, and to highlight practical system-level improvements that can reduce placement disruption, caregiver burnout, and long-term downstream costs.

Methods

We conducted a combined clinical-practice and community-based review by:

1. Analyzing diagnostic trends from a Kansas City psychiatric practice specializing in neurodevelopmental assessment, including patterns of missed or delayed FASD recognition among children with foster care histories.
2. Integrating frontline observations from a regional foster care coordination program serving biological families, kinship caregivers, and traditional foster homes.
3. Synthesizing caregiver experience from raising a child with FASD within the foster-to-adoptive system.
4. Reviewing national and state-level policies, screening tools, and implementation barriers that affect identification and service access in foster care.

This mixed perspective prioritizes translational relevance and the lived expertise of families and community programs.

Results

Across both clinical and community settings, three consistent themes emerged:

1. **Underdiagnosis and diagnostic overshadowing:** Children with prenatal alcohol exposure frequently receive multiple behavioral diagnoses (ADHD, ODD, attachment-related presentations) without evaluation of neurodevelopmental differences characteristic of FASD.
2. **System strain and placement instability:** Misunderstood behaviors drive placement disruption, which in turn exacerbates trauma exposure and reduces long-term permanency prospects.
3. **Missed prevention and support opportunities:** Caregivers often access FASD-informed resources only after exhausting multiple failed placements, school suspensions, or escalating behavioral crises.

Discussion

Findings demonstrate a critical need for system-wide awareness and early identification strategies that integrate trauma-informed, brain-based, and strengths-aligned approaches. Translational opportunities include: embedding routine FASD screening within foster care intake processes; training foster parents and case managers in neurodevelopmental interpretation of behavior; and strengthening referral pathways for diagnostic evaluation. Centering the voices of caregivers and adults with FASD ensures the work remains respectful, non-stigmatizing, and grounded in real-world impact.

Conclusion

Children in foster care are uniquely vulnerable to undiagnosed FASD, yet the system is poorly equipped to recognize and support them. Collaborative, cross-sector approaches that elevate both clinical and lived experience can significantly improve identification, stability, and outcomes. This presentation offers actionable, community-validated strategies to strengthen understanding, reduce stigma, and enhance support for families navigating FASD in the foster care system.

B2ii: Multidisciplinary Collaboration in FASD Research: A Pilot Study to Assess the Prevalence of FASD in San Diego Foster Care and Justice-Involved Youth

Kelly Rain Collin, Sarah Mattson

Fetal alcohol spectrum disorders (FASD) reflect cognitive and behavioral difficulties associated with prenatal alcohol exposure (PAE). FASD is often underdiagnosed/misdiagnosed due to stigma, similarities to other neurodevelopmental disorders (e.g., ADHD), and barriers to accessible screening/diagnosis. In high-risk groups such as individuals involved with the foster care and justice systems, the prevalence of FASD may be 10-40 times higher than the general population. However, relatively few studies have examined FASD prevalence rates in these populations and even fewer have partnered with foster care and justice agencies to undertake this important work. Further, there are few brief/online FASD screening tools and little research on the accuracy of brief/online tools compared to traditional dysmorphology/neuropsychological examinations. We describe a new collaborative pilot study involving the University of California San Diego, San Diego State University, and the San Diego Departments of Child and Family Well-Being and Probation. The goals of the study are to estimate FASD prevalence in youth involved with the foster care and justice systems in San Diego County and assess the accuracy of brief/online FASD screening tools in these populations.

Methods

Data will be collected from 18-25 year-old individuals with previous or current involvement with (1) the foster care (n=100) and/or (2) justice systems (n=100). Participants will complete questionnaires assessing mood/behavior, childhood adversity, and PAE; undergo both brief and traditional physical dysmorphology examinations; and complete both in-person and online neuropsychological testing. A person knowledgeable about participants' histories (e.g., social/case worker, justice facility staff, public defender) will provide information on PAE to corroborate information from participants. This information will be used to screen participants for FASD. At study completion, we will increase knowledge regarding: (1) FASD occurrence in these high-risk settings and (2) the accuracy of brief/online assessments for FASD screening compared to traditional dysmorphology/neuropsychological examinations. We will also provide an opportunity for participants to attend a self-advocacy training designed to help individuals think about their strengths and challenges, how these might play out in day-to-day life, and what strategies they can use to advocate for support and accommodations in educational, occupational, and community settings.

Results

We expect that the proportion of youth who screen positive for FASD in the foster care and justice systems to be higher than the prevalence rate of FASD in the general population (1.1 to 5% in school-aged children in the U.S.). We also expect that brief/online FASD screening tools will be comparable to traditionaldysmorphology/in-person neuropsychological examinations in accurately identifying individuals at risk for FASD.

Discussion/Conclusion

There may be broad implications related to legal accommodations and defense strategies that take FASD into consideration and FASD-specific interventions, particularly for youth involved in the foster care and justice systems. Expanding collaborative efforts across research and county agencies may contribute to increased accessibility of validated screening tools and better understanding of FASD prevalence rates in high-risk populations, ultimately improving lifelong well-being for individuals with PAE.

B2iii: An Exploration of Alcohol Screening Practices among Pregnant People in a Perinatal Care Hospital in Mexico

Aranza Lilian Perea Caballero, Esteban Nolla Hernández

Prenatal alcohol exposure is associated with a range of outcomes collectively known as fetal alcohol spectrum disorders (FASD). In Mexico, routine screening for alcohol use during pregnancy is not consistently implemented in prenatal care, and limited documentation practices may contribute to the under-detection of prenatal alcohol exposure.

This study aimed to describe screening and follow-up practices for alcohol consumption among pregnant women attending their first prenatal consultation at a tertiary-level hospital in Mexico City, and to estimate the prevalence of documented alcohol consumption during pregnancy in this population. An observational, descriptive, cross-sectional study was conducted through a retrospective review of medical records of pregnant women who attended their first outpatient consultation at the Gynecology and Obstetrics service of the National Institute of Perinatology between January 2022 and December 2023. Sociodemographic variables, documentation of alcohol and other substance use, screening practices, referrals to specialized services, and follow-up information were collected and analyzed using descriptive statistics.

A total of 894 medical records were reviewed. In 80.5% of cases, no documentation of alcohol consumption during pregnancy was found in the clinical records. Alcohol consumption at some point during pregnancy was documented in 11% of cases, while 8.5% reported no consumption. Among patients with a history of alcohol use, 78.6% reported having discontinued consumption, 2% reported continued use, and 19.4% had no information regarding continuation. The average gestational age at cessation was 8.5 weeks. Among women who reported alcohol consumption during pregnancy, 44.9% also reported tobacco use and 29.6% reported use of other substances; of these, 86.4% and 72.4%, respectively, reported having discontinued use.

Importantly, none of the medical records documented the use of standardized alcohol screening tools. This finding highlights a significant gap in the systematic identification and documentation of prenatal alcohol exposure within prenatal care.

Strengthening routine screening protocols, incorporating validated screening tools, and training healthcare professionals in brief interventions and referral pathways could improve the identification and clinical management of alcohol use during pregnancy in Mexico.

B3 - Population-Based FASD Screening, Diagnosis, Surveillance, Intervention, Prevention, and Policy Development: Statewide Sustainable Success Stories From Washington State and Alaska

Susan (Astley) Hemingway, Marilyn Pierce-Bulger

Background
Progress in fetal alcohol spectrum disorder (FASD) screening, diagnosis, intervention, surveillance and prevention hinges on development of an evidence-based method for diagnosis of individuals with prenatal alcohol exposure (PAE). The FASD 4-Digit Diagnostic Code, developed in 1997, achieved that goal in Washington State. The University of Washington opened the first CDC-sponsored interdisciplinary FASD diagnostic clinic in 1992 that was later sustained from 1997 to the present though WA State Senate bill 5688. Clinic data was used to develop the FASD 4-Digit-Code, paving the way for expansion of the clinic into a statewide network of FASD diagnostic clinics (the Washington Fetal Alcohol Syndrome Diagnostic & Prevention Network), now in its 33rd year. Alaska adopted this interdisciplinary FASD diagnostic model in 1999. Both states have participated in the CDC Pregnancy Risk Assessment Monitoring System (PRAMS) and Behavioral Risk Factor Surveillance System (BRFSS) since the 1990s. Study objectives were to describe the two statewide FASD diagnostic networks; compare the 4-Digit-Code FASD diagnostic outcomes and PAE histories documented over 2-3 decades and illustrate how network data helped establish and guide FASD public health policies and track successful prevention efforts.

Methods
Retrospective descriptive analysis of the WA and AK statewide FASD and PRAMS/BRFSS datasets.

Results
FASD diagnostic outcomes were comparable across the 2,532 WA patients and 2,469 AK patients evaluated over 2-3 decades. The proportion of pregnancies with reported PAE in each State followed similar annual trajectories from 1991-2020. Both States observed significant decreases in the prevalence of FAS and PAE in the 1990s. Network data helped set public health policies that better met the needs of individuals and families impacted by FASD.

Conclusions
WA and AK have demonstrated the feasibility and value of establishing sustainable statewide interdisciplinary FASD diagnostic clinics that serve as the foundation for FASD screening, surveillance, intervention, prevention, education and translational research. Legislative support, centralized data collection, and use of an evidence-based FASD diagnostic system have been key to the long-term success of these two clinical networks. Free training and diagnostic tools have

led to the successful replication of this model in over 65 countries. Twenty years of patient surveys confirm a FASD 4-Digit Code interdisciplinary diagnosis afforded substantial access to interventions that patients report met their needs across the lifespan. In 2023, the WA State Legislature approved House Bill 1168 to expand FASD diagnostic clinics and support intervention efforts.

References

1. (Astley) Hemingway SJ, Baldwin M, Pierce-Bulger M. (2023) Washington and Alaska Statewide
2. Fetal Alcohol Spectrum Disorder Diagnostic Clinical Networks: Comparison of Three Decades of 4-Digit Code Diagnostic Outcomes and Prenatal Alcohol Exposure Histories. https://depts.washington.edu/fasdpn/pdfs/WA-AKdiags2024.pdf
3. Astley SJ.(2014) Twenty years of patient surveys confirm a FASD 4-Digit-Code interdisciplinary diagnosis afforded substantial access to interventions that meet patients' needs. https://depts.washington.edu/fasdpn/pdfs/FAR_13_22_e81_e105_Astleypublished.pdf
4. WA State Senate Bill 5688 (1995) https://depts.washington.edu/fasdpn/pdfs/senatebill5688.pdf
5. WA House Bill 1168 (2023) https://depts.washington.edu/fasdpn/pdfs/Housebill1168.pdf

BREAKOUT SESSION B

B4 - Bridging Thinking and Communication: A Translational Approach to Support Individuals with FASD

Lucy Esralew, Monica Hudnall

As of 2024, The Center for Disease Control estimates that the full range of FASDs in the United States among school-aged children is up to 1 in 20 or 5% of the population. Individuals with FASDs can experience lifelong challenges, including in neurodevelopmental differences. The session highlights the importance of promoting best practices that enhance daily functioning and social participation. A recent bibliometric review of studies that focused on FASD revealed there was a relative focus on diagnosis and screening, compared to prevention and intervention.

Furthermore, research articles mostly focused on the following topics:

- Neurodevelopmental phenotype of FASD (e.g., learning, memory, attention, and executive functioning) [27%]
- Diagnosis/screening for FASD [19%],
- Neuroscience (e.g., brain imaging [12%]
- Research on FASD interventions [12%] (McQuire et al., 2024)

Clinically, attention should be directed intervention/support and services that address both executive and language-based difficulties. Individuals with FASDs often experience difficulties in executive functioning (e.g., planning, working memory, impulse control) and pragmatic language (the social use of language). These challenges are interconnected and affect learning, relationships, and daily functioning, but they do not fit neatly into the scope of any single profession. Collaboration allows professionals to integrate perspectives on brain function, behavior, communication, and environment to create a more complete picture of an individual's strengths and challenges.

This session focuses on improving everyday outcomes for people FASDs by rethinking how we understand and support them. It looks at daily functioning and social participation through a combined view of activities of daily living (ADLs)/instrumental activities of daily living (IDALs), executive functioning and language. This approach helps turn research into practical strategies that can be used in schools, clinics, and communities. Our goal is to promote discussions on the adaptation and refinement of intervention models and guide research that translates into accessible, effective support systems. This approach helps reduces stigma and helps both clinical and non-clinical communities work together to improve outcomes for individuals with FASDs and their families.

B5 - The Joys and Challenges of Long Term Personal Relationships

Mary Schalk, Mary Byrnes, Suzanne Emery

Marriages/long-term relationships in general have their challenges. When a partner has an FASD, those challenges are likely to increase. Children and other family members are also impacted. This 60-minute facilitated panel discussion will challenge learners to explore how they can best support adult loved ones in experiencing satisfying and stable long-term relationships.

Learning objectives

1. Learners will recognize potential challenges in long term relationships when a partner has an FASD.
2. Learners will gain strategies for managing day-to-day challenges in a way that can support successful and satisfying long-term relationships.

Panelists will share their own experiences and tips for success, while acknowledging that each of us has unique strengths and challenges and therefore there is no universal approach. Discussion prompts will spark conversation. Discussion items will include:

- Perspective of the partner with an FASD, and the perspective of the partner who is a caregiver in an unexpected way.
- How each partner can communicate what they need in a manner that can be understood
- How to have that delicate conversation when FASD is suspected but not diagnosed
- What is the impact on children, and what do they need to understand?

Questions and comments from the audience will be gathered throughout the conversation and responded to either during, or after the initial discussion prompts are addressed.
It is anticipated that this discussion will make more clear how the impact of pre-natal alcohol exposure influences relationships, the need for open communication about those influences, and strategies that can strengthen and stabilize relationships.

Panelists will offer a brief summary of their recommendations for successful relationships. Learners will be encouraged to make note of 2 actions they will take as a result of the discussion.

B6 - FASD in Incarcerated Individuals: Can We Change Their Course?

Nancy Whitney, Dan Dubovsky

About 20 to 30 percent of women in the United States have reported drinking during pregnancy, typically during the first trimester (Ethan, et al., 2009). Prenatal alcohol exposure is a leading preventable cause of birth defects and neurodevelopmental disabilities in the United States. Despite the prevalence of Fetal Alcohol Spectrum Disorders (FASD) in the general population (1-9%, depending on the study) it is usually unrecognized or misdiagnosed. Individuals with FASD are often given a variety of psychiatric diagnoses. While some of these diagnoses may be correct (it is possible to have an FASD and also have mental health issues), they are also likely to have been given when FASD was not considered by the clinicians. While the disability does not always present with an intellectual disability, many individuals struggle in school and end up involved in the criminal justice system. Juveniles with an FASD are 19 times more likely to be incarcerated (Popova et al., 2011), and a long-term study documented 60% of the FASD participants over the age of 12 had criminal histories (Streissguth, et al., 1996). Canadian studies of incarcerated adult populations have shown a 17%- 32% prevalence rate for FASD. The behavior problems of individuals with an FASD mean that they are likely to be repeat offenders and often have difficulties in custody.

This presentation will be focused on two populations- those who have a known FASD and those who have never been identified.

For those with a known diagnosis, we will provide information and strategies for working with these individuals while they are in custody. Information provided by family and supports can be critical, but it has to get to the right people in a language that staff can understand and put to use. It is also important the individual's defense team is aware of the diagnosis.

For those that have never been identified, clinicians working in correctional facilities have an opportunity to not only assist in identifying individuals who likely have an FASD, but can assist the individual, the corrections staff, and other providers to educate about FASD and improve outcomes for these individuals. Clinicians and researchers can play an important role in increasing awareness of this population and encouraging legal and judicial systems to implement screening processes and provide training to all staff. An example from Crawford County Juvenile Probation, in Pennsylvania will be discussed.

For both groups, the functional deficits associated with an FASD can lead to problems in custody which can impact the individual's access to programs and services. Those functional deficits, if not known, or not addressed, can impact the individual's ability follow rules or understand court proceedings, which may lead to repeated conflicts with staff. The individual and staff can learn to manage these issues in a way that decreases problems.

The presenters will provide participants with a review of FASD challenges, how to screen for FASD, and implement strategies to assist individuals in managing their disabilities. Participants will also discuss strategies for educating custody staff, to include them in working with individuals with FASD.

B7 - Coming Together to Weave and Fill the Basket: A Collaborative Circles of Care Approach to Supporting Individuals and Families with FASD

Suzie Kuerschner, Carolyn Hartness, Cindy Smith

This presentation introduces the Collaborative Circles of Care Model, a strength-based, culturally responsive framework designed to support individuals and families impacted by fetal alcohol spectrum disorders (FASD) through coordinated, relational, and contextually grounded systems of care. Grounded in Indigenous knowledge and community practice, the model emphasizes collaboration across family, community, service providers, and—when applicable—justice systems.

Participants will learn how Circles of Care are intentionally developed from community and family asset inventories, identifying natural helpers such as extended family members, elders, community health workers, and cultural mentors. The presentation will highlight the role of a coach or navigator working alongside a family lead to coordinate services across domains including education, behavioral health, housing, employment, and re-entry support.

Using justice-system involvement as a focused example, the session will demonstrate how culturally responsive observation and adaptive procedures can inform supportive probation conditions, sentencing considerations, and re-entry planning for individuals with FASD. Rather than emphasizing punitive responses, the approach centers predictability, relational safety, and concrete supports that align with an individual’s cognitive, emotional, spiritual, and cultural strengths.

Through case examples and facilitated reflection, participants will explore how weaving together multiple perspectives—clinical, cultural, familial, and systemic—creates a “basket” strong enough to hold complex needs while honoring dignity, reciprocity, and long-term community wellbeing.

PLENARY

High Prevalence of Prenatal and Postnatal Risks Among 2,652 Patients With Prenatal Alcohol Exposure Evaluated for FASD at the Washington State Fetal Alcohol Diagnostic & Prevention Network

Susan (Astley) Hemingway

Background/Objectives: Individuals with prenatal alcohol exposure (PAE) often present with a myriad of other prenatal (e.g. exposure to tobacco, other illicit drugs, poor prenatal care) and postnatal risks (e.g. multiple home placements, neglect, physical/sexual abuse)–all of which can adversely impact their growth and development. Documenting these risks is an important component of a comprehensive fetal alcohol spectrum disorder (FASD) diagnostic evaluation and serves to inform intervention recommendations. The present study documents the prevalence of other prenatal and postnatal risks among individuals with PAE diagnosed at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN).

Methods: The records of all 2,652 patients with PAE receiving a FASD diagnostic evaluation by an interdisciplinary team using the FASD 4-Digit Diagnostic Code at the Washington State FASDPN from 1993 through 2024 were utilized. In preparation for a FASD evaluation, the FASDPN collects and reviews all prior records (birth, medical, school, social service). All prenatal and postnatal risks are documented and ranked in severity on 4-point Likert scales.

Results: This study confirmed that individuals with PAE seeking an FASD evaluation at the FASDPN clinics presented with a multitude of other prenatal and postnatal risks. Only 5 of the 2,652 patients presented with PAE as their only risk factor. The prevalences observed in the Washington State FASDPN clinical population were comparable to those observed in other FASD diagnostic clinical populations (Flannigan et al., 2021, McLachlan et al., 2015). The prevalences of most prenatal and postnatal risks were substantially higher in the FASDPN clinic population than estimates reported in the U.S. general population respectively: PAE (100%, 15%), PAE all three trimesters (63%, 8%); prenatal tobacco exposure (73%, 8-10%); prenatal marijuana exposure (40%, 1-8%); prenatal cocaine exposure (35%, 0.3%); prenatal methamphetamine exposure (20%, 0.7-4.8%); prenatal illicit drug exposure (64%, 8%); poor prenatal care (32%, 7%); other syndromes/congenital birth defects (2.0%, 3-4%); Tourette's syndrome (0.7%, 0.3-0.6%); ASD (9.5%, 3.2%); premature birth (26%, 9%); out-of-home placement (71%, 0.4%); physical abuse (30%, 18%) and sexual abuse (18%, 9%).

Discussion/Conclusion: Bearing in mind the following: 1) The high prevalence of other prenatal and postnatal risks among individuals with PAE; 2) the substantial overlap in adverse outcomes associated with PAE and other prenatal and postnatal risks; and 3) the fact that PAE alone was rarely the only risk explaining adverse brain outcomes and on occasion appeared to play no significant role in the adverse outcomes (Astley Hemingway et al., 2020), it is clear why, as stated by Eliason et al., (2024) “Correctly attributing a clinical presentation of neurodevelopmental differences solely to PAE is problematic.” A better understanding of the impacts other prenatal and postnatal risks have on the growth and development of individuals with PAE can inform more effective intervention and prevention strategies and illustrates the need for caution when labeling a diagnosis based on a single etiologic agent.

PLENARY

Beyond the Diagnosis: Introducing a Functional Classification Model for FASD Intervention and Support Proposal for a Functional Classification Model

Yasmin Senturias

Background/Objectives

Diagnosis tells us what an individual has—but families, schools, clinicians, and adults with FASD are asking a different question: What do I need to be successful? Current diagnostic systems such as the University of Washington 4-Digit Code, Hoyme, DSM-5, and the Canadian Guidelines are essential for determining whether an individual meets criteria for FASD; however, these systems do not clarify the level or type of support required in everyday life. The 2023 Society of Developmental and Behavioral Pediatrics survey revealed substantial variability in diagnostic practices and indicated that many clinicians feel under-prepared to translate diagnostic findings into tailored intervention recommendations. This plenary introduces a Functional Classification Model (FCM) that complements all diagnostic systems and offers a practical, levels-based framework for guiding intervention and support across the lifespan.

Methods

An anonymous electronic survey was distributed to 913 SDBP members; 199 clinicians responded, with 97 reporting active involvement in FASD diagnosis or management. The survey assessed diagnostic approaches, clinician preparedness, and training needs. Descriptive analysis was combined with current literature and clinical expertise to develop a Functional Classification Model aligned with neurobehavioral presentation and real-world functional needs.

Results

Survey findings demonstrated significant variability in diagnostic practices: 34% used the University of Washington 4-Digit Code, 34% DSM-5 ND-PAE, 26% Hoyme/NIAAA, 12% CDC 2004 criteria, and 7% the Canadian 2016 guidelines. One quarter used multiple systems, and 6% used none. Only 24% of clinicians felt "very prepared" to diagnose FASD, while 58% wanted additional training in both diagnosis and management. Clinicians reported limited confidence in determining support intensity and difficulty translating diagnostic labels into clear recommendations for educators, therapists, and adult-service systems—highlighting the need for a shared functional framework.

Functional Classification Model for FASD Intervention and Support

The proposed FCM organizes support needs into three levels:

- **Level 1 (Mild/Subtle Needs):** Mild executive function challenges, concrete thinking, and mild learning or social difficulties. Supports include structured routines, visual aids, executive function strategies, social coaching, and parent education emphasizing brain-based expectations.
- **Level 2 (Moderate/Significant Needs):** Consistent challenges with self-regulation, adaptive functioning, impulsivity, and social vulnerability across settings. Supports include explicit adaptive-skills instruction, FASD-informed caregiver interventions (e.g., Families Moving Forward), trauma-informed therapy, coordinated school supports, and respite to reduce caregiver strain.
- **Level 3 (Severe/Pervasive Needs):** Extensive and often lifelong support needs related to pervasive neurobehavioral impairments, safety risks, or limited insight. Supports include wraparound case management, supported living environments, crisis planning, vocational and daily-living skills programs, and guardianship or supported decision-making when appropriate.

Discussion/Conclusion

The Functional Classification Model does not replace any diagnostic framework. Instead, it serves as a unifying overlay that makes FASD diagnosis more meaningful by linking clinical findings to actionable, developmentally appropriate intervention pathways. By addressing the variability and uncertainty identified in the SDBP survey, the model enhances communication among clinicians, families, educators, and adult-service providers. This plenary will demonstrate how adopting a functional, levels-based approach can strengthen decision-making, improve access to appropriate supports, and enhance long-term outcomes for individuals with FASD across the lifespan.

PLENARY

Disentangling Diagnostic Overlap: A Hybrid Scoping Review of Neurodevelopmental Profiles in FASD and Autism Spectrum Disorder

Julianne Myers

Background:
Fetal alcohol spectrum disorder (FASD) and autism spectrum disorder (ASD) are both highly prevalent developmental disabilities that represent a spectrum of neurobehavioral presentations. However, significant discrepancies exist between diagnostic and prevalence rates, with FASD remaining undetected in more than 80% of affected individuals across the lifespan. Under-recognition likely reflects several factors, including the complexity of differentiating neurobehavioral features of FASD that overlap with a variety of other developmental disabilities such as autism. Additionally, there is variability in published co-occurrence rates of FASD and ASD (5-72% in clinical samples). Clarifying similarities and differences in neurobehavioral profiles is critical to improving provider education, diagnostic accuracy, access to services, and cross-disciplinary research integration.

Methods:
This plenary will review the state of clinical and research perspectives on overlapping characteristics of FASD and ASD. Topics will include important characteristics of each diagnosis, historical context, and considerations of the current challenges in the clinical and service domains. The presentation will draw from an ongoing hybrid scoping/umbrella review (OSF preregistration #: K5398) examining seven domains of functioning that are commonly considered when initiating diagnostic conceptualization for developmental disabilities. These domains include sensory processing, language, social communication, social skills, adaptive functioning, executive functioning, and self-regulation. Findings will be synthesized to highlight shared and unique features, research gaps, and implications for differential diagnosis and intervention.

Results:
Four reviewers are conducting a PRISMA-guided literature review across three online databases (1,378 non-duplicate articles screened) with substantial screening reliability (κ=.754, p<.001). Findings for FASD and ASD will be organized by each neurobehavioral domain, emphasizing conceptual trends, shared features, distinctive patterns, and gaps in knowledge. Attendees will be given visual tools to better distinguish FASD and ASD in clinical settings. In addition to review findings, prior literature on co-occurrence, prevalence, and lessons learned will be discussed.

Discussion:
Both FASD and ASD populations have experienced societal stigma and barriers to equitable care. As the field of autism has advanced toward broader acceptance and access to supports, it is

essential that FASD be recognized with equal accuracy and systemic supports. This moment offers an opportunity to strengthen clinical understanding of differential diagnosis and promote interdisciplinary education among providers. Attendees will be invited to consider ways in which understanding of these two developmental disabilities can enhance research, policy, and direct services.

PLENARY

The Complexity of Neurodiversity: FASD and Autism Spectrum Disorder Differential Diagnostics

Erin Olson

Background: Little research has been conducted regarding the differences and similarities between FASD and autism spectrum disorder (ASD). Those that do vary in focus, approach, and sample size. Prevalence of ASD in FASD populations was also highly variable ranging from 2.6% to 68% (Lange et al 2018, Mukherjee et al 2019). Interestingly, multiple large studies found no association between maternal drinking during pregnancy and ASD between 2003-2017. Also, Tan and associates (2020) did not find association with alcohol-related facial features and behavioral or cognitive features of ASD.

ASD is multifactorial with genetic and environmental causes, no single cause has been identified. In contrast, FAS is caused by prenatal alcohol exposure. Previous research indicates that there are overlapping symptoms within both diagnostic populations. This study aims to describe and compare the developmental profiles of individuals with autism within a sample of patients with prenatal alcohol exposure. Prevalence and trends will be shared. Neurodiversity and complexity due to prenatal exposure and possible genetic influences will be discussed.

Methods: A subsample from the 35-year University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network (FASDPN) database of individuals with either autism spectrum disorder or suspected autism was selected from a 20-month period between 2023-2024 (n=21). All patients within this sample had confirmed PAE. The subset was analyzed to identify and compare symptoms and developmental profiles to other research findings as well as the profiles of patients with FASDs within the FASDPN database. Continued analysis is being conducted by reviewing records of FASDPN patients within the larger sample.

Results: The prevalence of individuals with ASD within this subset was 17.5% which is greater than prevalence in both the general population and most prevalence studies involving PAE. Most patients were diagnosed with static encephalopathy, alcohol exposed (57.1%). Four of these individuals also had documented genetic conditions, one had full facial features associated with FAS. The other three met criteria for SE-AE.

The symptom pattern in this subset was consistent with the current literature. These findings were (1) similarities across both diagnoses: difficulty forming, maintaining, and/or understanding relationships; insistence on sameness; inflexibility; sensory processing differences; motor delays; concerns began before age 3 and differences/deficits result in functional impairment; (2) differences in FASD only symptoms: social motivation and memory challenges; and (3) differences in ASD only symptoms: social initiation challenges and nonverbal communication deficits.

Discussion/Conclusion: The results of this small subsample were consistent with findings in previous literature. This study aims to add further diagnostic and developmental profile information from a large sample of individuals with PAE and those with both ASD and PAE by reviewing the entire FASDPN clinical sample. More data exists within this database that may shed light on nuanced differences and similarities of FASD and ASD to inform accuracy of diagnosis and targeted accommodations and interventions. PAE adds to the complexity of diagnosis as well as an individual's functioning warranting further discussion of neurodiversity as a construct for understanding and supporting those with prenatal exposures and experiences of adversity.

C1i: Early Indicators of Comorbidities in Children and Adolescents with PAE

Christina Chambers

Background: The core developmental effects of prenatal alcohol exposure (PAE) are well described and encompassed under the diagnostic umbrella term fetal alcohol spectrum disorders. However, accumulating evidence supports the fact that there are numerous serious comorbidities which may occur more frequently and at earlier ages of onset in adults with PAE. While these comorbidities may be recognized and treated in adults through routine clinical practice, children and adolescents with PAE who show early signs of developing these comorbid conditions could benefit greatly from early intervention.
An evidence-based approach to pediatric clinical care that screens for and identifies children/adolescents with PAE for signs of early onset comorbid conditions could help improve general health outcomes and quality of life for children/adolescents and adults with PAE. prevalence and age at onset of these specific comorbidities is of interest to families and health care providers in children with PAE.

Methods: As part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), a cross-sectional study design was used to evaluate a broad range of clinical and subclinical markers of comorbid conditions in a sample of children and adolescents 3-17 years of age who did or did not have documented PAE. The study is being conducted at UC San Diego and Emory University. The study measures included questionnaires, neurobehavioral assessments, clinical laboratory measures, and a general pediatric examination.

Results: Between 2023 and 2025, data were collected from 58 children/adolescents and their care givers from the San Diego site. This preliminary sample included 38 PAE and 19 unexposed, ages 3-17 years. From the clinical evaluation, 2 (5.2%) in the PAE group had Stage 1 hypertension; 3 (7.9%) had elevated triglycerides; and 4 (10.5%) had vision abnormalities, while none in the unexposed comparison group had any of these findings. From questionnaire data, 19 (52.8% of the PAE group and 4 (21.1%) in the no PAE group scored in the mild to severe range on the PROMIS Sleep Impairment measure (p=0.043). A total of 11 (31.4%) in the PAE group and 1 (5.3%) in the no PAE group scored in the elevated range on the Spence Anxiety measure (p=0.039). Similarly, 14 (40.0%) in the PAE group and 1 (5.3%) in the no PAE group scored in the high average to very elevated range on the Child Depression Inventory (p=0.009). On the ACES measure 26 (74.3%) in the PAE group and 3 (15.8%) in the comparison group scored in the intermediate to high-risk category (p<0.001).

Conclusion: In this small sample, selected clinical findings suggest that early biomarkers in children with PAE may be important in routine health screenings for children with

PAE. Furthermore, mental health concerns and alterations in sleep were quite prevalent in the PAE group at young ages and merit close follow-up. As recruitment continues and the second recruitment site is added, the target sample size of 200 children/adolescents in this study will help guide future recommendations for families.

C1ii: Social Engagement and Challenging Behaviors in Children with FASD

Riley Felicicchia

Purpose: Fetal Alcohol Spectrum Disorders (FASD) have been associated with challenges in social functioning, which may impact social engagement. There is little research on engagement in social activities and factors that impact social participation in children with FASD. This study aimed to explore social engagement in children with FASD compared to controls and to examine if challenging behaviors impact social engagement in children with FASD.

Methods and Data: As part of a larger research project, data were collected from participants (5-17y) with FASD (n = 147) and controls (n = 82) recruited from a university research program. Caregivers reported prenatal alcohol exposure history and completed the Child Behavior Checklist (CBCL). Social engagement was measured by the subscales from the CBCL Total Competency Scales (social competence and activities), and caregiver-reported number of close friends and time spent with friends. Challenging behaviors were measured by the CBCL Total Problems summary scale. In the first analysis, independent samples t-tests and chi-square analysis were conducted to examine mean differences in social engagement variables in FASD compared to controls. In the second analysis, the sample consisted of only participants in the FASD group (n = 147). Linear regression for continuous outcomes and multinomial logistic regression for categorical outcomes were performed to ascertain the effect of total challenging behaviors on social engagement after controlling for age, sex, ethnicity, and race.

Results: The overall sample was 53.9% (n = 125) male, 68.1% (n = 158) White, and 37.5% (n=87) Hispanic/Latino with a mean age of 11.2y (SD = 3.23). There was a significant difference in social competence in children with FASD (M = 34.98, SD = 9.89) and controls (M = 43.63, SD = 9.38); t(230) = 6.489, p < .001, but not a significant difference in activities. There was significant association between FASD and number of friends, $\chi^2(3) = 35.948$, p < .001, and time spent with friends, $\chi^2(2) = 18.545$, p < .001. The FASD group reported fewer friendships and less time spent with friends. Challenging behaviors significantly predicted social engagement, b = –0.502, t(144) = –4.799, p < .001, $\beta = -.369$, but not activities. Challenging behaviors also significantly predicted the number of friends $\chi^2(3) = 15.776$, p < .001, but not time spent with friends.

Conclusion: Caregivers reported that children with FASD are enrolled in many activities such as sports, hobbies, and other group activities and there is no difference in participation in activities compared to controls. However, results revealed significant differences in social competency, friendships, and time spent with friends. Challenging behaviors were associated with less social engagement but were not related to activity participation. These findings highlight a potential protective factor in that participating in activities may provide valuable opportunities for social skill development in children with FASD. These results also underscore the importance of implementing targeted interventions to enhance social engagement by reducing emotional and behavioral difficulties to better support the needs of children with FASD. Research supported by NIAAA grants U01 AA014834 and F31 AA031883.

C1iii: Learning With FASD: Evaluation of a Research Translation Initiative to Disseminate Evidence-Based Resources on FASD for Secondary School Teaching and Support Staff

Julia Riches

Background:
In Australia it's estimated that FASD affects between 2% to 4% of the general population, which means it is likely there is a child in every classroom with FASD. Adolescence can be a particularly challenging time for young people with FASD. Appropriate supports can greatly reduce the risk of difficulties associated with FASD, such as a disrupted education. There is a significant need for secondary school teaching and support staff to be equipped with evidence-based resources that assist them to create an inclusive and supportive learning environment for students with FASD. Learning with FASD is a research translation website that houses high-quality evidence-based resources to help educators understand and support children with FASD. To date, Learning with FASD has had over 80,000 site users, 165,000 page views and 11,000 resource downloads. Sixty-seven percent of the users are Australian, and 33% are based internationally (including in the United States, Canada and the United Kingdom).

Methods:
We conducted an evaluation (via an online survey) with Australian secondary school teaching and support staff to assess the impact of the website and resources. We used mixed effects logistic regression to investigate changes over time in educators' knowledge, confidence and behaviours with respect to supporting and managing children with FASD in the classroom. For knowledge and confidence, we investigated changes over time in those who said they were "confident" or "very confident" compared with those who said they were "not confident at all", "not very confident", or "somewhat confident". For behaviours, we compared changes over time in those who said they had performed a particular behaviour, compared with those who had not.

Results:
One hundred and twelve educators completed the baseline survey (79% female). Ninety-seven participants completed the follow-up survey three months after the baseline (retention rate: 87%). Overall, Learning with FASD was effective in increasing both knowledge and confidence in relation to FASD. The results revealed that from baseline to three-month follow-up, the odds of being "confident" or "very confident" significantly increased. For example, at follow-up participants were 4.5 times more confident in their knowledge of the presentation of FASD (95% CI: 2.61 to 11.49) and 4.3 times more confident in their ability to recognise a student displaying behaviours or problems consistent with FASD (95% CI: 2.43 to 10.45). The website was also effective at increasing the implementation of behaviours to better support students with FASD

in schools. The odds of implementing FASD-informed strategies to manage behaviour in the classroom increased 2.6 times from baseline to three-month follow-up (95% CI: 1.24 to 4.52). Participants were also 7.2 times more likely to have communicated with a colleague about Learning with FASD (95% CI: 5.74 to 21.52).

Discussion:
The impact of Learning with FASD was clearly demonstrated by the increased knowledge and confidence and reported changes in behaviour from baseline to three-month follow-up. Learning with FASD is
an effective research translation tool to disseminate evidence-based resources and information to build capacity in educators to better support young people with FASD in the school environment.

BREAKOUT SESSION C

C1iv: Enhancing Educators' Capacity to Support Students with FASD: A Participatory Program Evaluation

Stacey Kelsh

Background

To address the complexities of supporting students with FASD, a provincial outreach program (POPFASD) was created in 2006 to build educators' and school districts' capacity in British Columbia, Canada. Working throughout the province for the past 20 years, this provincially funded program has supported over 20,000 BC educators through a variety of FASD-informed resources, training, and support. This presentation will provide an overview of the program and findings from a longitudinal four-year mixed-methods program evaluation.

Objectives of your Research Project

This evaluation utilized a collaborative program evaluation approach. The overarching goal of this evaluation was to examine the effectiveness of this program's training options and support.

Methods

Ethics approval was obtained through the institutional Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. All participants provided informed consent. Data were collected through 6 sources: 1) Pre (n= 1528) and post-questionnaires (n = 382) for program attendees, 2) Annual reports (n= 4), 3) Teacher interviews (n = 6), 4) Program collected feedback, 5) POPFASD leader interviews (n = 6), and 6) Parent and student interviews (n = 2). The quantitative data were analyzed descriptively and inferentially (e.g., ANOVAs). The qualitative data were analyzed thematically using NVivo.

Results

Findings suggest a high level of success in equipping educators with practical strategies for better supporting students with FASD. Most participants (92%) reported that POPFASD had increased their understanding of FASD, and many (66%) described changes in their practice. Six themes were identified from the qualitative data and included: 1) barriers, 2) current strategies, 3) desired training outcomes, 4) benefits of training, 5) integration into practice, and 6) recommendations.

Conclusions

In conclusion, this program evaluation has highlighted the effectiveness of the POPFASD training and framework. Further, we hope this presentation equips participants with a model that could be adapted for use in their context.

C1v: Taking FASD-Informed Care from Research to the Real World: Disseminating, Implementing and Expanding the Families Moving Forward Program

Anika Trancik, Joanne Sparrow, Heather Carmichael Olson

Background/Objectives: There is a pressing need for evidence-based interventions for families caring for youth with FASD. Although a supportive family environment in childhood is a vital protective factor, caregivers raising youth with FASD experience unmet needs and high stress levels. Individuals with FASD have strengths appropriate treatment can enhance. Yet they often face co-occurring risks (e.g., trauma), and without supports/services can show increased rates of adverse life experiences. Promising family-oriented interventions are being developed. Yet few have been empirically tested, and even fewer disseminated and implemented in the "real world."

The Families Moving Forward (FMF) Program team has promoted a continuum of care for families raising children with FASD/prenatal alcohol exposure and behavior problems for over two decades. The team developed and tested the original, relationship-based intervention, now called "FMF Foundations." This caregiver-focused behavioral consultation model has demonstrated efficacy and has now moved from research to community use.

Methods: With CDC research funding, the original FMF intervention was developed, tested and refined by 2010-2011. Then community implementation procedures were developed via sequential implementation projects. Currently, as a business model, the FMF Program Office has created partnerships to sustainably disseminate FMF Foundations into community use. Additionally, research collaborators have used the FMFlogic model, procedures and materials to generate various products that comprise an "FMF Continuum of Care."

The FMF Foundations model incorporates "essential elements" of FASD-informed care (Olson et al., 2023). The team created: (1) intervention and supervision materials for trained mental health clinicians/supervisors; (2) an intervention fidelity and video review process for quality assurance; and (3) implementation materials. FMF Foundations training programs were developed at Specialist, Supervisor and Trainer levels. The FMFWebsite was built, allowing public information and rapid provider access to password-protected materials. Lastly, systematic support was established for agencies and governmental entities interested in implementing FMF Foundations.

Results: Moving an intervention into community use is gradual and labor-intensive, even with promising efficacy data. Multiple barriers must be surmounted. It takes time to develop realistic, effective implementation procedures, especially with limited resources. At the Seattle Children's-based FMF Program Office, systematic dissemination/implementation efforts are ongoing and growing. Currently, 300+ providers from 15 states and 4 countries are trained. A statewide initiative to disseminate/implement FMF Foundations among community agencies in Michigan has been ongoing since 2018, with other statewide initiatives emerging. Additionally, innovative derivative products have emerged based on FMF principles and procedures. Through research and clinical collaborations, these products are expanding the age range and promoting accessibility.

Conclusion: The Families Moving Forward Program experience reveals important components for successfully moving intervention from research to the real world. These are: strategic research funding; promising efficacy data; tenacious staff and key champions; supportive family/provider feedback; productive collaborations to expand the continuum of care; institutional infrastructure; dedicated clinicians/agencies/states able to pay service fees; philanthropic donations to bridge funding gaps; and a sustainable business model. It takes long-term collaboration between family advocacy groups, service providers, and policymakers to make FASD-informed care more available.

C2i: Bridging Care Models: Exploring an FASD-Informed Therapeutic Assessment Model in Inpatient Psychiatric Care

Jasmin Barrett

Background: Individuals with prenatal alcohol (PA) and/or substance exposure (SE) often have complex developmental profiles and increased risk for challenging mental health outcomes later in life. Consequently, individuals with PA/SE experience need for inpatient psychiatric care at greater rates. Inpatient and outpatient settings substantially differ in treatment goals, with inpatient settings primarily focusing on crisis stabilization and outpatient settings primarily focusing on long-term support. In outpatient, comprehensive evaluation, tailored and developmentally appropriate accommodations are central to care. The Specialized Neurodevelopmental Assessment and Consultation Service (SNACS) clinic utilizes an FASD-informed approach providing therapeutic assessment and short-term consultations. Preliminary findings have demonstrated this model's efficacy in meeting family needs in an outpatient setting. This model has not yet been evaluated within an inpatient setting; though given the high rates of PA/SE in inpatient psychiatric settings, the Seattle Children's Psychiatry and Behavioral Medicine Unit has implemented the SNACS model of care to provide families with therapeutic evaluation in co-occurrence with acute crisis stabilization. This talk will explore the feasibility of adapting this model for an inpatient setting, comparing needs and effectiveness across settings.

Methods: We conducted a mixed-methods evaluation of the SNACS clinic, operating in both inpatient and outpatient settings, using pre- and post-assessment caregiver surveys via the Redcap data gathering platform and chart review. Findings will focus on descriptive factors, family needs met, and caregiver clinical outcomes to understand what elements of the model may best be serving patients and families.

Results: Within outpatient settings (N=30), our findings demonstrate that the SNACS model meets caregiver's needs, by providing diagnostic and developmental clarity and tailored appropriate recommendations. Additionally, caregivers report feeling that their child's developmental profile and needs were well supported by providers. In the inpatient setting, 21% of children had confirmed prenatal exposures, indicating a higher prevalence of prenatal alcohol/substance exposure on inpatient units—consistent with previous research. When comprehensive evaluation was offered during acute crisis stabilization, families found this service valuable for planning next steps. While the primary focus of inpatient hospitalization is crisis stabilization, these evaluations serve to address family needs by offering a comprehensive understanding of their child's complexity and developmentally appropriate recommendations to support them after discharge. Providing this service on the inpatient unit also allowed tailoring of accommodations during hospitalization based on therapeutic assessment results.

Conclusion: Findings suggest that a therapeutic assessment model offers meaningful services for children with PA/SE and their families in both outpatient and inpatient settings.
By embedding PA/SE screening, stigma reduction, psychoeducation, and a neurodevelopmental lens – we have found that families feel supported and better equipped to meet their child's needs in outpatient settings. Given the high rates of PA/SE within inpatient psychiatric settings, it is reasonable to utilize this setting, to offer families comprehensive evaluation with the goal of increased neurodevelopmental understanding and connecting families to outpatient services for continued support following discharge. Future studies will seek to explore whether the SNACS model in inpatient settings reduces rehospitalization in this population.

C2ii: From Awareness to Action: Immersive Community-Based FASD Training for Pediatric Care Teams

Kendra Gludt

This presentation describes an in-person immersion training delivery of the SAFEST Choice National Learning Collaborative curriculum for pediatric health care teams to increase their knowledge, confidence, and intent to change practices related to the identification and care management of children with possible or diagnosed FASD.

For over four years the SAFEST Choice Learning Collaborative has successfully trained interprofessional healthcare teams about FASD using the ECHO model that included 10 virtual sessions run over 5-10 months. Because the time commitment of a longitudinal training is not suitable for all healthcare teams, we developed and evaluated a 2-day, immersive, in-person FASD training using the same core curriculum. This in-person immersion program provided interprofessional pediatric health care teams with focused engagement on FASD education and skill-building, and included personal connections to local FASD resources and cross collaboration between clinic teams within a specific geographic area (Los Angeles County). The program included didactics, small group and case-based learning, interactive skills practice and a panel discussion with individuals with living experience. Months after the in-person training, participants were invited to attend and present challenging cases at two virtual “Putting it into Practice” sessions. Using a pre/post-test evaluation design, program outcomes included participation, satisfaction, and changes in participant FASD-related knowledge, confidence, and intent to change practice.

Participants reported they were better able to screen for prenatal alcohol exposure, support patients and families through FASD diagnosis, and provide FASD-informed care and resources. All participants agreed that their FASD-related knowledge increased, which was consistent with the improvements on the objective knowledge assessment. All participants improved their confidence in screening, referring, and providing care for patients with FASD, with 98% stating they planned to make changes in their clinical practice based on what they learned in the training.

The SAFEST Choice National Learning Collaborative successfully trained pediatric healthcare teams in a condensed, in-person immersion training. Participants had increased knowledge and skills related to FASD identification, care management, and demonstrated intent to make practice change. This program offers a promising educational model to improve the care of individuals with possible or diagnosed FASD.

C2iii: Advancing Pediatric Care: Successful Strategies for Supporting Children with FASD

Rosa Arvizu, Hope Barett

Children with fetal alcohol spectrum disorders (FASDs) present with complex developmental, behavioral, and medical needs that require coordinated, family-centered care across the pediatric lifespan. Despite the prevalence of FASDs, many pediatricians continue to report challenges in screening for prenatal alcohol exposure (PAE) and diagnosing FASDs.

In response, the American Academy of Pediatrics (AAP) has prioritized strengthening provider knowledge and enhancing clinical confidence through innovative educational strategies. This presentation highlights the development and implementation of a new practical tool, “A Roadmap to Managing FASDs in the Pediatric Medical Home,” created by the AAP FASD Champions Network. The roadmap translates evidence-based diagnostic frameworks into a concise, mnemonic-based guide that supports clinicians in recognizing key indicators of FASDs, initiating appropriate screening and differential diagnosis, and accessing referral pathways for multidisciplinary evaluation and co-management.

The job aid was developed through a collaborative process involving pediatricians, developmental-behavioral subspecialists, family advocates, and members of the AAP FASD Champion Network. To support dissemination and adoption, the roadmap was integrated into a national Virtual Learning Collaborative (VLC), AAP FASD Toolkit, roundtable discussions, and AAP communication channels, including social media and newsletters.

FASDs remain significantly underdiagnosed or misdiagnosed in pediatric settings, in part due to screening barriers and complex diagnostic approaches. Educational tools like the roadmap can help overcome these challenges by reinforcing foundational knowledge and promoting early identification and coordinated management. This presentation will share lessons learned from AAP FASD programs and discuss ongoing strategies to improve clinical capacity and reduce stigma surrounding FASDs.

C2iv: Australian Occupational Therapists' Awareness, Knowledge and Practice of FASD

Catherine Hilly

Background/objectives: Fetal alcohol spectrum disorder (FASD) is a lifelong neurodevelopmental condition associated with diverse strengths and complex challenges that can impact participation in everyday living and across environments. Occupational therapy is well-positioned to support people with FASD and their families, yet there is limited literature available that demonstrates intervention and management strategies through an occupational therapy lens. Developing a FASD-informed occupational therapy workforce is important across all practice contexts. This research examines Australian occupational therapists' knowledge, awareness and practices in supporting people with FASD and their families, as well as their resources and professional development needs.

Methods: A mixed-methods survey was conducted between May and June 2024. The survey consisted of 23 questions divided into four sections: basic demographic details, knowledge, awareness and practice. Data were analysed statistically using IBM SPSS and with inductive content analysis. Second, semi-structured in-depth interviews were conducted with seven experienced Australian occupational therapists who worked with children and/or adolescents with FASD. Participants were asked to reflect on their practice, including their intervention strategies, evidence-based resources, their perceived confidence and identification of support needs. Reflexive thematic analysis was used to identify key themes.

Results: There were 105 survey respondents, of whom the final analysis included 99 participants. The results showed that there were statistically significant associations between: (i) completing professional development and confidence in recognising FASD ($p< .001$); (ii) having a higher confidence in reliable evidence-based research and preparedness to talk to clients about referrals for FASD assessment ($p < .001$); (iii) therapist preparedness to discuss referring individuals to a medical practitioner on suspicion of FASD ($p< .001$). Qualitative survey results showed limited awareness of occupational therapy-specific guidelines, with occupational therapists relying on existing theory, experience and practice knowledge. Six themes were generated from the in-depth interviews: (i) "developing relationships and maintaining those relationships," valuing child- and family-centred care, (ii) "a full wrap-around of support," the importance of collaborative practice, (iii) "it's part of the picture," FASD knowledge informing clinical reasoning, (iv) "it's more of an eclectic mix," an integration of complex occupational therapy reasoning, (v) "I don't have one for FASD," advocating for diagnosis specific resources, training and knowledge, and (vi) "imposter syndrome is real," occupational therapists' perceived confidence.

Discussion/conclusion: Australian occupational therapists rely on their clinical experience and adaptable, complex professional reasoning to support people with FASD and their families. Access to reliable, evidence-based sources of information and professional development may enhance a FASD-informed and confident occupational therapy workforce. Occupational therapists seek context-specific and occupational therapy-FASD-specific research, resources and professional development.

C2v: Building Better Pathways to FASD Care: National Insights on Clinician Readiness, Cultural Safety and Barriers to Early Identification in Canada

Marwa Ibrahim, Margaux Bouillard

Background/objectives

In Canada, individuals with FASD are undiagnosed or misdiagnosed, despite growing evidence that timely diagnosis and support can improve education, health and life outcomes. Diagnostic services remain concentrated in a few specialized clinics with long wait times and inequitable access. Individuals with FASD often move through primary care, community mental health, justice, and disability services without their needs being recognized as related to prenatal alcohol exposure (PAE). Frontline clinicians in these settings report limited FASD training and discomfort asking about PAE, yet no data exist on how they approach screening, referral and interventions, or how they navigate cultural safety and stigma in practice. This study directly addresses this gap by providing pan-Canadian evidence examining how equipped practitioners are to identify, screen, refer individuals with suspected PAE, and what knowledge and system-level barriers shape early FASD identification and intervention. The study aims to assess clinicians' knowledge and training, describe current screening and referral practices, evaluate preparedness for culturally safe PAE inquiry, and identify barriers and facilitators across regions and professions.

Methods

A cross-sectional, mixed-methods online survey will assess how frontline practitioner capacity relates to underdiagnosis and inequities in FASD identification. Participants include psychologists, physicians, nurse practitioners, social workers, speech-language pathologists, and mental health care workers. Recruitment will occur through provincial and national professional associations, school and clinical networks, and Indigenous-serving organizations. Survey design is informed by the Canadian diagnostic guidelines, Canadian Academy of Health Sciences (CAHS) assessment, and Consolidated Framework for Implementation Research (CFIR). Questions focus on constructs from the CFIR's Characteristics of Individuals domain. Survey sections are organized into three areas: training and knowledge readiness, screening and referral practices, and cultural safety readiness. The instrument includes Likert-scale items, quantitative questions and open-ended responses. A target sample of approximately 200 practitioners is expected, which is sufficient to identify cross-regional trends. The survey will be pilot tested with individuals from FASD specialty teams to refine clarity, cultural sensitivity, and relevance.

Results/Discussion/Conclusion

We will share preliminary national findings on how prepared frontline practitioners feel to identify and support individuals who may be affected by prenatal alcohol exposure, and how this varies by profession, setting, and region. We will describe common practice patterns, including when FASD is considered, how prenatal alcohol exposure is discussed, and what pathways exist for referral and support through interventions. We will also highlight practitioner-identified barriers as well as facilitators and promising practices that may be scalable.

This study responds to urgent CAHS recommendations to strengthen screening, training, and workforce development for FASD in Canada. Furthermore, data on current interventions used in practice will support the development of national guidelines. To date, Germany is the only country that has established guidelines for FASD interventions. The findings will inform future development of a standardized measure to compare intervention outcomes – an urgently needed resource. By mapping current practice patterns and identifying key training gaps and implementation barriers across regions and professions, this project will provide the foundational evidence needed to inform national guidelines, training strategies, and policy planning.

BREAKOUT SESSION C

C3: Seeing the Unseen: How Social Workers Can Transform FASD Identification and Support

Angela Geddes, Anna Webster

Fetal Alcohol Spectrum Disorder (FASD) is one of the most prevalent yet under-identified neurodevelopmental disabilities globally. Conservative estimates suggest approximately 4% of the population may be affected. Yet recent international research (Popova et al., 2024) indicates that fewer than 2% of those who would meet criteria have access to assessment services and receive a formal diagnosis.

This is not simply a clinical gap.
It is a systems and policy failure.

Across child welfare, education, mental health, justice, and social assistance systems, individuals affected by prenatal alcohol exposure (PAE) frequently present with complex cognitive, adaptive, relational, and regulatory challenges. Without structured neurodevelopmental screening and functional assessment, these presentations are often misinterpreted as willful noncompliance, trauma alone, personality disturbance, or parenting failure.

The consequences are significant: service fragmentation, inappropriate interventions, caregiver burnout, preventable justice involvement, and intergenerational harm.

In a world where multidisciplinary diagnostic access remains severely limited due to geography, cost, workforce shortages, and long waitlists, we cannot continue to rely on diagnosis as the sole gateway to understanding and support.

We must change how frontline systems operate.

This session calls for a coordinated shift in practice and policy. We need to prioritize understanding the impact of PAE across all social welfare programs and equip frontline professionals with the tools to build diagnostic clarity over time.

Reframing the Frontline Role

Social workers and allied health professionals are positioned at critical points of system entry. They observe patterns across home, school, community, schools, and justice contexts long before a diagnostic team becomes involved—if one ever does.

Yet most professional training programs do not adequately prepare frontline providers to recognize or screen for neurodevelopmental vulnerability related to PAE.

Rather than functioning solely as referral agents, frontline practitioners must be equipped to:

- Implement structured neurodevelopmental screening
- Conduct meaningful functional assessments
- Document longitudinal patterns across settings
- Contribute high-quality evidence to multidisciplinary teams
- Advocate effectively within and across systems

When we strengthen screening and functional assessment at the frontline, we reduce “wrong doors” for individuals and families—particularly those who are most vulnerable.

Training in neurodevelopment and PAE impact should be foundational—not optional—across social welfare sectors.

Strengthening Diagnostic Clarity Through Collaboration

A central focus of this workshop is strengthening the bridge between frontline social work practice and medical assessment.

Angela Geddes will present structured screening tools, comprehensive functional assessment templates, and neurodevelopmentally aligned documentation frameworks designed specifically to complement multidisciplinary diagnostic teams.

These tools systematically capture:

- Cross-setting adaptive impairments
- Executive functioning patterns
- Emotional regulation differences
- Developmental history indicators
- The interaction between trauma, attachment, and neurodevelopmental vulnerability

This structured, data reduces ambiguity for medical providers and strengthens referrals—particularly in systems where families often present with fragmented histories.

Dr. Clare Mitchell, Developmental Pediatrician, will discuss how medical providers use this organized functional information within comprehensive evaluations. When frontline professionals provide clear, defensible documentation:

- Diagnostic interviews become more precise
- Differential diagnosis is strengthened
- Misattribution decreases

- Assessment efficiency improves

Importantly, this collaborative approach improves outcomes even when prenatal alcohol exposure cannot be formally confirmed or when full diagnostic clarity must be delayed.

Medical providers routinely rely on functional evidence—not solely confirmed exposure—to guide recommendations. Structured social work assessments can therefore support:
- Educational accommodations
- Adaptive functioning supports
- Mental health treatment adjustments
- Environmental scaffolding
- Justice diversion strategies
- Access to funding streams and community resources

Intervention does not need to wait for a diagnostic label.

When functional impairment is clearly documented and collaboratively interpreted, supports can begin immediately—reducing harm and stabilizing families while diagnostic processes continue.

This model strengthens the diagnostic ecosystem. It acknowledges limited access while refusing to allow that limitation to stall care.

Brain-Based Therapeutic Caregiving: A Dual-Track Imperative

Understanding behaviour through a brain-based lens is central to meaningful change.

Children and young people with FASD, ADHD, or autism often experience significant challenges with emotional regulation, executive functioning, relational safety, and adaptive skills. When these needs go unmet, behaviours escalate—and caregivers and practitioners are often left overwhelmed.

Anna Webster will introduce the Neurowise Brain-Based, Dual-Track Approach, which builds upon PACE by integrating neuroscience, Acceptance and Commitment Therapy (ACT), psychodynamic understanding, and behavioural science.

This model is dual-track because it strengthens both:
1. The child or young person
2. The caregiver or practitioner

Caregivers and professionals are regulated nervous systems within the therapeutic environment. Without support for adult wellbeing and psychological flexibility, sustainable implementation is compromised.

By strengthening adult regulation and reflective capacity, the dual-track approach increases adult capacity in precisely the areas where neurodiverse children struggle. This creates a positive ripple effect: more predictable environments, improved relational safety, and practical skill-building aligned with neurodevelopmental capacity.

In contexts where diagnosis is delayed or inaccessible, this approach allows intervention to begin immediately—while collaborative functional evidence continues to build over time.

A Call for Policy and Practice Change

We now know that prenatal alcohol exposure affects a significant portion of the population.
We know that diagnosis remains inaccessible for the vast majority.
We know that misinterpretation fuels stigma and system failure.

Therefore, we must act differently.

We need:

- Mandatory neurodevelopmental and PAE training across social welfare systems
- Structured frontline screening protocols
- Cross-sector collaboration frameworks
- Recognition of functional need—not diagnosis alone—as a basis for support
- Investment in workforce development to build diagnostic clarity over time

Frontline professionals cannot eliminate global diagnostic shortages alone—but they can transform how systems respond in the meantime.

Seeing more clearly together means building diagnostic equity.
It means reducing wrong doors.
It means embedding neurodevelopmental understanding into policy, practice, and training.

Together, we can move from invisibility to accountability.
From fragmentation to coordinated care.
From delayed diagnosis to immediate, meaningful support.

C4 - FASD and Autism Across Development: Distinguishing Social Profiles From Childhood to Adolescence - A Conversational Roundtable

Yasmin Senturias, Roxanne Chang, Tanaporn Jasmine Wilaisakditipakorn, Kimberly Burkhart, Catherine Lipman, Denise Bothe

---

Background / Objectives

Fetal Alcohol Spectrum Disorders (FASDs) and Autism Spectrum Disorders (ASD) are neurodevelopmental conditions affecting social interaction, communication, executive functioning, and adaptive skills. Although overlapping behaviors occur in both childhood and adolescence, the mechanisms differ: FASDs are associated with impairments in executive function, processing speed, memory, and adaptive behavior (Mattson, Bernes, & Doyle, 2019), while ASD reflects intrinsic differences in social cognition, reciprocity, and reward pathways for social engagement (Pelphrey, Shultz, Hudac, & Vander Wyk, 2011). These distinctions persist across development, though adolescence heightens complexity as peer expectations and independence demands increase.

Clinicians frequently encounter diagnostic uncertainty when youth with prenatal alcohol exposure demonstrate autistic-like behaviors (Waite & Burd, 2023), or when both conditions appear plausible. This session aims to:

1. Distinguish social, neurocognitive, and adaptive profiles of FASDs and ASD across development;
2. Identify effective adolescent interventions for FASDs, ASD, or both; and
3. Strengthen communication approaches with families, schools, and teens.

Methods

This 90-minute conversational roundtable includes developmental-behavioral pediatricians, a general pediatrician, and clinical psychologist.

- Two detailed clinical cases highlighting diagnostic dilemmas
- Real-time audience polling
- Panel discussion comparing testing data and contextual information
- Guidance on interpreting neuropsychological findings (executive function, Theory of Mind, adaptive skills)
- Review of intervention strategies informed by developmental stage
- Audience Q&A to integrate multidisciplinary perspectives

Results (Case-Based Learning Examples)

Case 1: FASD With Social Vulnerability

A 15-year-old boy with confirmed prenatal alcohol exposure presents with impulsivity, inconsistent reciprocity, and difficulty following multi-step directions. Elevated Childhood SRS-2 scores indicate concern for ASD, though ADOS-2 findings were nonspecific—a recognized limitation in FASD evaluations (Bishop et al., 2017). By adolescence, rising peer complexity revealed EF-driven challenges: susceptibility to manipulation, conflict escalation, and poor judgment. Testing showed weaknesses in working memory, processing speed, and cognitive flexibility—patterns characteristic of FASD (Riley, Infante, & Warren, 2011). This illustrates how autistic-like behaviors may arise from EF deficits rather than primary social-cognition differences, with important implications for therapeutic approach.

Case 2: Co-occurring FASD + Autism

A 17-year-old girl with prenatal alcohol exposure exhibited limited joint attention, sensory hypersensitivities, and repetitive behaviors in childhood. Adolescence brought persistent reciprocity deficits, rigid interests, and marked sensory distress—features aligning with ASD (APA, 2013). Executive dysfunction and poor adaptive functioning were consistent with FASD. Elevated SRS-2 and CBCL scores, combined with ADOS-2 results, supported a dual diagnosis. Identifying both conditions enabled targeted interventions addressing social cognition, self-regulation, and safety.

Discussion / Conclusion

Distinguishing FASDs from ASD requires recognizing that similar behaviors stem from different neural roots. In FASD, social challenges arise from disruptions in executive functioning, processing speed, and other cognitive deficits (Mattson et al., 2019). In ASD, impairments originate from differences in social-brain circuitry and social motivation (Pelphrey et al., 2011). Adolescence amplifies these patterns.

Accurate diagnosis guides access to services. Effective supports for adolescents with FASD prioritize environmental structuring, EF coaching, predictable routines, and safety planning. ASD interventions often target social communication and sensory needs. Co-occurring diagnoses require blended, individualized approaches.

C5 - Three Generations of FASD: Unmasking Lived Experiences, Trauma, and the Healing Power of Culture

Jenelle McMillan, Sherrie McMillan

Background:
Fetal Alcohol Spectrum Disorder (FASD) is a complex neurodevelopmental condition with significant, often intergenerational, impacts that extend beyond the individual diagnosis to the entire family system. Dominant narratives frequently focus on prevention and clinical aspects, often overlooking the deeply personal, lived experiences of individuals with FASD, their birth mothers, and other caregivers. Furthermore, the role of cultural identity and healing journeys in navigating these challenges is rarely explored in depth.

Presentation Focus/Objectives:
This presentation will use a powerful, multi-generational narrative approach to provide an authentic, first-person account of how FASD has affected our family across three generations. We aim to:

- Enhance a broader understanding of what it is truly like to live with FASD from individual, family, and birth mother perspectives.
- Offer insight into the intersecting impacts of trauma, addiction, recovery, parenting, education, and work life on personal and family relations.
- Highlight the significant role of culture in our lives and its importance in our healing journey.

Methods/Approach:
Our presentation is a qualitative, narrative account based on the shared lived experiences and vulnerable truths of three (four) family members: three individuals with FASD, and a birth mother. This storytelling approach will provide a unique, human-centered perspective, offering a rich and detailed understanding of the challenges and triumphs faced.

Conclusion:
By sharing our vulnerable truths and triumphs, we hope to foster empathy, challenge stereotypes, and promote more compassionate, culturally informed approaches to supporting families living with FASD. Our stories emphasize the need for support systems that address the whole person and family across the lifespan, acknowledging both struggles and inherent strengths.

Attendees will gain valuable insights into the realities of FASD beyond clinical descriptions. Key takeaways include:

- Recognition of the resilience and self-awareness of individuals living with FASD.

- Understanding the systemic and personal stigma experienced by birth mothers and families.
- Appreciation for culturally grounded approaches to healing and support within the context of FASD.

BREAKOUT SESSION C

C6 - FASD Across the Lifespan: Bridging Research, Community Supports for Lifelong Well-Being

Tamara Bodnar, Danna Ormstrup

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong condition that affects brain, body, and behaviour, yet many supports and research efforts remain focused on childhood. This interactive session brings together researchers and community service providers to illuminate the realities, challenges, and opportunities of supporting people with FASD across the lifespan.

Tamara Bodnar will share emerging research focused on adults with FASD, to better understand what health and well-being look like into midlife and beyond. This work explores both biological and social dimensions of health, highlighting not only the risks associated with lifelong neurodevelopmental changes but also the resilience, adaptability, and strengths that many adults with FASD demonstrate. By identifying the factors that promote positive outcomes, this research aims to inform approaches that move beyond deficit-based models toward a more holistic, strength-oriented understanding of adulthood in FASD.

Danna Ormstrup and staff from the Foothills Fetal Alcohol Society will build on these insights through their creative and experiential presentation “A Lot of Hats!”, which explores the diverse roles, communication tools, and relationships that sustain individuals and families living with FASD. Drawing on more than 20 years of experience running the FASD Integrated Response Program in rural Alberta, the team will share real-world examples of how natural and paid supports collaborate to ensure continuity across life stages.

Finally, team members from the Calgary John Howard Society, led by Mark Cruz, Brittany Blake, and Amanda Bitz, will discuss their work with adults with FASD, focusing on adaptive functioning, housing stability, employment, and community integration. Their experiences illustrate how flexible, relationship-based supports can promote independence, dignity, and inclusion, especially during transitions to adulthood and beyond.

Together, presenters will bridge research, practice, and lived experience to demonstrate how integrated, lifespan-oriented approaches can foster resilience, connection, and belonging for individuals with FASD and their communities.

BREAKOUT SESSION C

C7 - Implementing a Process to Support Youth and Families within a Behavioral Health Treatment Modality

Dan Dubovsky, Maggy Cappella, Ephraim Stockwell

Individuals with an FASD may develop mental health issues, often due to struggling with challenges and themselves and their families not understanding why they behave the way they do. Children and adolescents are frequently brought to treatment by families who may hope to "fix" them, and adults may seek treatment to understand their life better. In many instances, treatment providers proceed with therapeutic modalities on which they have been trained. FASD is most often not considered in examining challenges and how to approach them, resulting in approaches that are either ineffective or detrimental to those with an FASD.

An overall goal then is to have treatment settings develop the ability to identify individuals with a probable FASD and work with them and their families to understand them better, identify their strengths and abilities, and utilize those strengths and strategies to help them reach their best potential. For families, helping them view behaviors and not willful and purposeful but rather due to the impact of alcohol on their developing brain and how that informs behavior.

This session begins with an overview of a protocol to identify a probable FASD. Although the gold standard is that this will lead to a diagnostic evaluation, in many instances that may not be available due to a lack of necessary documentation, long waiting lists, or a lack of diagnostic availability. In any of these instances, if we recognize that someone may well have an FASD and has been struggling with typical approaches, we need to intervene as soon as possible to hopefully avoid increased stresses and further mental health concerns.

The session focuses on a Family Based Therapy Program that has implemented this protocol. A discussion of benefits and barriers of implementing this, along with preliminary data and sharing of anecdotal examples of how this protocol has been received is a key component.

C8 - Ability Mapping: A Powerful Tool for Increasing Understanding, Education and Advocacy about FASD (and Other Complex Neurodivergence)

Vanessa Spiller, Elizabeth Elliott

This presentation will showcase how comprehensive FASD assessments (using the new Australian Diagnostic Guidelines (2025)) can be combined with "Ability Mapping" to produce a simple, easily understandable, one-page tool to help families, health professionals and educators better understand, explain, advocate for, and support those living with FASD. Although we will focus on how "Ability Mapping", a visual tool, can be utilised to help understand and support individuals with FASD, we will demonstrate its applicability for others with complex neurodivergence (e.g., Autism, ADHD, ODD, PTSD, etc.) using a case example.

One of the key challenges for supporting people with FASD is explaining their complexity, including both their strengths and weaknesses, to others who need to understand them. This includes schools, support staff, family members, justice workers, professionals, etc., who often need accurate information about the individual's capabilities and needs but are time-poor and may not have time to read long reports, technical assessments, and other documentation. "Ability mapping" enables families and professionals to create a single-page map of a person's underlying strengths and weaknesses across 11 universal brain-based domains of functioning and much more. It can be used as an easily accessible tool to:

Explain the brain-based strengths and weaknesses of an individual young person or adult with FASD

Visually explain why and where individuals with specific patterns of brain-based strengths and weaknesses need supports and accommodations

- Explain and map the brain-based skills and abilities needed to be successful in specific environments, e.g., share house, classroom, workplace, playground, online gaming, etc
- Explain and map the brain-based skills and abilities needed to perform specific life tasks and activities, e.g., playing, filling in a form, attending therapy, waiting in line
- Provide information needed to advocate for and justify funding requests for support within a disability framework, including the right to reasonable adjustments and accommodations in educational, justice and other settings
- Visually explain and map the brain-based reasons for complex behavioural symptoms, e.g., stealing, physical and verbal aggression, sexualised behaviours, by highlighting the crucial role of demand outstripping ability

- Visually explain and map the brain-based reasons why many common behaviour management techniques and traditional parenting strategies may be less effective for people with FASD (and other complex neurodiversities) and how to select more effective interventions

In this interactive session, participants will learn the basics of Ability Mapping, receive practical examples of how it can be used for each of the purposes listed above, and have the opportunity to practice "Ability Mapping" themselves using a clinical scenario.

BREAKOUT SESSION D

D1i) A Neurodevelopmentally Informed Probation Framework: The Collaborative Support Supervision Triad (CSS-T) Model for Individuals with Fetal Alcohol Spectrum Disorder (FASD) Employing the Nash Theory of Equilibrium

Carl Young

This presentation examines why individuals with Fetal Alcohol Spectrum Disorder (FASD) fail probation at disproportionately high rates. While common explanations focus on behavior, this talk proposes that the instability may be structural rather than individual.

Traditional supervision operates as a two-actor system between an authority and an individual under conditions of incomplete information. Authorities cannot directly observe cognitive capacity, and individuals may struggle to communicate their limitations. Despite this uncertainty, supervision systems assume stable executive functioning—consistent ability to plan, remember, organize, and follow through.

FASD challenges this assumption. Executive functioning is often variable and stress-sensitive, meaning capacity fluctuates across contexts. This creates a mismatch between institutional expectations and neurodevelopmental reality.

A key mechanism in this mismatch is linguistic masking. Individuals with FASD may present with fluent, articulate speech, which is often interpreted as evidence of competence. However, expressive language does not guarantee reliable execution of tasks. As a result, institutions may overestimate capacity, and when inconsistencies occur, they are more likely to be interpreted as willful noncompliance.

These dynamics can produce a recurring interaction pattern. When noncompliance occurs, authorities respond by increasing monitoring or sanctions. This increases stress, which further degrades executive functioning, leading to greater variability and additional noncompliance. Over time, this cycle stabilizes into a maladaptive equilibrium in which both actors behave rationally, yet outcomes remain unstable. Neither actor can improve the situation alone.

The Collaborative Support Supervision Triad (CSS-T) introduces a third actor: the Translation and Support Provider (TSP). This role redistributes executive and communicative demands by translating conditions into concrete tasks, buffering stress, and improving information flow between actors.

By reducing cognitive load, stabilizing behavior, and correcting misinterpretation, CSS-T alters the structure of the interaction itself. The model predicts that reducing stress and improving translation will increase compliance stability and reduce escalation.

The central claim is that when systems assume stability in populations characterized by variability, failure is predictable. CSS-T proposes that changing the structure of supervision may change the outcome—an empirical question now open to testing.

D1ii) Reflecting on Prenatal Marijuana Exposure: Why Monitoring for Prenatal Ethanol Exposure Is Essential

Guida Brown

Recent Data on Prenatal Cannabis Exposure

As indicated by a national toxicology study, prenatal cannabis exposure rates are significantly higher in states with medical and/or recreational cannabis laws, with positivity rates reaching up to 30.5% in some regions. This demonstrates how policy, access, and social factors can drive substance use trends among pregnant individuals.

Parallels with Prenatal Alcohol Exposure

Like cannabis, ethanol (alcohol) is a commonly used substance with well-documented risks to fetal development. Fetal Alcohol Spectrum Disorders (FASD) are a direct consequence of prenatal alcohol exposure, leading to lifelong neurodevelopmental and behavioral challenges.

Why Cannabis Data Underscores the Need for Alcohol Monitoring

The robust toxicology data for cannabis highlights several key lessons:

- Substance Use Is Often Underreported: Just as self-reported cannabis use underestimates true exposure, alcohol use during pregnancy is frequently underreported due to stigma and legal concerns.
- Biological Specimen Testing Is Critical: The success of toxicology-based cannabis monitoring demonstrates the value of objective, biological specimen testing (e.g., meconium, umbilical cord, maternal hair) for detecting prenatal alcohol exposure and identifying at-risk infants.
- Policy and Practice Matter: State laws and hospital protocols directly affect detection rates. Consistent, universal monitoring for both cannabis and ethanol is needed to ensure early identification and intervention for affected newborns.

Call to Action for FASD Prevention

The increase in prenatal cannabis exposure should serve as a wake-up call for the medical and public health community:

- Expand Monitoring Protocols: Integrate routine, validated toxicology testing for ethanol exposure alongside other substances.
- Educate and Advocate: Use data-driven insights to inform policy, reduce stigma, and promote maternal abstinence from alcohol and other drugs during pregnancy.
- Protect the Most Vulnerable: Early detection enables timely referral and support for infants exposed to alcohol, reducing the long-term impact of FASD.

D1iii) Stronger Than Stigma: What People with Living Experience Have Told Researchers Over the Past 20 Years

Lauren Perovsek, Kaitlyn Drafton

Background/Objectives:
Individuals with prenatal alcohol and/or substance exposure and their families experience considerable stigma, impacting their well-being, education, and access to care including medical/psychological assessment and treatment. For this community, stigma is multifaceted, not only including discrimination, but also encompassing negative social narratives, biases, and stereotypes. Literature in this area is conceptually scattered, often siloed within independent disciplines (e.g., education, psychology, medicine) and typically unidimensional, focusing solely on one substance exposure (despite polysubstance exposure being a common experience). Within the FASD community, advocacy groups, like the Changemakers, have made significant and positive contributions in bringing light to stigmatizing experiences, providing concrete, actionable steps to reduce stigma and address systemic discrimination. Our review seeks to build upon this important work by sharing what individuals with prenatal exposures and their families have shared with researchers over the past 20 years. This presentation will provide an overview of the current literature that emphasizes the perspectives of those with lived experience as well as highlight gaps and areas for future research.

Methods:
This presentation will review the state of the literature examining stigma within the prenatal substance/alcohol exposure community, including individuals, birth parents, and caregivers. This presentation will include data from an ongoing scoping review. Data was synthesized from a comprehensive search conducted across APA PsychInfo, CINAHL, Embase, Ovid MEDLINE, PubMed, and Web of Science. Search terms targeted concepts of prenatal alcohol/substance exposure and stigma, biases, stereotypes, and discrimination. Empirical peer-reviewed manuscripts were included if they directly addressed stigma experienced by this community from their perspective. Each article underwent an initial title/abstract review, full-text review, and data extraction, double coded by a minimum of two reviewers.

Results:
Four reviewers conducted a scoping review following PRISMA guidelines. Following initial search results (N=13,629), duplicate manuscripts were removed, and the remaining articles were sent to title and abstract review (N=6,288). Findings from a thematic analysis on existing stigma literature will be presented in order to synthesize distinctive patterns and highlight next steps within this area of research. In addition to themes previously presented by changemakers (e.g., insidious stigma, negative labels, stigmatizing language), we will also highlight themes found in

our review, including intersectional stigma, community level stigma, and consequential reduced access to appropriate care. Within this presentation, there will be brief opportunities for attendees to share their own experiences and discuss perspectives on what is missing within the current literature.

Conclusion:
Individuals with prenatal alcohol/substance exposure and their families experience considerable and consequential stigma, shaping their experiences across life. This review underscores the need for a clearer conceptualization and synthesis of the forms of stigma encountered by this community, as well as a call to action for next steps in advancing research and implementing practical stigma reduction. Findings highlight the importance of non-stigmatizing communication and care practices across disciplines (e.g., educational, medical, justice, etc), with particular attention to centering and honoring the perspective of those with living experience.

D2i) Association Between Paternal Alcoholism and Adverse Outcomes Observed in Individuals With PAE Receiving an FASD Diagnostic Evaluation at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network Clinic

Emma Esteve Manley

Background/Objectives: Fetal alcohol spectrum disorder (FASD) is a condition that can result from maternal consumption of alcohol during pregnancy. This condition is characterized by unique facial structural features, brain abnormalities, and growth deficiencies. Prenatal alcohol exposure (PAE) increases the risk of the child developing lifelong disabilities that can affect learning, behavioral, emotional, and physical development. In the last couple of years, researchers are starting to uncover possible epigenetic associations between paternal alcohol consumption and FASD (M.C. Golding presentation at 2025 Seattle FASD conference). The objective of this study is to determine if there is a correlation between paternal alcoholism and adverse fetal outcomes among individuals with PAE attending a FASD diagnostic clinic.

Methods: We will be analyzing data from the Fetal Alcohol Syndrome Diagnostic & Prevention Network Clinic (FASDPN) (n ~ 3,000) at the University of Washington. All patients evaluated in the FASDPN clinic complete a New Patient Information From that includes documentation of potentially inheritable medical conditions including paternal alcoholism. This study will assess if paternal alcoholism is correlated with increased magnitude of adverse outcomes and FASD diagnoses among patients with PAE.

Results: From looking at a subset of data of about 300 patients, we have found the relationship between paternal alcoholism and increased adverse outcomes and FASD diagnoses to be statistically significant. Full results are still pending will be completed by the conference in April 2026

Discussion: The results of this study will be compared to outcomes published to date on paternal alcohol exposure and fetal growth and development. As stated by Golding, because maternal and paternal alcohol use is interrelated, there is now an urgent need to understand how male drinking interacts with maternal alcohol exposures to influence and potentially exacerbate FASD outcomes.

D2ii) Impacts of Prenatal Alcohol Exposure on Neurobiological, Psychopathological, Behavioural, and Cognitive Outcomes Across Adolescence: An Adolescent Brain Cognitive Development (ABCD) Study

Emma Devine

Background: Globally, 9.8% of women consume alcohol during pregnancy, with this prevalence being variable and higher in regions such as the United States. Research to date has tended to focus on the impacts of heavy PAE during pregnancy, finding it to be linked to a host of adverse outcomes, the most disabling of which is FASD. However, less is known about the impacts of low and moderate levels of exposure, despite this being the most common form of alcohol consumption during pregnancy. Moreover, there is a lack of research investigating how PAE impacts development across adolescence, a period characterised by dynamic biological and psychosocial changes. The Adolescent Brain Cognitive Development (ABCD) Study provides a unique opportunity to address these research gaps.

Methods: Participants were a demographically matched sample of 4,840 adolescents from the 6.0 data release of the ABCD Study. PAE was conceptualised as 1) a binary categorical variable reflecting any alcohol use at any time during pregnancy, 2) the total number of drinks consumed during pregnancy, and 3) PAE exposure patterns, including abstainers, use throughout pregnancy, and use early in pregnancy only. PAE variables and covariates were derived from the baseline assessment wave (ages 9-10), while the outcome variables were obtained from all assessment waves for which they were available (ages 9-17). Using a series of Generalised Additive Mixed Models (GAMMs), we investigated the impact of PAE on the following outcomes over adolescence: structural neurobiology, psychopathology, motivation, impulsivity, cognitive assessments of memory, attention, and executive functioning, and school grades.

Results: Overall, there was a trend for those with any PAE to present with distinct developmental trajectories across the neurobiological, psychopathological, motivational, impulsivity, and cognitive outcomes, when compared to those without PAE. Interestingly, our dose response hypothesis, which stated that PAE would be associated with attenuated or poorer outcomes in a dose response manner, was not consistently supported. Instead, the timing of PAE had the greatest impact, particularly exposure early in pregnancy, which occurred prior to knowledge of pregnancy. Looking first at the neurobiological outcomes, we found that those who were exposed to alcohol early in pregnancy tended to show less growth in subcortical volumes and cortical surfaces areas, and either less growth or steeper declines in cortical thickness and volume. Across the psychopathological, motivational, impulsivity and cognitive outcomes, there was a trend for those exposed in early pregnancy to have greater symptomatology in early adolescence but then to show less growth, or a greater decline, in symptoms across adolescence.

Discussion: PAE, even at low levels, is associated with altered developmental trajectories across adolescence, and understanding these variable impacts has important implications for the provision of appropriate supports for individuals with PAE. Our findings also indicate that those exposed to PAE early in pregnancy may be particularly susceptible to attenuated outcomes. This finding further underscores the importance of PAE prevention efforts targeting the preconception period to optimise future population health.

D2iii) Prenatal Alcohol Exposure and Nailfold Capillary Morphology in Children Aged 3–17 Years: Preliminary Results

Florencia Anunziata

Background

Individuals with Fetal Alcohol Spectrum Disorders (FASD) show elevated rates of chronic health conditions — including hypertension, diabetes, and autoimmune disorders — at earlier ages than the general population. Growing evidence suggests children with prenatal alcohol exposure (PAE) may follow an accelerated cardiometabolic risk trajectory, yet reliable early biomarkers remain largely unidentified. Nailfold video capillaroscopy is a non-invasive imaging technique that visualizes the microvasculature at the fingertip, offering a window into systemic vascular health. In adults, microvascular changes have been linked to hypertension, metabolic dysfunction, and inflammation; pediatric applications have been limited primarily to rheumatologic conditions. Whether similar microvascular alterations are present in children with PAE, and whether they could serve as early biomarkers of cardiometabolic risk, has not been previously investigated.

Learning Objectives

1. Identify early microvascular alterations detectable in children with PAE and their relevance as potential biomarkers of cardiometabolic risk.
2. Describe how nailfold video capillaroscopy can reveal subclinical vascular changes in pediatric FASD populations.
3. Discuss how early physiological detection in PAE populations can inform pediatric screening, prevention, and long-term health strategies.

Methods

This study is part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), a multi-site NIAAA-funded consortium, designed to examine subclinical and clinical indicators of chronic disease in children and adolescents with and without PAE. The full target sample size includes 120 participants with confirmed PAE and 80 with no or minimal exposure, recruited across two sites (UC San Diego and Emory University). Participants complete a single clinical session encompassing physical examination, health questionnaires, blood and saliva biomarkers, cognitive assessment (NIH Toolbox), 3D facial imaging, and nailfold video capillaroscopy. This preliminary report presents data from the nailfold video capillaroscopy measure collected at the UC San Diego site. Using a high-resolution video microscope (Optilia Instruments), capillaroscopy was used to assess microvascular quantitative measures (capillary density, average width, inter-capillary distance) and qualitative morphological abnormalities (enlarged, branched, crossed, multi-crossed, broken capillaries). Inter-rater reliability was high across all metrics (ICC > 0.80). Group differences were examined using least-squares linear regression adjusting for age and sex.

Results

This preliminary sample included 37 children aged 3–17 years (mean age 9.1 ± 4.4; 51.4% male): 27 with confirmed PAE (mean age 8.3 ± 4.0 years; 52% male) and 10 with no or minimal PAE (mean age 11.2 ± 4.7 years; 50% male). After adjusting for age and sex, children with PAE showed significantly lower capillary density (9.4 ± 2.6 vs. 13.2 ± 3.0 cap/mm; $p < 0.001$), wider average capillary width (43.9 ± 11.4 vs. 35.2 ± 6.1 µm; $p < 0.01$), greater inter-capillary distance (171.3 ± 28.9 vs. 136.6 ± 27.3 µm; $p < 0.01$), and a higher proportion of enlarged capillaries (71.4 ± 19.1% vs. 46.6 ± 13.8%; $p < 0.001$) compared to controls. Notably, the PAE group was younger on average — an age at which density is expected to be higher — making the density difference particularly striking. Enlarged capillaries are of clinical interest given their established associations with inflammation and autoimmune conditions in children, and with pre-hypertension and metabolic dysfunction in adults. Other morphological abnormalities were numerically higher in the PAE group but did not reach statistical significance.

Conclusion

These preliminary findings reveal a pattern of microvascular alteration in children with PAE that is detectable as early as age three using a non-invasive, low-cost imaging technique. If replicated in a larger multi-site sample and linked to concurrent cardiometabolic measures (e.g., blood pressure, lipids, body mass index, sleep, and dietary patterns), nailfold capillaroscopy could serve as an early biomarker to identify children with PAE at heightened risk for future cardiovascular or metabolic disease, enabling earlier and more targeted intervention in this vulnerable population.

Funding: Supported by the National Institute on Alcohol Abuse and Alcoholism (NIAAA) within the CIFASD consortium.

D3 - Celebrating Families!: A Community-Based, Trauma-Informed Whole-Family Approach to Healing Intergenerational Substance Use and Supporting Families Living with FASD

Mary Beth Collins

Background/Objectives

NACoA (National Association for Children of Addiction) incorporated Celebrating Families! (CF!) to fill a critical gap in prevention and intervention for families impacted by substance use disorders (SUDs), including fetal alcohol spectrum disorders (FASD). CF! is a strength-based, culturally inclusive, whole-family curriculum developed specifically for families dealing with or at high risk for complex problems: substance use disorders (SUDs); intergenerational trauma; physical and mental health challenges; cognitive deficits due to trauma, genetics, or in-utero substance exposure; and safety (child abuse/neglect and family violence). CF! addresses these needs through nurturing healthier living by incorporating education and skill development in every session, resulting in strengthening relationships within the family, improving resilience, and increasing protective factors. This program operates across systems — including treatment courts, child welfare, community health, and incarceration reunification settings — supporting healing and breaking intergenerational cycles of trauma and substance misuse.

Methods

CF! delivers 16 interactive sessions to families using an evidence-informed, trauma-responsive framework. Sessions are co-facilitated by trained professionals and paraprofessionals. The program empowers families with tools for healthy living, including nutrition, sleep, exploring emotions, and positive communication. The program addresses substance use and mental health challenges in every session, helping all family members learn how to trust, identify feelings, and communicate in a healthier way. Education support groups place families into peer groups to discuss topics age appropriately. Parents develop the skills needed to strengthen sobriety, nurture relationships, and improve safety for the family. Through a growing respect for the whole person, every member of the family learns how to identify and celebrate individual strengths and examine challenges/anxiety/depression/learning disabilities, and FASD and how to connect to appropriate resources for support. Increased sensitivity is provided to parents who often evaluate the impact of their behavior/substance use on their children, as well as the impact from their own parents' behavior/substance use. The curriculum is adaptable to various cultures and settings, and includes modules specific to justice-involved families, caregivers in recovery, and kinship care providers.

Results

- Significant increases in effective parenting skills, including positive discipline strategies

- Strengthened protective factors: 80% increase in family meals, emotional expression, and community service engagement
- 93% no longer used substances to cope with emotions like sadness or anger
- 91% of children reported they feel “more hopeful about their family’s future.”
- 89% of parents talk to their children about feelings

- 89% of parents reported improved communication and connection with their children.
- 83% of participants said they use fewer harmful coping strategies post-program.
- 100% of parents said they are good at protecting their child’s safety.
- 94% of parents are now strong advocates for their children.

Discussion/Conclusion
CF! exemplifies a public health approach to FASD prevention and supportive intervention — one that centers families and recognizes the lifelong impact of relational health. It supports systemic change by equipping communities with tools to respond compassionately and effectively to families with complex needs. This session will share practical implementation tools, evaluation outcomes, and guidance for adapting CF! across sectors and cultural contexts.

Presentation Summary: Learning Objectives (read-only)
Identify key components of the CF! curriculum and how it supports relational health, FASD prevention/intervention.
Describe strategies for cross-system collaboration in delivering trauma-informed, family-centered care.
Explore approaches to adapting CF! to various cultural and justice system settings without stigmatizing families.

D5 - The Animation Curriculum: Acceptability, Feasibility and Engagement of a Specifically Designed FASD Educational Intervention in Two Mainstream Classroom Settings

Jessica Rutherford, Stacey Kelsh

This presentation begins with POPFASD programme lead and educator, Stacey Kelsh offering the perspective of an FASD-informed educator in British Columbia, Canada, discussing the complexities of supporting students with FASD in a school setting alongside many other students with their own complexities, and highlighting the increased difficultly if the educator's approach is not FASD-informed. Drawing on many years of experience as an educator supporting many students with FASD, Kelsh identifies that students experience the most success when we utilize their strengths and interests, understand their unique needs and challenges, and create environments that promote learning. This learning environment includes structure, routine, repetition, consistency, clarity, and strong relationships.

Jessica Rutherford, in response, describes this feasibility study assessing the acceptability, logistical implications of and student engagement with The Animation Curriculum, a novel educational intervention which uses arts practices to deliver curricular content to students aged 7 to 10 years. The Animation Curriculum is a seven module, cross curricular programme acting as a mode of delivery through which a whole class of students completes a series of tasks and actions producing a series of outputs. This approach is multi-sensory, tactile and multimodal with a strengths based approach for those with FASD. Through this feasibility study, educators at a school in North East England and British Columbia, Canada (supported by POPFASD) identify topics of learning to be delivered to the class before completing training in The Animation Curriculum delivery and working closely with researchers to produce detailed delivery documentation to support the specific needs of their class population in line with the chosen topic of learning.

A mixed method approach collected both quantitative and qualitative data showing promising results, with students with FASD scoring 0.42 points (of 28 total) lower on the Engagement Scale (Carpenter et al, 2015.) than the class as a whole across each module. Interviews with teachers were carried out and thematic analysis completed using NViVo with teachers stating, "this is up there with the most engaging thing these kids have had", "they learned so much more than I was expecting", "I was quite worried about doing it right but once we started the students just got on with it" and "they worked the entire session, which is so unlike them".
The presentation concludes that this approach could be highly valuable for this population, and ends with an open discussion around our plans for Phase 2 as we aim to expand across more school districts and more countries to scale testing before moving towards a Randomised

Control Trial in Phase 3. Conclusions are supported by Kelsh who adds, "POPFASD sees this inclusive approach as a viable and valuable approach for educators, and we are happy to support its development and implementation."

D6 - Breaking the Myth of Independence Making Invisible Supports Visible

Tami Eller, Julianne Myers

Background:
Dominant societal culture promotes transitioning to adulthood at 18, with independence as a sign of success. This independence is typically marked by actions such as leaving home to pursue secondary education, getting a job, or joining the military. Often, individuals who need support to achieve these milestones are deemed a “failure to launch”, thus increasing stigma for themselves and their families. Many individuals with fetal alcohol spectrum disorders (FASD) frequently benefit from additional time and support in the transitioning years, yet often do not qualify for traditional or formal systems. A “safety net of interdependence” is needed for individuals with FASD to avoid the effects of systems’ inequity, including challenges of adaptive, social-emotional, and occupational well-being. By considering the components of interdependent growth seen through existing systems of scaffolding adulthood (e.g., college), we can break down the myth of independence as a normative goal.

Methods:
This presentation will engage participants in interactive activities that promote critical examination of how society provides a built-in “safety net of interdependence” for many young adults launching into adulthood, and, further, how this “safety net” is often inaccessible to those with FASD. We will discuss how interdependence is so ingrained for those in our society who frequently unknowingly rely upon through systems such as the military and secondary education. The audience will identify how these systems provide a scaffold in areas of financial, social, adaptive, and employment, therefore allowing young adults to slowly learn and take accountability for full adult responsibilities in a safe and managed environment. Lastly, participants will leave with a tool for developing an individualized “safety net of interdependence” plan for individuals impacted by FASD.

Results:
Based on living experience and lessons learned, presenters have seen ways that the process of scaffolding adulthood may help individuals gain necessary skills for interdependent autonomy through the challenges of transition. Attendees increase their understanding of how individuals with FASD may benefit from breaking the myth of independence, normalizing interdependence, and building a safety net that allows them to reach their fullest potential while maintaining autonomy. Through this workshop, participants will gain an understanding of how to challenge beliefs about the “myth of independence,” identify accommodations needed for neurocognitive differences in those with FASD, and use concrete tools to create an adequate “safety net of interdependence.”

Discussion:

Society outside formal systems—such as secondary education, military service, or formal disability services—is not designed as a safety net for those with FASD as they launch into adulthood. Drawing on lived experience, lessons from providers, and a critical examination of societal supports, it is clear that more scaffolded supports are needed. Utilizing tools and exercises in this presentation to create a “safety net of interdependence” will help individuals with FASD, caregivers, and providers to reimagine what transitioning to adulthood looks like in FASD. As we challenge the idea of independence, we can reduce stigma and shame, as well as systemic inequalities for individuals with FASD.

D7 - Integrated Care for Adolescents with FASD: A Community Clinic Model in Los Angeles

Michele Walker-Bauer, Haylee Turner, Ana Cardenas Rolon, Janis Yue, Stephani Gharehptian

Adolescents diagnosed with an FASD present biopsychosocial complexities requiring significant support from caregivers, educators, and other providers to increase resiliency and promote positive outcomes. Numerous studies reveal challenges teens with FASD face as they navigate developmental processes of adolescence. These include disability identity processing and formation (Eodanable et al., 2024), establishing and maintaining safe and meaningful relationships, and developing adaptive living skills (Åse et al., 2012).

Teens with this neurodevelopmental condition face many barriers to accessing appropriate and informed care, especially in the child welfare system (Palk & Wekerle, 2025). Barriers include diagnostic complexity and stigma, limited professional knowledge and training, and systemic problems of service availability and eligibility (Petrenko et al., 2015). Treatment for adolescents with FASD is critical due to increased vulnerabilities to substance use, high-risk sexual behavior, and other high-risk activities (Paley & O'Connor, 2011). However, strengths-based interventions are also crucial to building resiliency and improving quality of life (Petrenko & Kautz-Turnbull, 2021).

The Violence Intervention Program (VIP) is a community-based mental health clinic in Los Angeles. VIP is the only clinic providing specialized FASD-informed and trauma-informed services for children and adolescents in Southern California. This presentation highlights services to support adolescents with FASD and their caregivers offered at VIP.

Initiated in 2006, the LA General HUB FASD Medical Clinic is a high volume, single provider assessment model for youth involved with child welfare and the larger community. A pediatrician or nurse practitioner complete a physical exam, caregiver interview, and review existing documents in order to classify physical and medical findings, evidence of functional impairment, and determine prenatal history to determine if criteria are met for an FASD diagnosis. Once an adolescent is diagnosed with an FASD or suspected of having an FASD, a report is completed with recommendations for FASD-informed client-centered and caregiver-focused supports/services. In 2024, given increasing demand, a public-private partnership between LA General Medical Center and VIP resulted in a pilot project to increase FASD screening/assessment capacity.

With a growing complement of services over the years, VIP now provides adolescents with an individualized menu of trauma- and FASD-informed individual therapy, family therapy, occupational therapy, neurofeedback, rehabilitation services, case management, and psychiatric services. Additionally, strengths-based rehabilitation groups focused on disability processing, health relationships, and life skills were developed and implemented to support holistic development of teens with FASD. Caregivers are an essential part of treatment for teens with FASD. Therefore, VIP provides Triumph Through the Challenges of FASD parenting classes and (with permission) has piloted use of Families Moving Forward (FMF) Foundations, an evidence-based intervention, to support caregivers of teens. Ongoing caregiver support is also provided through a monthly parent support group.

Beyond direct services, since 2009, VIP clinical staff have trained LA County providers (mental health, DCFS, educators, medical and legal professionals) to increase awareness of FASD as a lifelong condition. VIP clinical staff work with FASD advocacy groups at county and state levels. Future programmatic improvements will include direct involvement of self-advocates and family advocates in the FASD continuum of care at VIP (Skorka et al., 2024).

Learning Objectives:

1. Understand the full range of services (continuum of care) provided directly to adolescents with FASD and their caregivers at a community mental health clinic
2. Analyze why VIP offers this continuum of care to adolescents with FASD, given the developmental processes unfolding during adolescence among teens with neurodevelopmental diversity
3. Examine the strengths and challenges of VIP's screening/assessment, intervention, and education and advocacy processes

PLENARY

The Power of Knowledge: Insights from Birth Moms

Yolanda Ross, Julie Gelo, Jenelle McMillan

PLENARY

Half the Equation: Why Fathers Matter in FASD Risk

Siara Rouzer

Fetal Alcohol Spectrum Disorders (FASD) are among the leading preventable causes of neurodevelopmental disability and have traditionally been attributed exclusively to maternal alcohol use during pregnancy. While this maternal focus has yielded critical advances in prevention and diagnosis, it has also created a major gap in understanding the full range of biological and environmental factors that contribute to intergenerational risk. This session will examine emerging evidence demonstrating that paternal alcohol exposure prior to conception represents an important, but underrecognized, contributor to offspring development and neurobehavioral health.

The session will begin with a brief historical overview highlighting how paternal contributions to offspring health have been documented for over a century but were largely deprioritized following the initial clinical description of FASD in 1973. This context sets the stage for understanding why paternal exposures remain absent from most diagnostic criteria, screening tools, and prevention frameworks.

The presentation will then review findings from large-scale human studies demonstrating associations between paternal alcohol use disorder prior to conception and increased risks of stillbirth, infant mortality, and long-term health complications in offspring. Clinical cohort studies further show that paternal drinking patterns are associated with measurable differences in child growth and cognitive function, even after controlling for maternal alcohol and tobacco exposure. Notably, the greatest impairments are observed when both parents consume alcohol, suggesting that dual-parental exposure may interact to shape developmental outcomes in ways that cannot be explained by maternal exposure alone.

To complement these human findings, the session will present results from controlled preclinical mouse models that isolate maternal, paternal, and combined parental alcohol exposure. These studies demonstrate that paternal alcohol exposure alone can produce sex-specific alterations in offspring anxiety-like behavior and compulsive-like responding. Furthermore, dual-parental exposure generates distinct behavioral phenotypes not observed following single-parent exposure, including altered novelty preference and disrupted circadian-patterned activity. These findings provide experimental evidence that paternal alcohol exposure contributes directly to offspring neurobehavioral outcomes and may influence neural systems involved in motivation, stress regulation, and addiction vulnerability.

Because fathers do not gestate or directly interact with the developing fetus during pregnancy, the session will next focus on biological mechanisms that may explain these intergenerational effects. Emerging research demonstrates that sperm carry epigenetic information beyond DNA sequence, including DNA methylation patterns, retained histone proteins, and small regulatory RNAs. Alcohol exposure can alter these molecular signals, which in turn can influence gene expression during early embryonic development and shape long-term brain and behavioral trajectories. These findings provide a biological framework linking paternal alcohol exposure to offspring developmental outcomes.

Finally, the session will discuss implications for research, clinical practice, and public health. Incorporating paternal alcohol history into FASD risk assessment may improve identification of vulnerable individuals and help explain variability in outcomes among children with similar maternal exposures. Expanding research to include paternal contributions will also improve mechanistic understanding of intergenerational transmission of neurodevelopmental risk and identify new targets for prevention and intervention.

Overall, this session will challenge the traditional maternal-only model of FASD by presenting multidisciplinary evidence that paternal alcohol exposure is a meaningful and modifiable contributor to offspring health. Recognizing the role of both parents is essential for advancing scientific understanding, improving prevention strategies, and promoting healthier outcomes across generations.

PLENARY

Expanding FASD Prevention: Combined Parental Alcohol Use Shapes Offspring Aging and Chronic Disease Risk

Michael Golding

Background & Objectives

Parental alcohol use disrupts mitochondrial function and redox homeostasis, which contributes to the conditions seen in fetal alcohol spectrum disorders (FASDs). However, the long-term effects throughout an individual's lifespan—especially when both parents consume alcohol—are not fully understood. Our studies explored how paternal alcohol use before conception and maternal alcohol exposure around the time of conception, both individually and together, impact offspring aging, systemic inflammation, and disease susceptibility. We particularly focused on conditions that exhibit additive effects in offspring exposed to alcohol from both parents.

Methods

We employed a 2×2 parental exposure model to compare the effects of no alcohol use (Control) with Maternal, Paternal, and Dual-Parental alcohol use, focusing on long-term health outcomes in C57BL/6J mice. Initially, we evaluated aging phenotypes in middle-aged adult offspring (postnatal day 300) by measuring mitochondrial activity, the NAD^+/NADH balance, oxidative stress, inflammatory cytokine production, and cellular senescence in both brain and liver tissues. Following this, we investigated susceptibility to hepatocellular carcinoma after neonatal injection of diethylnitrosamine (DEN), assessing tumor incidence, multiplicity, fibrosis, steatosis, inflammation, and dysfunction of mitochondrial complex I.

Results

Both maternal and paternal alcohol consumption independently reduced mitochondrial function, decreased NAD^+/NADH ratios, and increased oxidative stress and inflammatory markers. The offspring exhibited heightened senescence-associated β-galactosidase activity and histological signs of age-related liver disease. Notably, male offspring from parents who both consumed alcohol displayed the most severe phenotypes, including more significant liver fibrosis, oxidative damage, and senescence than those from single-exposure cases. In the diethylnitrosamine (DEN) model, offspring from dual-exposed parents had the highest incidence and multiplicity of tumors, along with worsened steatosis, fibrosis, elevated IL-6 levels, and impaired complex I function, surpassing the effects seen with single-parent exposure.

Discussion & Conclusions

The findings indicate that both maternal and paternal alcohol consumption can accelerate aging, promote chronic inflammation, and increase the risk of cancer in offspring. Notably, when both parents drank alcohol, the effects were cumulative, leading to greater mitochondrial dysfunction and more severe health outcomes than when only one parent consumed alcohol. These results highlight the need to consider paternal influences in research and prevention strategies related to fetal alcohol spectrum disorders (FASD). To mitigate long-term health risks for children, preconception interventions and messaging should address both parents.

PLENARY

Addressing Mental Health in Teens with FASD: Building Accessible and Community-Informed Treatment Approaches

Madeline Delage

Background: Teens with FASD experience high rates of mental health challenges. Yet few evidence-based therapies have been formally adapted or tested for this population. Dialectical Behavior Therapy (DBT) is a promising intervention for teens with FASD, given its focus on emotion dysregulation and interpersonal skills. This talk integrates findings from a systematic review of DBT for neurodivergent populations, a community-engaged adaptation of DBT for teens with FASD, and a mixed-methods feasibility trial of the adapted program. This talk will then show attendees how to systematically adapt mental health interventions for this population moving forward.

Learning Objectives:

1. Understand current gaps and opportunities in mental health interventions for teens with FASD.
2. Identify key adaptations that make mental health treatment more accessible, relevant, and effective for teens with FASD.
3. Explain how community-engaged and implementation science approaches can guide the adaptation of evidence-based mental health treatments to improve accessibility and sustainability in real-world clinical settings.

Methods: First, a systematic review was conducted to examine the effectiveness of DBT with neurodivergent youth, examine existing program adaptations, and understand the barriers and facilitators to program implementation. Next, we gathered community-member input from an advisory board of teens with FASD, as well as broader community input from caregivers and DBT clinicians through qualitative interviews and an online survey. A formal adaptation of DBT program materials was then undertaken, guided by the community members' feedback. The adapted intervention was then implemented in a mental health clinic with teens with FASD, their caregivers, and DBT clinicians. Data included measures of mental health symptoms, treatment engagement, fidelity ratings, and qualitative interviews assessing feasibility and acceptability.

Results: The systematic review identified an urgent need for effective mental health supports for neurodivergent youth, alongside a growing body of evidence supporting DBT's effectiveness for this population. It also highlighted the importance of adapting interventions to improve accessibility and overall fit. Throughout the adaptation process of DBT for teens with FASD, input from teens, caregivers, and clinicians underscored the value of simplified materials, slower pacing, and concrete examples. Community members emphasized that successful implementation required repetition, hands-on learning, and strong caregiver-clinician collaboration. As part of the adaptation, a comprehensive package was developed, including an FASD-adapted DBT manual, slide decks for group sessions, participant workbooks, and clinician training on FASD. In the feasibility trial, both teens and caregivers reported satisfaction with the adapted program, endorsed emotion regulation and relationship improvement, and provided suggestions for further refinement. Clinicians underscored the intervention's compatibility with existing DBT structures and highlighted the usefulness of the adapted materials as well as training to effectively serve teens with FASD.

Discussion: This work demonstrates the need for and feasibility of FASD-informed mental health interventions, designed with the community it aims to serve. This project provides a replicable model for a systematic approach to adapting evidence-based interventions for neurodivergent youth. Together, these findings support a broader shift toward participatory, implementation-focused mental health research that values living experience as essential expertise. Future directions include a larger-scale trial, dissemination of training materials and manuals, an intervention adaptation model for FASD, and continued collaboration with community members. This will provide an essential foundation for developing accessible mental health care for neurodivergent youth.

E1i: Navigating Young Adulthood with FASD: Goals, Challenges, and Role of Social Support Networks

Emily Speybroeck, Sam Moehlig

Background: Young adulthood is a critical period of transition, marked by increased independence and the need to navigate complex social, educational, and employment environments. For individuals with fetal alcohol spectrum disorders (FASD), this transition is particularly challenging. Limited resources exist to support young adults with FASD, leaving many without adequate guidance as they age out of childhood services. This study aims to address this gap by exploring the daily lives, goals, and social support networks to inform intervention development.

Methods: Two qualitative interviews were conducted with 17 young adults with FASD, 14 of whom completed a second qualitative interview. Interview 1 focused on understanding participants' daily lives, including employment, education, social life, transportation, strengths, and strategies for success. Participants also completed a card sort activity to visually prioritize their current goals. The three top ranked goals were discussed with regards to facilitators and barriers for goal progress. Interview 2 used Network Canvas software to create a detailed map of the participants' social network, identifying key relationships and types of support (e.g., emotional, financial, daily tasks). Rigorous and Accelerated Data Reduction (RADaR) was used to organize and condense data into manageable data tables. Thematic analysis was then employed to identify patterns and themes, providing insight into participants goals and support systems.

Results: Findings revealed key insights into the daily lives, challenges, and support networks of young adults with FASD. Most participants held part-time jobs in retail or restaurants, and some were not employed due to full-time schooling or difficulties related to FASD symptoms. Employment challenges included understanding multi-step instructions and interacting with customers. Socially, participants often had small, close friend groups or relied on online interactions, but faced challenges in maintaining friendships and feeling understood. Transportation was a significant focus, with many participants working toward obtaining driver’s licenses. Participants identified strengths such as personal characteristics, skills, and prosocial behaviors, while strategies for success included routines, relaxation techniques, and social support. Barriers included mental and physical health challenges, executive functioning difficulties, and limited autonomy. The top three most cited goals of this sample were physical health, relationships, and employment. The least cited goals were in the areas of medication management and housing. Social networks primarily consisted of family, friends, coworkers, and therapists, with parents providing material and daily task support. Participants desired greater autonomy and increased in-person social support, particularly from friends.

Discussion: Interviews provided valuable insights into the unique needs, strengths, and challenges of young adults with FASD. By understanding daily life, goals, and social support networks, researchers and practitioners can develop interventions that address barriers to success while leveraging existing strengths and supports. These findings can serve as a foundation for future research and program development aimed at supporting young adults with FASD during this critical transitional period.

E1ii: Cardiovascular Disease in a Retrospective Cohort of Adults with FASD

Olivia Weeks

Background: Fetal alcohol spectrum disorders (FASDs) impact up to 5% of U.S. school age children; however, the incidence of congenital and acquired cardiovascular disease in current FASD patient populations is largely undocumented.

Methods: To test the hypothesis that prenatal alcohol exposure (PAE) predisposes to congenital heart defects (CHDs) and cardiovascular disease (CVD), we conducted a retrospective cross-sectional study examining metabolic and cardiac health outcomes in adults with FASD. Using a Research Patient Data Registry, we identified patients >18 years with a FASD (n = 208) and controls matched for age, sex, and race/ethnicity (n = 824). The FASD cohort had a mean age of 38.4±14.5 years at evaluation.

Results: Consistent with prior literature, we found that the FASD cohort had a higher incidence (p<0.05) of low high-density lipoprotein, high triglycerides, hyperlipidemia, overweight/obesity, and type 2 diabetes mellitus, which are risk factors for CVD. The FASD group was also more likely (p<0.001) to have a CHD (6.3%) than controls (1.2%). Additionally, the FASD group had a higher incidence of CVD diagnoses, with significantly (p<0.05) more FASD patients experiencing heart failure (6.3% vs 2.3%), adult structural heart changes (10.6% vs 5.2%), myocardial infarction (5.8% vs. 1.5%), cardiac arrhythmia (8.2% vs. 3.5%), stroke (3.9% vs 0.7%), and thrombosis/embolism (4.3% vs 1.1%). We identified an interaction between sex and age-adjusted rates of hypertension, cardiac arrhythmia, and heart failure, with FASD females but not males displaying significantly higher rates of diagnosis relative to matched controls. Unexpectedly, rates of atrial fibrillation and atrial remodeling were comparable between control and FASD cohorts. We next sought to confirm these findings using an adult zebrafish cohort study where there is greater control over genetic and environmental factors. We observed that embryonic alcohol exposed (EAE) zebrafish had a higher incidence of CHDs, ventricular structural anomalies, cardiomyopathy, and adult-onset diastolic dysfunction.

Conclusions: Together, these data suggest that PAE increases the risk for CHDs, adult CVD, and associated metabolic abnormalities. Patients with FASD or significant PAE may require comprehensive cardiovascular evaluations and early intervention to prevent adverse cardiac outcomes.

E1iii*:* Prenatal Alcohol-Exposure and Perinatal Alcohol-Use by Mothers Enrolled in the Parent-Child Assistance Program in Washington State, 2006-2021

Susan Stoner

Background: The Parent-Child Assistance Program (PCAP) is a three-year intensive case management program for individuals with at-risk alcohol or drug use during pregnancy. PCAP aims to decrease the likelihood that future children will be exposed to alcohol or drugs prenatally by helping clients to build recovery capital and engage in substance use disorder treatment. A major goal of the program is to prevent FASD.

Methods: Data were examined for 4928 clients, who enrolled in the program in Washington State between May 2006 and June 2021. Enrolling clients were administered an expanded version of the Addiction Severity Index at intake that included questions about their own prenatal alcohol exposure and substance use during pregnancy.

Findings: Among clients for whom pregnancy-related substance use data were obtained, 33.0% reported alcohol use (17.1% binge alcohol use) in the first trimester of pregnancy or the month prior and 13.5% (5.8% binge alcohol use) in the second or third trimester. With regard to their own prenatal alcohol exposure status, 22.2% of clients did not know if their birth mother drank during pregnancy. Of those who purported to know, 81.5% said she didn't drink while pregnant, 5.9% said she drank lightly, and 12.6% said she drank heavily. Clients with any self-reported prenatal alcohol exposure were significantly more likely to report any alcohol use, $c^2(1, N=3627) = 71.70$, $p < .001$, or binge alcohol use, $c^2(1, N=3626) = 68.79$, $p < .001$, in the first trimester or month prior, and any alcohol use, $c^2(1, N=3610) = 60.24$, $p < .001$, or binge alcohol use, $c^2(1, N=3610) = 51.47$, $p < .001$, in the second or third trimester. However, they were no less likely than those who denied prenatal alcohol exposure to complete the three-year program.

Conclusion: Findings point to the potential benefit of targeting prevention interventions to individuals with prenatal alcohol exposure to increase the likelihood that their own pregnancies will not be affected by alcohol use.

E2i: The changing presentation of neurodevelopmental impairments with age in Australian adolescents living with FASD

Elizabeth Elliott

Background: Fetal Alcohol Spectrum Disorder (FASD) may result from prenatal alcohol exposure and is characterised by a range of neurodevelopmental disabilities.
It has been suggested that adolescents may experience higher rates of impairment at diagnosis which impact health, daily functioning, social interactions and well-being.

Objective: To identify adolescents with FASD in Australia and describe the pattern neurodevelopmental problems according to age at presentation.

Methods: Each month the Australian Paediatric Surveillance Unit (APSU) collected data on newly diagnosed (incident) cases of FASD in children aged <15 years from participating paediatricians nationally between January 2015 - December 2024. Adolescents were defined as individuals 10 years or older, according to the WHO. Associations between age and severe neurodevelopmental impairment in ten functional domains at the time of diagnosis (Australian Guide to FASD diagnosis 2020) were estimated using odds ratios (OR) and 95% confidence intervals (CI) derived from binary logistic regression models.

Results: During the ten-year surveillance period, 1870 FASD notifications were received by the APSU and 1399 FASD cases were confirmed after exclusion of duplicates and ineligible cases. Of the confirmed cases, 529 (38%) were adolescents (aged 10 to <15 years) with a median age at FASD diagnosis of 12.3 years. Of these, 67% were male and the majority (87%) presented with less than 3 sentinel facial features. Adolescents included in this study came from every state and territory and 16% live in remote or very remote areas of Australia and 58% (306/529) were of Aboriginal and/or Torres Strait Islander descent. Of the adolescents, 39% (207/529) lived in foster care or with adoptive parents; 303 (57%) had any contact with child protection services, and 114 (22%) had at least one sibling with FASD. The most frequently impaired neurodevelopmental domains in ages 10-<15 years were attention (81%), adaptive behaviour, social skills, or social communication (77%); and executive function (75%). When examining the relationship between age and severe neurodevelopmental impairment using multivariable logistic regression models adjusted for sex, remoteness index of Australia, and child's racial background, each additional year of age was associated with increased odds of severe impairment in executive function, affect regulation, and memory. The respective odds ratios were 1.25 (95% CI: 1.06–1.47, p=0.008), 1.23 (1.04–1.44, p=0.01), and 1.21 (1.04–1.41, p=0.02). Conversely, each additional year of age was associated with decreased odds of severe impairment in attention (OR 0.82, 95% CI: 0.69-0.98, p=0.03). The odds of being diagnosed with attention-deficit hyperactivity disorder (ADHD, DSM-5) decreased by 22% per year of age, OR 0.78 (0.67-0.91) p=0.001.

Discussion/Conclusion: Adolescents with FASD represent a highly vulnerable and diverse group. Increasing age is linked to greater odds of severe impairments in executive function, affect regulation, and memory at diagnosis, but lower odds of impairment in attention problems or a formal ADHD diagnosis. These findings highlight the changing presentation with age and the need to assess adolescents with FASD, including for executive function, affect regulation, and memory to inform clinical care and family support and optimise outcomes in health and quality of life.

E2ii: Early-Life Exposures, Lasting Imprints: Gut Microbiota-Metabolite Alterations Linking Prenatal Alcohol and Cannabinoids to Adult Addiction Risk

Deepa Upreti

Introduction: Prenatal alcohol exposure (PAE) is a leading cause of neurodevelopmental disabilities, collectively termed, FASDs, including a spectrum of systemic and neurobehavioral deficits that adversely influence health across a lifespan. Adults with FASDs is also found to commonly struggle with alcohol and substance use disorders (AUDs/SUDs). Moreover, alcohol is often co-used with other psychoactive substances like cannabis, each of which has been independently linked to neurobehavioral and developmental effects. Co-exposure during pregnancy can lead to stronger, synergistic, or distinct adverse effects on fetal brain development and long-term neurobehavioral outcomes, therefore evaluating the impact of PAE versus the interaction of PAE with other psychoactive substances is critical, however currently limited. Finally, emerging evidence links PAE to long-term alterations in gut microbiome and metabolites. These alterations are associated with anxiety-like behaviors, a risk factor for AUDs/SUDs. These studies suggest that gut health may explain the emergence of AUDs in PAE offspring, however, the effect of PAE in combination with other psychoactive substances on the gut microbiota and metabolome in adult offspring, and the gut role in neurobehavioral outcomes, especially alcohol-seeking behaviors, is unknown.

Objective: To examine the impact of prenatal exposure to alcohol, cannabinoids, or both on the gut microbiota and metabolites and neurobehavioral outcomes in adult offspring.

Method: Pregnant C57Bl/6J mice were exposed to ethanol (95% vapor ethanol), cannabinoid (CP-55940), or simultaneous alcohol and cannabinoid (SAC) at gestational days 12-15, corresponding to a critical period of cerebral cortical plate neurogenesis and angiogenesis. Adult behavior was assessed between postnatal days 107-253, and fecal (from caecum) and plasma samples were collected at ~8.5 months (n=16-17/group). Shotgun metagenomics was performed on cecal samples and global metabolomics was conducted on both plasma and cecal samples and analyses were conducted.

Results and Discussion: We found persistent changes in the gut microbiome and metabolites with co-exposure, which are correlated with alcohol-seeking behavior in adult offspring. α-diversity was significantly reduced in the alcohol-exposed exposed group, indicating loss of microbial richness, β-diversity revealed distinct group clustering, suggesting exposure-specific microbial shifts. Prenatal alcohol and/or cannabinoid exposure reduced key butyrate-producing bacteria, suggesting impaired gut health. Plasma LPS level were significantly higher in the co-exposure group, suggesting impaired gut barrier integrity, potentially increased translocation of endotoxin into circulation and elevated chronic inflammation. Correlation analysis identified several microbial taxa and metabolites associated with alcohol-seeking behavior in co-exposed animals, linking gut dysbiosis to behavioral vulnerability and highlighting a gut-brain axis link shaped by prenatal exposure.

Conclusion: Prenatal exposure to alcohol and/or cannabinoid induces long-lasting changes on the gut microbiome and metabolism in adult, influencing neurobehavioral health outcomes. By understanding these alterations, we could identify gut-derived biomarkers and targets for early intervention in addiction risk. Over time, these studies will establish a mechanistic framework for developing microbiome- or metabolite-based interventions to reduce neurobehavioral risks associated with adverse early life experiences.

E2iii: Predictors and Opportunities for Prevention of Mental Health Disorders in Remote-Dwelling Australian Aboriginal Adolescents With FASD: The Bigiswun Kid (Adolescent) Project

Elizabeth Elliott

Background/Objectives: In 2009, Aboriginal communities in Western Australia initiated the population-based Lililwan (little children) study on FASD prevalence, partnering with the University of Sydney. Of children born in 2002-3 in remote Fitzroy Valley communities, 55% had PAE and 19% had FASD at age 7-9 years. The Bigiswun Kid (adolescent) study was initiated to follow-up this cohort 10 years later because community was concerned that some adolescents were struggling. The overall aim was to identify health/mental health needs of adolescents to inform development of culturally appropriate services to improve health and social emotional well-being (SEWB). Specific aims were to document rates of FASD, adverse childhood experiences (ACE); self-reported symptoms of mental ill-health and wellbeing (psychological distress and thriving); and diagnosed mental health disorder (MHD) in adolescents with and without FASD and to determine predictors of and protective factors for MHD.

Methods: Aboriginal Participatory Action Research (APAR) methods (Aboriginal leadership, community consent, research co-design, translation during data collection). Active case ascertainment of the Bigiswun Kid cohort. Interviews with 94 (83%) of all adolescents (17-19 years) and 89% (n=101) of their parents. Use of validated tools (Revised ACE, Strong Souls Inventory, Hunter Opinion Personal Expectation Scale, HEEADSSS, Child Behaviour Check List-Teacher Report Form (CBCL-TRF). Predictive and protective factors for MHD were identified.

Results: Overall, 23% adolescents had FASD and 11% had a diagnosed MHD. Adolescents with FASD had five times more psychiatrist-diagnosed MHD [OR 5.33 (95% CI 1.32, 24.84) P=0.02] and were less resilient [OR -2.43 (95% CI -0.47, -0.11) P=0.04]. ACE were universal with no difference in mean scores, or the proportion with scores >4 in adolescents with or without FASD (P>0.05). However, there was no difference in self-reported anxiety, depression, PTSD or suicidal ideation, hopefulness or life satisfaction.

In adolescents with FASD, the risk of a MHD was increased in those with ‘no-one to go to when they were sad’ [OR 4.85 (95% CI 1.004, 20.95)] and a higher Total Behaviour Problem score [OR 1.04 (95% CI 1.01, 1.06)] or Externalising problem score [OR 1.09 (95% CI 1.03, 1.06)] on the CBCL-TRF at 7-9 years. Protective factors for MHD included Living >100km from town [OR 0.43 (95% CI 0.098, 0.54) P=0.04], Strong parent attachment [OR 0.75 (95% CI 0.59, 0.92) P=0.007]. Strong peer attachment [OR 0.87 (95% CI 0.75, 0.99) P=0.033] and Closeness to family/household members [OR 0.099 (95% CI 0.01, 0.49) P=0.003]. MHD was unrelated to hours of sleep or exercise in the past week, alcohol or Ganja use, death or suicide of someone close, number of homes lived in, Internalising problems at 7-9years (CBCL-TRF) or impaired cognition, executive function or adaptive function.

Conclusion: Building resilience in adolescents with FASD may assist them to overcome ACE and cope with the complexity of adolescence. Identification and treatment of externalising and behaviour problems in childhood, strengthening family function and peer relationships with parenting and social skills training, and facilitating engagement in traditional cultural activities may improve SEWB. Advocacy using these data led to funding for a social-emotional wellbeing program including a Night Hub.

E3 - Stress in Life and in Work: What Causes It and How to Cope

Dan Dubovsky, Nancy Whitney

Everyone experiences stress in their lives. Those working in the fields of behavioral health, as well as other service providing fields experience stress in their personal and professional life. Individuals with an FASD and their families may experience higher levels of stress. There are many causes of stress, including the struggles of everyday living, being misunderstood, fighting with agencies and systems to get needed services, relationship issues, parenting issues, financial issues, as well as more global stresses.

These stresses can be overwhelming at times and can interfere with day to day functioning. We need to be able to break these stresses down into manageable components so that we can feel in control of our lives.

This session begins with a review of research regarding stress and its effects on a person. A discussion with attendees regarding stresses that people may experience follows. We have an activity or two for participants to experience, that they can use in the future as well. We then discuss further methods for managing stress.

The session encourages discussion and questions within the parameters of helping everyone feel they are getting some specific techniques to use.

E4 - Seeing the Invisible: Prioritizing FASD in Adolescent Education

Jody Dickerson, Domenica Steele

Fetal Alcohol Spectrum Disorder (FASD) is one of the most common yet chronically under-recognized neurodevelopmental conditions affecting school-aged youth. Although prevalence estimates exceed those of autism, FASD remains largely invisible in educational systems due to under-identification, diagnostic barriers, stigma, and the tendency to explain presenting concerns through behavioral or mental-health lenses rather than neurodevelopmental etiology.

Under-recognition is particularly consequential during adolescence, when demands for independence, executive function, and social cognition dramatically increase and outpace developmental capacity. Adolescents with FASD commonly exhibit inconsistent performance, reduced working memory, slowed processing speed, difficulty with cause-and-effect reasoning, social vulnerability, and significant challenges with generalizing learned skills across settings or time. These needs are frequently misinterpreted as defiance, avoidance, or lack of motivation, leading to inappropriate intervention plans, ineffective behavior systems, and disproportionate exposure to exclusionary discipline. This misalignment between brain function and environmental expectations contributes to disengagement from school, academic failure, increased involvement in the juvenile or criminal legal system, and poor adult outcomes in employment, safety, and independent living.

This session will bridge current neuroscience, brain-based educational frameworks, and applied school practice to examine: (1) how brain injury of prenatal origin manifests differently in adolescence than in early childhood; (2) how to apply a neuro-educational lens to screening, data collection, and eligibility decisions across MTSS, 504, and IDEA (with attention to misclassification under SLD,SED, or Autism, without addressing root causes); and (3) research-aligned instructional, environmental, and relational supports that accommodate brain-based variability rather than attempt to extinguish it. Emphasis will be placed on the distinction between skill deficits and willful noncompliance, the role of trauma co-exposure, the fallacy of "traditional behavior plans" for this population, and the importance of conceptualizing FASD as lifelong, chronic brain injury rather than a childhood-limited disorder.

Through case vignettes, decision-making tools, and application to real-world school processes, this presentation will equip educators, evaluators, and system leaders with a replicable framework to improve identification accuracy, reduce discipline and placement errors,and design programming aligned with the developmental reality of students living with FASD into adolescence and transition. Attention will also be given to equity implications for rural and historically underserved communities where diagnostic access is limited, and school identification may be the first and only point of recognition.

BREAKOUT SESSION E

E5 - Enhancing Attachment, Regulation, and Family Stability in FASD: Outcomes of a TBRI-Integrated Clinical Approach

Erin Goodman, Shanna Crockett

Fetal Alcohol Spectrum Disorders (FASD) present complex, lifelong challenges affecting neurodevelopment, emotional regulation, behavior, and attachment. Children with prenatal alcohol exposure frequently experience dysregulation, executive functioning deficits, and relational difficulties that can overwhelm caregivers and increase the risk of family instability or placement disruption. While awareness of FASD has grown, there remains a critical need for practical, relationship-based interventions that are both clinically effective and sustainable within the home.

This presentation introduces a TBRI-integrated clinical model developed at the Papillion Center, designed to address the unique neurological and relational needs of children with FASD. Trust-Based Relational Intervention (TBRI), developed by Karyn Purvis and David Cross through the Karyn Purvis Institute of Child Development, provides a trauma-informed, attachment-based framework that emphasizes connection, regulation, and skill-building. When applied through an FASD-informed lens, TBRI principles are adapted to account for dysmaturity, sensory processing differences, and neurobehavioral challenges, allowing caregivers to respond effectively to behaviors rooted in brain-based differences rather than willful defiance.

The first portion of the presentation, led by a clinician, will outline the structure and implementation of this model, including caregiver training, individualized intervention planning, and ongoing family support. The approach integrates the three pillars of TBRI—Empowering, Connecting, and Correcting—while emphasizing the importance of aligning expectations with developmental capacity. Clinical insights will highlight how reframing behavior, prioritizing co-regulation, and supporting caregiver capacity lead to measurable improvements in child functioning and family dynamics. Case examples will demonstrate gains in emotional regulation, reduced behavioral escalation, and strengthened attachment relationships.

The second half of the presentation offers a unique and critical perspective: that of a parent who has participated in this intervention and subsequently become an FASD specialist. Drawing from lived experience, this co-presenter will illustrate how TBRI-informed strategies translate into daily life within the home. Attendees will gain insight into the practical application of techniques such as proactive regulation supports, structured routines, and connection-based responses during moments of dysregulation. This portion will also explore the parent’s journey—from navigating the challenges of raising a child with FASD to developing confidence, competence, and ultimately a passion for supporting other families facing similar circumstances.

The inclusion of both clinical and lived perspectives underscores the real-world applicability and sustainability of the Papillion Center’s model. Families engaged in this approach report increased confidence in parenting, decreased stress, and stronger relational bonds with their children. Importantly, the parent co-presenter’s experience highlights how effective intervention not only stabilizes the family system but can also empower caregivers to become advocates and resources within their communities.

This integrated presentation bridges the gap between research and practice by demonstrating not only what works, but how it works in everyday life. Attendees will leave with a deeper understanding of TBRI-informed, FASD-responsive care, as well as practical strategies that can be implemented across clinical, home, and community settings. Additionally, the presentation offers a replicable framework for professionals seeking to support both children with FASD and the caregivers who play a central role in their long-term outcomes.

By combining evidence-informed clinical practice with authentic lived experience, this session contributes to a more holistic understanding of effective FASD intervention and highlights the transformative potential of connection-based, neuroscience-informed care.

E7 - Translating Brain Science into Practice: Neurobehavioral Interventions for FASD

Eric Flake, Jennifer Wisdahl, Tami Eller, Michele Walker-Bauer, Joanne Sparrow

This session integrates current evidence and multidisciplinary clinical experience to introduce a brain-based, child-centered framework for supporting long-term developmental and behavioral outcomes in individuals with Fetal Alcohol Spectrum Disorders (FASD) and related neurodevelopmental conditions.

Recognizing that FASD is frequently underdiagnosed or unidentified, the session addresses the realities of supporting individuals whose neurodevelopmental differences may not be formally named but significantly shape functioning across the lifespan.

Moving beyond surface-level behavior management, the session reframes intervention through a functional lens focused on regulation, relationship, and resilience. Emphasis is placed on how the highly variable and individualized brain impacts of prenatal alcohol exposure influence self-regulation, learning, adaptive behavior, and participation across the lifespan.

Participants will explore why traditional evidence-based behavioral and therapeutic approaches require additional insight into brain-based challenges that impact individuals with FASD, and how misalignment between intervention demands and neurodevelopmental capacity can contribute to frustration, escalation, and stigma for both individuals, caregivers, and therapists.

Drawing on literature synthesis and real-world practice across healthcare, education, and community systems, this panel will highlight the importance of targeting brain function rather than outward behavior alone. The framework emphasizes responsive, brain-based strategies that align with cognitive, emotional, and sensory profiles, particularly in the context of diagnostic uncertainty.

Integration of existing therapeutic approaches will be discussed with a focus on adaptation rather than replacement to better meet neurodevelopmental needs.
This panel brings diverse experts to examine real-world challenges in the assessment and treatment of children and adults when FASD is often unrecognized, inconsistently diagnosed, or co-occurring with other conditions. Panelists will discuss practical adaptations that have emerged through clinical experience across multiple systems of care (military, state, and educational), including flexible assessment practices, function-based outcome measures, and treatment modifications informed by evolving understanding of the FASD brain.

Attention is given to merging training needs for providers and caregivers, balancing child-centered and caregiver-focused approaches, and advancing research that prioritizes adaptability, functional growth, and lived experience alongside traditional evidence standards.

Participants will leave with a broader understanding of how individual-centered and family-supported treatments are synergistic, and with actionable strategies for designing developmentally aligned, brain-informed interventions that promote regulation, wellness, and resilience, even if an FASD diagnosis is not formally established.

E8 - Designing Dignity: Self-Advocates on Successful Housing for Adults with FASD

Kathryn Meinhardt, Olga "Alex" Nussbaum

Adults with Fetal Alcohol Spectrum Disorders (FASD) often face significant barriers to maintaining stable housing. Differences in executive functioning, memory, sensory regulation, and adaptive life skills can make navigating traditional housing environments difficult. Most housing systems are designed around neurotypical expectations and often fail to accommodate brain-based differences. As a result, many adults with FASD experience repeated housing instability, including eviction, homelessness, involvement with the justice system, or cycling through crisis-based services.

This presentation explores how brain-informed, dignity-centered housing approaches can improve housing stability and quality of life for adults with FASD. The session emphasizes that housing challenges are frequently the result of environments and systems that are not designed to support neurodevelopmental differences, rather than individual failure. When housing models are intentionally adapted to align with how individuals with FASD process information and manage daily living tasks, outcomes can improve dramatically.

A central feature of the session is the inclusion of self-advocates—adults living with FASD who share firsthand perspectives on what has helped them succeed in housing settings. Their lived experience provides critical insight into practical supports that are often overlooked in traditional service models. Elevating self-advocate voices ensures that housing strategies are informed not only by research and professional practice but also by the experiences of those directly affected.

The presentation integrates three primary sources of insight: evidence-informed neurobehavioral principles related to FASD, practical housing strategies from programs implementing supportive environments, and self-advocate narratives describing effective supports. Case examples illustrate how relatively simple environmental adjustments can significantly improve housing stability. These adjustments may include predictable routines, simplified living spaces, visual reminders, and reduced sensory stimulation to support executive functioning and daily task management.

Several key themes consistently emerge across both evidence and lived experience. Predictability and routine help reduce overwhelm and increase residents' ability to manage responsibilities. Environmental design modifications, such as organized spaces, visual cues, and low-stimulation environments, can support memory, attention, and independence. Consistent and supportive relationships with housing staff also play a crucial role, helping to build trust, reduce misunderstandings, and address challenges early.

In addition, community-based supports—including transportation assistance, appointment reminders, budgeting help, and life-skills coaching—can significantly improve long-term housing retention. Self-advocates emphasize that respect, autonomy, and being heard are essential elements of successful housing experiences.

This session concludes that adults with FASD do not fail housing systems; rather, housing systems often fail individuals when supports are not aligned with neurodevelopmental needs. By integrating predictable structure, supportive environments, flexible services, and informed relationships, dignity-centered housing models create conditions in which adults with FASD can thrive.

By combining research, practical strategies, and lived experience, this presentation offers a roadmap for housing providers, service organizations, and policymakers seeking to develop stable, respectful, and sustainable housing solutions for adults with FASD.

F1i: Prenatal Alcohol and Cannabinoid Exposures Disrupt Acetylcholine Receptor Subunit Expression in Adult Mouse Offspring

Tia Pandey

BACKGROUND: Established research has demonstrated that teratogens like alcohol and cannabinoids have the ability to alter acetylcholine (ACh) nicotinic receptor (nAChRs) subunit expression. Notably, changes in nAChR subunit expression within the dorsal striatum (DS) is associated with an increase in anxiety-like behavior, motor dysfunction, impaired learning, and substance use, all of which are characteristic of symptoms in individuals with Fetal Alcohol Spectrum Disorders (FASD). FASD is caused by prenatal alcohol exposure (PAE), and this is well understood; however, increased prevalence of polysubstance use raises concerns about dual exposure to alcohol and cannabinoids. Both exposures are prevalent among young adults of reproductive age, and it is yet unknown how prenatal alcohol and cannabinoid exposure impacts the association between nAChR expression and FASD behavioral symptoms.

METHODS: Pregnant C57B1/6J mice were divided into four treatment groups: control, alcohol exposure, cannabinoid exposure, and SAC exposure. Exposure was administered daily on gestational days 12-15, corresponding to the end of the first trimester of human pregnancy. Mice were given an intraperitoneal injection of cannabinoid agonist CP-55940 (750 µg/kg) or the equivalent volume of saline. Then they were transferred to vapor chambers for 30 minutes of inhalation of 95% ethanol or room air. Approximately a year after birth, tissue samples from the DS were collected for RNA isolation and sequencing. After quality verification using Galaxy software, the relative transcript abundance of nAChR subunits was assessed across exposure groups and sexes and compared with previously assessed behaviors, including operant self-administration of alcohol, open-field test activity, and rotarod test coordination.

RESULTS: nAChR subunits CHRNA4, CHRNA7, and CHRNB2 were the most abundant within offspring DS. Our analyses revealed no main effects of sex or exposure on CHRNA4 or CHRNA7. However, prenatal alcohol exposure significantly decreased CHRNβ2 expression, exclusively in males. In preliminary within-group comparisons of gene expression and behaviors, motor coordination was negatively correlated with CHRNβ2 and CHRNα4 levels in offspring that were not alcohol-exposed. However, in PAE offspring, motor coordination instead significantly corresponded with higher CHRNα7 levels, indicating that PAE may change the relationship between nAChR subunit expression and associated behaviors. Prenatal alcohol and cannabinoid exposure created a distinct negative correlation between CHRNβ2 expression and motor coordination that was not observed from PAE alone.

DISCUSSION: Prenatal exposure to alcohol produces distinct, sex-specific changes in CHRNB2 expression in the adult DS, and prenatal alcohol exposures alter the relationships between nAChR subunits and multiple offspring behavioral phenotypes. The disruption of relationships between behaviors and nAChR subunits by prenatal exposure suggests that there are network-level changes in biological activity underlying FASD-like behaviors. Future investigations targeting offspring nAChR function following prenatal exposure can further determine how changes in subunit expression alter physiological activity through these receptors.

F1i: Bridging the Gap: Behavior Parent Training for Caregivers with Children with Childhood Adversities

Taniyah Roach

Background/objectives: Prenatal alcohol and substance exposure and other early adversities are strongly linked to long-term emotional, behavioral, and developmental challenges. Caregivers play a critical buffering role, and their sense of efficacy is central to supporting children with these experiences. Behavioral parent training (BPT) is an evidence-based approach shown to strengthen parenting skills and improve child outcomes. Despite its effectiveness, few BPT models are explicitly designed for caregivers of children with early adversities (FASD, prenatal alcohol and substance exposure, complex trauma, ACES). Existing programs often target behavior without integrating an accommodation-focused and adversity-informed perspective. This study investigates the acceptability of a parent training intervention tailored specifically to the needs of families navigating early adversity to address this gap.

Methods: Caregivers of children aged 6-11 with living experiences of early adversities were enrolled in a tailored behavioral parent training intervention. The program included 6 sessions, integrating additional instruction on accommodations and adversity-informed content with the traditional BPT strategies of First Approach Skills Training Behavior (FAST-B) program. Acceptability of this tailored program was evaluated using post-intervention semi structured interviews and qualitative feedback. Caregivers with birth, kinship, and foster/adoptive relationships to their children were included in this study. Qualitative responses were coded using thematic analysis.

Results: Preliminary analyses indicate that parents reported high levels of satisfaction with the program. Early qualitative analysis suggest that caregivers found the intervention beneficial and aligned with their needs, for example feeling a sense of shared experiences with other parents and the experiences of their children. Parents also provided constructive feedback on program structure and content, several components of which have already been incorporated into the updated program model such as including more information about applicability of specific interventions to trauma and early adversities.

Discussion/conclusion: These preliminary findings underscore the program's value to participating families and highlight opportunities for continued enhancement. Parents' feedback has already contributed to meaningful improvements in the revised program, demonstrating a responsive and iterative development process. As data analysis continues, additional insights are expected to further inform implementation and ensure the program's alignment with family needs.

F1iii: Adaptive Function Outcomes in FASD: Comparing Facial Phenotype and Associated Risk Factors

Tanaporn Jasmine Wilaisakditipakorn

Background:

Children with Fetal Alcohol Spectrum Disorders (FASD) show wide variability in adaptive functioning. Facial features associated with FASD are often assumed to reflect greater neurodevelopmental impairment, but evidence remains mixed. This study examined adaptive behavior profiles and potential factors associated with significantly low adaptive functioning in a clinically evaluated cohort of children with FASD. We compared children who did and did not have sentinel facial features of FASD and investigated whether FASD diagnostic category, comorbidities, and early interventions influenced adaptive function outcomes.

Methods:

We reviewed 61 children (ages 2 months–20 years) diagnosed with FASD in the Developmental-Behavioral Pediatrics (DBP) Clinic and the FASD Clinic at the UC Davis MIND Institute. Baseline characteristics, comorbidities, medical diagnoses, and caregiver information were collected. To assess the adaptive function profile, participants were classified into two groups: those with sentinel facial features, comprising individuals diagnosed with Fetal Alcohol Syndrome (FAS) or partial FAS, and those without sentinel facial features, comprising individuals diagnosed with Alcohol-Related Neurodevelopmental Disorder (ARND). Adaptive function was measured using Adaptive Behavior Assessment System, Third Edition (ABAS-3) or Vineland Adaptive Behavior Scales, Third Edition (Vineland-3). Logistic regression was used to examine associations between demographic/clinical factors and significantly low adaptive functioning (below –2 SD on either adaptive function measure).

Results:

Of the 61 participants, 16% were diagnosed with FAS, 38% with partial FAS, and 46% with ARND. Children with sentinel facial features were diagnosed earlier (mean 5.14 vs. 8.17 years, $p<0.001$), and early interventions were more frequently received among children with sentinel facial features (48% vs. 17%, $p=0.024$). Comorbidities, including autism, ADHD, PTSD, and GDD/ID, were common in both groups, with no significant group differences.

Adaptive functioning was impaired across both groups. Mean ABAS-3 General Adaptive Composite scores were low (70.16 vs. 72.88; $p=0.516$), with the group with sentinel facial-feature showing a slightly higher proportion of individuals meeting criteria for significant impairment. Vineland composite scores showed a similar pattern, with 43–75% demonstrating impairment and no significant differences between groups.

Regression modeling found no significant associations between adaptive impairment and age at diagnosis, gender, presence of facial features, or cognitive impairment. Autism as a comorbidity showed the strongest trend toward increased odds of significantly low adaptive function (aOR 4.80; p=0.061) but did not reach statistical significance. There was a trend of early interventions as a protective factor for impaired adaptive outcomes (aOR 0.65; p=0.601) but did not reach statistical significance.

Conclusion:

Children with FASD demonstrated substantial adaptive function impairment regardless of the presence of facial features. Facial phenotype, age at diagnosis, and early intervention history were not significantly related to adaptive function outcomes. These findings reinforce that FASD-related adaptive challenges occur across all FASD diagnostic categories with or without the presence of sentinel facial features. Screening, intervention planning, and support services should be guided by functional needs rather than facial features or diagnostic categories alone.

BREAKOUT SESSION F

F2i: Supporting the Mental Health of Students with FASD: POPFASD On-Demand Course FASD 103

Fatima Natascha Lawrence, Stacey Kelsh

CANFASD (2024) has argued that mental health is an essential consideration for people with FASD despite the challenges they face in accessing mental health services and support. Studies such as the "Lay of the Land" (Himmelreich et al., 2020) have presented how FASD is a whole-body diagnosis, arguing that services and interventions must focus on the holistic experiences of individuals with FASD. The FASD Changemakers recently presented (2023) the secondary results of the Lay of the Land Survey, which highlighted the inequalities and inequities faced by adults with FASD, particularly in their access to effective services, such as FASD-informed mental health treatment. Despite the importance of adequate mental health services for individuals with FASD, there is little research or resources, particularly for educators.

In this workshop, the Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD), in partnership with Registered Clinical Counsellor Supervisor and Educational Consultant Fatima Natasha Lawrence, will discuss their new course, FASD and Mental Health. The mandate of POPFASD is to increase educators' capacity to meet the learning needs of students with FASD, and this free, on-demand online course aims to empower educators and schools to support the holistic mental health needs of all students with FASD.

F2ii: From Clinic to Classroom: Investigating IEPs and Diagnostic Clinical Evaluation Recommendations for Students with a FASD Diagnosis

Emalise Mitchell

Children with FASD often have complex learning and behavioral needs that require coordinated support across medical, educational, and family systems. Clinical evaluations conducted through interdisciplinary diagnostic teams, such as the Washington State FAS Diagnostic & Prevention Network (FAS DPN), provide detailed reports that include educational recommendations for interventions and accommodations. However, these recommendations are not always reflected in children's Individualized Education Programs (IEPs), which guide school-based services. This project examines the alignment—or mismatch—between clinical recommendations and educational documentation for students evaluated through the FAS DPN. The goal is to identify where gaps occur and to inform practices that promote consistent, responsive supports for students with FASD.

This study involves a systematic review of clinical reports and school IEPs for children seen at the FAS DPN between 2021 and 2024 who were between ages 8-18 and WA state residents. Analyses focus on descriptive and comparative patterns, such as how often specific service areas (e.g., occupational therapy, speech-language, behavioral supports, transition planning) recommended in clinical reports are also documented in IEPs. Additional analyses explore whether alignment varies by diagnostic classification within the FASD spectrum (e.g., FAS, Static Encephalopathy/Alcohol Exposed, Neurobehavioral Disorder/Alcohol Exposed).

Results indicated that most children with FASD receive some form of educational support, yet there are frequent discrepancies between clinic recommendations and IEP documentation. Clinical reports often emphasize executive functioning, self-regulation, and adaptive skills, whereas IEPs more commonly highlight academic or behavioral goals. Occupational therapy, speech-language, and social-emotional supports are less consistently carried over from the clinic to the school setting.

This study contributes to highlighting the importance of interdisciplinary recommendations being effectively implemented within educational systems. Findings help identify specific points in the evaluation and educational service planning process where alignment breaks down—offering opportunities for collaboration between clinicians, educators, and families. Strengthening this bridge can ensure that diagnostic insights directly inform individualized school supports, improving educational and developmental outcomes for children with FASD. Beyond individual cases, results have broader implications for policy and practice: enhancing cross-system communication, informing training for school psychologists and special educators, and guiding state or district protocols for integrating clinical findings into IEP development. Ultimately, this work aims to support families in feeling understood and empowered while promoting systems of care that recognize the strengths and challenges of students with FASD without reinforcing stigma or blame.

F2iii: FASD, Faith, and Spiritualty - Sharing our Testimonies

Gina Schumaker, Emily Hargrove

Gina has leaned on her faith to navigate both trials and triumphs, finding strength, resilience, and joy through spiritual practices. She credits her faith and faith community for providing accommodations that empower her to live a fulfilling life. Since her diagnosis ten years ago, outside of discussions with Emily, she has never encountered a conversation about how faith and faith communities can serve as vital supports for those impacted by FASD. By sharing her journey, Gina hopes to encourage others to embrace faith practices and lean into community resources that can sustain them.

Emily, who has both lived experience with FASD and years of ministry alongside her husband, came to a similar realization when she began her qualitative study. Despite her background, she discovered how little is known about the intersection of FASD and spirituality. As she developed her theoretical foundation, she found this area remains largely unexplored. Emily's and Gina's experiences, where faith provided strength and coping, are only two narratives among many. They believe countless other stories—including those of study participants—are waiting to be shared, offering deeper insight into how spirituality can shape identity, resilience, and support within the FASD community.

Gina and Emily will openly share their faith journey to help others see how personal faith can provide grounding, optimism, and resilience during stress and adversity. They will highlight the importance of engaging with faith communities for practical supports and accommodations that strengthen the ability to navigate adult responsibilities successfully. Early findings from Emily's ongoing study on Spirituality and FASD reveal significant patterns in how faith offers support, structure, and identity. Understanding spiritual experiences within the FASD community can empower individuals with FASD to better know themselves and guide spiritual leaders in offering more effective support.

Gina will candidly share her struggles to show how personal faith can provide grounding, optimism, and resilience during stress and adversity. She emphasizes the importance of engaging with faith communities, which can offer practical supports and accommodations that strengthen the ability to navigate adult responsibilities successfully. Gina credits her faith and community for empowering her to live a fulfilling life and hopes her story encourages others to lean into these resources.

Emily's ongoing study on Spirituality and FASD—the first of its kind—reveals meaningful patterns in how faith functions as support, structure, and identity for many participants. Understanding spiritual experiences within the FASD community can help individuals better understand themselves while equipping spiritual leaders to provide more effective guidance.

Together, Gina and Emily highlight faith's vital role in supporting those impacted by prenatal alcohol exposure.

Although research links spirituality and developmental disabilities to positive outcomes, Gina and Emily's literature review found no studies examining faith-based engagement or faith community involvement in supporting individuals with FASD. Their presentation seeks to highlight this gap and serve as a call to action for formal research. They emphasize the potential of faith communities as informal yet powerful resources that can enhance well-being and success for those impacted by prenatal alcohol exposure.

F3 - Tribal Therapeutic and Problem-Solving Courts: A Collaborative Team-Building Approach to Responding with Care for Individuals with FASD in the Justice System

Peter Boome, Susan (Astley) Hemingway

Drawing on his experience as a Tribal Court judge in Washington State, Judge Peter Boome offers an inside look at how courts can recognize when justice-involved individuals need more than punishment—they need support. This interactive session invites participants to ask how Tribal Courts identify needs, respond with culturally grounded, supportive interventions, and reduce harm. This session will also explore how these principles and court practices can be adapted and transferred to other courts across the country, particularly through collaboration with multidisciplinary diagnostic teams to support identification, training, and FASD-informed judicial responses.

F5 - Hope Rising Clinic, A Model for Therapeutic Intervention for Children and Families Affected by FASD and Prenatal Substance Exposure (PSE)

Alex Lundy, Ryan Conley, Brie Anderson-Feldman

Background & Rationale
Children with Fetal Alcohol Spectrum Disorders (FASD) and prenatal substance exposure (PSE) experience brain-based differences that influence executive functioning, emotional modulation, sensory processing, and regulation. These neurological differences often manifest as behaviors that are misunderstood as intentional or defiant, leading caregivers and professionals to rely on behavior focused strategies that inadvertently increase stress and shame. When expectations exceed a child's neurodevelopmental capacities, both caregivers and children may feel blamed, discouraged, or disconnected from one another.

The neurobehavioral model reframes these behaviors as expressions of a child's neurological needs. By understanding how the brain regulates emotional states, manages sensory input, and processes information, caregivers and providers can more accurately interpret behavior, prioritize nervous system regulation as the foundation for learning and engagement, and learn to implement effective accommodations that support advocacy and agency. This shift reduces stigma, strengthens relationships, and provides caregivers with tools to better understand their child's unique neurodevelopmental profile.

Approach
Participants will learn about Hope Rising Clinic (HRC) and its clinical application of the neurobehavioral model. HRC combines multiple evidence-based modalities—occupational therapy (OT), behavioral health, caregiver education and coaching, and advocacy in educational and community environments—within a single coordinated system. Central to the model is a 10-week caregiver education program, completed after an initial multidisciplinary assessment, that equips families with tools for understanding neurodevelopment and attachment theory, reframing behaviors, and making accommodations. Special emphasis is placed on understanding the child's nervous system responses and recognizing dysregulation as a barrier to learning and connection.

Upon completion of the caregiver education program, working through a primary service provider (PSP) model, families begin the therapeutic phase of service delivery. During this phase families can expect:

- integration of OT, behavioral health, and continued education

- prioritization of nervous system regulation and caregiver-child attachment through child-led, experiential play therapy
- caregiver coaching, linking learned concepts to action
- shared professional language around regulation and brain-based needs
- identification of successful accommodations, to facilitate advocacy in school and other settings

Scenarios will be used to help participants understand the application of the neurobehavioral lens to real world challenges and develop practical accommodations.

Discussion & Conclusion

The material presented encourages participants to reconsider how they interpret the behaviors of children with FASD and PSE by grounding their understanding in the child's underlying neurodevelopment. When behaviors are reframed as expressions of brain-based differences rather than willful defiance, caregivers and providers can respond with empathy, reduce shame, and create environments that support nervous system regulation—the essential prerequisite for learning, connection, and skill acquisition. Participants will explore how a regulation-first mindset changes expectations across home, community, and clinical settings. This reinforces the value of slowing down, adjusting demands, and recognizing dysregulation as a signal for support, not discipline.

The HRC model serves as a practical example of how these principles can be implemented through a coordinated, primary service provider framework. Discussion will highlight how HRC's emphasis on caregiver education, transdisciplinary collaboration, and use of a primary service provider can reduce overwhelm, increase caregiver confidence, and promote more consistent, compassionate responses to children's needs.

By prioritizing regulation, adjusting expectations, and supporting caregivers as the primary agents of change, HRC helps to create environments that respect neurodiversity and build the foundations for long-term resilience. Clinical models like HRC demonstrate that when families are understood, supported, and equipped with the right tools, both children and caregivers experience greater connection, decreased stress, and improved opportunities for growth.

BREAKOUT SESSION F

F6 - Prevent Sexual Exploitation and Human Trafficking for Clients with FASD

Tenisha Brown, Kayla Ann Brown-Kivi

People with FASD make up a population of vulnerable people targeted by perpetrators of Sexual Exploitation and Human Trafficking. The nature of the disability often has impacted individuals unable to meet basic needs without supports. These needs create vulnerabilities which perpetrators use to groom for the purpose of exploitation and trafficking. Ensuing brain domain challenges associated with FASD may leave the individual unable to recognize the abuse or the ability to stop or prevent it, allowing the crimes against them to continue until the perpetrator no longer has use for them or the individual's life has ended, often prematurely. .

Not a Number is a prevention program on Sexual Exploitation and Human Trafficking created by LOVE146 out of Connecticut, USA and adapted to meet Canadian audiences by Willow Winds Support Network. In the US the target audience is currently youth with plans for expansion. In Canada the program is delivered to youth, people with disabilities, immigrants and newcomers to Canada. Willow Winds recognized these groups together represent a vulnerable population impacted by these crimes with some similar learning needs. Utilizing Wellness Resiliency and Partnership 2.0 strategies Willow Winds has made further accommodations to ensure the program delivery is meaningful, relatable and comprehensive to audiences with differentiated learning requirements.

As a participant you will learn about the cross-section of FASD and Sexual Exploitation and Human Trafficking as well as how to become a facilitator of the Not a Number program in order to implement it with your vulnerable clients on an ongoing basis as part of the curriculum within your organization and community.

Learning Objectives:

- Learn about the disturbing cross section between Sexual Exploitation and Human Trafficking in USA and Canada within the FASD sector.
- Learn about the Sexual Exploitation and Human Trafficking prevention program Not a Number.
- Learn how to make your organization or home a safe place with the skills necessary to assist your vulnerable clients/individuals impacted by FASD, Sexual Exploitation and Human Trafficking.

BREAKOUT SESSION F

F7 - Trauma-Informed, Family-Centered Care for Children with Polysubstance Exposure and FASDs

Prachi Shah, Roxanne Chang, Rachel Sing

Children exposed to substances during pregnancy, including alcohol, often face lifelong challenges in learning, behavior, and health. The American Academy of Pediatrics (AAP) recommends a trauma-informed care approach, meaning care that understands how stress and adversity affect a child's development and focuses on creating safety, trust, and support for families. This presentation introduces a family-centered model that helps reduce harmful stress and strengthen healthy relationships for children and families affected by prenatal substance exposure, including children with fetal alcohol spectrum disorders (FASDs).

Speakers will share practical strategies for working across systems (health care, behavioral health, and community services) to coordinate care; screening early and often to identify needs; and engaging families in ways that are clear and supportive. The session will show how these approaches apply to children with prenatal alcohol exposure and how partnerships with community organizations can ensure families get the help they need.

AAP's trauma-informed care model helps professionals respond to the unique needs of children affected by prenatal substance exposure. By focusing on safe, stable, nurturing relationships (SSNRs) and reducing stress, systems can improve outcomes for children and families living with substance exposure and FASDs.

Learning Objectives

- Apply AAP's trauma-informed care principles to support children with prenatal substance exposure, including fetal alcohol spectrum disorders (FASDs).
- Identify strategies to promote relational health and resilience in families affected by trauma and substance use.
- Apply family-centered, cross-sector approaches that reduce stigma and strengthen supportive relationships for children with substance exposure.

Families affected by FASDs and polysubstance use often feel judged or misunderstood. This approach centers their strengths, builds trust, and ensures care is compassionate and respectful. This presentation shows how pediatric, behavioral health, and social service systems can use trauma-informed care to better support children with FASDs and prenatal substance exposure. It provides practical tools for providers, policymakers, and communities to reduce stigma, enhance coordination, and foster healing.

BREAKOUT SESSION F

F8 - Affirming and Supporting FASD—Improved Outcomes with the FASCETS Neurobehavioral Approach

Melissa Elligson, Nathalie Brassard, Suzanne Emery

Traditional supports for people with FASD often overlook individual brain differences, relying on uniform approaches. The FASCETS Neurobehavioral Approach provides ethical, and strengths-based support tailored to each person, reducing stigma and promoting understanding. It recognizes families and individuals with FASD as experts, moving beyond outdated methods to foster individualized, effective accommodations.

In this 60-minute session, attendees will receive the foundational concepts of the FASCETS Neurobehavioral Approach based on research. Recounting lived experiences, presenters will demonstrate the real-life transformation the approach supports. Together we will discuss the ethics of effectively accommodating brain-based differences. Through an introduction to the FASCETS tools for building effective accommodations based on strengths, we will demonstrate the potential for well-being, meaningful participation, and connection that comes from applying this approach. Attendees will leave with new ideas for practice and renewed hope.

F9 - Not Your Typical Growing Up Guide

Angela Geddes, Kaye Hamilton-Smith

Youth and adults living with complex neurodevelopmental differences—including Fetal Alcohol Spectrum Disorder (FASD), ADHD, autism, learning disabilities, trauma impacts, sensory differences, and co-occurring mental health challenges—are frequently misunderstood within education, healthcare, justice, and community systems. Difficulties with memory, impulse control, emotional regulation, and social interpretation are often interpreted through a behavioural, mental health or compliance lens rather than understood as neurologically based differences. As a result, many individuals and their caregivers experience repeated cycles of frustration, shame, conflict, and preventable risk across the lifespan.

Not Your Typical Growing Up Guide was developed to address this gap by providing a practical, accessible, and non-stigmatizing resource designed for youth, families, professionals, and adults who may be newly exploring or receiving clarity about their neurodevelopmental profile. Rooted in clinical social work practice and informed by Acceptance and Commitment Therapy (ACT), functional neurodevelopmental assessment, and lived experience perspectives, the guide translates complex neurodevelopmental concepts into language that individuals can understand and apply in their daily lives at various stages of development. The resource emphasizes dignity, safety, and interdependence while supporting individuals in recognizing their strengths and navigating predictable vulnerabilities.

This presentation introduces the guide as both an educational tool and a practical intervention framework for use across systems of care. Participants will explore how reframing behaviour through a neurodevelopmental lens can reduce shame, strengthen communication, and create safer pathways for youth transitioning toward adulthood, as well as for adults who are making sense of their experiences later in life. The guide's central message—helping individuals understand their "complicated and beautiful brains"—supports people in shifting from self-blame toward insight, self-compassion, and informed decision-making.

The session begins by establishing the broader context that led to the development of the resource. Many individuals with neurodevelopmental differences remain misdiagnosed, undiagnosed or receive diagnoses later in life, leaving youth, families, and adults searching for ways to explain persistent challenges without reinforcing stigma. The presentation highlights how systems often rely heavily on behavioural explanations while overlooking neurological, sensory, and trauma-related factors that influence functioning. Participants will examine how shame and misunderstanding can increase vulnerability, while accurate explanations and supportive relationships can significantly reduce risk at any age.

Using the structure of the guide as a framework, the presentation walks participants through six core areas that support healthy development and safer life navigation for neurodivergent youth and adults.

The first section focuses on understanding the brain, emphasizing that neurological differences—not character flaws—often underlie challenges related to memory, impulse control, and emotional regulation. Participants will explore concepts such as dysmaturity, neurological variability, and the relationship between brain development, trauma, and body-based stress responses. This foundational reframing allows youth, adults, and caregivers to interpret behaviour through a compassionate and biologically informed lens.

The second section addresses safety, structure, and everyday support systems. Many individuals with neurodevelopmental differences require ongoing guidance and interdependence in order to remain safe and successful throughout their lives. This portion of the presentation explores the importance of supportive rules, predictable routines, and collaborative problem-solving strategies. Rather than viewing support as a limitation, the framework positions interdependence as a life skill that strengthens resilience and stability across the lifespan.

The third section examines relationships, emotional regulation, and social vulnerability. Youth and adults with neurodevelopmental differences often possess strong empathy and a deep desire for connection, yet may struggle with interpreting social cues, understanding consent, or recognizing potentially unsafe situations. Participants will explore tools that help individuals navigate friendships, dating, boundaries, and attachment in ways that promote both connection and safety at different developmental stages.

The fourth section explores coping strategies, addictions, and daily living skills. Rather than approaching substance use or impulsive behaviour solely through abstinence-based models, the framework incorporates harm-reduction principles that prioritize safety and realistic decision-making. Participants will examine how executive functioning supports, environmental structure, and collaborative planning can reduce risk while respecting individual autonomy for both youth and adults.

The fifth section highlights the importance of identity, culture, and community connection. Neurodivergent individuals often experience significant stigma or internalized shame, whether identified early or later in life. Strength-based conversations that acknowledge identity, cultural context, and living experience can help buffer these effects. The presentation explores how naming strengths and building supportive community networks can serve as powerful protective factors across the lifespan.

The final section focuses on building a meaningful and sustainable life path. Success for individuals with neurodevelopmental differences may not follow traditional timelines or expectations. The guide encourages youth and adults to focus on values-aligned goals, realistic growth, and supportive relationships rather than unattainable ideals of independence. Interdependence, dignity, and belonging are emphasized as central outcomes of effective support systems.

A companion workbook is also introduced as part of the presentation. The workbook provides practical exercises, reflection prompts, and structured tools designed to externalize memory and support learning through collaborative use with helpers. Participants will see examples of how these tools can be used in clinical, educational, and family settings to strengthen insight and problem-solving skills for both youth and adults.

In addition to the guide and workbook, the presentation introduces a customized support and health screening tool developed to help professionals, families, and adults themselves better understand functional needs across multiple life domains. The tool is designed to identify strengths, vulnerabilities, and environmental supports without requiring formal diagnosis. Importantly, the presentation clarifies the ethical distinction between screening and diagnosis. While diagnostic assessments remain critical for understanding the details and complexities of the brain's strengths and areas of challenge, and accessing some services, many individuals continue to require meaningful support regardless of diagnostic status. Functional screening tools can therefore guide safer, more responsive supports across systems including healthcare, education, housing, employment, and justice.

Early implementation of Not Your Typical Growing Up Guide in social work, youth justice, mental health, and family support settings has demonstrated promising outcomes. Practitioners report that youth and adults show increased insight into their own neurological differences and reduced feelings of shame when discussing behaviour and challenges. Families benefit from a shared language that improves communication and reduces blame. In many cases, safety planning and harm-reduction strategies developed through the guide have helped prevent predictable risks and crises. Professionals also report increased confidence in explaining complex neurodevelopmental concepts in clear, compassionate ways.

Ultimately, this framework reflects a broader shift in how neurodevelopmental differences are understood and supported across the lifespan. Rather than attempting to “fix” individuals, the approach emphasizes working with the brain and body as they are. By integrating accurate neurological explanations, practical safety strategies, and strengths-based communication, the guide supports youth and adults in developing self-understanding and building safer, more connected lives.

For individuals with complicated and beautiful brains, their caregivers, and professionals working across disciplines—including social work, education, mental health, healthcare, justice, and community services—this presentation offers practical tools that can be implemented immediately. Participants will leave with strategies to reduce stigma, improve communication, and strengthen collaborative supports for individuals living with complex neurodevelopmental needs at all ages.

At its core, Not Your Typical Growing Up Guide offers a compassionate and realistic framework that recognizes the inherent dignity and potential of every individual. By helping people understand their brains and build supportive environments around them, the guide invites a shift from misunderstanding to understanding, from blame to collaboration, and from risk to safety—supporting youth and adults alike to feel understood, supported, and capable throughout their lives.

PLENARY

United States - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Susan Shepard Carlson, Jennifer Wisdahl, Chris Melfi

---

1. What policy or legislative action has most advanced FASD, and what made it politically viable?

The first major milestone was the 1998 authorizing bill, shaped by the landmark 1996 IOM study establishing that alcohol causes greater harm than other drugs combined. Political viability came from a powerful combination of dedicated champions like Senators Arlen Specter, Lisa Murkowski, and Ted Kennedy; tribal and Alaska connections as early drivers; parent advocacy; and public visibility through media and celebrity involvement. Now, the passage of the FASD Respect Act provisions marks the next great leap forward, a moment built on everything that came before it and a renewed signal that the field has reignited, and that states are ready to act.

2. What made that policy most effective influencing decision-makers?

It was never one factor alone. It was the intersection of evidence, living experience, accountability, and stakeholder engagement. Research milestones like the IOM (1996) and JAMA (2018) studies shifted perceptions, while champions and parent advocates built sustained political will. The Respect Act provisions succeeded for the same reasons. That combination remains the model going forward, and the good news is the infrastructure to sustain it is stronger than ever.

3. What barriers nearly stopped progress, and how were they navigated?

Stigma, fragmentation across agencies, loss of Hill champions, competition with autism advocacy for resources, and SAMHSA's uncertainty about where FASD fit all threatened to stall progress at key moments. They were overcome through persistent advocacy, less stigmatizing messaging, and individual champions stepping in with earmarks when broader appropriations faltered. These barriers haven't disappeared, but the passage of the Respect Act provisions gives advocates a stronger platform than ever to address them, just as the 1998 bill did for the generation that followed.

4. Where does current policy fall short, and what comes next?

Gaps remain: no unified clinical practice guidelines, reimbursement structures that limit diagnostic access, and a federal budget proposing to zero out NIAAA and cut CDC birth defects funding by $205 million. But the passage of the Respect Act provisions is a genuine turning point. Just as the original 1998 legislation required sustained appropriations and advocacy to deliver real impact, so does this. The field now has authorization, momentum, and state-level readiness. The work ahead is to ensure that promise is funded, championed, and protected so that individuals and families finally receive the meaningful outcomes they deserve.

PLENARY

Canada - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

James Reynolds

1. **What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment?**

Released by Health Canada in 2003, *Fetal Alcohol Spectrum Disorder: A Framework for Action*, is a foundational Canadian policy document that was designed to guide collaborative efforts across all levels of government and community organizations. The Framework was the result of a growing awareness over the previous decade of the adverse outcomes associated with prenatal alcohol exposure. These were described in the 1992 report from the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women entitled *Foetal Alcohol Syndrome: A Preventable Tragedy,* and the 1996 *Joint Statement on the Prevention of Fetal Alcohol Syndrome/Fetal Alcohol Effects in Canada*, issued by Health Canada and 18 national professional associations. The Framework reflected the views of hundreds of individuals and organizations, captured during national consultation efforts in 1999 and again in 2002-2003, and was developed as a statement of shared commitment among the federal government, provinces, and territories to address what was then becoming recognized as a significant public health concern.

2. **What made that policy most effective in influencing decision-makers? Was it the combination of evidence, living experience, accountability, and stakeholder engagement—or one factor in particular?**

The Framework provides a flexible, non-restrictive structure aimed at improving prevention, diagnosis, and support for individuals with FASD. It identified five broad goals, with the intention that more specific and measurable objectives and action plans would be developed by all jurisdictions and sectors over time.

The Framework has served as a guiding document for the Public Health Agency of Canada's National Strategic Projects Fund, which has supported numerous high-impact FASD projects, including:

- Development and updating of the Canadian FASD Diagnostic Guidelines.

- Estimation of population-based FASD prevalence among elementary school students and economic costs associated with FASD in Canada.

- Projects delivered through the First Nations and Inuit Health Branch, now Indigenous Services Canada, such as the Atlantic First Nations Health Partnership which led to the implementation of FASD services and positions in nine Atlantic First Nations.

The Framework has often been cited in the development of recent, more comprehensive initiatives, including Bill S-234, the proposed National FASD Framework currently under consideration in the Senate of Canada.

3. **What barriers nearly stopped progress (e.g., stigma, fragmentation, competing priorities), and how were they navigated?**

Despite the growing evidence of the high prevalence and socio-economic burden of FASD in Canada, funding at the federal level for FASD initiatives has not changed since 1999.

4. **Where does your country's policy currently fall short in delivering meaningful outcomes for individuals and families?**

Since its release in 2003, the Framework has undergone periodic review and evaluation of its impact. The most recent evaluation of the Framework by the Public Health Agency of Canada (2023) concluded that despite having ambitious objectives, FASD-dedicated funding is limited, and that important gaps to addressing FASD in Canada remain.

A feature of most FASD strategies is the recognition of the critical importance of effective mechanisms to ensure coordination and collaboration among the many different sectors of government that need to work together. These should include explicit articulation of who will participate, the governance structure, and mechanisms for accountability. However, the 2023 evaluation report cited above noted that, in Canada ”there is no national approach or strategy that defines the roles and responsibilities of all FASD key partners and stakeholders to help coordinate efforts.”

PLENARY

Australia - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Elizabeth Elliott

---

1. What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment?

The launch of the *National FASD Strategic Action Plan 2018-28* by the Australian Department of Health, Disability and Ageing on 21 November 2018 constituted the single most impactful policy response to FASD ever seen in the country. The aim of the Plan is to improve quality of life for children and adults living with FASD by addressing four key national priorities: prevention of FASD, screening for and diagnosis of FASD; support and appropriate management for individuals and their families; and a focus on priority groups and people at increased risk.

The Plan was politically viable because: it was informed by a relevant stakeholder group; was supported by both major political parties; was accompanied by a funding commitment; and recommended formation of a *National FASD Advisory Group* (established on 18 September 2019) to monitor and report on progress on the implementation of the plan and gaps in its implementation.

2. What made that policy most effective in influencing decision-makers? Was it the combination of evidence, living experience, accountability, and stakeholder engagement—or one factor in particular?

The plan was effective in influencing decision-makers because it was informed by research evidence - predominantly from Australia - and by clinicians, researchers, and the voices of lived experience, who were consulted extensively during development and reporting of the plan. The lived experience voice – assisted by the *National Organisation for FASD Australia (NOFASD)* was particularly powerful during the stakeholder consultation. In addition to health professionals, the concerns of teachers and justice professionals were considered. Finally, the time was right for a formal, 10-year plan. It followed almost two decades of advocacy for funding to more holistically address FASD in Australia, two national government inquiries into FASD, and sound political engagement.

3. What barriers nearly stopped progress (e.g., stigma, fragmentation, competing priorities), and how were they navigated?

To date, the plan has progressively been rolled-out as intended.

4. Where does your country’s policy currently fall short in delivering meaningful outcomes for individuals and families?

Available funding is insufficient to adequately address all the needs identified in the Plan. A successful national community awareness campaign has been fully funded. Warning labels on the harms of alcohol in pregnancy have been mandated. The diagnostic guidelines have been updated. Multidisciplinary clinics have been established. There remains an urgent need to better address primary prevention of FASD, including through legislation to minimise alcohol harms; to promote equitable access to screening and diagnosis of FASD nationally, especially for disadvantaged groups; to better support adolescents and adults with FASD; and to upskill health, education and justice professionals.

PLENARY

Poland - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Magdalena Borkowska

1. **What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment?**

The State Agency for Prevention of Alcohol-Related Problems (PARPA) in Poland, which operated under the Ministry of Health from 1993–2021, undertook several key actions: raising public awareness on FASD, training professionals, supporting and conducting research, and building socio-political and fostering economic awareness of the impact of prenatal alcohol exposure. Since 1996, PARPA was operated under the legislative bill called "Act on Upbringing in Sobriety and Counteracting Alcoholism". In 2020, PARPA was merged with the National Bureau for Drug Prevention to form the National Center for Addiction Prevention, (KCPU).

Efforts to address FASD intensified at the beginning of 2007 with the launch of a nationwide public awareness campaign titled "Pregnancy Without Alcohol," organized by PARPA and implemented across local governments throughout Poland. The primary goal of this campaign was to disseminate knowledge about the teratogenic effects of alcohol on the fetus among the public, including professionals. Campaign educators delivered presentations in public institutions such as schools (teachers and students), municipal offices, and uniformed services, thereby broadening awareness across diverse audiences.

Another significant step was the ALICJA population-based study conducted by PARPA (Okulicz-Kozaryn K., et al., 2015), which estimated that FASD affects at least 20 per 1,000 children aged 7-9 in Poland, with FAS occurring in no fewer than 4 per 1,000 children in the same age group. This data highlighted the scale of the problem and the urgent need for targeted prevention, diagnosis, and intervention.

In response, FASD-related provisions were included in the National Health Program (NHP) for 2016–2020 and continued in the NHP for 2021–2026. These provisions focused on addressing prevention, education, standards and procedures, research, and the development of FASD support systems at the local government level.

In an effort to standardize the diagnostic process for FASD, the first Polish diagnostic guidelines were published by PARPA in 2020, and later updated in 2025 by KCPU (Okulicz-Kozaryn K., et al., (2021); Dyląg K., et al. (2026)).

Another key government bill was the National Program for Prevention and Resolution of Alcohol-Related Problems covering the periods 2022–2025 and 2026–2029.

2. **What made that policy most effective in influencing decision-makers?**

What made the policy most effective in influencing decision-makers was its foundation in scientific research, professional training, published educational materials, and engagement of parents and caregivers. These combined efforts led to the establishment of regional FASD diagnostic and treatment centers in Lublin – Regional Point for FASD Diagnosis and Therapy at the Regional Center for Social Policy in Lublin, Łódź -Regional FASD Diagnosis and Therapy Point at the Regional Center for Social Policy in Łódź, and Kraków - Center for Comprehensive Diagnostics and Therapy for Children with FASD at the Provincial Specialist Children's Hospital of St**.** Ludwik in Kraków.

3. **What barriers nearly stopped progress, and how were they navigated?**

Although there has been a progress, major barriers remain, such as limited access to child psychiatrists, lack of appropriate FASD recognition and classification in educational and social systems, absence of cross-sector systemic solutions, and stigma preventing families from seeking support.

4. **Where does your country's policy currently fall short in delivering meaningful outcomes for individuals and families?**

The major challenge is the absence of a nationwide care model, that offers systematic solutions, such as ensuring access to serives to all individuals with FASD and their families, providing a comprehensive range of serives, and coordinating services effectively. At this point there is only one center in Gdynia – FASD Diagnostic and Therapeutic Centre, that provides long-term support for children, youth and young adults with FASD in the city of Gdynia.

There is hope for improvement. In 2025, efforts led by MP Monika Rosa and inter-ministerial collaboration, resulted in a formal request to incorporate FASD into national legislation across the health, education, and social policy systems.

References:

- Okulicz-Kozaryn K., et al. (2015). FASD Prevalence among Schoolchildren in Poland. Journal of Applied Research in Intellectual Disabilities 2015
- Okulicz-Kozaryn K., et. al. (2021). Diagnosis of Fetal Alcohol Spectrum Disorders (FASDs): Guidelines of Interdisciplinary Group of Polish Professionals. International Journal of Environmental Research and Public Health 2021, 18, 7526.
- Dyląg K., et al. (2026). Updating guidelines for the diagnosis of fetal alcohol spectrum disorders (FASD) in Poland. Advances in Clinical and Experimental Medicine, ISSN 1899–5276 (print), ISSN 2451–2680 (online)

- The National Health Program 2016 – 2020 (https://www.gov.pl/web/zdrowie/npz-2016-2020)
- The National Health Program 2021-2026 (https://www.gov.pl/web/zdrowie/npz-2021-2025)

PLENARY

México - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Esteban Nolla Hernández

---

1. What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment?

In Mexico, the situation is paradoxical. On one hand, there are policy signals: the General Health Law partially recognizes the risk by framing alcohol use during pregnancy as harmful when excessive, and clinical guidelines acknowledge the risk. Warning labels are also mandated on alcoholic beverages.

However, these signals have not translated into system readiness: there are no specific guidelines for prenatal alcohol exposure or FASD, limited awareness, and insufficient capacity for detection or care .

Over the past year, we have focused on closing that gap. We held the first international FASD conference, launched national training efforts, engaged key health institutions, and joined global networks. Importantly, we also generated the first hospital-based data on screening for alcohol use during pregnancy in over 30 years.

So while Mexico is not yet advancing formal policy implementation, we are building something essential: the system that will allow existing policy signals to become real outcomes.

2**. What made that policy most effective in influencing decision-makers? Was it the combination of evidence, living experience, accountability, and stakeholder engagement—or one factor in particular?**

In Mexico, I would say the key factor is not yet policy enforcement, but agenda-setting. Because there is still no specific FASD legislation, the first step has been building awareness and generating local evidence. This is where FISAC's work has been particularly relevant: through research, scientific communication, and convening stakeholders, we are helping place prenatal alcohol exposure and FASD on the national public health agenda. Without visibility, it is very difficult for decision-makers to prioritize legislative action.

3. What barriers nearly stopped progress (e.g., stigma, fragmentation, competing priorities), and how were they navigated?

The lack of awareness and public understanding of this issue in Mexico may represent the main barrier to initiating and advancing FASD legislation in the country. There is currently a significant research gap, as well as a shortage of trained human and professional resources for diagnosis. In addition, stigma surrounding alcohol consumption during pregnancy, together with limited awareness among families, healthcare professionals, and the general public, may further hinder progress.

4. Where does your country's policy currently fall short in delivering meaningful outcomes for individuals and families?

The lack of training on prenatal alcohol exposure and FASD among healthcare professionals creates a critical gap in screening and recognition. In practice, this often translates into little to no systematic screening, limited clinical suspicion, and missed opportunities for early identification. As a result, many families do not receive a timely diagnosis or access to the multidisciplinary care and support that affected children require. Right now, FASD remains an invisible issue within our health system.

Resources:

Mexico´s General Health Law

https://www.diputados.gob.mx/LeyesBiblio/pdf/LGS.pdf

Norma Oficial Mexicana NOM-007-SSA2-2016, Para la atención de la mujer durante el embarazo, parto y puerperio, y de la persona recién nacida.

https://www.dof.gob.mx/nota_detalle.php?codigo=5432289&fecha=07/04/2016#gsc.tab=0

Guía de Práctica Clínica Control prenatal con atención centrada en el paciente

https://www.imss.gob.mx/sites/all/statics/guiasclinicas/028GER.pdf

PLENARY

France - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Berenice Roy-Doray

1. **What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment?**
   The most significant legislative action was the 2006/2007 mandate requiring a pregnancy warning logo (pictogram) on all alcohol bottles. It became politically viable largely due to the strong, dedicated championship of Senator Anne-Marie Payet from the overseas territory of La Réunion.

2. **What made that policy most effective in influencing decision-makers? Was it the combination of evidence, living experience, accountability, and stakeholder engagement—or one factor in particular?**
   The progress was primarily driven by strong stakeholder engagement and relentless advocacy from key individuals. The collaboration between civil society, medical professionals, and government bodies—specifically the national agency MILDECA (*Interministerial Mission for Combating Drugs and Addictive Behaviors)*, the Regional Health Agency, and the University Hospital—was crucial in establishing a highly successful, evidence-generating pilot region in La Réunion that serves as a model for decision-makers.

3. **What barriers nearly stopped progress (e.g., stigma, fragmentation, competing priorities), and how were they navigated?**
   Progress was heavily hindered by deep cultural ties to alcohol (wine, beer, and rum) and powerful industry lobbying groups that actively opposed initiatives like "Dry January" and continuously tried to make the warning logo invisible. These barriers are being navigated through the persistent pushback of civil society, medical professionals, and patient support groups (like "Vivre avec le SAF"), as well as by using the successful La Réunion pilot program to set an example for the rest of the country.

4. **Where does your country's policy currently fall short in delivering meaningful outcomes for individuals and families?**
   The policy currently falls short due to a persistent lack of comprehensive FASD training for healthcare and social professionals, and a historical reliance on isolated actions rather than cohesive State policy. Most critically, geographical inequality is a major issue:

as of 2026, the country's only dedicated resource and diagnostic centers are located in La Réunion—10,000 kilometers away from mainland France.

PLENARY

South Africa - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Leana Olivier

---

1. Most important policy/legislative action on FASD in South Africa, and why it was politically viable

South Africa does not have a dedicated national FASD policy or Act. Instead, progress has occurred indirectly through:

- **Alcohol control and public health legislation**
    - The draft National Liquor Act is currently being reviewed again, as the previous draft (2017) was never promulgated.
- **Department of Health**
    - National programmes such as *The First 1000 Days of Life* and the *Basic Antenatal Care Programme* highlight the dangers of prenatal alcohol use.
- **Department of Education**
    - The Inclusive Education Policy applies to children living with FASD. According to this policy, learners with disabilities and learning barriers must attend mainstream schools and receive appropriate support.
- **Department of Social Development**
    - The National Drug Master Plan provides guidelines for prevention, management, and rehabilitation for all substances of abuse.

The above policies are politically viable as they address various international agreements and objectives (e.g. UNICEF, WHO)

A key challenge remains securing the support, buy-in, and recognition of politicians and policymakers to formally acknowledge FASD and to develop and implement appropriate policies and programmes.

2. What made these policies/guidelines effective in influencing decision-makers

Key factors:

- **Evidence and expert consensus**
    - Published research findings, including extremely high FASD prevalence rates (26–310 per 1,000), have strengthened the case for action.

    - This evidence base gives the issue scientific legitimacy and makes it more difficult for decision-makers to dismiss it as advocacy alone.
- **Multisectoral framing**
    - FASD is explicitly linked to health, education, social development, and justice, helping it resonates across multiple government departments rather than being viewed as a “health-only” issue.
- **Lived experience and service-provider input**
    - Testimonies and contributions from individuals living with FASD, their parents and caregivers, and service providers are increasingly used in media, reports, and conferences.
- **Accountability logic (even if weakly enforced)**
    - By outlining what a comprehensive FASD response should include, such as awareness and support programmes, screening, training of professional service providers, management guidelines and support to professionals, referral pathways, parental support, guidelines create a benchmark against which government inaction can be assessed.

3. Barriers that nearly stopped progress, and how they were navigated

Major barriers:

- **Stigma and moral judgement around alcohol use in pregnancy**
    - Pregnant women who drink are often portrayed as “irresponsible,” rather than as individuals facing complex social and economic pressures.
    - This stigma limits open discussion, screening, and help-seeking.
- **Fragmentation across sectors**
    - FASD spans health, education, social development, and justice, yet no single department has taken full ownership.
    - This leads to a “someone else’s problem” dynamic.
- **Competing priorities and limited resources**
    - Issues such as HIV, TB, maternal mortality, and NCDs often overshadow FASD in political and budgetary priorities.
    - FASD is long-term and less visible than acute crises, making it easier to deprioritise.
- **Absence of a binding national policy**
    - Although guidelines exist, implementation remains inconsistent without a dedicated national programme and budget line.

    - Progress is often dependent on NGOs and local champions.

How these barriers were partially navigated:

- **Positioning FASD within broader alcohol-harm and maternal health agendas**
    - Advocates framed FASD prevention as part of existing maternal and child health, social development, education, and alcohol-control efforts.
- **Partnerships with NGOs and research institutions**
    - Organisations such as FARR (Foundation for Alcohol Related Research) have led awareness campaigns, community programmes, and diagnostic services where government capacity is limited.
    - Other NGOs have focused on prevention and public awareness.
- **Developing guidelines rather than waiting for legislation**
    - Recognising that a dedicated FASD Act would be slow to materialise, experts developed guidelines that could be integrated into existing policy frameworks.
    - These guidelines are used by FARR in training professionals and government employees.

4. Where South Africa's current policy landscape falls short for individuals and families

This is where the gap between policy and lived experience becomes most visible.

Major shortcomings:

- **No dedicated national FASD policy or programme**
    - Despite existing guidelines, there is still no coordinated, funded, multisectoral national programme.
    - A 2025 call to action highlights the continued absence of a national FASD prevention strategy.
- **Unequal and limited access to diagnosis and support**
    - Diagnostic services are scarce and concentrated in a few NGO- or research-linked sites.
    - Only children and adults who engage with FARR are formally diagnosed, limiting access to appropriate educational and disability support.
- **Weak integration into education and social services**
    - Although guidelines recommend undergraduate training for health professionals, educators, and social workers on FASD awareness, prevention, and management, this is not implemented nationally.

  - Families often navigate behavioural, learning, and social challenges with minimal structured support.
- **Insufficient prevention at scale**
  - Awareness campaigns exist but are largely NGO-driven.
  - There is no sustained, nationwide, government-led prevention campaign on alcohol use during pregnancy.
- **Limited recognition of FASD as a lifelong disability**
  - While policy language increasingly acknowledges developmental disabilities, FASD-specific pathways for long-term support remain underdeveloped.

PLENARY

Ireland - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Aine O'Halloran

---

1. **What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment? &**
2. **What made that policy most effective in influencing decision-makers? Was it the combination of evidence, living experience, accountability, and stakeholder engagement—or one factor in particular?**

   There is no policy or legislation referring to Foetal Alcohol Spectrum Disorder (FASD) in Ireland. In a reply to a Parliamentary Question by the Minister of State for Disability on 26 March 2025, the Minister stated "Ireland does not recognise FASD as a disability at this time."

3. **What barriers nearly stopped progress (e.g., stigma, fragmentation, competing priorities), and how were they navigated?**

   One of the largest barriers that is preventing progress with policy in Ireland is that there is a huge lack of knowledge among Civil Servants about FASD. Comments such as "*Well it only affects women over 50*" or *"FASD must be on the decline as everyone knows not to drink alcohol"* have been said at recent meetings attended by Government officials. It has to be said that Government are terrified of overloading the Health system with c381,000 people living with FASD, despite assurances from medical professionals that most of these people are already in the system, but not receiving appropriate support and care. Given that FASD is not recognised as a Disability in Ireland, many if not most Health Professionals are unwilling to progress assessments or provide diagnosis of FASD, instead opting for any one of the 428 co-morbid conditions to ensure that the person will receive some help, rather than no help at all. This lack of recognition by state is reinforcing stigma. FASD is not rare in Ireland, it is just rarely diagnosed.

4. **Where does your country's policy currently fall short in delivering meaningful outcomes for individuals and families?**

   Recognition is still the biggest challenge. The HSE (Ireland's Health Service Executive) now provides limited public health information about FASD and tells families to enquire with a GP or Public Health Nurse, however the guidance also states that there is "no specific treatment" and refers families to seek out any local supports that may exist.

There is no national assessment protocol or diagnostic pathway. Responses to Parliamentary Questions raised in 2024 stated there is no standard diagnostic policy or guidelines for assessment or supporting children with FASD in Ireland, and the issue is still recognised as a service gap today. The Royal College of Surgeons in Ireland (RCSI) 2025 research "FASD in Ireland" described a mismatch between likely prevalence and the absence of coordinated policy and standardised diagnostic pathways.

Framework for Support:

Policy is still not providing any access to services after assessment/diagnosis or suspected diagnosis. Even where children or adults are considered to live with FASD, support is largely routed through HSE Primary Care, independently operated Children's Disability Network Teams (CDNTs), Child and Adolescent Mental Health Service (CAMHS), school via the Special Education Needs Co-ordinator (SENCo), or Social Care systems rather than through a dedicated FASD model of care. The Minister of State for Disability acknowledged in 2024 that CDNTs and CAMHS did not have statutory guidance or the clinical experience to diagnose FASD, and that the response needed to span disability, primary care, mental health, justice and education. That means families are often left navigating multiple systems that do not share a clear FASD framework.

Funding:

The response remains too dependent on ad-hoc or fragile supports rather than guaranteed public provision. The State has part-funded FASD Ireland, however replies to Parliamentary Questions in January and March 2026 confirm funding was €200,000 in 2024 and 2025 and that the HSE was still negotiating a business case for funding in March 2026. Whilst funding FASD Ireland is helpful, and provides for a national telephone helpline, offering independent support, sign-posting and advocacy services, it is not the same as delivering a nationally recognised assessment/diagnosis pathway and framework of support. In practice, people living with FASD and their families still rely heavily on one specialist NGO hub for support and advocacy.

Prevention:

Prevention policy is stronger on messaging than on implementation, and even there it has weakened over recent months. The Chief Medical Officer and HSE clearly states "No amount of alcohol is safe to drink at any stage of pregnancy" and this is replicated on leaflets provided to pregnant women who engage with some HSE services. The Public Health (Alcohol) Act 2018, had a specific clause relating to labelling of alcohol. Ireland has to wait for the EU to agree to the style of label and the information contained on it, and this was granted in 2023. Alcohol-labelling regulations stated that containers of alcohol must carry a harm to pregnancy warning icon on any products sold after 22 May 2026. However on 22 July 2025 the Minister of State for Health said the Government decided to defer alcohol labelling requirements until 2028. This was following an objection from the alcohol industry that claimed the label would detrimentally affect exports of alcohol from Ireland to North America at a time when export tariffs were threatening the industry as a whole. The Government did not consult with stakeholders and implemented the deferral at incredibly short notice. Since population-level prevention depends on repeated, visible cues and public awareness, that delay matters.

Stigma:

Policy has not yet produced the joined-up, life-course supports that families need. The strongest recent Irish summaries point to gaps not just in diagnosis, but in outcomes: stigma deters families from seeking help, Teachers and Special Needs Assistants (SNAs) need training that includes FASD, Health Professionals need to grow their knowledge about FASD, and families and carers need targeted support. RCSI's 2025 report called for a national clinic plus better supports for carers, schools, healthcare staff and the public. A UCD public-policy paper similarly argues that Ireland's gap is not only prevention but also identification, assessment and service delivery across systems.

From the 2026 Pre Budget Submission:

FASD Prevalence Survey:

There is no definitive date on the prevalence of Foetal Alcohol Spectrum Disorder (FASD) in Ireland. While the HSE (Health Service Executive) estimates 2.8% to 7.4% may be affected, this is based on international data from 2017. Reliable data is essential to design effective public health, education, and social care supports. Current estimates are too broad and based on other countries, limiting policy planning. A national study would identify the scale of FASD, highlight regional trends, and guide targeted interventions and future policy, including diagnostic guidelines and awareness campaigns. The UK's Greater Manchester study (2021) successfully used school-based screening and diagnostics to identify prevalence rates of 1.8%–3.6%, many previously undiagnosed. Key strengths of that model: Feasible school-based design Local health and education collaboration Population-based data now informing UK policy Ireland can replicate this success, using a targeted study to finally understand and address the national impact of FASD.

FASD Aware Schools:

FASD prevalence in the education system is high yet supports remain generic. A 2023 survey led by Dr Katy Tobin at Trinity College Dublin, found 89% of parents/carers felt school support for FASD was inadequate. Over half of children struggled with schoolwork, and 61% were receiving SNA support. Young people aged 15–24 remain the most likely to binge drink (38%). Though exact data is lacking, national studies confirm a significant proportion of students become sexually active during school years, increasing the risk of prenatal alcohol exposure. Despite this, education on FASD, its risks, and prevention is not part of the school curriculum. Most FASD cases go unrecognised due to delayed symptoms and lack of awareness.

FASD Ireland proposes an awareness programme for 4th year Secondary school students. (Ages 15 – 17)

Teaching FASD awareness during 4th year reaches students as they begin engaging in drinking and sexual activity. It builds early understanding, combats stigma, and encourages healthy choices. It also fosters peer empathy and school-wide support for students with FASD. Existing public health messaging has a narrow focus - often targeting women already pregnant. We now understand that FASD is a conception issue, and the risks are present for both men and women. This programme addresses the information gap earlier, empowering students with knowledge to avoid risk.

Ringfenced Alcohol Related Harm Fund:

Ireland has one of the highest global rates of alcohol use during pregnancy, with 81% of women reportedly consuming alcohol while pregnant - far above the global average of 10%. This is a major contributor to FASD, estimated by Ireland's HSE to affect up to 7.4% of the Irish population, compared to 1.98% in the WHO European Region. Despite this public health issue, there is no dedicated fund to support FASD prevention, education, or services. FASD is estimated to cost Ireland €4.6 billion annually, yet investment in harm reduction remains limited and fragmented.

FASD Ireland proposes introducing a social responsibility levy known as 'The Alcohol Related Harm Fund' on alcohol sales, based on the "polluter pays" principle. The proposal is: 1% levy on on-trade sales (pubs, restaurants) 2% levy on off-trade sales (off-licences, supermarkets) Using 2021 Central Statistics Office data, this could raise over €100 million annually. A portion should be ring-fenced for FASD-focused services, prevention, and education, with the balance being shared amongst other related providers.

This levy would shift the financial responsibility of alcohol-related harm onto the industry, not taxpayers. It would make all FASD-related recommendations in this submission cost-neutral, while reducing long-term burdens on the health, education, and justice systems. Ring-fencing funds for FASD would ensure sustainable support, transparency, and public trust.

New Zealand operates a government-administered alcohol levy, now generating NZD $16.6 million annually. Collected from alcohol producers and importers, it funds public health campaigns and treatment services under the Pae Ora Act. Ireland faces similar challenges, and this proven model offers a feasible, transparent approach that could be adapted domestically to combat FASD and related harm.

PLENARY

Germany - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Kathleen Kunath

There is a lot left to do to improve the lives of everyone affected by FASD. If there was one topic to choose, I would pick this:

The structural difference that we frequently observe in Mini-ICF-APP ratings of impairment between self-ratings by people with FASD and ratings provided by their caregiver network.

Why is that important? Because people with FASD over-rate themselves, perhaps in an attempt to present a better, more capable self. The external view is frequently more realistic, pointing to a more comprehensive need for assistance. That is important because payors and authorities would rather spend less and are happy to choose the "better version". That leaves people with FASD short of the actually required level of assistance.

Here is the long story with some background on the German situation:

1. **What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment?**
    - We have a history of Nazi-times in Germany with systematic murder of „unworthy life" and subsequent change towards a more appreciative stance towards people with disabilities and democratization.
    - Many offices resided with central government, replacement post-war more federally structured.
    - This means that representation by (FASD) interest groups needs more effort and needs to be present in many regions (support, advice, self-help groups, contact to experts). There is continuous communication with subject-matter experts in political parties and government. On the level of the German Federal Government there is cooperation with the Federal Commissioner for Drugs and the Federal Ministry of Health. Information campaigns and Flyers were created. Financial support for support programs was and is granted, e.g., Competence Center Bavaria or Sonnenhof Berlin to develop Intervention Methods.
    - Academia in Germany enjoys significant freedoms. Financial support is available that allows researchers to address FASD-specific issues. In addition, support is available from public bodies such as the Lotto Foundation, Aktion

    Mensch (a non-profit dedicated to support causes of people with disabilities), and the European Social Fund.

  - Research and exchange is possible because public funds are available to support FASD congresses, FASD expert forums, FASD Counseling Offices, and publishing of FASD information materials.

2. **What made that policy most effective in influencing decision makers? Was it the combination of evidence, living experience, accountability, and stakeholder engagement—or one factor in particular?**

  - There is constant lobbying by Not-for-Profit Organizations, volunteers, and volunteer networks.
  - Sharing of experience took place, especially by FASworld, of parents' associations, self-help groups supported by FASD Deutschland e.V..
  - We engage in continuous multimodal cooperation of experts in the medical, psychological, and caregiving fields. Multiple merit awards by the German government were granted (Bundesverdienstkreuz).
  - The FASD community is publishing position papers on diagnostics, caregiving, amongst others for adult persons with FASD.
  - Disclosure and testimonials about life with FASD by people with FASD.
  - The combination of scientific evidence, real-world evidence, concrete experience, and accountability proved most effective in getting policy makers to make the right decisions.
    - Long-term clinical studies by Prof. Spohr, scientific publications and studies by Prof. Dr. Psych Mirjam Landgraf, Gela Becker, Lina Schwerg significantly advanced the quality of diagnostics and interventions.
    - Educational work, including Psycho-Education, is taking place, sometimes in painfully small steps and with huge effort, driven by self-help associations and individual contributors all over Germany.
    - People with FASD are presenting convincing testimonials of their everyday life, speaking to resources and barriers in their personal lives.
    - The adoption of the so-called "S3-Guideline for FASD in Children and Adolescents, Diagnostics and Interventions", the outcome of multimodal research and public debate, has lead to widespread

political acceptance of FASD as a cause for disorders and subsequent public funding of diagnostics since 2012 (FAS) and 2016 (partial FAS and Alcohol-related neurodevelopmental disorders ARND).

    - FASD Deutschland e.V. was heavily involved and contributed meaningfully to developing this guideline and getting it over the finish-line
        - Parliament hearings in the Federal Parliament's Healthcare Committee
        - Involvement of people with FASD
        - Joint press statement by FASD Deutschland e.V. with the then Federal Drug Commissioner, Marlene Mortler
        - In 2018, organization of the European Conference on FASD in Berlin
        - In 2024, contributions to a position paper on FASD diagnostics of adult persons with FASD
- Caregiving Foster Parents have successfully applied legal action, on behalf of children, adolescents, and young adults with FASD in order to get approval for measures to ensure participation in public life, support programs, counseling, funding, legal support to prove legal incapacity.

3. **What barriers nearly stopped progress (e.g., stigma, fragmentation, competing priorities), and how were they navigated?**
    - Fear of stigmatization, being shamed, and being ashamed are widespread phenomena.
    - On the micro-level of families: Competing interests of parents with one parent arguing that her/his child is capable of doing everything despite FASD and the other arguing that there will be a lifelong need for assistance.
    - On the macro-level: Competing interests of interest groups and/or pressure groups who are concerned about limited financial resources under the assumption that funding availability for healthcare and social care is a zero-sum situation, i.e., what one group gains might be lost to others, thus limiting willingness for joint action.
    - Fragmentation of interest groups, leading to loss of effectiveness in the advocacy effort.

- Solutions included, but were not limited to
    - Accept segmentation into smaller groups while working tirelessly towards reaching the same goals
    - Utilizing legal appeals and process to enforce government and authority compliance with legally guaranteed rights
    - Conduct psycho-education of policy-makers, caregivers, authorities, and wider public about FASD
    - Achieve full coverage of the country by regionally-anchored self-help groups and approachable subject-matter experts

4. **Where does your country's policy currently fall short in delivering meaningful outcomes for individuals and families?**
    - Starting with what is working well, there are now three tools:
        - The so-called "Bundesteilhabegesetz" (Federal Law on Participation), a law granting rights to participation in public life and society to every citizen, in particular to those with disabilities of any kind, came into force on January 1st, 2017. The focus is now less on "care" and more on "participation". Fundamentally a good change, but with dangers due to the potential discrepancy of impairment assessments by people with FASD vs. assessment by their care network.
        - The second tool, the so-called "Eingliederungshilfe" (Assistance for Inclusion), provides care resources, both personnel and funding, to implement the right to participation in life and society.
        - The third tool is the so-called "Teilhabefachdienst" (Qualified Assistance for Participation) whose mission is to ensure that special needs of children and adults with FASD are looked after and that required assistance, physically and financially, is being made available in order to reduce barriers to participation.
        - Funds needed to implement the above are being provided and administered by Healthcare Payors and Welfare Authorities. Not always sufficient, but usually a good start.
        - Assistance for participation is provided by both individual and collective school assistants and qualified counseling.
        - The need for assistance is documented, amongst others, by an official statement of an individual's degree of disability.
    - That said, there are dangers and deficiencies:
        - The granting of funds and assistance is still extremely dependent on whether or not the case worker in the respective responsible public authorities understands FASD.
        - There is a tendency to take overoptimistic self-assessments of the person with FASD as a welcome basis to not provide needed assistance.

  - External assessments, e.g., by case workers can provide much-needed clarity of (unsually higher) required levels and intensity of assistance, but is not always considered.
  - Legal Guardians can be appointed in order to safeguard the interests of a person with FASD. Their appointment can be inactivated in case the relationship with their guardian child or person is not working. However, the work of Legal Guardians is not well-compensated and there is therefore frequently a shortage of Legal Guardians.
  - As a consequence of the above, awareness of FASD in public and with political decision makers needs to improve. Also, psycho-education both of people with FASD and their care network needs constant effort and attention.
- Immediate next steps planned by FASD Deutschland e.V. are, amongst others:
  - Raising public awareness is the focus of the next “Tag des Alkohol-geschädigten Kindes” (day to recognize alcohol-impacted children) on September 9, 2026
  - Continued media work
  - Self-empowerment by creation of a film and flyer about persons with FASD by persons with FASD (translation into English planned) and other publishing efforts
  - Reinforcement of “Experience Expert Program”:
    - Involvement of persons with FASD in training caregivers about special needs of persons with FASD
    - Training program for Experience Experts to enhance their effectiveness in providing their input to participants in caregiver trainings

Last but not least:
More funding is needed for additional research in to FASD!

PLENARY

United Arab Emirates - From Momentum to Systems Change: What the FASD Respect Act Teaches Us About Building Policy

Jessica Rutherford

---

1. **What policy or legislative action has most advanced FASD in your country? What made it politically viable at that moment?**

Alcohol use is screened in registration at ante-natal appointments and substance exposed pregnancies here are treated as high risk however there is no specific policy around FASD.

2. **What made that policy most effective in influencing decision-makers? Was it the combination of evidence, living experience, accountability, and stakeholder engagement—or one factor in particular?**

3. **What barriers nearly stopped progress (e.g., stigma, fragmentation, competing priorities), and how were they navigated?**

Messaging around alcohol use and alcohol harm is not a priority here in the UAE as it is a Muslim country where alcohol use is only legal for non-Muslims. The purchase of alcohol is heavily regulated and it is only sold in dedicated stores which require a license for you to buy from. Alcohol is not available in supermarkets and cannot be consumed in public spaces. Any stigma there may be here around alcohol use in pregnancy will only be associated with the non-Muslim, expatriate population and is therefore less likely to be featured on the government agenda. The emirate of Sharjah is entirely dry, alcohol is not licensed for sale or consumption at all in the emirate.

4. **Where does your country's policy currently fall short in delivering meaningful outcomes for individuals and families?**

I am not aware of any services here that specifically support those with FASD or their families. I am not aware of any families at all here living with FASD despite working in the field myself. My work remains entirely remote. Anyone with a diagnosis of FASD living in the UAE may have access to disability support services like any other under who meet the criteria of "People with Determination". Whilst not FASD specific, there are specialist developmental pediatrician's, OT, SLT and others who have a understanding of FASD and can support intervention through their work.

POSTER SESSION

2: FASD: Ireland's Silent Epidemic

Tristan Casson-Rennie, Robert O'Connell, Aine O'Halloran, Jacob Casson-Rennie

FASD Ireland’s work highlights the urgent need for recognition of FASD as a disability and the development of a national diagnostic and support framework. The organisation bridges the gap between lived experience and policymaking, advocating for inclusive services and systemic reform. Its efforts have laid the groundwork for future developments, including the establishment of a fully operational specialist clinic and regionally based FASD hubs.
By collaborating with government bodies, professionals, and communities, FASD Ireland continues to build a more inclusive society where individuals living with FASD can thrive. The presentation will explore the organisation’s advocacy model, key findings from its research, and the next steps in policy and service development.

3: Fetal Alcohol Spectrum Disorder: An Exploration of Causes, Prevention, and Supports

Moheb Attaalla

Fetal Alcohol Spectrum Disorder (FASD) is a complicated, epigenetic neurodevelopmental disorder caused by the parents' consuming alcohol preconception and maternal alcohol consumption during pregnancy and lactation. The discussion explores the paternal contribution to FASD via epigenetic-mediated alterations in sperm, and the seldom-studied influence of maternal alcohol consumption on oocyte quality and postnatal offspring outcomes. This review integrates animal and human research to demonstrate how alcohol perturbs neurodevelopmental trajectories, guided by neurodevelopmental, epigenetic, and ecological systems theories within a biopsychosocial framework. Integrative thematic synthesis is employed to systematically collect and appraise empirical research on the intergenerational effects of alcohol. The discussion highlights the need for inclusive, trauma-informed, and culturally safe public health interventions, arguing for a shift away from the blame placed on mothers to an understanding of dual parental responsibility for reproductive health. Ultimately, this review aims to enhance FASD prevention through preconception counselling, widespread screening, and system changes that support disadvantaged populations. This paper also seeks to increase the knowledge of young couples about the harmful impact of alcohol before, during, and after pregnancy. It suggests the shared responsibility of both parents. It offers new knowledge to mental health professionals, counsellors, and policymakers striving to reduce stigma and to promote resilience in families living with FASD.

Keywords: Biopsychosocial framework, counselling, epigenetics, Fetal Alcohol Spectrum Disorder (FASD), intervention, Neuro Behavioural Disorder associated with Prenatal Alcohol Exposure (ND-PAE), parental alcohol consumption, prevention, public health
POSTER SESSION

13: Elevating FASD Across the Association of University Centers on Disabilities (AUCD) Network: Building Visibility, Capacity, and Community to Strengthen National Systems of Support

Elizabeth Cleveland, Brandon Lewis

Background

FASD is among the most common neurodevelopmental disabilities, yet it remains substantially under-recognized across disability systems like healthcare and education. Provider training is inconsistent, diagnostic pathways vary widely, and individuals and families often struggle to find informed and coordinated support. The Association of University Centers on Disabilities (AUCD) network, which includes over 150 programs and partners, provides a unique infrastructure for elevating FASD awareness and strengthening national capacity. In recent years, FASD visibility across AUCD has grown rapidly through interdisciplinary trainings, leadership development activities, and formal and informal cross-center partnerships. This poster highlights how specific AUCD programs and initiatives, taken together, are increasing FASD visibility and expanding systems of support for individuals and families.

Methods

A descriptive approach was used to identify and summarize existing FASD- related activities across the AUCD network. Sources included interdisciplinary trainings, conference events, technical assistance activities, and leadership development opportunities. Key AUCD initiatives were reviewed, including the National Trainee Network Exchange (NTNE), LEND Junior Faculty leadership roles, the Guided Utilization of Interdisciplinary Diagnostic Expansion (GUIDE) Model, and the work of the FASD Special Interest Group (SIG). Broader AUCD activities, such as the pre-conference on FASD at the 2024 AUCD Annual Meeting and the AUCD Trainee Mini Conference at FASD Impact Week, were also examined. These activities were organized into five major themes: workforce development, diagnostic and clinical capacity-building, lived-experience leadership, cross-center collaboration, and early-career engagement. This descriptive method documents the expansion of FASD visibility across the AUCD network rather than evaluating any single program.

Results

Across the network, FASD-focused activity is growing in frequency, visibility, and integration. LENDs and UCEDDs have expanded their incorporation of FASD-specific didactic and clinical trainings. The NTNE created structured opportunities for trainees to experience cross-state collaboration related to FASD. The GUIDE model brings FASD directly into interdisciplinary capacity-building efforts through diagnostic expansion and sustainability. Junior Faculty integration of FASD highlighted living experience importance within diagnostic and training contexts, offering a model for disability-centered leadership development.

AUCD-wide platforms also demonstrated increased commitment. The FASD SIG emerged as a central hub for resource sharing and professional networking, with increased participation and higher visibility across the network. The 2024 AUCD Annual Meeting featured a dedicated pre-conference on FASD, and AUCD partnered with national partners to deliver a Training Mini Conference on FASD during FASD United's Impact Week.

Discussion and Conclusion

The expansion of FASD-focused activities across AUCD shows how visibility can operate as a form of systems change. Network-wide efforts, such as NTNE, GUIDE, and the FASD SIG, have improved workforce readiness, expanded opportunities for trainees and early-career professionals, and increased capacity for diagnostic and community-based supports. The inclusion of FASD within national events signals a broader recognition of FASD as a critical public health and disability priority. Importantly, living experience leadership across several initiatives strengthens the inclusivity and responsiveness of FASD training and systems development. Continued investment in FASD visibility and cross-network collaboration has the potential to improve support and outcomes for individuals and families across the lifespan.

POSTER SESSION

15: Mini-ICF-APP : Discrepancy between self- and other-perception of people with FASD – a clue for further research

Kathleen Kunath

Background: The International Classification of Functioning, Disability and Health (ICF) is increasingly used as a supplement to the ICD or DSM-5 for the classification of participation impairments. However, this remains a problematic instrument for FASD because, due to the diffuse brain damage, often simple (not significant) impairments in participation only result in a complex disability when combined. For assessments, the Mini ICF APP developed by Linden (Linden et al., 2015) is gaining popularity as a manageable tool.

Methods:

- Sample of 12 people with FASD, of whom 8 had FAS and 4 had pFAS; Work capacity: 1 person reported being employed part-time
- 7 people reported being unable to work
- 1 person reported working less than 4 hours per day
- 3 people reported working 6 or more hours per day

Other diagnoses:

- 9 people reported no additional diagnoses
- 3 people reported comorbidities, including: depressive disorders, agoraphobia, epilepsy, and sleep disorders

Comparison between self- and other-ratings:

Discussion: Functional impairments are pronounced in FASD, more so than in people with depressive and anxiety symptoms (see comparison to the study with patients in general practitioners' offices).

These impairments are rated as less severe by people with FASD themselves, compared to assessments made by people in their social environment.

Conclusion: Further research into functional impairments (including self- vs. other-ratings) in people with FASD is indicated.

Since adults are usually diagnosed alone, this is a clear indication of the risk of false-positive assessments in evaluations.

23: - The impact of epileptiform discharges on memory circuits following third-trimester alcohol exposure

Abbey Myrick

Third trimester alcohol exposure (TTAE) damages the Hippocampal-Retrosplenial cortical circuit (HRCC), a critical neural pathway for learning and memory that propagates information via high frequency oscillations (HFOs). Changes in the function of the HRCC are therefore speculated to drive differences in learning and memory observed in certain individuals with prenatal alcohol exposure. In the current study using a mouse model of TTAE we unexpectedly discovered epileptiform discharges - pathological events associated with epilepsy and neurodegeneration - and assessed their impact on HFOs.

Male and female TTAE and control (saline) mice were produced using a single day, double alcohol injection model (5 g/kg total) at postnatal day 7. After postnatal day 60, electrodes were implanted into the retrosplenial cortex and hippocampus. Following recovery, home cage electrophysiological recordings were collected in 24-hour epochs following a daily learning and memory task called the Barnes maze.

Epileptiform discharges happened more frequently during Non-Rapid Eye Movement (NREM) sleep, a behavioral state where HFOs most commonly occur. Interestingly, we found an increase in HFOs of the Retrosplenial cortex within 20-100 ms of the epileptiform discharges. These ‘Rapid HFOs’ exhibited a negative correlation with time from ED and duration, frequency, power and maximum amplitude. While compared to HFOs outside the 20-100 ms window, they are overall larger in all four metrics indicating unchecked recruitment of cells and potential loss of information. Additionally, in a subset of mice with Hippocampal implants we discovered that epileptiform discharges arrived at the Hippocampus first more frequently than the Retrosplenial cortex, however the Retrosplenial cortex still leads a number of events. These temporal differences suggest that epileptiform discharges pass through multiple pathways within the larger HRCC circuit. Importantly, mice did not exhibit outward symptoms of epileptic activity.

These results identify and characterize HRCC epileptiform discharges as a potential mechanism for learning and memory differences through the disruption of memory consolidation during NREM. While higher rates of abnormal EEG readouts and epilepsy have been noted clinically in groups exposed to alcohol prenatally, this is the first preclinical model to our knowledge to discover epileptiform discharges in this crucial memory circuit. We are actively investigating the mechanistic driver of these events and how cell populations within ripples may be altered as a result of them.

35: Long-term retention of motor learning is impaired by prenatal alcohol exposure

Priscilla Pang

Motor development in children can not only be used as a predictor for motor function but also cognitive development and school aged outcomes. However, children with fetal alcohol spectrum disorder (FASD) often show delays in motor development and have impairments in gross and fine motor skills, which leads to difficulties in performing daily tasks such as eating, dressing, grooming, and shoelace tying. Similarly, our animal model of FASD exhibits difficulties in motor learning. However, their motor learning impairments can be improved by pharmacological blockade of potassium calcium-activated channel subfamily N member 2 (SK2/KCNN2) channels. While initial motor learning abilities are important, another aspect of motor function is the ability to retain learned motor skills long-term without frequent practice. Though our animal model can improve their initial learning after pharmacological treatment, they have difficulties retaining their learned motor skill four weeks later, suggesting lack of long-term treatment efficacy. However, based on findings in humans, we tested and found that continuously stimulating primary somatosensory cortex (S1) after initial learning improves motor retention. Given that S1 makes connections to primary motor cortex (M1), we hypothesize that the S1 activation that is required for forming long-term motor memories in M1 is disrupted in FASD. Because the mechanism behind the role of S1 in motor retention is less understood, we will investigate underlying circuits between S1 and M1 before motor learning and in the retention phase between control and FASD mice. We will simultaneously record neuronal activity from S1 and M1 in acute brain slices using high density multi-electrode array and evaluate firing rate, spike amplitude, interspike interval and network synchronicity in spontaneous activity and evoked activity following S1 stimulation. These results will reveal possible differences in the FASD brain that contribute to motor retention difficulties. Additionally, we evaluate synaptic gene expression of the S1-M1 synapse in retention between control and FASD animal model, as local gene expression at the synapse has been shown to contribute to neuronal plasticity and formation of lasting memories. We will isolate the synaptosome from S1-M1 synapses and perform RNA sequencing to obtain differentially expressed genes between control and FASD mice four weeks after motor learning. With these results, we seek to identify possible differences in synaptic gene expression that contribute to difficulties in motor retention and could be a target for therapy. Overall, our studies aim to better understand motor retention in FASD and find therapies that have long-term impacts on it.

POSTER SESSION

51: Preclinical Development of FASD-Specific Nasal Peptide Medications Targeting Root Causes of Neurocognitive Challenges

Kazue Hashimoto-Torii

This session presents a mechanism-driven therapeutic development program led by Thyntra Therapeutics (Cogthera's DBA), a preclinical spin-off from Children's National Hospital uniquely dedicated to developing intranasal peptide medicines purpose-built for individuals with FASD. Unlike current practice, where treatment relies heavily on repurposed drugs for ADHD or other behavioral symptoms developed for different conditions, Thyntra's programs directly engage FASD-relevant biology. We will outline two complementary preclinical candidates: a peptide that modulates an ion channel implicated in learning and memory deficits, and a peptide strategy that addresses a dysregulated lipoprotein pathway linked to anxiety and cognitive performance in FASD and related neurologic conditions. Both programs leverage nasal delivery to enable non-invasive, brain-targeted, repeatable dosing suitable for daily use. Thyntra's programs are currently in preclinical development with first-in-human trials anticipated in Q1 2028, aiming to move beyond symptom-only management toward a new class of FASD-tailored therapeutics aligned with the lived realities of patients, families, and providers

POSTER SESSION

58: Transitioning to Adulthood with FASD: Family Members' Perspectives on Wellbeing and Access to Supports

Anna Wilhelm, Hannah Barton, John Thorne, Sara Kover

Many young adults with FASD experience stress and a loss of critical support (e.g., language and communication services) as they age out of public schools (Egerton, 2014; Roux et al., 2015). This study sought to understand experiences of family members of adults with FASD with respect to communication, executive function, and access to services during the transition to early adulthood. Drawing upon a strengths-based framing of FASD (Petrenko & Kautz-Turnbull, 2021), this study centers the values, experiences, and voices of families of adults with FASD. The current study explores the following research questions:

- RQ1(Qualitative): What are caregiver experiences with receiving support for well-being during the transition years for their adult children with FASD, including around communication and executive function?
- RQ2 (Quantitative): What are self-reported levels of well-being and ease of access to community or social supports for caregivers of adult children with FASD?
- RQ3 (Mixed Methods): What experiences do caregivers report with communication and executive function supports during the transition into adulthood for their children with FASD, and how do these reflections contextualize caregiver ratings of support and wellbeing?

Methods: This study used a convergent parallel mixed-methods design to understand caregiver perspectives on wellbeing in early adulthood (defined as ages 18 to 30) for individuals with FASD. Caregivers were asked to reflect upon services and support for wellbeing, communication, and executive function. Caregivers (N=12) participated in qualitative semi-structured interviews and online questionnaires.

Quantitative data were completed by caregivers via REDCap. Participants completed the Modified - Family Support Scale (Bromley et al., 2004) and Parental Experiences Scale (Gibaud-Wallston & Wandersman, 1978). These measures explored caregiver reflections on wellbeing and access to family and community support. Qualitative interviews were recorded and transcribed for analysis. Interviews were coded using deductive procedures for thematic analysis.

Results: Quantitative survey data (responses on a 1 to 5 Likert-scale) indicated that parents reported varying experiences and levels of support for their adult children during the transition to adulthood. While 83% of parents reported receiving SLP services for their child, the level of services varied with some parents reporting those services were only "slightly" meeting their child's communication (M= 2.42; SD = 1.24) or executive functioning needs (M=2.25; SD=1.14).

When asked to rank the amount of support received from their community (e.g., spouses, therapists, doctors), parent respondents indicated that they received only some helpful support (M=1.45, SD =0.74). Despite reporting low levels of support, respondents indicated high levels of parenting satisfaction and commitment to their adult children with FASD. Preliminary qualitative analyses show emerging themes of caregivers lacking adequate support and a mismatch of societal systems to family needs, which will be explored in detail.

Discussion/Conclusion: Family members in this study reported low levels of support within the community, and varied experiences with communication supports provided by speech-language pathologists. These experiences can be used to design more supportive services for communication and executive functioning for young adults with FASD as they transition into early adulthood.

POSTER SESSION

64: Lifelong Impacts of PAE on Stem Cell Health: Implications for Healthy Aging in FASD

Harshini Davuluri

Research in animal models has shown that prenatal alcohol exposure (PAE) alters the behavior of stem cells across the body in early development. For example, some stem cells exhaust their capacity to make additional cells, including stem cells. Given that healthy stem cells are required for healthy aging, we are investigating whether PAE's effects on early-life stem cells contribute to aging-related difficulties by reducing their capacity to repair and replenish tissues. By using a human stem cell model, we will determine if the stem cell impacts found in animal models also occur in humans with PAE and/or FASD diagnosis. In our initial assessments, we found that human induced pluripotent stem cells (hiPSCs) exhibit reduced health and increased inflammation following ethanol exposure in culture. Interestingly, we find that female stem cells may be more sensitive to the impacts of ethanol than male stem cells. Ongoing work will determine if a history of PAE/FASD diagnosis has similar impacts on stem cell health using patient-derived hiPSCs. These data will help us understand the long-term consequences of PAE for stem cell health and whether interventions to improve stem cell health can promote healthy aging for individuals with FASDs.

POSTER SESSION

65: microRNA Biomarkers in Maternal–Child Pairs Provide New Insights Into Risk for Atypical Neurodevelopment

Darius Miranda-Sohrabji

There is a shortage of early and accurate diagnostics for fetal alcohol spectrum disorders (FASDs). Critically, we know that early identification can improve quality of life for individuals with FASDs. We have found that microRNAs (miRNAs), small RNA molecules, present in the blood, may act as early warning signals for developmental challenges related to prenatal alcohol exposure (PAE).

Here, we compared miRNA patterns in pregnant mothers and their children, using blood plasma samples from a longitudinal study in Ukraine. In the 52 maternal-child pairs assessed, we identified groups of miRNAs that likely work together to impact biology and correlate with neurocognitive performance in infancy. Some of these miRNA patterns were associated within each mother–child pair, suggesting a biological link between changes in the mother during pregnancy and outcomes in the child.

One maternal miRNA group was particularly interesting: it was associated with the child’s neurocognitive assay performance, and in mothers of female children, it was associated with PAE. The miRNAs in this group were tied to processes important for brain development and cellular stress. Their matching child miRNA group reflected early developmental and tissue-repair processes. These data indicate that we can identify a trajectory of miRNA biology from pregnant women to their children that could help with early detection of risk for atypical development in children.

Overall, we find that by looking at blood miRNAs across maternal-child pairs we can identify risk and resiliency to PAE-associated developmental challenges. This could support earlier diagnosis, more tailored clinical care, and better long-term outcomes.

Supported by U01AA014835
Collaborative Initiative on Fetal Alcohol Spectrum Disorders, cifasd.org

POSTER SESSION

70: FASDPlay© - An Evidence Based Holistic Trauma Therapy for Individuals with FASD Across the Lifespan

Fatima Natascha Lawrence

Organizations such as CANFASD (2024) have argued that mental health is an essential consideration for people with FASD despite the challenges they face in accessing mental health services and support. Studies such as the "Lay of the Land" (Himmelreich et al., 2020) have presented how FASD is a whole-body diagnosis, arguing that services and interventions must focus on the holistic experiences of individuals with FASD. The FASD Changemakers recently presented (2023) the secondary results of the Lay of the Land Survey, which highlighted the inequalities and inequities faced by adults with FASD, particularly in their access to effective services, such as FASD-informed mental health treatment.

Despite the importance of effective mental health services for individuals with FASD, there is little practice or evidence-based research exploring interventions or modalities.
In this presentation, case studies and clinical experiences will be shared on how to support the holistic mental health needs of individuals with FASD. Clinical expertise will highlight successful FASD-informed mental health treatment considerations, adaptations, modifications, and interventions across the lifespan and argue for FASD-specialized mental health interventions and modalities.

This presentation will highlight current research gaps and the subsequent formation of FASDPLAY©. This evidence-based, person-centred trauma therapy modality incorporates research and clinical considerations from interpersonal neurobiology, somatics, neurodiversity-affirming care, disability-affirming care, child-centred play therapy, Synergetic Play Therapy, Expressive Arts Therapy, and traditional modalities.
This presentation is for mental health professionals, educators, frontline workers, caregivers, and individuals with FASD. Interventions presented can be used across multiple settings.

76: FASD and Youth Justice: A Prevalence Study Among Young People Sentenced to Detention in Reunion Island (France)

Berenice Roy-Doran

Objectives:
FASD is the most frequent cause of neurocognitive disorders and social maladjustment. Neurodevelopmental impairments due to FASD can predispose youth to,legal issues. Young people with FASD (FASD in the publication) are 19 times more likely to experience incarceration compared to their peers (Popova et al. 2011).
Reunion Island, the French region most affected by FASD, has implemented a comprehensive plan for prevention, identification, diagnosis and support, notably through the establishment of a FASD resource center.

The objectives of this study was to estimate the prevalence of FASD among youths in detention in Reunion Island. Canadian and Australian studies identified FASD in 11%-36% of young people in corrective services.

Design: A multidisciplinary assessment was conducted for all young people before 18 who were sentenced to detention at the only youth detention centre in Western Australia, from May 2015 to December 2016. FASD diagnoses were made according to the Australian Guide to the Diagnosis of FASD. Additionally, this study considered the recently recognized harmful impact of issue of the harmful role of preconception paternal exposure.

Participants: Thirty-six young people completed a full assessment, 94% were male. Seventeen cases were excluded, due to the lack of a dysmorphological examination (1 case), the absence of neuropsychological assessment (6 cases) and refusal or withdrawal from the study (10 cases).
Findings: Thirty young people (83%) demonstrated at least one domain of severe neurodevelopmental impairment. Classical FASD with maternal exposure (including 4 cases of Fetal alcohol syndrome) was identified in 10 cases (28%). Additionally, 6 cases exhibited phenotypes consistent with alcohol-related neurodevelopmental disorder and had confirmed paternal preconception alcohol exposure were also described.

Conclusions: This first French study, conducted with a representative sample of youths people in detention on Reunion Island, revealed a high prevalence of FASD and severe neurodevelopmental impairment, the large majority of which had not been previously identified. These findings underscore the vulnerability of young people within the justice system and the urgent need for improved diagnosis to identify their strengths and challenges,ultimately guiding and enhancing their rehabilitation.

POSTER SESSION

80: Exploring spatial navigation in children and adolescents with FASD

Felicha Candelaria-Cook

Background: Exposure to alcohol during prenatal brain development may result in lifelong cognitive deficits. Spatial navigation challenges are especially common and impact daily functioning, including mobility, safety, and independent living. Preclinical research demonstrates that hippocampal and entorhinal regions are highly vulnerable to prenatal alcohol exposure (PAE). Yet, the neural mechanisms underlying spatial learning challenges in children with FASD remain poorly understood. Bridging this gap requires translational approaches that capture real-world navigation behaviors while probing the functional integrity of underlying neural networks.

Methods: To investigate neural circuitry supporting spatial learning, children and adolescents with and without FASD completed a computerized Virtual Morris Water Task (VMWT). Participants navigated toward a hidden platform, as well as visible-platform, and a single no-probe trial to assess memory retrieval. The VMWT was performed in two neuroimaging sessions; Magnetoencephalography (MEG) measured theta-band (4–8 Hz) oscillatory activity during task performance, and functional MRI (fMRI) identified regions preferentially engaged during spatial navigation. Behavioral performance and neural responses were compared between groups.

Results: Data processing and analysis are ongoing. Preliminary results evaluate behavioral performance across hidden and visible trials, including path length and latency. Based on previous preclinical and clinical literature, we predict that children with FASD will demonstrate less efficient search patterns, along with altered theta oscillatory dynamics during the VMWT. Findings will clarify whether neural responses during goal-directed navigation differ between children with and without FASD and how these patterns relate to other behavioral measures.
Discussion: This study integrates ecologically valid spatial navigation behavior with high-resolution multimodal neuroimaging to assess neural mechanisms underlying spatial memory challenges in FASD. By examining hippocampal theta oscillations in relation to task performance, this work aims to clarify how PAE disrupts core navigation circuitry. Identifying brain-behavior markers of navigation impairment may inform early assessment strategies and support the development of targeted interventions in individuals with FASD.

POSTER SESSION

83: A Virtual Interprofessional Collaborative to Improve FASD: Recognition and Management in Child Welfare Populations

Roxanne Chang, Michelle Walker-Bauer

Fetal Alcohol Spectrum Disorders (FASDs) are highly prevalent in child welfare populations yet remain widely under-recognized, leading to fragmented care and adverse life outcomes. Integrated, cross-sector care models are essential, but implementation is often hindered by provider knowledge gaps, stigma, and a lack of coordinated systems. To address these challenges, we tested the feasibility of a grassroots, interprofessional, and interagency virtual collaborative within Los Angeles County designed to increase provider knowledge, improve care coordination, and strengthen clinicians' confidence in identifying and managing FASDs.

The collaborative was structured using the COM-B behavior change model to support capability through education, opportunity through networking, and motivation through a shared relational space for case discussion. Led by a pediatrician specializing in foster/adoptive care and a psychologist directing a FASD-informed intervention clinic, the collaborative convened monthly 1.5-hour Zoom conferences. Meetings included introductions, updates, resource exchange, and case-based discussions of diagnostic complexity, clinical management, and referral pathways. Program effectiveness was assessed through a voluntary six-question survey and a facilitated focus group.

Over the 32-month period, 21 conferences were held. Attendance grew organically from an initial four participants to a consistent 15–20 per session, with 41 individuals on the listserv at the time of evaluation. Participants represented a broad array of disciplines—including medicine, psychology, social work, occupational therapy, education, behavioral health, parent partners, disability support services, and national FASD program leadership—reflecting the collaborative's cross-sector reach. Three participants identified as having lived experience with FASD.

Survey responses (n=20) demonstrated strong perceived benefits. The majority of respondents agreed or strongly agreed that participation increased their knowledge of FASD recognition, assessment, and management, and improved their understanding of the variability in FASD presentations. Most participants also reported feeling more supported and less isolated in their work and endorsed meaningful expansion of their professional networks. Respondents further indicated greater confidence in applying FASD-informed recommendations and reported implementing at least one idea from the collaborative into their clinical practice. Focus group feedback aligned with survey data, with participants describing improved understanding of FASD presentations and treatment strategies, increased confidence managing cases without immediate specialty referral, and a desire for more training in frontline screening, interagency collaboration, and advocacy. Clinical scheduling conflicts were the most commonly cited barrier to participation.

Collaborative discussions directly facilitated interagency problem-solving for 15 child-welfare–involved cases, resulting in multiple successful referral linkages, revised individualized education program (IEP) eligibility decisions, and averting two potential adoption dissolutions. One additional child was subsequently placed with a disability-trained caregiver following a disrupted prospective adoption.

These findings suggest that a lightly structured, relationship-centered, virtual interagency collaborative is both feasible and effective in increasing provider knowledge, strengthening professional networks, and supporting more coordinated care for children with FASD. This model may be generalizable to other communities. Future work should examine integrated service delivery models and measure specific patient and family outcomes using frameworks such as relational coordination

Provide relevance of findings for 1) the broader field of FASD (e.g., providers, policymakers, and communities) 2) benefiting of individuals and families living with FASD or the prevention of FASD in a way that does not further stigmatize families. Both answers must use plain language, understandable by a general, lay audience.

1) Relevance of Findings for the Broader Field of FASD

These findings matter for the wider FASD community—including providers, policymakers, and local systems—because they show that a simple, low-cost, relationship-based learning group can make a real difference in how professionals understand and support people with FASD. Many clinicians want to help but have little formal training, and agencies often work in isolation. This project demonstrates that when professionals come together regularly to share practical knowledge, discuss cases, and learn from one another, they become more confident and better equipped to recognize FASD and connect families with the right resources. For policymakers, the results highlight the need for cross-agency collaboration and consistent training opportunities. For communities, it shows that improving care does not always require major programs or funding—sometimes connection, communication, and shared understanding can change outcomes.

2) Benefits for Individuals and Families Living With FASD

This collaborative ultimately benefits individuals and families by helping professionals better understand the unique needs that come with FASD. When providers are more knowledgeable and coordinated, families experience less confusion, fewer repeated assessments, and more consistent support. Parents and caregivers—who often feel overwhelmed or misunderstood—are more likely to be met with compassion and practical guidance rather than blame. These efforts also help create safer and more stable environments for children, reducing school struggles and preventing unnecessary placement moves. On a community level, improving awareness and coordination supports earlier identification and family-centered care, which can prevent secondary difficulties and help people with FASD thrive. Importantly, the focus is on understanding and supporting individuals rather than judging families, recognizing that all caregivers deserve respect, partnership, and access to clear information.

POSTER SESSION

86: My Health Coach 2.0: A Scalable Mobile Health Tool for Adults to Aid With FAS Self-Management

Cristiano Tapparello

Background: Fetal alcohol spectrum disorders (FASD) affect the health and development of people across the lifespan (Moore & Riley, 2015). Adults with FASD desire meaningful inclusion in their communities. As with most adults in today's world, efforts at independence and self-advocacy often means accessing the internet. Yet online information about FASD is often deficit-focused, stigmatizing, and not written at an appropriate literacy level. Unfortunately, adults with FASD also experience significant barriers to care across systems. Accessible and scalable solutions are needed. We have developed a mobile health (mHealth) application, called "My Health Coach," to provide adults with FASD evidence-based information about their condition and tools to promote their self-management and health advocacy goals. The mHealth intervention is based on self-determination theory (SDT; Ryan & Deci, 2000) and uses a just-in-time adaptive intervention to provide the right type and amount of support when users are most receptive.

Methods: This project represents a community partnership between researchers at the University of Rochester and members of the International Adult Leadership Collaborative (ALC) of FASD Changemakers, an international group of adults with FASD. This project follows an established user-centered design approach to app development and evaluation (Petrenko et al., 2021). This methodology includes seven phases, with feedback loops allowing iterative change. This process involves a multidisciplinary development team and engagement of community members. After establishing CAB infrastructure with ALC partners, we reviewed SDT constructs and brainstormed mHealth functionalities (phases 1-2). In phase 3, we developed interactive prototypes and obtained iterative feedback from advisory board members. In phases 4-5, ALC-led focus groups (n=26) and surveys (n=26) with adults with FASD refined the designs. Phase 6 involved a feasibility study (n=43) to optimize acceptability and effectiveness. We are now recruiting adults with FASD for Phase 7, which involves a Randomized Controlled Trial (RCT).

Results: Focus group and survey analyses showed overall positive global impressions of the initial design of the My Health Coach app. Initial feedback informed the development of the first version of the app, which was evaluated on a feasibility trial. Feasibility trial analysis has shown high acceptability of app features across users, and qualitative interviews showcased app functionality and recommendations for further refinements. These recommendations have been used to develop My Health Coach 2.0, which will be shown on this poster.

Conclusion: This project demonstrates the advantages of community engaged partnerships in FASD research. Adults with FASD have strong interest in scalable mHealth tools and described high acceptability of our initial design. Feasibility testing showed user acceptability, technological functionality, and recommendations for further refinements. We are currently conducting and actively recruiting for the last phase of the project, a larger Randomized Controlled Trial.

POSTER SESSION

93: FASD State Needs and Services Assessment

Reuben Kittrell

Introduction

Fetal Alcohol Spectrum Disorders (FASD) are a group of diagnosable medical conditions experienced by some people who have been exposed to alcohol before birth. Effects are lifelong and may include mental health conditions, learning disabilities, sensory issues, and physical manifestations such as heart defects, problems with hearing and seeing, and more (Centers for Disease Control and Prevention, 2025a). In the United States, FASD affects an estimated 1 in 20 people (May et al., 2018). FASD is also the largest known cause of intellectual disability in the United States (Greenspan & Novick Brown, 2022).

Like all individuals, people with FASD have their own unique talents, interests, and strengths, and benefit from strong and lasting relationships with peers and family. Increased societal, professional, and familial FASD awareness and education can help to increase understanding of the challenges associated with FASD. Prioritizing approaches that recognize and leverage individual strengths and interests can help to improve outcomes for people with FASD by decreasing the short and long-term impacts of misunderstanding, stigma, and deficit-based focus on challenges like low-self-esteem, isolation, incarceration, and education and housing issues (Kautz-Turnbull et al. 2022).

FASD affects individuals in a variety of ways, and at different levels of severity. Although many people with FASD meet the diagnostic criteria for intellectual disability, many others do not. People with FASD without intellectual disability may still experience significant challenges. Many of them have scattered developmental profiles with average or above average intellectual abilities while struggling with other skills, including executive and adaptive functioning, social communication, and self-regulation (Patenaude, 2016). In Massachusetts, people with FASD without intellectual disability are not yet eligible for many services, including services offered by the Department of Developmental Services (DDS).

FASD is an umbrella term which encompasses several distinct diagnoses. Examples from this category include Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE), and Alcohol-Related Birth Defects (ARBDs). There are also an estimated 428 comorbidities associated with FASD (FASD, Mental Health, and Comorbidities, 2023). These conditions present in different ways and are often challenging to identify. For example, only around 10% of people with FASD have the primary facial features often associated with this disability (palpebral fissures, smooth philtrum, and thin upper lip) (Alaska FASD Strategic Plan Workgroup, 2022).

Background

There are currently two organizations in the state of Massachusetts with a focus on education and increasing awareness of FASD: MassFASD, funded by the Department of Public Health's Bureau of Substance Addiction Services and operated by the Institute for Health and Recovery (IHR), and SAFEST Choice National Learning Collaborative at Boston Medical Center (SAFEST Choice). MassFASD provides training, technical assistance, and consultation to a wide range of professionals, as well as caregiver navigation services and caregiver support groups. MassFASD also coordinates the Massachusetts FASD Task Force, a voluntary group comprised of professionals throughout the state working with this population. SAFEST Choice is a national learning collaborative that trains clinical care teams across the country, building a community of practice for providers to prevent prenatal alcohol exposure and improve care for people with FASD. There are very few providers in Massachusetts currently offering specialized care, adapted services, or diagnostic options to people with FASD.

While FASD is a developmental disability, most people in Massachusetts with FASD are not classified as having a developmental disability. State regulations indicate that only people with IQ scores below 70 can be considered to have a developmental disability (Disability Law Center, 2024); and FASD is not listed under the state's definition of developmental disability (Public Welfare, XVII § 1 et seq, 2025). The uneven cognitive skills and deficits associated with FASD challenge service eligibility or recognition of individuals' needs within many public systems. For example, language is one of the neurodevelopmental or "brain domains" that are affected by FASD and assessed to diagnose FASD. People with FASD often have slower receptive language processing speeds and memory issues but possess strong expressive language abilities. Their ability to engage in conversations is more complex, due to the vast difference between these receptive and expressive language abilities, even among people with FASD whose IQ scores do not indicate intellectual disability (University of Sydney, 2025).

Many professionals such as educators, first responders, and direct service providers, regularly interact with people with FASD yet have not been trained to identify and support people with these conditions. As a result, FASD-affected families and individuals often lack service and resource options or experience approaches or interventions that do not meet their needs. Many people with FASD experience accumulated harms due to repeated and sustained interactions with systems, environments, and people that misunderstand their behaviors and presentation. This may result in low self-esteem, isolation, disruptions in housing, schooling, family life, incarceration or institutionalization, as well as risky behaviors such as truancy, self-harm, and substance use. While no single intervention will meet the needs of all people impacted by FASD, several behavioral interventions designed for children with FASD and their caregivers show promise. These include Good Buddies groups to improve social skills; Families Moving Forward (FMF), providing support to families whose children exhibit severe behavior problems; Math Interactive Learning Experience (MILE) to help with both mathematics and handwriting skills;

and Parents and Children Together (PACT) to improve executive function and self-regulation (Centers for Disease Control and Prevention, 2025b). Additionally, the Alert Program is a validated FASD-specific occupational therapy which functions as the basis for PACT and the Zones of Regulation, another method that addresses self-regulation and emotional control (American Academy of Pediatrics, 2024). The neurobehavioral model is another primary approach for treating people with FASD. Additionally, some (but not all) interventions and service models designed for people with other conditions may be helpful for people with FASD when selected, adapted, and implemented to support their specific needs.

Purpose

The assessment was conducted with the purpose of gaining a better understanding of the current knowledge base of professionals in Massachusetts regarding FASD, and the resource needs of individuals and families impacted by FASD. One aim of the survey was to evaluate the level of knowledge Massachusetts residents have about FASD, with a specific focus on those who are integral to providing FASD-informed services such as healthcare, human services, and education professionals. The survey also aimed to assess the number of providers capable of providing FASD diagnoses, FASD-informed interventions, and care in Massachusetts. Finally, the questionnaire aimed to identify areas for improvement regarding services and knowledge across Massachusetts in order to better serve individuals and families impacted by FASD. This is the first Massachusetts Needs Assessment developed specifically to focus on the needs of people with FASD and their families.

Between November 26, 2024 and February 7, 2025, a total of 121 professionals, caregivers, and community members provided insights into current knowledge, service gaps, challenges, and priorities.

Key Findings

1. Professional Knowledge Gaps
    - Nearly half of respondents had never received FASD-specific training.
    - Recognition of core FASD characteristics varied widely across healthcare, education, behavioral health, state agencies, and first responder sectors, despite frequent interaction with individuals impacted by FASD.
2. Inconsistent Prevention Messaging
    - Most respondents understood that no amount of alcohol is safe during pregnancy.
    - Massachusetts lacks standardized prevention messaging, unified screening practices, and consistent public health communication related to prenatal alcohol exposure and FASD.
3. Limited Diagnostic Capacity
    - Very few clinicians statewide are trained to diagnose FASD.
    - Diagnostic services are concentrated in Eastern Massachusetts, resulting in long wait times, extensive travel, and frequent out-of-state referrals that delay diagnosis and place financial and emotional burdens on families.

  - Underdiagnosis and misdiagnosis remain widespread due to limited screening, inconsistent documentation of prenatal alcohol exposure, and lack of clinician training.
4. Challenges in Educational Settings
   - Most educators reported receiving no formal FASD training.
   - Many educators believed they had never taught a student with an FASD, highlighting significant under-identification in schools.
5. Caregiver Barriers and Service Gaps
   - Families face substantial financial, geographic, and informational barriers when seeking diagnosis, services, and ongoing support.
   - Massachusetts lacks FASD-informed services such as respite care, peer support, coordinated family programs, and specialized statewide programs.

Priority Needs Identified

1. Expand FASD training and education across all professional sectors.
2. Strengthen prevention messaging and prenatal alcohol exposure screening.
3. Increase statewide diagnostic capacity and improve geographic accessibility.
4. Equip educators with FASD-informed strategies and resources.
5. Develop comprehensive, accessible supports for caregivers and families.
6. While the assessment highlights significant gaps in awareness, services, and systems capacity, it also reveals strong positive momentum for meaningful change. Professionals across sectors expressed a clear interest in receiving FASD training. Caregivers and advocates identified concrete, actionable solutions to improve supports statewide. Massachusetts is nationally recognized for healthcare innovation and has the foundational infrastructure needed to build an equitable, coordinated, and effective system of FASD prevention, identification, and support.
7. With improved public awareness, standardized screening practices, expanded diagnostic capacity, and FASD-informed supports across education, health, and community systems, the Commonwealth has the opportunity to significantly improve outcomes for individuals with FASD and their families. This Needs Assessment marks an important first step and offers a clear, achievable path forward to ensure that individuals with FASD are recognized, supported, and fully included in their communities across Massachusetts.

References

Alaska FASD Strategic Plan Workgroup. (2022). 9 Core messages: What everyone should know about prenatal alcohol exposure. https://improvinglivesalaska.org/wp-content/uploads/2022/10/9-Core-Messages_-What-Everyone-Should-Know-About-Prenatal-Alcohol-Exposure.pdf

American Academy of Pediatrics. (2024, December 17). Behavioral Interventions in Fetal Alcohol Spectrum Disorders. https://www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/health-supervision/behavioral-interventions-in-fetal-alcohol-spectrum-disorders/

Centers for Disease Control and Prevention. (2025a, May 8). About Fetal Alcohol Spectrum Disorders. https://www.cdc.gov/fasd/about/index.html

Centers for Disease Control and Prevention. (2025b, May 8). Types of Treatment for FASDs. https://www.cdc.gov/fasd/treatment/types.html

Disability Law Center (2024). Eligibility For Adult Services And Supports From The Department Of Developmental Services (DDS). https://www.dlc-ma.org/wp-content/uploads/2024/03/DDS-Eligibility-2024-02.pdf

FASD, Mental Health, and Comorbidities (2023, July 27). Edmonton and area Fetal Alcohol Network Society. https://edmontonfetalalcoholnetwork.org/2023/07/27/fasd-mental-health-and-comorbidities/

Greenspan, S., & Novick Brown, N. (2022). Diagnosing intellectual disability in people with fetal alcohol spectrum disorder: A function of which diagnostic manual is used?. Behavioral sciences & the law, 40(1), 31-45. https://doi.org/10.1002/bsl.2551

Kautz-Turnbull, C., Adams, T. R., & Petrenko, C. L. M. (2022). The Strengths and Positive Influences of Children With Fetal Alcohol Spectrum Disorders. American journal on intellectual and developmental disabilities, 127(5), 355-368. https://doi.org/10.1352/1944-7558-127.5.355

May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., Kopald, D., Hasken, J. M., Xu, R., Honerkamp-Smith, G., Taras, H., Manning, M. A., Robinson, L. K., Adam, M. P., Abdul-Rahman, O., Vaux, K., Jewett, T., Elliott, A. J., Kable, J. A., Akshoomoff, N.,… Hoyme, H. E. (2018). Prevalence of Fetal Alcohol Spectrum Disorders in 4 US communities. JAMA, 319(5), 474-482. https://doi.org/10.1001/jama.2017.21896

Patenaude. M. (2016, September 8). Q&A: Understanding fetal alcohol spectrum disorders. https://www.rochester.edu/newscenter/qa-understanding-fetal-alcohol-spectrum-disorders/

Public Welfare, XVII § 1 et seq. (2025) https://malegislature.gov/Laws/GeneralLaws/PartI/TitleXVII/Chapter123b/Section1

University of Sydney. (2025). Language and communication strategies to support primary aged children with FASD. https://learningwithfasd.org.au/resources/fact- sheets/language-and-communication-strategies-to-support-primary-aged-children-with-fasd/

POSTER SESSION

98: From the Land Translations: Understanding the Whole Person and Unveiling Gifts

Courtney Farrow-Lawrence

This poster presentation explores how shifting from deficit-based Western interpretations of FASD to strengths-based, relationship-centered Indigenous worldviews transforms understanding and practice. Rather than framing individuals through labels such as “behavioral issues” or “lack of capacity,” this work centres neurodiversity, identity, interdependence, and inherent gifts. Behaviours are understood as communication, adaptation, and responses to unmet needs within broader social and systemic contexts.

The poster highlights whole-person, culturally grounded, and community-led approaches to assessment, programming, and support across the lifespan. It emphasizes reducing masking pressures, strengthening cultural identity, and creating environments rooted in relational safety, belonging, and self-determination. Examples illustrate how services can be redesigned to honour Indigenous knowledge systems and community authority.

This work also calls for systemic change. By examining policies and institutional practices that create barriers for Indigenous neurodivergent individuals and their families, the poster advances advocacy grounded in reconciliation and equity. The goal is to support transformation within health, education, and social systems so that Indigenous neurodivergent individuals are recognized not through deficits, but as knowledge carriers, leaders, and valued members of their communities.

This presentation contributes a strengths-based, culturally responsive framework to inform practice, partnership, and policy reform.

POSTER SESSION

103: Prenatal Alcohol Exposure Increases the Likelihood of Adaptive Functioning Difficulties in the Proposed ND-PAE Diagnosis in Children With ADHD

Christina Veziris

Background: The Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE) diagnosis is a proposed mental health diagnosis meant to capture the cognitive, behavioral, and adaptive functioning challenges associated with prenatal alcohol exposure (PAE); however, it is still in need of validation. Results of previous studies have shown that the ND-PAE diagnosis is able to differentiate individuals with PAE from individuals without PAE, but efforts are continuing to be made to ensure that the ND-PAE diagnosis can properly differentiate PAE from other neurodevelopmental disorders, such as ADHD. Our previous research has found that the Adaptive Functioning (AF) domain is the only ND-PAE domain that that is specific to PAE, and therefore the purpose of this study is to differentiate which AF criteria best differentiate PAE from ADHD in hopes of putting more emphasis on those criteria and, in consequence, making the ND-PAE diagnosis more specific to PAE.

Methods: Data were collected between 2007-2017 from six research sites during phases 2 and 3 of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD). Participants included children and adolescents (5-17y) with (n = 186, mean age = 10.80y, female = 41.4%) and without (n = 99, mean age = 10.33y, female = 36.4%) PAE. Additionally, all participants met criteria for ADHD as determined by the Diagnostic Interview Schedule for Children, Fourth Edition (DISC-IV) and were individually matched for IQ within 1 point. Caregivers of participants completed the Vineland Adaptive Behavior Scales, Second Edition (VABS-2) and the Child Behavior Checklist (CBCL), and scores from these measures were mapped onto AF criteria (Communication Difficulties; Difficulties with Social Communication; Difficulties with Daily Living Skills; Difficulties with Motor Skills). For each of the four AF criteria, four logistic regressions including age, sex, and CIFASD site were conducted to determine whether PAE significantly affected ND-PAE domain endorsement.

Results: PAE significantly predicted three of the four AF criteria endorsement (Communication: OR = 1.885, $p = .027$, 95% CI: [1.074, 3.307]; Social Communication: OR = 2.961, $p < .001$, 95% CI: [1.696, 5.168]; Daily Living Skills: OR = 2.780, $p < .001$, 95% CI: [1.605, 4.818]). An increase in age also significantly increased the likelihood of endorsement for two of the AF criteria (Communication: OR = 1.148, $p = .002$, 95% CI: [1.053, 1.251]; Social Communication: OR = 1.109, $p = .017$, 95% CI: [1.019, 1.208]) and decreased the likelihood of endorsing difficulties with motor skills (OR = 0.697, $p = .003$, 95% CI: [0.547, 0.887]).

Conclusion: In individuals with ADHD, PAE significantly increased the likelihood of experiencing difficulties with communication, social communication, and daily living skills. With their ability to differentiate PAE from ADHD, adaptive functioning challenges should be a central focus for future revisions to the ND-PAE diagnostic criteria to make ND-PAE more specific to PAE.

Research supported by NIAAA Grants U01 AA014834 and F31 AA031895.

POSTER SESSION

113: Teratogenic Effects of Ethanol in Monoaminergic Neurogenesis in Zebrafish Larvae

Javan Ostermann, Keilana Tsuda-Nguyen, Hyuna Lee

The neurological effects of FASD are detrimental to the lives of people who are affected by it. By researching the specific damage done to the brain structures, we hope to identify areas of the brain that are most affected by FASD, and discover information that will help scientists diagnose and treat FASD. By spreading greater awareness regarding the neurological causes behind FASD, we hope to encourage further research and identify ways to help support people who are affected by it, whether by more specific medical care for any disabilities, or by treatments to reduce the effect of FASD in the individual.

Background/Objectives

Zebrafish have become a popular model to study embryonic development due to their high fecundity, extrauterine development, clear embryos, and quick maturation. Further, 70% of human genes have an orthologous gene in zebrafish, making them an effective animal model for studying brain development. Introducing ethanol (EtOH) to developing zebrafish embryos has been a vital area of research due to its simulation of human FASD. Human fetuses exposed to EtOH in utero have central nervous system abnormalities such as smaller cranial size, agenesis of the corpus callosum and cerebral hypoplasia. Similarly, zebrafish larvae exposed to EtOH have shown craniofacial and brain structural defects. EtOH has been shown to disrupt neurogenesis, but its effects in distinct neuron groups in the developing zebrafish brain remain poorly understood. In this study, we used Tg(ETvmat2:GFP) zebrafish to examine the effects of EtOH on monoaminergic neurons, which are known to play a critical role in brain development and neuropsychiatric disorders.

Methods

Tg(ETvmat2:GFP) zebrafish adult breeding pairs were used as the parents for the experimental embryos. Zebrafish embryos were separated into two groups: control, which were untreated, and 1% EtOH, which were treated at 24hpf for a duration of 24 hours. All embryos were treated with PTU every 24 hours to minimize pigmentation. Larvae were mounted onto coverslips with 1% low melting point agarose gel, and were fixed in the dorsal position for imaging. They were imaged at 72, 96, and 120hpf using the Olympus Fluoview fv3000 confocal scanning microscope for viewing of monoaminergic neuron development in the cerebral zones. Using PixelCounter*, the different regions (pretectum, diencephalon, raphe nuclei, locus coeruleus, and hypothalamus) of the fluorescently labeled neurons were quantified and analyzed.

Results

Results were quantified and analyzed, investigating for a significant difference between control and ethanol-treated fish in neuron density of each brain structure at the 95% confidence interval.

During the summer 2024 research internship, significant disparities between the density of nervous tissue in both the medulla oblongata and the locus coeruleus of 120hpf larvae were observed. Other brain structures did not exhibit significant differences between the control and experimental fish.

In the following summer's research, it was found that neurons in the diencephalon of the 120hpf EtOH embryos had a significant decrease in density compared to the diencephalons of the control embryos. Other brain structures seemed to be unaffected by ethanol.

Discussion/Conclusion

Common characteristics of FAS, such as a smaller head and eyes, are displayed in zebrafish that have been exposed to 1% EtOH during fetal development. As their brains mature over the course of development, ETvmat2:GFP monoaminergic neurons display an increased density, particularly in the medulla oblongata and the hypothalamus. A significant decrease of monoaminergic neuron density in response to 1% EtOH exposure appears to be most prevalent in the region of the diencephalon. Compromised neurons in the diencephalon, important for sensory processing and neuroendocrine signaling, may affect shoaling behavior as adults. Other brain structures did not show significant differences between control and EtOH embryos.

POSTER SESSION

115: The Gifts you Carry: The Story of the Sacred Child and FASD

Fatima Natascha Lawrence, Courtney Farrow-Lawrence

Fatima Natascha Lawrence and Courtney Farrow-Lawrence have worked in the fields of FASD, mental health, diagnostics, education, justice, and Indigenous advocacy for a combined total of almost 40 years. However, education materials for children, youth, or families on FASD have not only been limited, but also never been through a culturally grounded lens.

As co-authors of the book "The Gifts You Carry: The Story of the Sacred Child and FASD," we hoped to shift the conversation about FASD for individuals, families, and communities.
This book is dedicated to our families, friends, and the community members we serve and love. As we walk our shared journey back to the land, we offer deep gratitude for the traditional teachings entrusted to us, teachings that honour neurodivergent children as carriers of specialized medicine and sacred knowledge.

It is our hope that this work contributes to healing and to the resurgence of Indigenous traditional knowledge, which upholds neurodivergent children as sacred star children who came to us with rare insight and wisdom to guide and strengthen our communities.
Special thanks to our children and the children and youth we support who have inspired us, taught us, and who have enriched our families and communities.

In this poster, concepts and teachings from the book will be highlighted, and communities' responses will be presented.

POSTER SESSION

119: Assessing Long-Term Social Consequences in Adult Zebrafish Embryonically Exposed to Ethanol

Caroline Moore, Hyuna Lee

For our research, we intend to assess social consequences of FASD in zebrafish to compare the effects as analogous to humans. By spreading greater awareness regarding the social impacts of FASD, we hope to encourage further research and identify ways to help support the people who are affected by it, whether by more specific medical care for any disabilities, or by discovering treatments to reduce the impact of FASD in the individual's social behaviors.

Background/Objectives

Zebrafish (Danio rerio) has emerged as a favorable model for investigating the effects of prenatal alcohol exposure on brain development and social behavior. Zebrafish are suitable subjects to study fetal alcohol syndrome (FAS) due to their conserved nervous system that mirrors that of humans. Previous studies have shown that zebrafish are highly social animals, preferring to be near other fish. However, the effects of FAS on shoaling behaviors is still largely unexplored. Zebrafish embryos were subjected to 1% ethanol (EtOH) exposure at 24 hours post-fertilization (hpf). This parallels fetal alcohol syndrome in humans, where the maximum exposure is 0.8%. Observing ethanol's downstream impacts on their social interactions, we can further understand the social behavior abnormalities commonly associated with alcohol-induced neurobehavioral disorders. In our experiment process, we used a video-tracking software called EthoVision to assess if FAS-induced zebrafish had a stronger tendency for shoaling or isolation.

Methods

Tg(ETvmat2):GFP adult transgenic zebrafish, (males n=41, females n=42) between 12.02 and 15.01 months old were used. The ethanol group had been embryonically exposed to 1% EtOH at 24hpf, and were tested with their same-aged control (ctrl) zebrafish. Two three-chamber open swim preference tests were assembled, such that one control fish and one EtOH fish could be tested simultaneously. While testing, the subject was placed in the middle tank to acclimate in isolation and was recorded for ten minutes while its view into the adjacent tanks was obstructed by manila folders. After ten minutes of acclimation, the folders were removed and the fish's behavior was recorded for fifteen minutes. Recording and analysis were done using Ethovision XT tracking software and an infrared backlight. Four zones were utilized to identify movement towards the bottom of the tank, which indicates anxiety, movement towards the shoal, and movement away from the shoal.

Results

During acclimation, the control males showed significant preference for the upper portion of the tank while the EtOH males remained mostly at the bottom. These trends were not present among females. After acclimation, on average, both EtOH males and females spent more time away from the shoal than the control males and females. Across all fish, very little time was spent in the bottom right corner of the tank, with the exception of the acclimation period, during which there was no preference for any one zone. EtOH females displayed a significant attraction for the top right corner, after the initial ten minute acclimation period.

Discussion/Conclusion

During the neurobehavior experiment, results showed that EtOH-exposed male zebrafish preferred spending time in the bottom of the tanks. The preference of the control males for the top half of the tank shows that they had lower anxiety levels. As anxious zebrafish typically prefer to stay at the bottom of a tank, this seems to imply that males are more susceptible to EtOH and tend to show more anxious behavior. The female and male EtOH zebrafish preferred to be away from the shoal, whereas the control zebrafish stayed near the shoal. These results show that ethanol affects social preference in females and males, and anxiety levels in males.

POSTER SESSION

Poster 122 - Taking FASD-Informed Care from Research to the Real World: Disseminating, Implementing and Expanding the Families Moving Forward Program

Anika Trancik, Joanne Sparrow, Heather Carmichael Olson

Background/Objectives: There is a pressing need for evidence-based interventions for families caring for youth with FASD. Although a supportive family environment in childhood is a vital protective factor, caregivers raising youth with FASD experience unmet needs and high stress levels. Individuals with FASD have strengths appropriate treatment can enhance. Yet they often face co-occurring risks (e.g., trauma), and without supports/services can show increased rates of adverse life experiences. Promising family-oriented interventions are being developed. Yet few have been empirically tested, and even fewer disseminated and implemented in the "real world."

The Families Moving Forward (FMF) Program team has promoted a continuum of care for families raising children with FASD/prenatal alcohol exposure and behavior problems for over two decades. The team developed and tested the original, relationship-based intervention, now called "FMF Foundations." This caregiver-focused behavioral consultation model has demonstrated efficacy and has now moved from research to community use.

Methods: With CDC research funding, the original FMF intervention was developed, tested and refined by 2010-2011. Then community implementation procedures were developed via sequential implementation projects. Currently, as a business model, the FMF Program Office has created partnerships to sustainably disseminate FMF Foundations into community use. Additionally, research collaborators have used the FMFlogic model, procedures and materials to generate various products that comprise an "FMF Continuum of Care."

The FMF Foundations model incorporates "essential elements" of FASD-informed care (Olson et al., 2023). The team created: (1) intervention and supervision materials for trained mental health clinicians/supervisors; (2) an intervention fidelity and video review process for quality assurance; and (3) implementation materials. FMF Foundations training programs were developed at Specialist, Supervisor and Trainer levels. The FMFWebsite was built, allowing public information and rapid provider access to password-protected materials. Lastly, systematic support was established for agencies and governmental entities interested in implementing FMF Foundations.

Results: Moving an intervention into community use is gradual and labor-intensive, even with promising efficacy data. Multiple barriers must be surmounted. It takes time to develop realistic, effective implementation procedures, especially with limited resources. At the Seattle

Children's-based FMF Program Office, systematic dissemination/implementation efforts are ongoing and growing. Currently, 300+ providers from 15 states and 4 countries are trained. A statewide initiative to disseminate/implement FMF Foundations among community agencies in Michigan has been ongoing since 2018, with other statewide initiatives emerging. Additionally, innovative derivative products have emerged based on FMF principles and procedures. Through research and clinical collaborations, these products are expanding the age range and promoting accessibility.

Conclusion: The Families Moving Forward Program experience reveals important components for successfully moving intervention from research to the real world. These are: strategic research funding; promising efficacy data; tenacious staff and key champions; supportive family/provider feedback; productive collaborations to expand the continuum of care; institutional infrastructure; dedicated clinicians/agencies/states able to pay service fees; philanthropic donations to bridge funding gaps; and a sustainable business model. It takes long-term collaboration between family advocacy groups, service providers, and policymakers to make FASD-informed care more available.