FORMERLY THE
VANCOUVER CONFERENCE

FASD United
THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NOFAS

NOW IN
SEATTLE, WA UNITED STATES

9th International Research Conference on

ADOLESCENTS AND ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDERS

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

SYLLABUS

APRIL 12-14 2024

Hyatt Regency, Seattle, WA

www.FASDUnited.org

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

Review, Respond, and Relate
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CONFERENCE DESCRIPTION AND OBJECTIVES

DESCRIPTION

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

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

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

LEARNING OBJECTIVES

- Connect the identified needs of community workers, healthcare providers, professionals in the FASD field, families, and individuals with FASD with the research community
- Gain insight into emerging research findings and how they might better assist ethical policy and decision-making and the development of integrated and collaborative approaches across systems
- Examine practice-based evidence, projects, and programs to understand the potential connections to research and potential longitudinal studies
- Engage in knowledge exchange and dialogue through multidisciplinary sessions
- Listen to individuals with FASD and their families share their direct experience

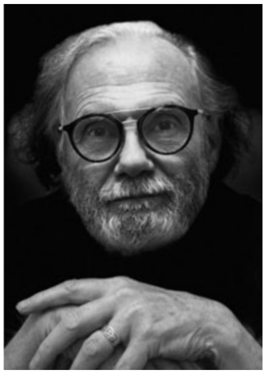
COMMITTEE LISTINGS

PROGRAM PLANNING COMMITTEE

Jan Lutke, Conference Chair, Vancouver, BC

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

Jo Votolato, Conference Director, FASD United, Washington, DC



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

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

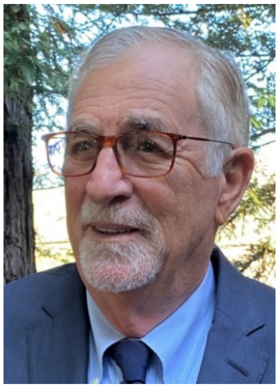
Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA

PROGRAM PLANNING COMMITTEE (CONT.)

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

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

Brenda Knight, Registered Psychologist, Private Practice, Vancouver, BC



Edward Riley, Ph.D., Distinguished Research Professor, Center for Behavioral Teratology, San Diego State University, San Diego, CA

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

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

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

LOCAL PLANNING COMMITTEE

Jan Lutke, Conference Chair, Vancouver, BC

Jo Votolato, Conference Director, FASD United, Washington, DC

Jennifer Wisdahl, Chief Operating Officer, FASD United, Washington, DC

Allison D. Brooks, Ph.D., Licensed Psychologist, University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network; Clinic Director, Brooks Powers Group, Seattle, WA

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

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

Carolyn Hartness, Fetal Alcohol Spectrum Disorders/Reentry Consultant/Trainer, Seattle, WA

Tracy Jirikowic, Ph.D., OTR/L, FAOTA, Professor | Department of Rehabilitation Medicine; Program Director, Division of Occupational Therapy; Co-Director, Program in Rehabilitation Science, UW Medicine, University of Washington, Seattle, WA

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

Michelle Kuhn, Ph.D., Assistant Professor of Psychiatry and Behavioral Sciences, University of Washington Medical School; Attending Psychologist, Seattle Children’s Hospital, Seattle, WA

Annette Kunzman, MBA, President, FASD Network of Southern California, member of FASDNow! Alliance Member, Manhattan Beach, CA

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

Erin Olson, Ph.D., Clinical Associate Professor, Psychiatry & Behavioral Sciences, University of Washington School of Medicine; Psychologist, Fetal Alcohol Syndrome Diagnostic & Prevention Network, Institute on Human Development and Disability University of Washington; Attending Psychologist, Autism Center, Seattle Children’s Hospital, Seattle, WA

Joanne Sparrow, Ph.D., Licensed Clinical Psychologist in Private Practice (Redmond, WA) and Special Projects Coordinator – Families Moving Forward Program (Seattle Childrens Research Institute), Seattle, WA

Karen A Steele, Attorney, Salem, OR

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

INTERNATIONAL ADVISORY COMMITTEE

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Myles Himmelreich, ALC FASD Changemakers, Victoria, BC

CJ Lutke, ALC FASD Changemakers, Vancouver, BC

Katrina Griffin, ALC FASD Changemakers, Vancouver, BC

Emily Hargrove, ALC FASD Changemakers, Paducah, KY

Justin Mitchell, ALC FASD Changemakers, Vancouver, BC

Anique Lutke, ALC FASD Changemakers, Vancouver, BC

Maggie May, ALC FASD Changemakers, Ireland

Jacob Dedman, ALC FASD Changemakers, Australia

Jessica Birch, ALC FASD Changemakers, Australia

Nury van Beers, ALC FASD Changemakers, Netherlands

Kim Dokter, ALC FASD Changemakers, Netherlands

Byron Jones, ALC FASD Changemakers, New Zealand

Gina Schumaker, ALC FASD Changemakers, AK

Shannon Butt, ALC FASD Changemakers, Ottawa, ON

Justin Shepherd, ALC FASD Changemakers

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Kate Boyce Reeder

INSPIRE KIDS
FASD SUPPORT SOCIETY OF BC

Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

Melissa Jacobus

EXHIBITOR LISTINGS

ABLE2

ABLE2 believes in an inclusive community where all people are seen as able, respected, and valued. People with disabilities face many challenges including stigma, accessibility, social isolation, discrimination, and inequity. Our programs and services empower persons of all ages across the disability spectrum and their families to build lives of meaning and joy as valued members of our community.

Dream Acres

As the first known FASD community providing supportive living and on-site jobs for adults living with an FASD, we feel that we can offer hope to so many conference attendees.
www.DreamAcresFASDCommunity.org

FASD Communities
We have created a successful residential program in WI for 4 young adults with FASD that has been up and running successfully for the past years. We also try to bring awareness to others about FASD.
www.fasdcommunities.org

Canada FASD Research Network
The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is Canada's first comprehensive organization to support this country's leadership in addressing the extraordinary complexities of FASD. CanFASD is a national, charitable organization with a mission to produce multidisciplinary, collaborative research that can be shared with all Canadians, leading to prevention strategies and improved outcomes for people affected by FASD. CanFASD's mission is to produce and maintain national, collaborative research designed for sharing with all Canadians, leading to prevention strategies and improved support services for people affected by Fetal Alcohol Spectrum Disorder. Why we would like to exhibit? CanFASD Research Network always participated in the Vancouver conference and we are excited to participate and network with our international partners and colleagues again. Integrating research, policy and practice is an important part of our work and we are looking forward to sharing our evidence-based tools and resources with conference delegates.

FASCETS (Fetal Alcohol Spectrum Consultation, Education, and Training Services)
FASCETS is a non-profit organization that celebrated its 25th anniversary in 2022. Our name is an acronym for Fetal Alcohol Spectrum Consultation, Education, and Training Services. All our services are based on the Neurobehavioral (or Brain-Based) Approach, which redefines behavioral symptoms in a manner consistent with research. By connecting presenting behaviors with underlying differences in brain function, a profound shift is created in moving from anger to compassion, from blaming to acceptance, lessening frustration on all sides, and improving outcomes. Though the approach was originally developed for FASD, its application is not limited to PAE-related symptoms of underlying brain dysfunction – it applies to understanding and developing accommodations for other brain-based conditions such as autism, ADHD, TBI, dementia and others. We offer workshops and consultation on the Neurobehavioral Model to parents, caregivers, support workers and professionals, to support the development and implementation of accommodations that recognize who the person is and how their brain functions (or functions differently), and to set the conditions for success. We also develop and sell materials about FASD and the Neurobehavioral Model. We want to exhibit to get an opportunity to promote our trainings and resources, provide more information about the Neurobehavioral Model, gather feedback and comments on our services as well as connect and network with everyone in our FASD Community.

NOFASD Australia
To network with those attending the conference; share resources and information from our organization, which we have found beneficial to those whom NOFASD supports.
https://www.nofasd.org.au/

FASD Collaborative Project

FASD Collaborative Project creates connection and community through informed partnerships. We believe organizations can unite to create innovative systems of care for individuals with FASD and other neurodevelopmental disorders. Currently, we have over 40 partners collaborating to provide support groups, online webinars, special interest groups, and Project ECHO series. Our work is centered on advancing research and implementation of best practices while embracing the belief that everyone has a story to tell.

Inspire Kids FASD – Family Support Society of BC

At Inspire Kids, our heart beats for families impacted by Fetal Alcohol Spectrum Disorder (FASD). We're here for biological parents, foster parents, kinship parents, adoptive parents, and every loving caregiver guiding a child through the challenges of FASD. Our mission is simple: To embrace and empower diverse families navigating the unique journey of FASD and make an impact in the lives of children and youth with FASD. We recognize that family structures come in many forms, and we stand with all parents and caregivers, offering unwavering support. No matter your family's shape or size, we're dedicated to ensuring you feel not only included but also genuinely supported and empowered by our services.www.inspirefasd.ca

State of Alaska Comprehensive FASD Program

The State of Alaska Fetal Alcohol Spectrum Disorders (FASD) Comprehensive Program comprises community, state, and national partners working to prevent and reduce harms related to prenatal alcohol exposure. The program supports, coordinates and funds efforts that directly impact individuals, families, communities, and systems change. This is accomplished through education, training, technical assistance, research, data analyses, policy review, clinical and support services.

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

For more than 40 years, The Florida Center for Early Childhood has been a leading provider of therapeutic services, early education, and healthy development for children in southwest Florida. Its programs focus on infants and children through fifth grade who are at-risk academically, socially, or economically. The Florida Center provides developmental therapies, mental health counseling, and the Starfish Academy preschool in Sarasota and North Port. The organization also offers Healthy Families, a home-visiting program that guides parents who need assistance. The state's only Fetal Alcohol Syndrome Disorders clinic has operated for nearly 20 years and our FASD Director Tamra Cajo, LCSW co-facilitates Florida's statewide advocacy group with our former CEO Kathryn Shea (board member of FASD United). The Florida Center FASD clinics are now located in Sarasota, Orlando, and Pensacola (opening Spring '24), offering evaluations for individuals of all ages who may have had prenatal alcohol exposure. The Florida Center Training Institute offers training focused on supporting parents, caregivers, and professionals working with individuals with FASD. www.thefloridacenter.org and www.floridacentertraining.org The Florida Center for Early Childhood has the only FASD Diagnosing Clinic in the state of Florida. We provide the Families Moving Forward Specialist Training, Training on the FASCETS Neurobehavioral Model, Intro to FASD, and other trainings. We are actively educating individuals across the country about FASD, and wish to have the latest research information. We are also interested in becoming more involved with others across the country supporting individuals with

FASD. One goal is to find others to collaborate with to present information through the Training Institute.

United States Drug Testing Laboratories Inc. (usdtl.com)
Specialty reference laboratory focusing exclusively on substance use toxicology in reservoir matrices such as umbilical cord, meconium, fingernail, and hair. We are the laboratory you want when you need cutting-edge testing with the longest window of detection. Working with the Department of Defense, child protection agencies, legal services, researchers, businesses, analytical/forensic laboratories, and more. We would like to attend to collaborate with researchers to offer cutting-edge testing for substance use toxicology.

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. We provide clients with credible, relevant, and useful measurement information that— • Informs program management and policy decisions • Reflects competency in developing and applying innovative research methodologies • Involves policy makers and program managers in the planning and implementation of research and evaluation projects • Reflects the use of multidisciplinary teams with substantive knowledge and methodological skills tailored to each project • We value independence and rigor in evaluation and flexibility and collaboration in our approach. We believe insight can empower decisions that impact people's lives. We are committed to diversity, equity, and inclusion. We hope to raise awareness and share knowledge and resources generated through the Children's Bureau's and CDC's contracts focused on identifying and caring for children with prenatal alcohol exposures and their families who are involved in the child welfare system. We have a set of timely resources to share with attendees that are geared towards caregivers, professionals, researchers, and policy-makers in this field. These include a recent two-volume Special Issue of Child Welfare focused on this topic "Opportunities for Child Welfare to Respond to Prenatal Alcohol and Other Substance Exposures," with publicly available/free copies of multiple articles included in the series, other published articles (literature review, environmental scan on PAE/FASD in tribal child welfare contexts), flyers describing upcoming webinar series and other soon-to-be released guides and tip sheets, and other materials. We will be at the exhibit table between sessions to be available to discuss with interested parties and to raise awareness of the work.

SPEAKER LISTINGS

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

Shameena Bake Ph.D., Assistant Professor, Department of Neuroscience and Experimental Therapeutics, Texas A&M Health Science Center, Bryan, Texas

Aileen Baldwin Ph.D., MPH, Assistant Laboratory Director for Research, United States Drug Testing Laboratories, Des Plaines, IL

Wanda Beland BEd, Executive Director, NWR FASD Society-Mackenzie Network, High Level, AB

Jessica Birch International Adult Leadership Collaborative (ALC), FASD Changemakers, Australia

Karen Bopp Executive Advisor, Children and Youth with Support Needs, BC Representative for Children and Youth, Victoria, BC

Magdalena Borkowska MSc, Researcher, The National Center for Prevention of Addictions (KCPU) Department of Prevention and Public Education, Warsaw, Poland

Laura Bousquet Family Navigator, FASD United, Washington, DC

Shannon Butt International Adult Leadership Collaborative (ALC), FASD Changemakers, Ottawa, ON

Elizabeth Carlson MA, Doctoral Student, School and Clinical Child Psychology Program, University Of Alberta, Edmonton, AB

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

Peter Choate RCSW, Ph.D., Clinical Social Worker Professor, Social Work Mount Royal University

Samantha Cocker Deputy Representative for Children and Youth of British Columbia, Victoria, BC

Marian Gaston San Diego Superior Court, San Diego, CA

Lynn Cole DNP, Clinical Associate Professor, University of Rochester School of Nursing, University of Rochester, New York, NY

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

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

Elizabeth Dang MPH, Behavioral Scientist, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

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

Tom Donaldson President & CEO, FASD United

Danijela Dozet MPH, Research Analyst, Institute for Mental Health Policy Research, Centre For Addiction And Mental Health; Ph.D. Student, Institute of Medical Science, Faculty of Medicine, University of Toronto; Toronto, ON

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

Elizabeth Elliott AM, MD, MPhil, MBBS, FRACP, FRCPCH, FRCP, Child and Adolescent Health, Sydney Medical School, University of Sydney; and The Sydney Children's, Hospitals Network, Westmead, Sydney, Australia"

Emily Fisher MD, MSc, FRCPC, Clinical Assistant Professor, Division of Developmental Pediatrics, Department of Pediatrics, Faculty of Medicine, University of British Columbia, Vancouver, BC

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

Katherine Flannigan PhD, RPsych, Research Associate, Canada FASD Research Network

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

Sam Galloway Practice Manager, START Taranaki, Kaponga, Taranaki, New Zealand

Angela Geddes CYC, MSW, RSW, YTT, Researcher, Social Worker, Private Practice, Elgin County, ON

Stephen Greenspan Ph.D., Department of Educational Psychology. University of Connecticut, Storrs, CT

Katrina Griffin International Adult Leadership Collaborative (ALC) , Vancouver,

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

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

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

Shannon Iacobacci MS Psychology, Embracing The Brain Founder, Certified Facilitator FASCETS Neurobehavioral Model, FASCETS board chair, FASDNow Alliance Member, Master IEP Coach®, FASD Collaborative Project Member, Manhattan Beach, CA

Vannesa Joly BA, Graduate Research Assistant, Department of Educational Psychology, University of Alberta, Edmonton, AB

Dawson Jones Youth Research Participant, BC Representative for Children and Youth, Victoria, BC

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

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

Brenda Knight Registered Psychologist, Private Practice, Vancouver, BC

Summer Krochta LCSW, Vice President of Programs, Children's Service Center, Wilkes-Barre, PA

Annette Kunzman MBA, President, FASD Network of Southern California, member of FASDNow! Alliance Member, Manhattan Beach, CA

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

Christine Loock MD, Social Pediatrician, University of British Columbia; Responsive Intersectoral, Community Health, Education, and Research (RICHER) Initiative

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

Jan Lutke Conference Chair, Vancouver, BC

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

Maggie May International Adult Leadership Collaborative (ALC), FASD Changemakers, Ireland

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

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

Jenelle McMillan Indigenous Chemical Addictions Specialist III, BGS, BEd with a Specialization in Indigenous Education, FASD and Addiction counsellor; Board Member, Métis Family Services, Owner/Operator of Wolf Song Healing Farm; K - 12 Culture and Nłeʔkepmxcn Language Teacher, Mother and Grandmother, Papsilqua IR2, BC

Mansfield Mela MBBS, FWACP, FRC Psych, MSc, FRCPC, Professor and Forensic Psychiatrist, Department of Psychiatry, University of Saskatchewan, Saskatoon, SK

Eva Moore MD, MSPH, FAAP, Clinical Associate Professor, Division of Adolescent Medicine, Department of Pediatrics, Faculty of Medicine, University of British Columbia, Vancouver, BC

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

Maria Pecotić District Court, New Zealand

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

Terri Pelton BSW, RSW, Child and Youth Advocate (Alberta), Edmonton, AB

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

Kristina Pikksalu BA, BScN, MScN, NP (F) (Primary Care), RICHER Social Pediatrics Program, BC Children's & Women's Health Centre

Marisa Pinson BS, Graduate Assistant Researcher, Neuroscience and Experimental Therapeutics, Texas A&M Health Science Center, Bryan, TX

Charlis Raineki Ph.D., Assistant Professor, Department of Psychology, Brock University, St. Catharines, ON

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

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

Nadia Samiya MS, Graduate Student, Texas A&M University Health Science Center, Bryan, TX

Dipak Sarkar Ph.D., DPhil, Board of Governors Professor, Director, Endocrinology Program; Distinguished Professor, Department of Animal Science, The State University of New Jersey

Gina Schumaker Vice-President, Alaska Center for FASD, Anchorage, AK Justin Shepherd International Adult Leadership Collaborative (ALC), FASD Changemakers, CO

Farida Sohrabji Ph.D., Distinguished Professor and Department Head; Director, Women's Health in Neuroscience Program, Department of Neuroscience and Experimental Therapeutics, Texas A&M University, Bryan, TX

Emily Speybroeck Graduate Student, Clinical Psychology, University of Rochester, New York, NY Susan Stoner Ph.D., Research Associate Professor,

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

Christiano Tapparello Research Associate Professor, Department of Electrical and Computer Engineering, University of Rochester, New York, NY

Kara Te Whata-Maynard PGDip, Learning Support Psychologist, Ministry of Education, New Zealand

Teri Tibbett President, Alaska Center for FASD/ Coordinator, Alaska Prenatal Alcohol Partnership, Juneau, AK

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

Nury Van Beers International Adult Leadership Collaborative (ALC), FASD Changemakers, Netherlands

Olivia Weeks Postdoctoral Research Fellow, Division of Cardiology, Boston Children's Hospital, Harvard Medical School, and Brigham and Women's Hospital, Boston, MA

Jennifer Wisdahl Chief Operating Officer, FASD United, Washington, DC

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

POSTER PRESENTER LISTINGS

Yisel Alaoui LCADC, ICADC, FASD, Community Education Coordinator for the Partnership For Maternal and Child Health of the Northern NJ, Newark, New Jersey.

Aileen Baldwin Ph.D., MPH, Assistant Laboratory Director for Research, United States Drug Testing Laboratories, Des Plaines, IL

Jacquelyn Bertrand Child Psychologist, Centers for Disease Control and Prevention

Leah Bouchard Research Associate, James Bell Associates

Cassidy Boyd MPH, Manager of Population Health at Rady Children’s Hospital-San Diego, San Diego, California

Elizabeth Cleveland PhD, Associate Director, University of Arkansas; Executive Director, Specialty Diagnostic Resource Center; Director of Training; Arkansas Leadership Education in Neurodevelopmental Disabilities; Chair, Association of University Centers on Disability FASD Special Interest Group

Pricilla Day MSW, Ed.D., Professor Emeritus of Social Work at University of Minnesota Duluth

Nicholas Deputy Health Scientist, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Luke Dumaran, LBA, Psychological Developmental Counselor, Autism Treatment Assistance Program, Nevada Department of Health and Human Services

Carly Dunn MPH, Senior Research Associate, James Bell Associates, Arlington, VA

Elizabeth Eaton Senior Manager of Child Welfare and Education, ICF

Shannon Foster Registered Social Worker, MCSW

Angela Geddes Integrative Support and Wellness

Kendra Gludt MPH, Director of National Programs, Proof Alliance, St. Paul MN

Megan Griffin Professor, School of Education, Whitworth University

Susan Hemingway PhD, Professor of Epidemiology/Pediatrics, University of Washington; Director, Washington State FAS Diagnostic & Prevention Network, Seattle WA

Erin Ingoldsby PhD, Director of Child Welfare Practice Area, James Bell Associates, Arlington, VA

(Fatima) Natascha Lawrence MA, RCC, BCRPT, CO-Founder FASD Institute

Nancy Lefler-Panela Consultant, ICF

Kristine MacDonald Registered Social Worker, MCSW

Annika Montag PhD, Department of Pediatrics, University of California San Diego, San Diego, CA.

Julianne Myers PhD, Postdoctoral Clinical Psychology Fellow, University of Rochester Mt. Hope Family Center; Division of Developmental and Behavioral Pediatrics, University of Rochester Medical Center, Rochester, NY

Julie Nanson Executive Director, Central Alberta FASD Network, Red Deer, Alberta

Sharon Newburg-Rinn Social Science Research Analyst, Children's Bureau

Berardino Petrelli Department of Biochemistry & Medical Genetics; Regenerative Medicine Program, Faculty of Medicine, University of Manitoba, Winnipeg, Canada.

Molly Pind The Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.

Rhonda Romero Southern California Tribal Health Clinic, CA

Siara Rouzer PhD, Postdoctoral Research Fellow, Texas A&M School of Medicine, Dept of Neuroscience & Experimental Therapeutics, Bryan, TX.

Jessica Rutherford Independent Researcher; Founder and CEO The Animation Curriculum

Susan Stoner PhD, Research Associate Professor of Psychiatry & Behavioral Sciences Ann Streissguth PhD Professor of Fetal Alcohol Spectrum Disorders, University of Washington School of Medicine, Seattle, WA.

John Thorne PhD., CCC-SLP, University of Washington: Associate Teaching Professor for the Department of Speech and Hearing Sciences; Discipline Leader for Speech-Language Pathology - Institute On Human Development and Disability; Clinician and Researcher - Fetal Alcohol Syndrome Diagnostic and Prevention Network; Seattle, WA.

Christina Tortorelli PhD (c), RSW. Assistant Professor and Acting Academic Director - Social Work, Mount Royal University, Faculty of Health, Community and Education Calgary, Alberta, Canada

Kathy Unsworth Managing Director, Canada FASD Research Network (CanFASD)

Julene Zizza MA, Special Education and rehabilitation, Co-facilitator Recovering Mothers Anonymous, Staffing Coordinator, English Teacher, Special Education Teacher, Colorado Springs School District 11, Colorado Springs, CO.

Results from FASD Changemakers Lay of the Land Survey #2: What Really Matters? Life as We Live It

Myles Himmelreich, CJ Lutke, Katrina Griffin, Emily Hargrove

Results from an ALC FASD Changemakers "Lay of the Land" Survey

Lay of the Land Survey #2

Quality of Life – Equality vs Equity

What Really Matters: Life as We Live It

International Adult Leadership Collaborative (ALC)

FASD Changemakers

opening plenary

9th International Research Conference on Adolescents and Adults with FASD

FASD United

Seattle, Washington, USA; April 12, 2024

fasdchangemakers@gmail.com

Survey Authors: CJ Lutke, Katrina Griffin, Myles Himmelreich, Justin Mitchell, Antique Lutke and Emily Hargrove

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Introductions - *Life as We Live It…*

AUTHORS AND PRESENTERS:

CJ Lutke: ALC FASD Changemakers, Speaker, Mentor, Blogger, Advisor/Consultant to Research Projects, Media

Myles Himmelreich: ALC FASD Changemakers, FASD Consultant, Speaker, Mentor

Katrina Griffin: ALC FASD Changemakers, Speaker, Mentor, Advisor/Consultant to Research Projects

Antique Lutke: ALC FASD Changemakers, Speaker, Advisor to Research Projects

Justin Mitchell: ALC FASD Changemakers, Speaker, Advisor to Research Projects

Emily Hargrove: ALC FASD Changemakers, Speaker, Advisor to Research Projects

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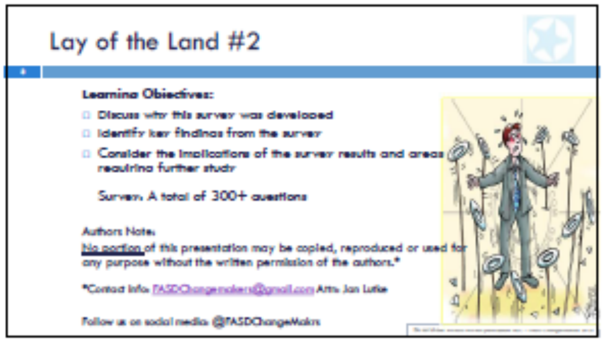

Lay of the Land #2

Learning Objectives:

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

Survey: A total of 300+ questions

Authors Note:
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*Contact info: FASDChangemakers@gmail.com Attn: Jan Lutke

Follow us on social media: @FASDChangeMakrs

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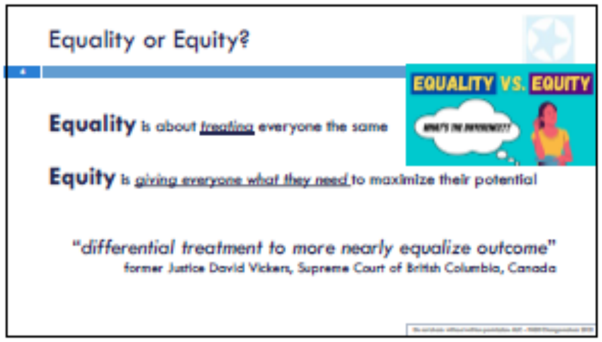

Equality or Equity?

Equality is about treating everyone the same

Equity is giving everyone what they need to maximize their potential

"differential treatment to more nearly equalize outcome"
former Justice David Vickers, Supreme Court of British Columbia, Canada

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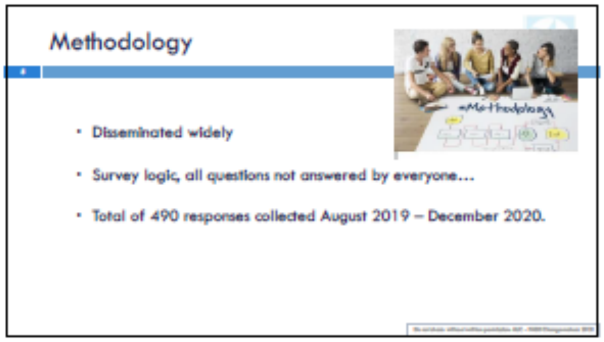

Methodology

- Disseminated widely
- Survey logic, all questions not answered by everyone…
- Total of 490 responses collected August 2019 – December 2020.

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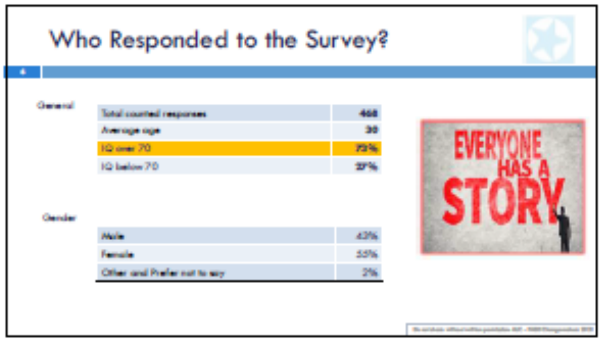

Who Responded to the Survey?

General

Total counted responses	468
Average age	30
IQ over 70	73%
IQ below 70	27%

Gender

Male	43%
Female	55%
Other and Prefer not to say	2%

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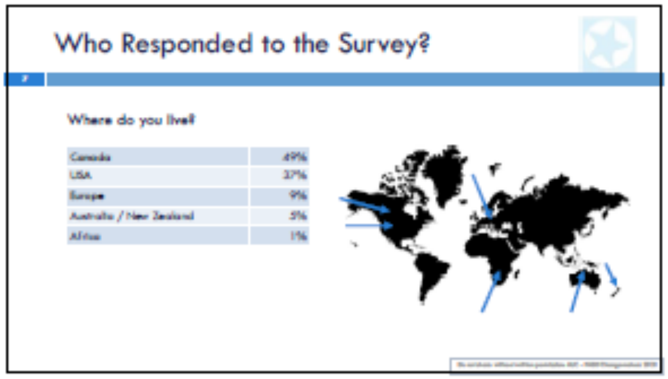
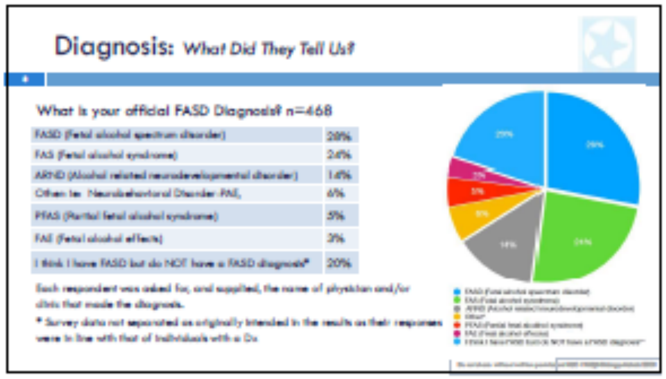


Who Responded to the Survey?

Where do you live?

Canada	49%
USA	37%
Europe	9%
Australia / New Zealand	5%
Africa	1%



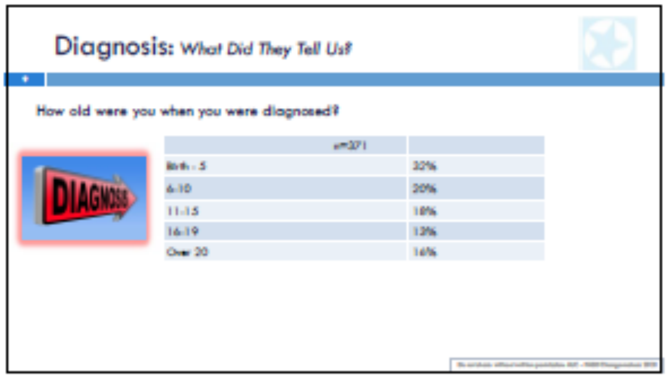
Diagnosis: *What Did They Tell Us?*

What is your official FASD Diagnosis? n=468

FASD (Fetal alcohol spectrum disorder)	28%
FAS (Fetal alcohol syndrome)	24%
ARND (Alcohol related neurodevelopmental disorder)	14%
Other ie: Neurobehavioral Disorder-PAE,	6%
PFAS (Partial fetal alcohol syndrome)	5%
FAE (Fetal alcohol effects)	3%
I think I have FASD but do NOT have a FASD diagnosis*	20%

Each respondent was asked for, and supplied, the name of physician and/or clinic that made the diagnosis.

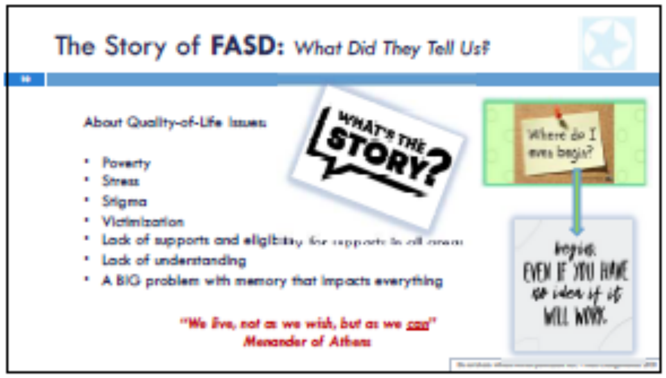
* Survey data not separated as originally intended in the results as their responses were in line with that of individuals with a Dx



Diagnosis: *What Did They Tell Us?*

How old were you when you were diagnosed?

n=371	
Birth - 5	32%
6-10	20%
11-15	18%
16-19	12%
Over 20	16%

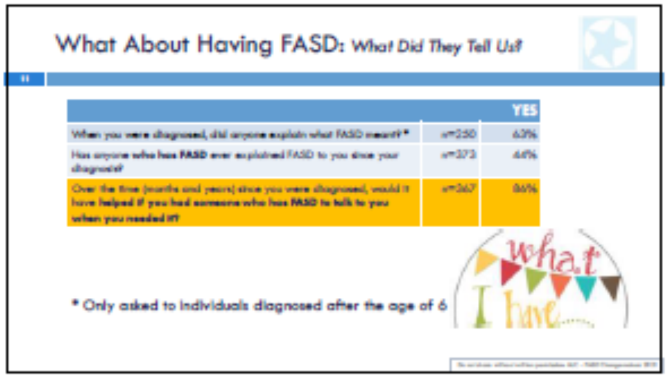


The Story of **FASD:** *What Did They Tell Us?*

About Quality-of-Life Issues:

- Poverty
- Stress
- Stigma
- Victimization
- Lack of supports and eligibility for supports in all areas
- Lack of understanding
- A BIG problem with memory that impacts everything

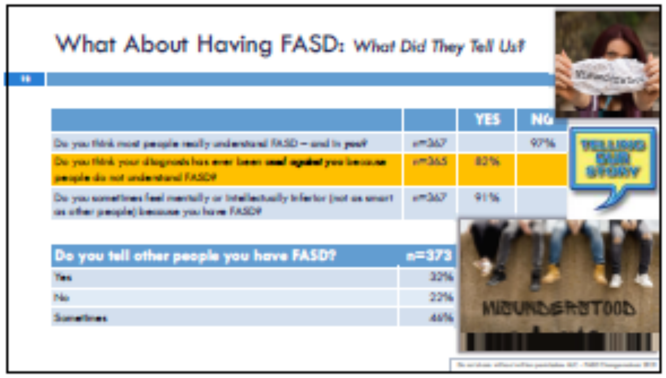
"We live, not as we wish, but as we can"
Menander of Athens



What About Having FASD: *What Did They Tell Us?*

		YES
When you were diagnosed, did anyone explain what FASD meant?*	n=250	63%
Has anyone who has **FASD** ever explained FASD to you since your diagnosis?	n=373	44%
Over the time (months and years) since you were diagnosed, would it have **helped if you had someone who has FASD to talk to you when you needed it?**	n=367	86%

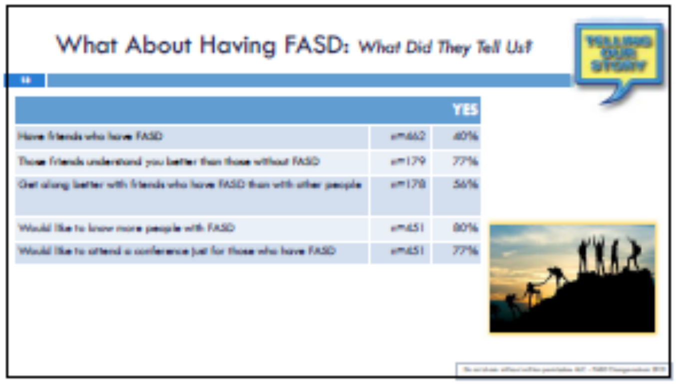
* Only asked to individuals diagnosed after the age of 6



What About Having FASD: *What Did They Tell Us?*

		YES	NO
Do you think most people really understand FASD – and in ***you?***	n=367		97%
Do you think your diagnosis has ever been ***used against*** you because people do not understand FASD?	n=365	82%	
Do you sometimes feel mentally or intellectually inferior (not as smart as other people) because you have FASD?	n=367	91%	

Do you tell other people you have FASD?	n=373
Yes	32%
No	22%
Sometimes	46%



What About Having FASD: *What Did They Tell Us?*

		YES
Have friends who have FASD	n=462	40%
Those friends understand you better than those without FASD	n=179	77%
Get along better with friends who have FASD than with other people	n=178	56%
Would like to know more people with FASD	n=451	80%
Would like to attend a conference just for those who have FASD	n=451	77%

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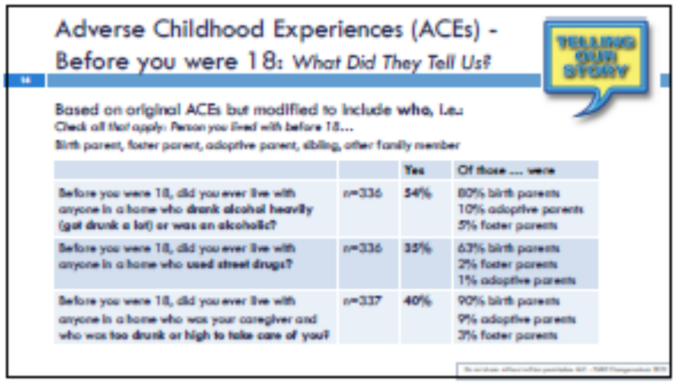

Adverse Childhood Experiences (ACEs) - Before you were 18: *What Did They Tell Us?*

Based on original ACEs but modified to include **who**, i.e.:
Check all that apply: Person you lived with before 18…
Birth parent, foster parent, adoptive parent, sibling, other family member

		Yes	Of those …. were
Before you were 18, did you ever live with anyone in a home who **drank alcohol heavily (got drunk a lot) or was an alcoholic?**	n=336	54%	80% birth parents 10% adoptive parents 5% foster parents
Before you were 18, did you ever live with anyone in a home who **used street drugs?**	n=336	35%	63% birth parents 2% foster parents 1% adoptive parents
Before you were 18, did you ever live with anyone in a home who was your caregiver and who was **too drunk or high to take care of you?**	n=337	40%	90% birth parents 9% adoptive parents 3% foster parents

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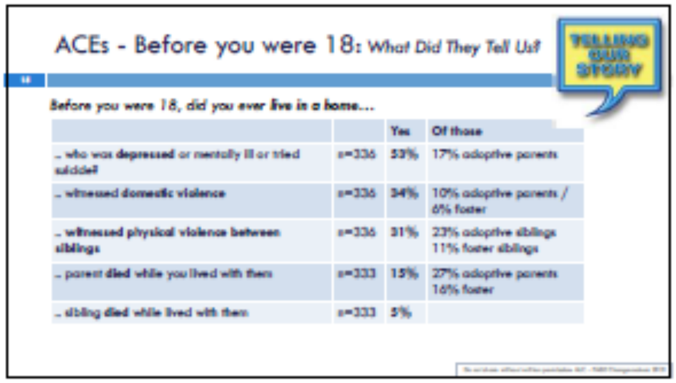

ACEs - Before you were 18: *What Did They Tell Us?*

Before you were 18, did you ever live in a home…

		Yes	Of those
… who was **depressed** or mentally ill or tried **suicide?**	n=336	53%	17% adoptive parents
… **witnessed domestic violence**	n=336	34%	10% adoptive parents / 6% foster
… **witnessed physical violence between siblings**	n=336	31%	23% adoptive siblings 11% foster siblings
… parent **died** while you lived with them	n=333	15%	27% adoptive parents 16% foster
… sibling **died** while lived with them	n=333	5%	

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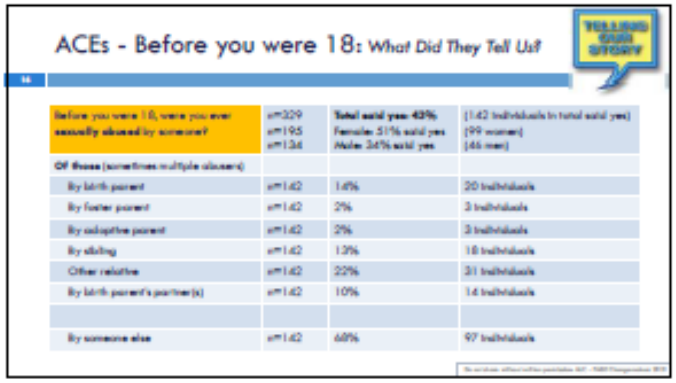

ACEs - Before you were 18: *What Did They Tell Us?*

Before you were 18, were you ever sexually abused by someone?	n=329 n=195 n=134	**Total said yes: 43%** Female: 51% said yes Male: 34% said yes	(142 individuals in total said yes) (99 women) (46 men)
Of those (sometimes multiple abusers)			
By birth parent	n=142	14%	20 individuals
By foster parent	n=142	2%	3 individuals
By adoptive parent	n=142	2%	3 individuals
By sibling	n=142	13%	18 individuals
Other relative	n=142	22%	31 individuals
By birth parent's partner(s)	n=142	10%	14 individuals
By someone else	n=142	68%	97 individuals

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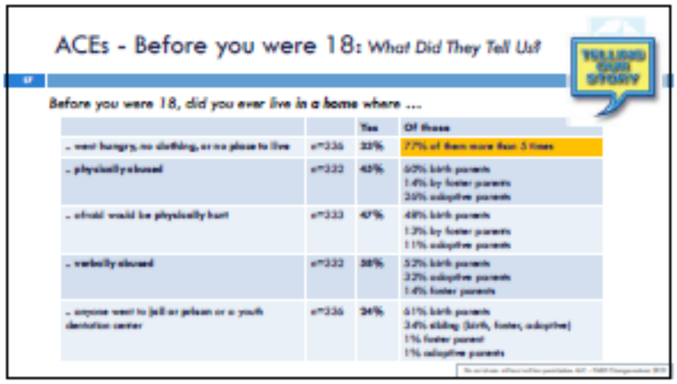

ACEs - Before you were 18: *What Did They Tell Us?*

Before you were 18, did you ever live in a home where …

		Yes	Of those
… went hungry, no clothing, or no place to live	n=336	33%	77% of them more than 5 times
… physically abused	n=333	43%	60% birth parents 14% by foster parents 26% adoptive parents
… afraid would be physically hurt	n=333	47%	48% birth parents 13% by foster parents 11% adoptive parents
… verbally abused	n=333	38%	52% birth parents 32% adoptive parents 14% foster parents
… anyone went to jail or prison or a youth detention center	n=336	34%	61% birth parents 34% sibling (birth, foster, adoptive) 1% foster parent 1% adoptive parents

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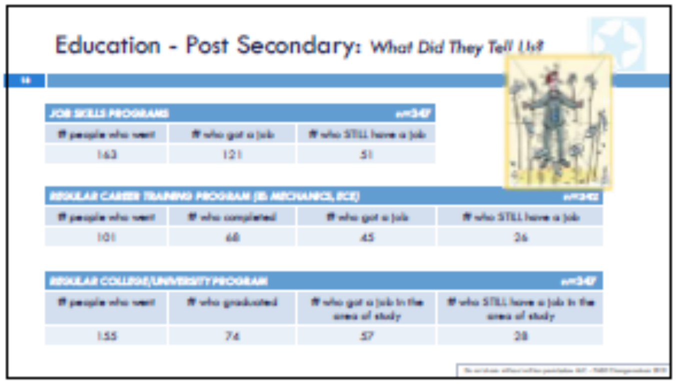


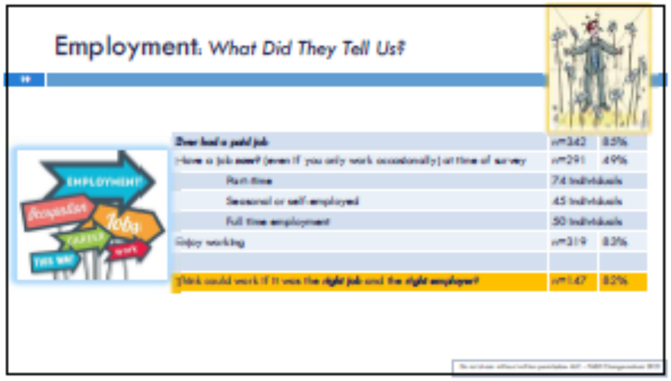
Education - Post Secondary: *What Did They Tell Us?*

JOB SKILLS PROGRAMS		n=347
# people who went	# who got a job	# who STILL have a job
163	121	51

REGULAR CAREER TRAINING PROGRAM (IE MECHANICS, ECE)			n=342
# people who went	# who completed	# who got a job	# who STILL have a job
101	68	45	26

REGULAR COLLEGE/UNIVERSITY PROGRAM			n=347
# people who went	# who graduated	# who got a job in the area of study	# who STILL have a job in the area of study
155	74	57	28

18



Employment: *What Did They Tell Us?*

Ever had a paid job	n=342	85%
Have a job **now?** (even if you only work occasionally) at time of survey	n=291	49%
Part-time	74 individuals	
Seasonal or self-employed	45 individuals	
Full time employment	50 individuals	
Enjoy working	n=319	83%
Think could work if it was the **right job** and the **right employer?**	n=147	82%

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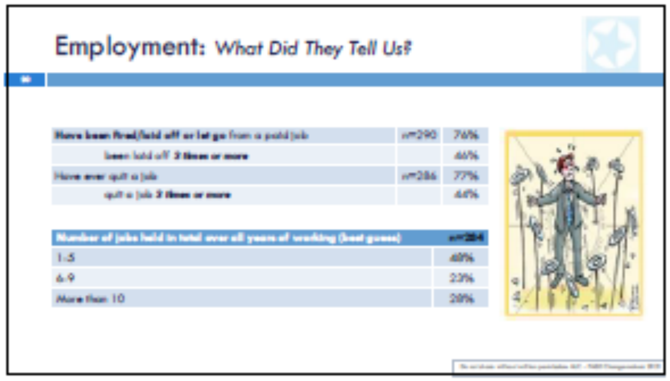

Employment: *What Did They Tell Us?*

Have been fired/laid off or let go from a paid job	n=290	76%
been laid off **3 times or more**		46%
Have ever quit a job	n=286	77%
quit a job **3 times or more**		44%

Number of jobs held in total over all years of working (best guess)	**n=284**
1-5	49%
6-9	23%
More than 10	28%

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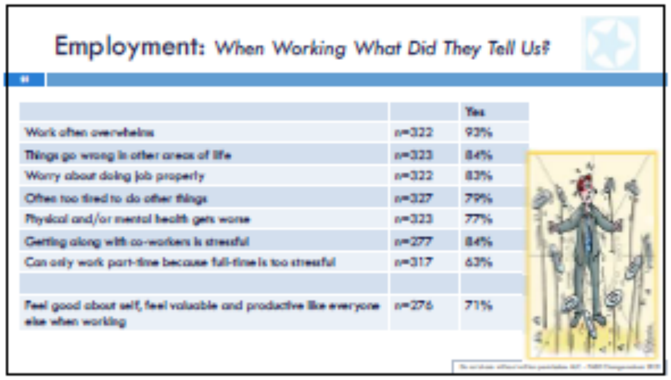

Employment: *When Working What Did They Tell Us?*

		Yes
Work often overwhelms	n=322	93%
Things go wrong in other areas of life	n=323	84%
Worry about doing job properly	n=322	83%
Often too tired to do other things	n=327	79%
Physical and/or mental health gets worse	n=323	77%
Getting along with co-workers is stressful	n=277	84%
Can only work part-time because full-time is too stressful	n=317	63%
Feel good about self, feel valuable and productive like everyone else when working	n=276	71%

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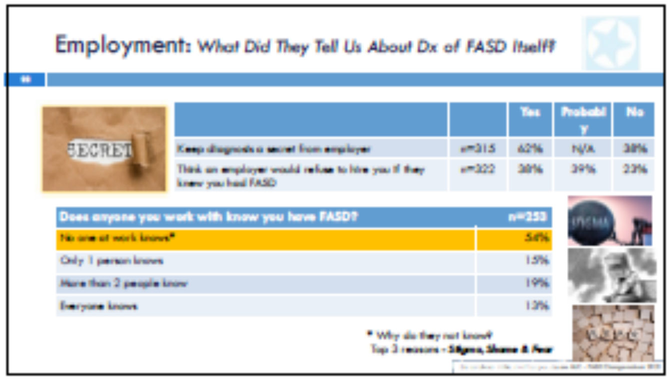

Employment: *What Did They Tell Us About Dx of FASD Itself?*

		Yes	Probably	No
Keep diagnosis a secret from employer	n=315	62%	N/A	38%
Think an employer would refuse to hire you if they knew you had FASD	n=322	38%	39%	23%

Does anyone you work with know you have FASD?	**n=253**
No one at work knows*	54%
Only 1 person knows	15%
More than 2 people know	19%
Everyone knows	12%

* Why do they not know?
Top 3 reasons - **Stigma, Shame & Fear**

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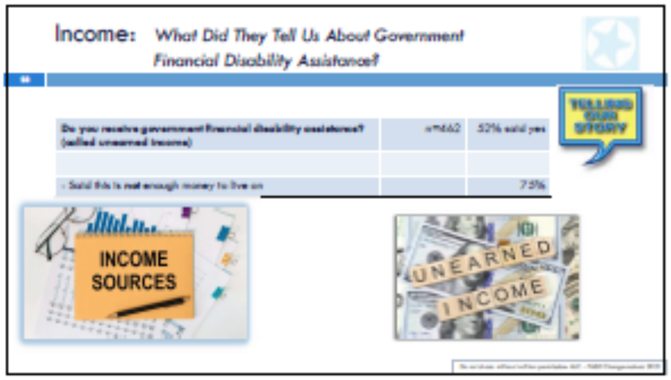

Income: *What Did They Tell Us About Government Financial Disability Assistance?*

Do you receive government financial disability assistance? (called unearned income)	n=462	52% said yes
- Said this is **not enough** money to live on		75%

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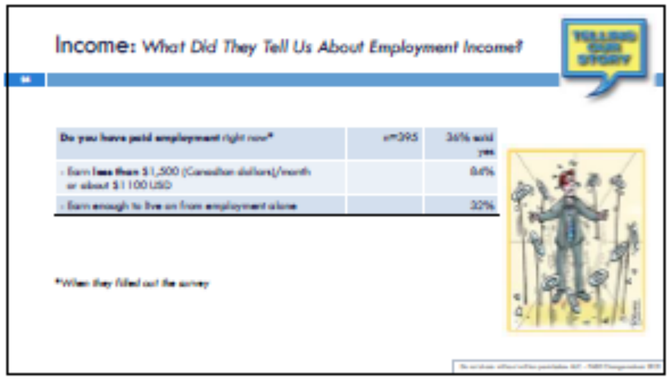

Income: *What Did They Tell Us About Employment Income?*

Do you have paid employment right now*	n=395	36% said yes
- Earn **less than** $1,500 (Canadian dollars)/month or about $1100 USD		84%
- Earn **enough** to live on from employment alone		32%

*When they filled out the survey

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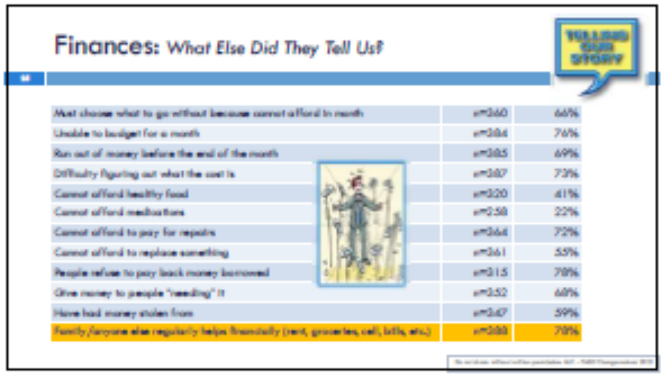
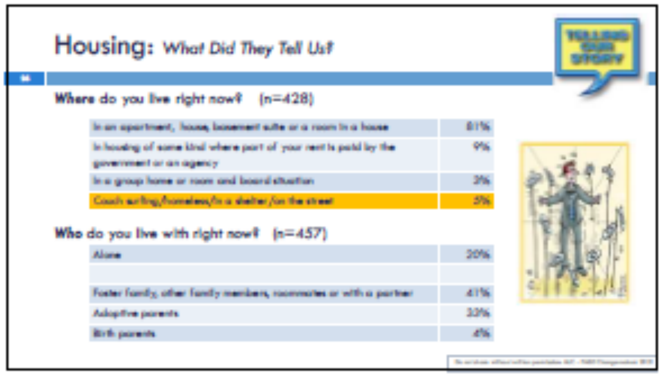


Finances: *What Else Did They Tell Us?*

Must choose what to go without because cannot afford in month	n=360	66%
Unable to budget for a month	n=384	76%
Run out of money before the end of the month	n=385	69%
Difficulty figuring out what the cost is	n=387	73%
Cannot afford healthy food	n=320	41%
Cannot afford medications	n=258	22%
Cannot afford to pay for repairs	n=364	72%
Cannot afford to replace something	n=361	55%
People refuse to pay back money borrowed	n=315	78%
Give money to people "needing" it	n=352	60%
Have had money stolen from	n=347	59%
Family/anyone else regularly helps financially (rent, groceries, cell, bills, etc.)	n=388	78%



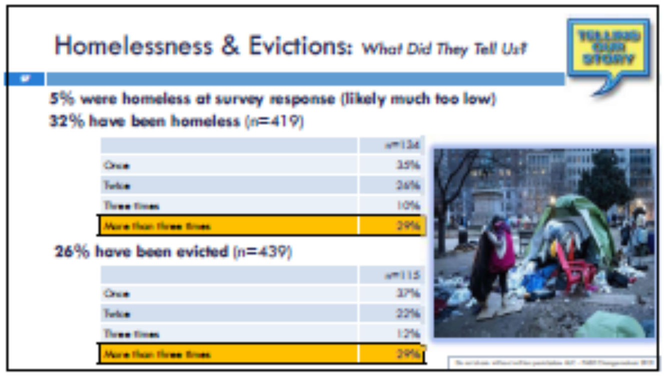
Housing: *What Did They Tell Us?*

Where do you live right now? (n=428)

In an apartment, house, basement suite or a room in a house	81%
In housing of some kind where part of your rent is paid by the government or an agency	9%
In a group home or room and board situation	3%
Couch surfing/homeless/in a shelter/on the street	5%

Who do you live with right now? (n=457)

Alone	20%
Foster family, other family members, roommates or with a partner	41%
Adoptive parents	33%
Birth parents	4%



Homelessness & Evictions: *What Did They Tell Us?*

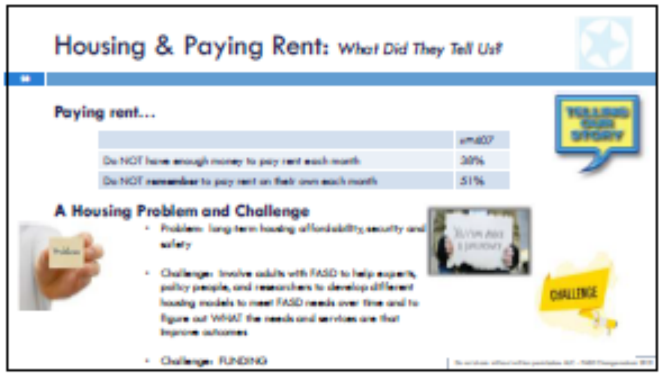
5% were homeless at survey response (likely much too low)

32% have been homeless (n=419)

	n=134
Once	35%
Twice	26%
Three times	10%
More than three times	29%

26% have been evicted (n=439)

	n=115
Once	37%
Twice	22%
Three times	12%
More than three times	29%



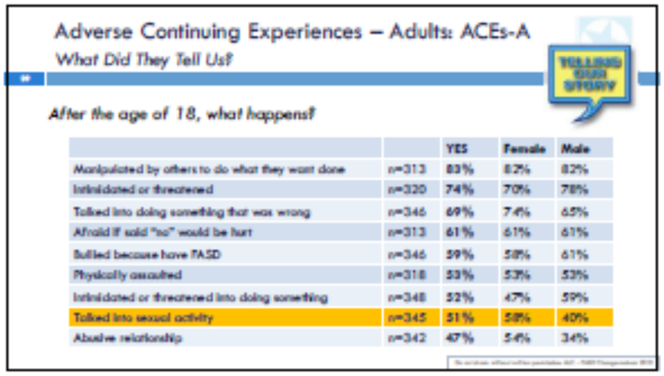
Housing & Paying Rent: *What Did They Tell Us?*

Paying rent…

	n=407
Do NOT have enough money to pay rent each month	38%
Do NOT remember to pay rent on their own each month	51%

A Housing Problem and Challenge

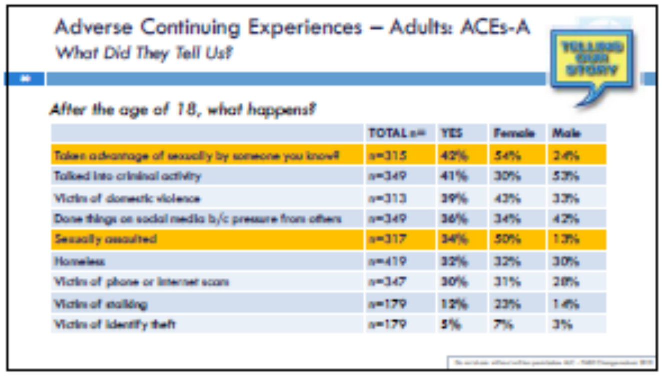
- Problem: long-term housing affordability, security and safety
- Challenge: Involve adults with FASD to help experts, policy people, and researchers to develop different housing models to meet FASD needs over time and to figure out WHAT the needs and services are that improve outcomes
- Challenge: FUNDING



Adverse Continuing Experiences – Adults: ACEs-A
What Did They Tell Us?

After the age of 18, what happens?

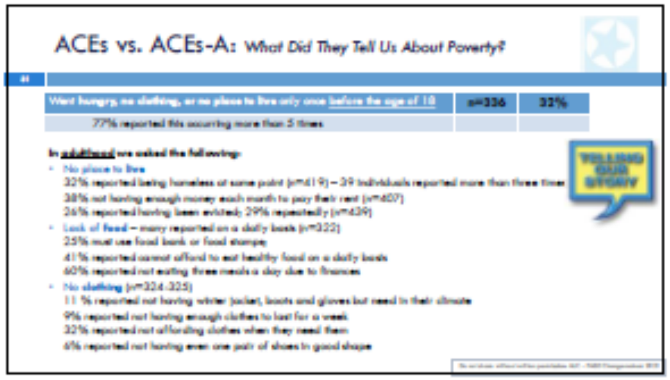
		YES	Female	Male
Manipulated by others to do what they want done	n=313	83%	82%	82%
Intimidated or threatened	n=320	74%	70%	78%
Talked into doing something that was wrong	n=346	69%	74%	65%
Afraid if said "no" would be hurt	n=313	61%	61%	61%
Bullied because have FASD	n=346	59%	58%	61%
Physically assaulted	n=318	53%	53%	53%
Intimidated or threatened into doing something	n=348	52%	47%	59%
Talked into sexual activity	n=345	51%	58%	40%
Abusive relationship	n=342	47%	54%	34%



Adverse Continuing Experiences – Adults: ACEs-A
What Did They Tell Us?

After the age of 18, what happens?

	TOTAL n=	YES	Female	Male
Taken advantage of sexually by someone you know?	n=315	42%	54%	24%
Talked into criminal activity	n=349	41%	30%	53%
Victim of domestic violence	n=313	39%	43%	33%
Done things on social media b/c pressure from others	n=349	36%	34%	42%
Sexually assaulted	n=317	34%	50%	13%
Homeless	n=419	32%	32%	30%
Victim of phone or internet scam	n=347	30%	31%	28%
Victim of stalking	n=179	12%	23%	14%
Victim of identify theft	n=179	5%	7%	3%



ACEs vs. ACEs-A: *What Did They Tell Us About Poverty?*

Went hungry, no clothing, or no place to live only once before the age of 18	n=336	32%
77% reported this occurring more than 5 times		

In adulthood we asked the following:

- No place to live
  32% reported being homeless at some point (n=419) – 39 individuals reported more than three times
  38% not having enough money each month to pay their rent (n=407)
  26% reported having been evicted; 29% repeatedly (n=439)
- Lack of **food** – many reported on a daily basis (n=322)
  25% must use food bank or food stamps
  41% reported cannot afford to eat healthy food on a daily basis
  60% reported not eating three meals a day due to finances
- No **clothing** (n=324-325)
  11 % reported not having winter jacket, boots and gloves but need in their climate
  9% reported not having enough clothes to last for a week
  32% reported not affording clothes when they need them
  6% reported not having even one pair of shoes in good shape

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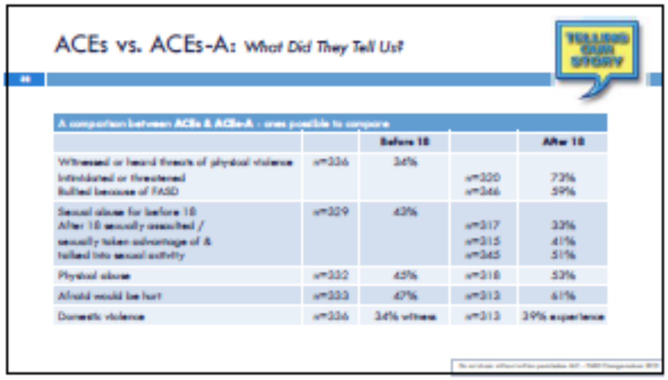

ACEs vs. ACEs-A: *What Did They Tell Us?*

A comparison between **ACEs & ACEs-A** : ones possible to compare

		Before 18		**After 18**
Witnessed or heard threats of physical violence Intimidated or threatened Bullied because of FASD	n=336	34%	n=320 n=346	73% 59%
Sexual abuse for before 18 After 18 sexually assaulted / sexually taken advantage of & talked into sexual activity	n=329	43%	n=317 n=315 n=345	33% 41% 51%
Physical abuse	n=332	45%	n=318	53%
Afraid would be hurt	n=333	47%	n=313	61%
Domestic violence	n=336	34% witness	n=313	39% experience

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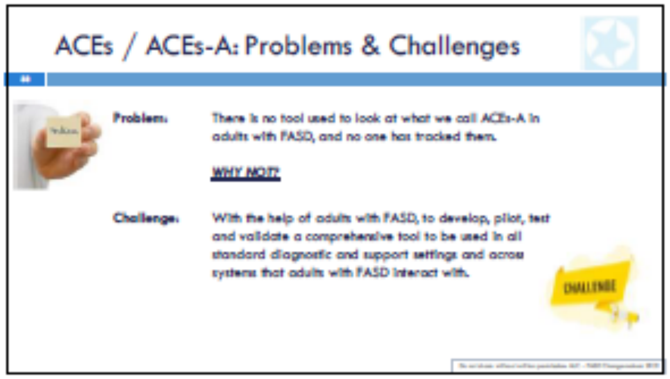

ACEs / ACEs-A: Problems & Challenges

Problem: There is no tool used to look at what we call ACEs-A in adults with FASD, and no one has tracked them.

WHY NOT?

Challenge: With the help of adults with FASD, to develop, pilot, test and validate a comprehensive tool to be used in all standard diagnostic and support settings and across systems that adults with FASD interact with.

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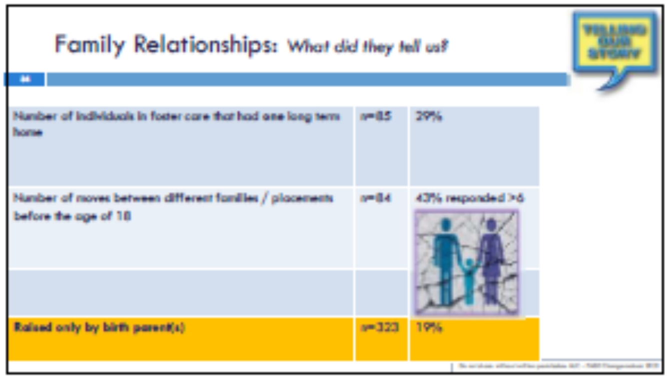

Family Relationships: *What did they tell us?*

Number of individuals in foster care that had one long term home	n=85	29%
Number of moves between different families / placements before the age of 18	n=84	43% responded >6
Raised only by birth parent(s)	n=323	19%

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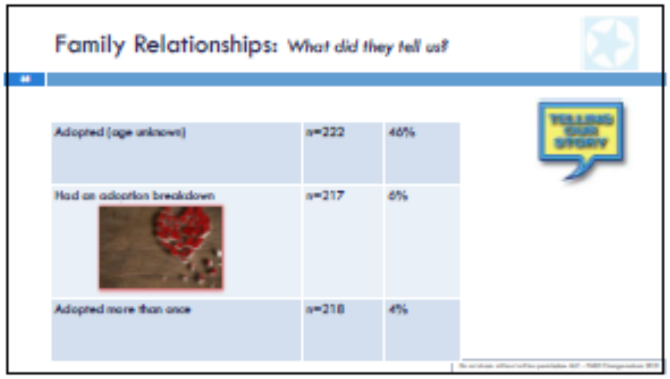
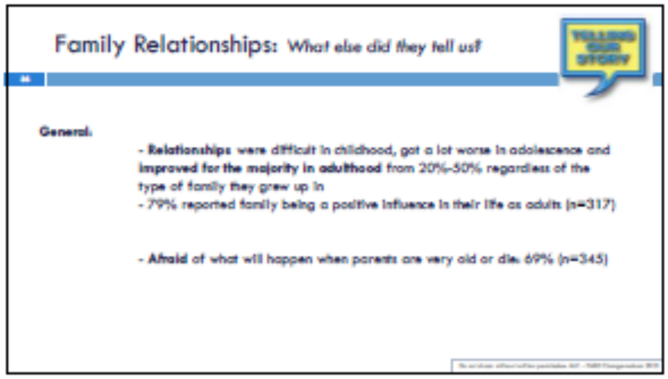


Family Relationships: *What did they tell us?*

Adopted (age unknown)	n=222	46%
Had an adoption breakdown	n=217	6%
Adopted more than once	n=218	4%

35



Family Relationships: *What else did they tell us?*

General:

- **Relationships** were difficult in childhood, got a lot worse in adolescence and **improved for the majority in adulthood** from 20%-50% regardless of the type of family they grew up in
- 79% reported family being a positive influence in their life as adults (n=317)

- **Afraid** of what will happen when parents are very old or die: 69% (n=345)

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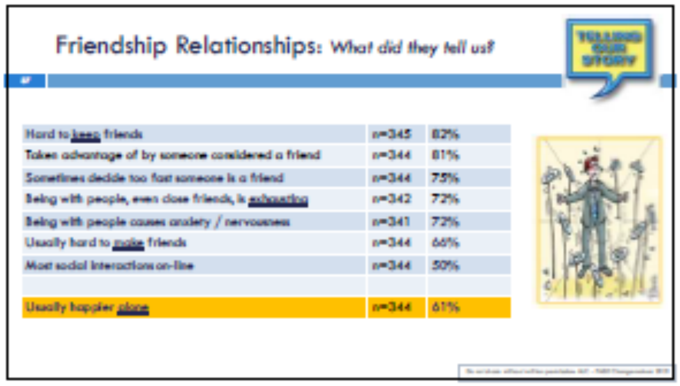

Friendship Relationships: *What did they tell us?*

Hard to keep friends	n=345	82%
Taken advantage of by someone considered a friend	n=344	81%
Sometimes decide too fast someone is a friend	n=344	75%
Being with people, even close friends, is exhausting	n=342	72%
Being with people causes anxiety / nervousness	n=341	72%
Usually hard to make friends	n=344	66%
Most social interactions on-line	n=344	50%
Usually happier alone	n=344	61%

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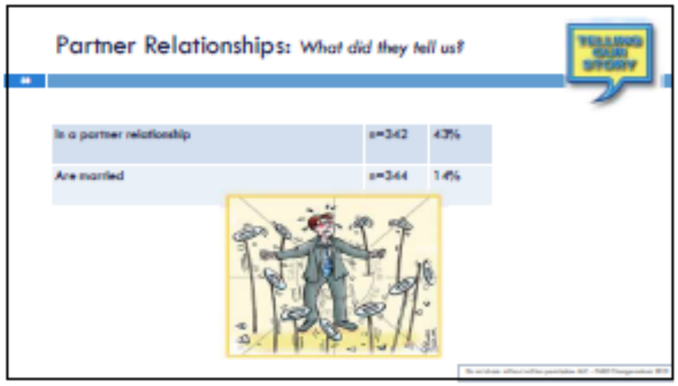

Partner Relationships: *What did they tell us?*

In a partner relationship	n=342	43%
Are married	n=344	14%

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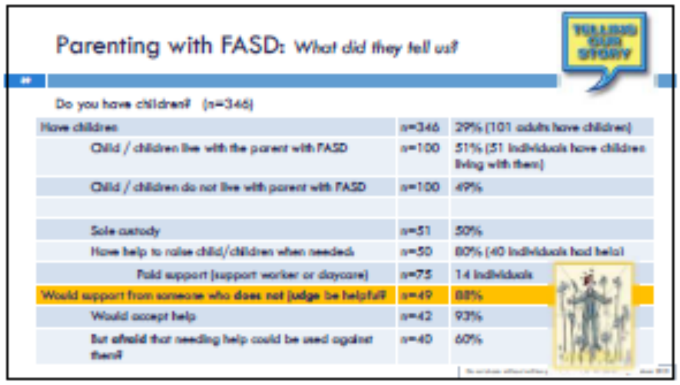
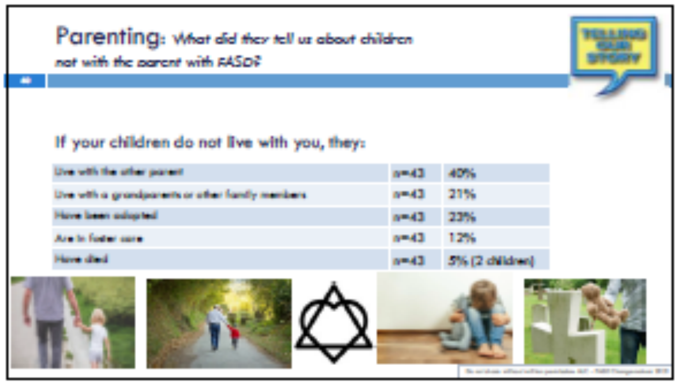


Parenting with FASD: *What did they tell us?*

Do you have children? (n=346)

Have children	n=346	29% (101 adults have children)
Child / children live with the parent with FASD	n=100	51% (51 individuals have children living with them)
Child / children do not live with parent with FASD	n=100	49%
Sole custody	n=51	50%
Have help to raise child/children when needed:	n=50	80% (40 individuals had help)
Paid support (support worker or daycare)	n=75	14 individuals
Would support from someone who **does not judge** be helpful?	n=49	88%
Would accept help	n=42	93%
But **afraid** that needing help could be used against them?	n=40	60%

39

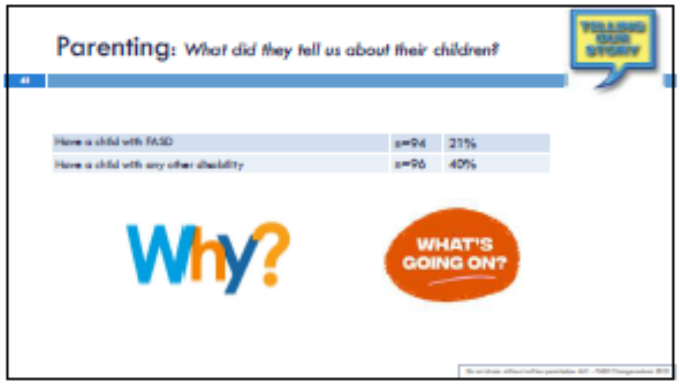


Parenting: *What did they tell us about children not with the parent with FASD?*

If your children do not live with you, they:

Live with the other parent	n=43	40%
Live with a grandparents or other family members	n=43	21%
Have been adopted	n=43	23%
Are in foster care	n=43	12%
Have died	n=43	5% (2 children)

40



Parenting: *What did they tell us about their children?*

Have a child with FASD	n=94	21%
Have a child with any other disability	n=96	40%

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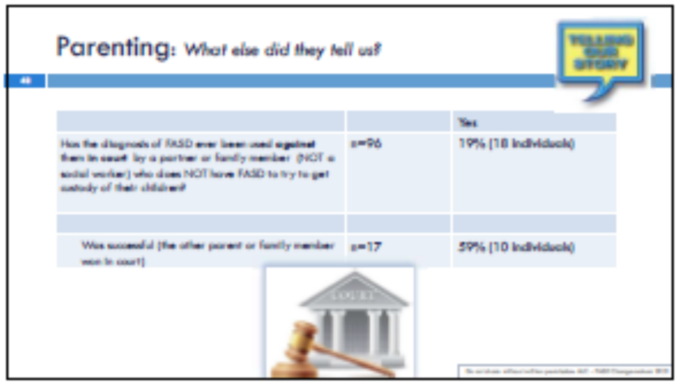

Parenting: *What else did they tell us?*

		Yes
Has the diagnosis of FASD ever been used **against them in court** by a partner or family member (NOT a social worker) who does NOT have FASD to try to get custody of their children?	n=96	19% (18 individuals)
Was successful (the other parent or family member won in court)	n=17	59% (10 individuals)

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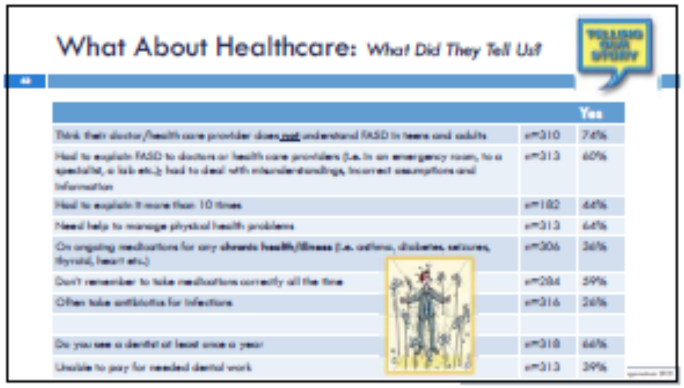
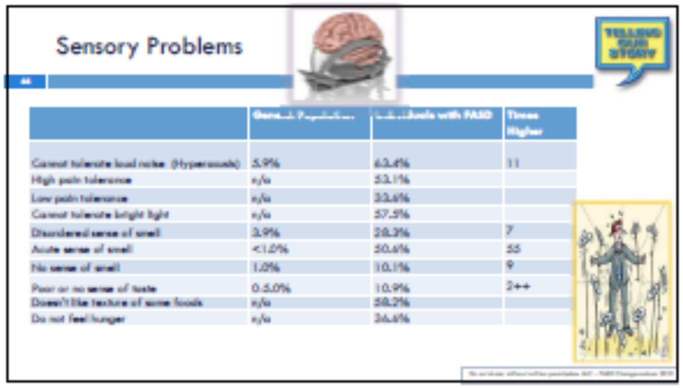


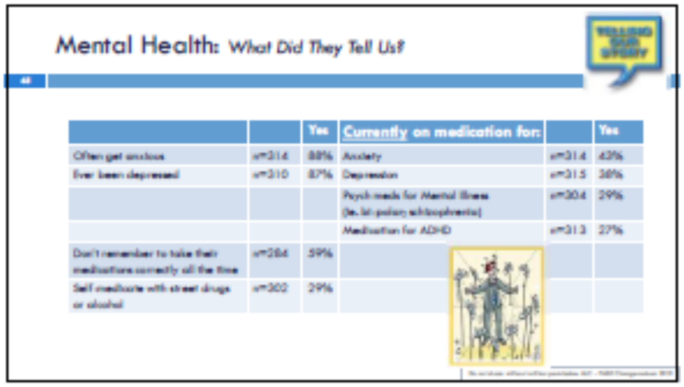
What About Healthcare: *What Did They Tell Us?*

		Yes
Think their doctor/health care provider does not understand FASD in teens and adults	n=310	74%
Had to explain FASD to doctors or health care providers (i.e. in an emergency room, to a specialist, a lab etc.); had to deal with misunderstandings, incorrect assumptions and information	n=313	60%
Had to explain it more than 10 times	n=182	44%
Need help to manage physical health problems	n=313	64%
On ongoing medications for any **chronic health/illness** (i.e. asthma, diabetes, seizures, thyroid, heart etc.)	n=306	36%
Don't remember to take medications correctly all the time	n=284	59%
Often take antibiotics for infections	n=316	26%
Do you see a dentist at least once a year	n=318	66%
Unable to pay for needed dental work	n=313	39%



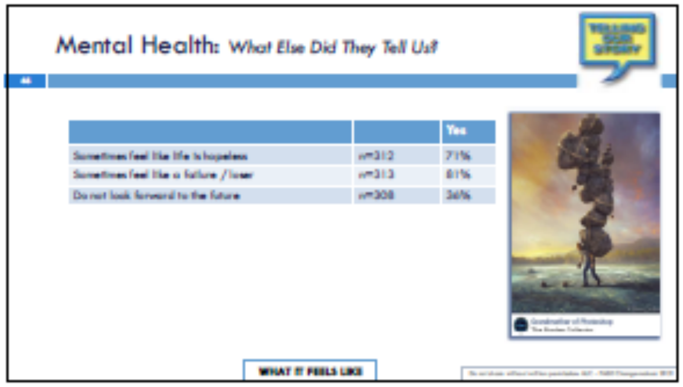
Sensory Problems

	General Population	Individuals with FASD	Times Higher
Cannot tolerate loud noise (Hyperacusis)	5.9%	63.4%	11
High pain tolerance	n/a	53.1%	
Low pain tolerance	n/a	33.6%	
Cannot tolerate bright light	n/a	57.5%	
Disordered sense of smell	3.9%	28.3%	7
Acute sense of smell	<1.0%	50.6%	55
No sense of smell	1.0%	10.1%	9
Poor or no sense of taste	0-5.0%	10.9%	2++
Doesn't like texture of some foods	n/a	58.2%	
Do not feel hunger	n/a	36.6%	



Mental Health: *What Did They Tell Us?*

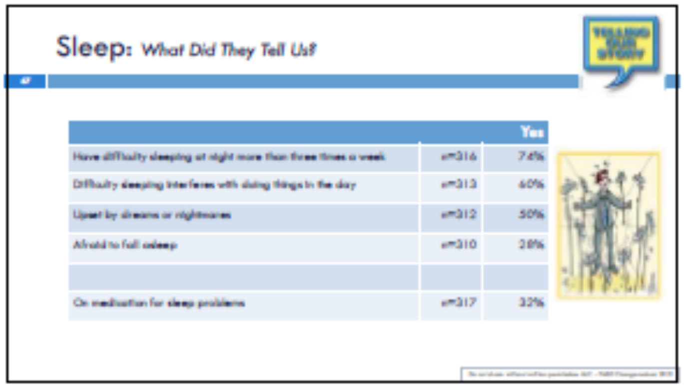
		Yes	Currently on medication for:		Yes
Often get anxious	n=314	88%	Anxiety	n=314	43%
Ever been depressed	n=310	87%	Depression	n=315	38%
			Psych meds for Mental Illness (ie. bi-polar, schizophrenia)	n=304	29%
			Medication for ADHD	n=313	27%
Don't remember to take their medications correctly all the time	n=284	59%			
Self medicate with street drugs or alcohol	n=302	29%			



Mental Health: *What Else Did They Tell Us?*

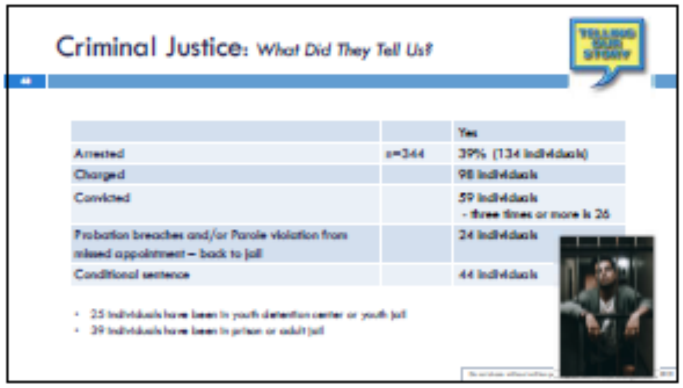
		Yes
Sometimes feel like life is hopeless	n=312	71%
Sometimes feel like a failure / loser	n=313	81%
Do not look forward to the future	n=308	36%

WHAT IT FEELS LIKE



Sleep: *What Did They Tell Us?*

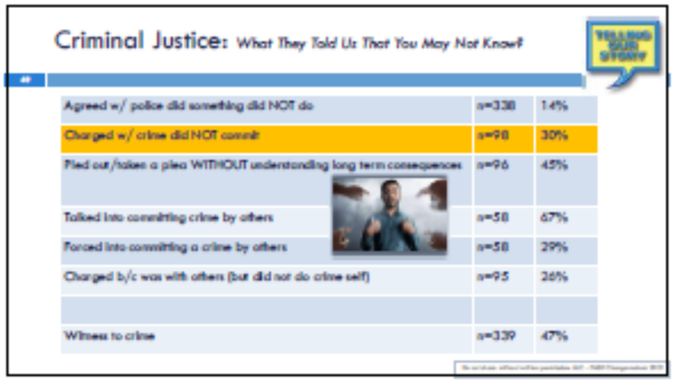
		Yes
Have difficulty sleeping at night more than three times a week	n=316	74%
Difficulty sleeping interferes with doing things in the day	n=313	60%
Upset by dreams or nightmares	n=312	50%
Afraid to fall asleep	n=310	28%
On medication for sleep problems	n=317	32%



Criminal Justice: *What Did They Tell Us?*

		Yes
Arrested	n=344	39% (134 individuals)
Charged		98 individuals
Convicted		59 individuals - three times or more is 26
Probation breaches and/or Parole violation from missed appointment – back to jail		24 individuals
Conditional sentence		44 individuals

- 25 individuals have been in youth detention center or youth jail
- 39 individuals have been in prison or adult jail



Criminal Justice: *What They Told Us That You May Not Know?*

Agreed w/ police did something did NOT do	n=338	14%
Charged w/ crime did NOT commit	n=98	30%
Pled out/taken a plea WITHOUT understanding long term consequences	n=96	45%
Talked into committing crime by others	n=58	67%
Forced into committing a crime by others	n=58	29%
Charged b/c was with others (but did not do crime self)	n=95	26%
Witness to crime	n=339	47%

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Criminal Justice: Victims of Crime: *What Did They Tell Us?*

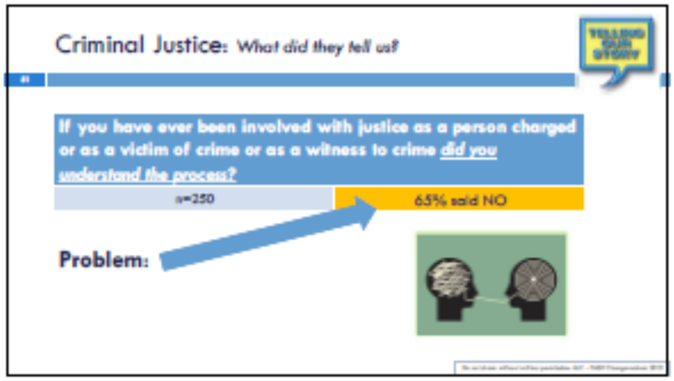
Been a VICTIM of crime	n=342	54%* (185 people)

Many reported at least three crimes against them (listed in the order of frequency)

1. Physical assault against (115 individuals)
2. Sexual assault against (89 individuals)
3. Domestic violence (78 individuals)
4. Financial Exploitation (taken advantage of) - (78 individuals)
5. Been robbed/mugged..... (70 individuals)

Not reported the crime against self to police	n=183	74%
Have ever not been believed by police	n=185	77%
Have ever been a victim of a crime and had Crown/District Attorney refuse to charge the person who committed the crime	n=180	24%**
** Why do you think the Crown / DA refused to lay charges?		
- *You cannot accurately give details of what happened in the crime*	n=46	74%
- ***Been told your FASD diagnosis makes you unreliable***	n=46	13%

50



Criminal Justice: *What did they tell us?*

If you have ever been involved with justice as a person charged or as a victim of crime or as a witness to crime *did you understand the process?*

n=250	65% said NO

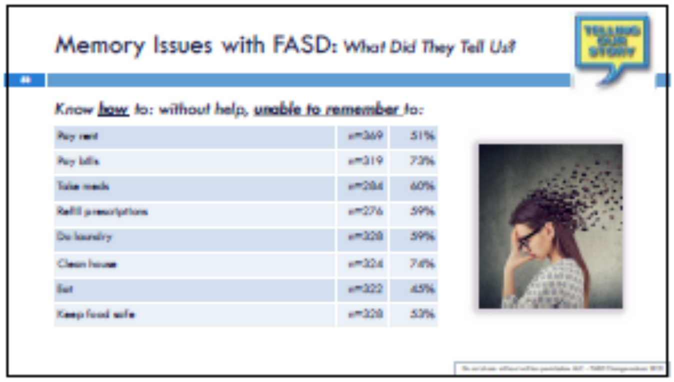
Problem:

51

Drugs and Alcohol: *What Else Did They Tell Us?*

They were talked into using even when did not want to	n=316	38%
Use drugs and alcohol to fit in with people	n=313	37%
Use street drugs / marijuana and/or alcohol to cope with *anxiety/trauma/grief*	n=318	40%

52

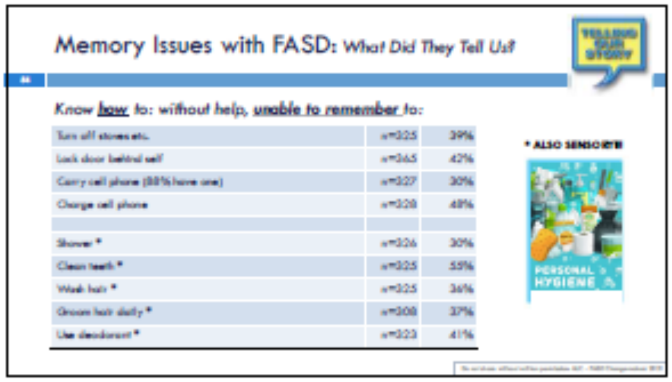


Memory Issues with FASD: *What Did They Tell Us?*

Know how to: without help, unable to remember to:

Pay rent	n=369	51%
Pay bills	n=319	73%
Take meds	n=284	60%
Refill prescriptions	n=276	59%
Do laundry	n=328	59%
Clean house	n=324	74%
Eat	n=322	45%
Keep food safe	n=328	53%

53



Memory Issues with FASD: *What Did They Tell Us?*

Know how to: without help, unable to remember to:

Turn off stoves etc.	n=325	39%
Lock door behind self	n=365	42%
Carry cell phone (88% have one)	n=327	30%
Charge cell phone	n=328	48%
Shower *	n=326	30%
Clean teeth *	n=325	55%
Wash hair *	n=325	36%
Groom hair daily *	n=308	37%
Use deodorant *	n=323	41%

*** ALSO SENSORY!!**

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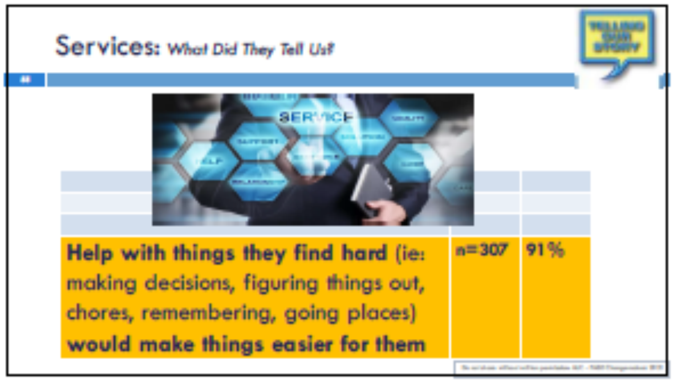
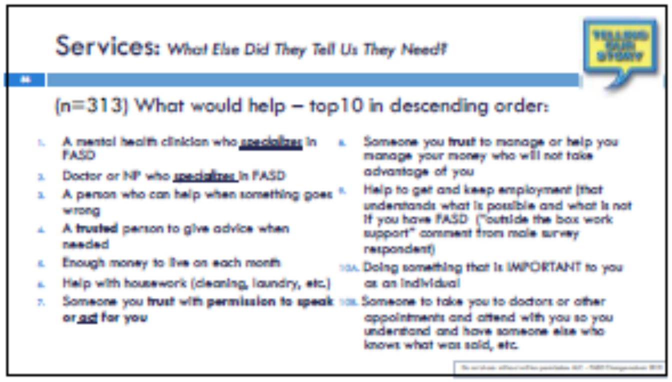


Services: *What Did They Tell Us?*

Help with things they find hard (ie: making decisions, figuring things out, chores, remembering, going places) would make things easier for them	n=307	91%



Services: *What Else Did They Tell Us They Need?*

(n=313) What would help – top10 in descending order:

1. A mental health clinician who specializes in FASD
2. Doctor or NP who specializes in FASD
3. A person who can help when something goes wrong
4. A **trusted** person to give advice when needed
5. Enough money to live on each month
6. Help with housework (cleaning, laundry, etc.)
7. Someone you **trust with permission to speak** or act for you
8. Someone you **trust** to manage or help you manage your money who will not take advantage of you
9. Help to get and keep employment (that understands what is possible and what is not if you have FASD ("outside the box work support" comment from male survey respondent)

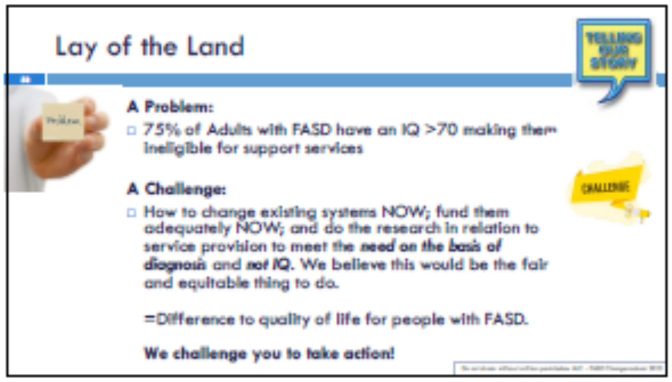
10A. Doing something that is IMPORTANT to you as an individual

10B. Someone to take you to doctors or other appointments and attend with you so you understand and have someone else who knows what was said, etc.

Meaning, Purpose & Satisfaction with Life:
What Did They Tell Us?

The future... – they...

Have hopes and dreams	n=307	83%
Have a goal they would like to accomplish	n=307	80%
Have something they do that is important/feel good about	n=308	77%
Feel that they contribute to the well-being of other people	n=305	77%
Have a pet they care for	n=312	70%
Have voted in an election	n=312	63%
Look forward to the future	n=308	64%
Feel like people who make decisions listen to their ideas	n=303	52%



Lay of the Land

A Problem:

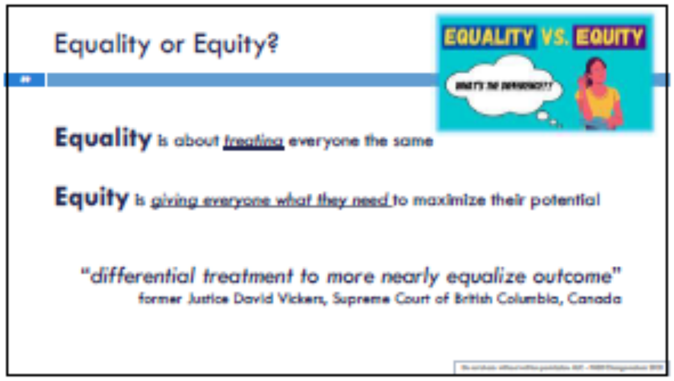
- 75% of Adults with FASD have an IQ >70 making them ineligible for support services

A Challenge:

- How to change existing systems NOW; fund them adequately NOW; and do the research in relation to service provision to meet the ***need on the basis of diagnosis*** and ***not IQ***. We believe this would be the fair and equitable thing to do.

=Difference to quality of life for people with FASD.

We challenge you to take action!

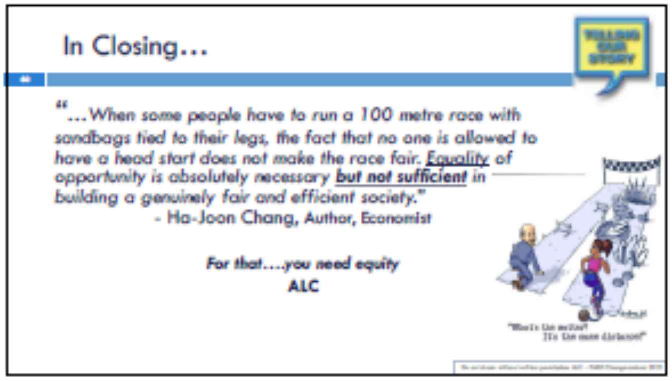


Equality or Equity?

Equality is about treating everyone the same

Equity is giving everyone what they need to maximize their potential

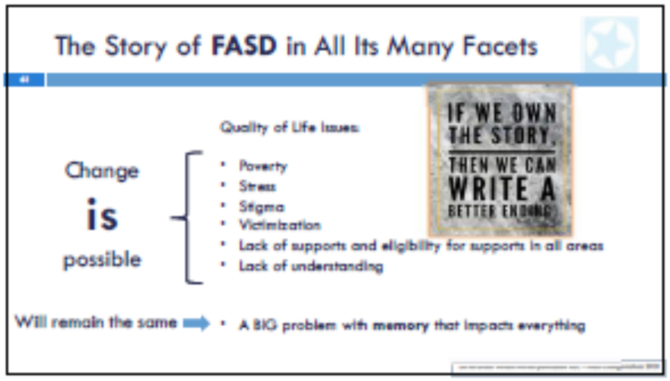
"differential treatment to more nearly equalize outcome"
former Justice David Vickers, Supreme Court of British Columbia, Canada



In Closing…

"…When some people have to run a 100 metre race with sandbags tied to their legs, the fact that no one is allowed to have a head start does not make the race fair. Equality of opportunity is absolutely necessary ***but not sufficient*** *in building a genuinely fair and efficient society."*
- Ha-Joon Chang, Author, Economist

For that….you need equity
ALC



The Story of **FASD** in All Its Many Facets

Change

is

possible

Quality of Life Issues:

- Poverty
- Stress
- Stigma
- Victimization
- Lack of supports and eligibility for supports in all areas
- Lack of understanding

Will remain the same ➡

- A BIG problem with **memory** that impacts everything

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ALC FASD CHANGEMAKERS
2024

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We live, not as we wish to, but as we can.

~ Menander of Athens

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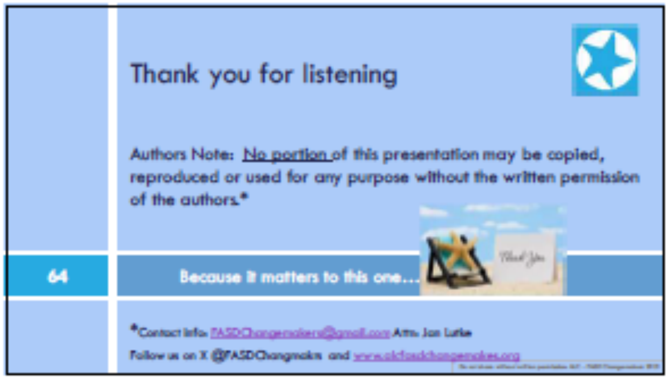

Thank you for listening

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Because it matters to this one…

*Contact info: FASDChangemakers@gmail.com Attn: Jan Lutke

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A1b

Disruption of Circadian Clocks in Children with FASD

Dipak Sarkar

A1c

Sex Differences in Cognitive and Behavioral Effects of Prenatal Alcohol Exposure in a Rat Model

Shameena Bake

Objectives

- Identify prenatal alcohol exposure (PAE) as a risk factor for the development of metabolic diseases in adulthood.
- Recognize the critical periods of vulnerability during prenatal development play a significant role in shaping the impact of PAE on adult health outcomes.
- Understand that PAE-related neurocognitive and affective disorders persist into adulthood.

Prenatal alcohol exposure (PAE) affects the fetal brain as well as several other tissues including immune, cardiovascular, renal, and musculoskeletal tissues. The effects of PAE are not limited to childhood and adolescence but may contribute to a constellation of challenges to health in adulthood as well. This phenomenon where early life experiences influence adult health outcomes has been termed the ‘developmental origins of adult disease (DoHAD). Our studies in a rat model identified that PAE during the first to second-trimester equivalent of human gestation resulted in greater glucose intolerance in adult females. Additionally, PAE altered immune cell alterations in peripheral immune organs and circulating cytokines. Furthermore, PAE caused sex-dependent impairments in different adult behaviors. For eg., PAE-females showed less social preference while the PAE-males exhibited more anxiety-like phenotype over the testing period. These data show that PAE results in diminished neurocognitive ability in adulthood. We need to be better prepared to anticipate the adverse health outcomes in FASD adults, using proactive measures through routine health screening to detect the onset of metabolic diseases and behavioral assessments to gain insights into the challenges of FASD individuals. These comprehensive measures are essential for developing individualized intervention plans and strategies.

A1d

Prenatal alcohol exposure impairs spatial learning in transgenic F344-AD in middle-aged rats

Nadia Samiya

Authors: Nadia Samiya, Shameena Bake, Rajesh C. Miranda, Farida Sohrabji

Objectives

- Learner will be able to recognize that prenatal alcohol exposure has potentially sex-specific effects on behavioral impairment in aging.
- Learner will be able to recognize that prenatal alcohol exposure has a lifelong impact on health which can increase the risk of accelerated AD related cognitive impairment.

Prenatal alcohol exposure (PAE) may contribute to adverse health outcomes in adulthood, though we have limited research on the long-term effects on aging adults with FASD. PAE can potentially lead to cognitive deficits and increased depression-related behaviors, which are early symptoms of Alzheimer's Disease (AD). We hypothesized that PAE in a transgenic rat model of AD, will accelerate behavioral dysfunction.

Wild-type (WT) Fisher F344 females were time-mated with Transgenic (Tg) F344-AD males to create both wild-type and heterozygous transgene positive offspring. Pregnant WT females were exposed to alcohol for 45 minutes daily through ethanol vapor chamber inhalation (or control air), from gestational day 11 through 16, to model consistent binge-like maternal exposure spanning the fetal neurogenic period. Tissue samples from offspring obtained at 21 days were processed for PCR analysis using primers for human APP and PS1 to confirm the genotype of offspring. Offspring from both control and PAE groups underwent testing for cognition and depressive-like behaviors. Barnes Maze test was performed at 10 months to assess cognition and special memory. Recall on Barnes Maze, assessed by time spent in the escape zone (during probe trial), was impaired in PAE Tg male and female rats. Social Interaction testing at 11 months revealed decreased time spent in the social chamber by PAE Wt and Tg females compared to controls. Surprisingly, PAE Tg males spent more time in the social chamber interacting with the conspecific than control Tg males. PAE Tg positive female offspring exhibited depressive-like behavior and cognitive decline, suggesting that PAE may accelerate the development of AD associated behavioral phenotypes.

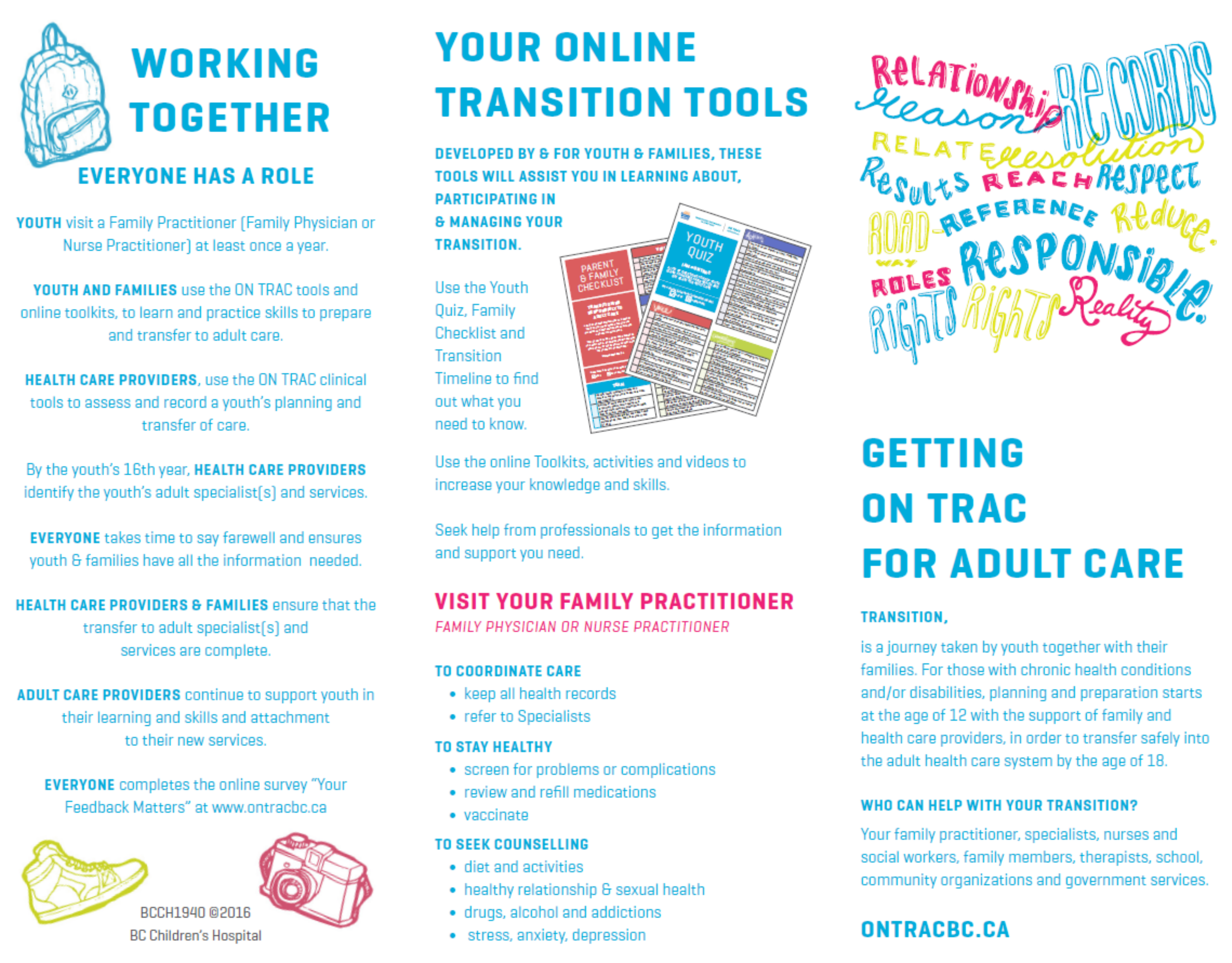
Examining the effect of PAE on aging in a clinically relevant model for Alzheimer's Disease will allow for improved understanding of the long term health consequences of individuals with FASD. This work revealed that prenatal alcohol exposure has a critical impact on behavioral impairment in aging rats and leads to questions about the biological mechanisms that link prenatal alcohol exposure to premature aging.

Understanding the effect of PAE on aging in a clinically relevant model for Alzheimer's Disease will allow for improved health management of people with FASD and the management of their increased risk for dementia.

A2a

Diversity, Equity and Belonging: Inclusive Strengths-based Approaches to Address FASD in Urban Indigenous Communities

Emily Fisher, Jenelle McMillan, Christine Loock, Kristina Pikksalu, Eva Moore



WORKING TOGETHER

EVERYONE HAS A ROLE

YOUTH visit a Family Practitioner (Family Physician or Nurse Practitioner) at least once a year.

YOUTH AND FAMILIES use the ON TRAC tools and online toolkits, to learn and practice skills to prepare and transfer to adult care.

HEALTH CARE PROVIDERS, use the ON TRAC clinical tools to assess and record a youth's planning and transfer of care.

By the youth's 16th year, **HEALTH CARE PROVIDERS** identify the youth's adult specialist(s) and services.

EVERYONE takes time to say farewell and ensures youth & families have all the information needed.

HEALTH CARE PROVIDERS & FAMILIES ensure that the transfer to adult specialist(s) and services are complete.

ADULT CARE PROVIDERS continue to support youth in their learning and skills and attachment to their new services.

EVERYONE completes the online survey "Your Feedback Matters" at www.ontracbc.ca

BCCH1940 @2016
BC Children's Hospital

YOUR ONLINE TRANSITION TOOLS

DEVELOPED BY & FOR YOUTH & FAMILIES, THESE TOOLS WILL ASSIST YOU IN LEARNING ABOUT, PARTICIPATING IN & MANAGING YOUR TRANSITION.

Use the Youth Quiz, Family Checklist and Transition Timeline to find out what you need to know.

Use the online Toolkits, activities and videos to increase your knowledge and skills.

Seek help from professionals to get the information and support you need.

VISIT YOUR FAMILY PRACTITIONER

FAMILY PHYSICIAN OR NURSE PRACTITIONER

TO COORDINATE CARE

- keep all health records
- refer to Specialists

TO STAY HEALTHY

- screen for problems or complications
- review and refill medications
- vaccinate

TO SEEK COUNSELLING

- diet and activities
- healthy relationship & sexual health
- drugs, alcohol and addictions
- stress, anxiety, depression

GETTING ON TRAC FOR ADULT CARE

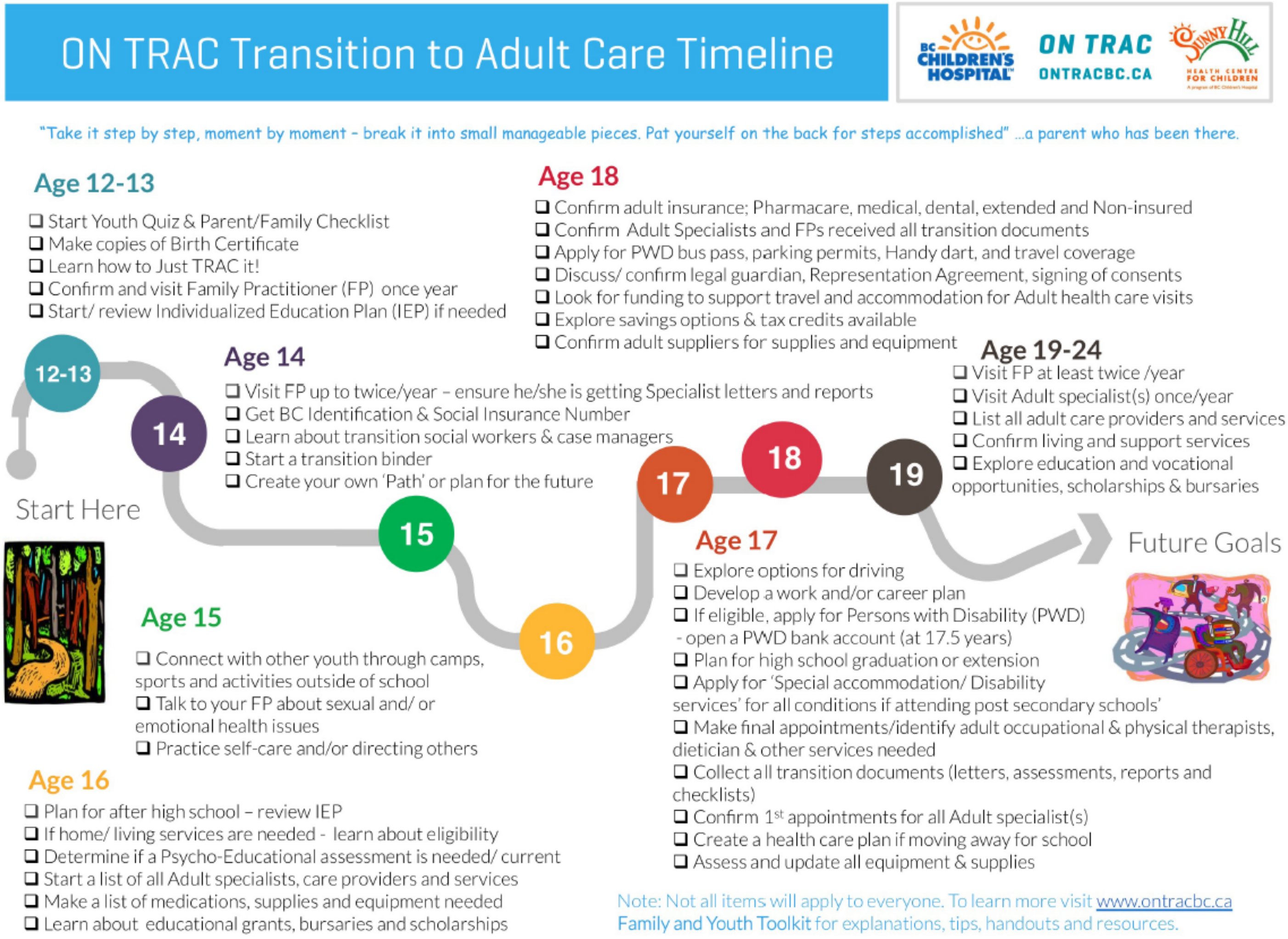
TRANSITION,

is a journey taken by youth together with their families. For those with chronic health conditions and/or disabilities, planning and preparation starts at the age of 12 with the support of family and health care providers, in order to transfer safely into the adult health care system by the age of 18.

WHO CAN HELP WITH YOUR TRANSITION?

Your family practitioner, specialists, nurses and social workers, family members, therapists, school, community organizations and government services.

ONTRACBC.CA



ON TRAC Transition to Adult Care Timeline

"Take it step by step, moment by moment - break it into small manageable pieces. Pat yourself on the back for steps accomplished" ...a parent who has been there.

Age 12-13

- ☐ Start Youth Quiz & Parent/Family Checklist
- ☐ Make copies of Birth Certificate
- ☐ Learn how to Just TRAC it!
- ☐ Confirm and visit Family Practitioner (FP) once year
- ☐ Start/ review Individualized Education Plan (IEP) if needed

Age 14

- ☐ Visit FP up to twice/year – ensure he/she is getting Specialist letters and reports
- ☐ Get BC Identification & Social Insurance Number
- ☐ Learn about transition social workers & case managers
- ☐ Start a transition binder
- ☐ Create your own 'Path' or plan for the future

Age 15

- ☐ Connect with other youth through camps, sports and activities outside of school
- ☐ Talk to your FP about sexual and/ or emotional health issues
- ☐ Practice self-care and/or directing others

Age 16

- ☐ Plan for after high school – review IEP
- ☐ If home/ living services are needed - learn about eligibility
- ☐ Determine if a Psycho-Educational assessment is needed/ current
- ☐ Start a list of all Adult specialists, care providers and services
- ☐ Make a list of medications, supplies and equipment needed
- ☐ Learn about educational grants, bursaries and scholarships

Age 17

- ☐ Explore options for driving
- ☐ Develop a work and/or career plan
- ☐ If eligible, apply for Persons with Disability (PWD) - open a PWD bank account (at 17.5 years)
- ☐ Plan for high school graduation or extension
- ☐ Apply for 'Special accommodation/ Disability services' for all conditions if attending post secondary schools'
- ☐ Make final appointments/identify adult occupational & physical therapists, dietician & other services needed
- ☐ Collect all transition documents (letters, assessments, reports and checklists)
- ☐ Confirm 1st appointments for all Adult specialist(s)
- ☐ Create a health care plan if moving away for school
- ☐ Assess and update all equipment & supplies

Age 18

- ☐ Confirm adult insurance; Pharmacare, medical, dental, extended and Non-insured
- ☐ Confirm Adult Specialists and FPs received all transition documents
- ☐ Apply for PWD bus pass, parking permits, Handy dart, and travel coverage
- ☐ Discuss/ confirm legal guardian, Representation Agreement, signing of consents
- ☐ Look for funding to support travel and accommodation for Adult health care visits
- ☐ Explore savings options & tax credits available
- ☐ Confirm adult suppliers for supplies and equipment

Age 19-24

- ☐ Visit FP at least twice /year
- ☐ Visit Adult specialist(s) once/year
- ☐ List all adult care providers and services
- ☐ Confirm living and support services
- ☐ Explore education and vocational opportunities, scholarships & bursaries

Note: Not all items will apply to everyone. To learn more visit www.ontracbc.ca Family and Youth Toolkit for explanations, tips, handouts and resources.

A2b

Accessible Strategies for Training Pediatric and Adult Primary Care Providers in FASD Diagnosis and Care

Lynn Cole, Christie Petrenko

Objectives

Attendees will be able to:

- Describe the strengths and challenges of the primary care landscape in care of adults with intellectual and developmental disabilities
- Discuss Project ECHO (Extension for Community Healthcare Outcomes), as a model of care to expand access to care for individuals with chronic complex conditions
- Discuss use of Project ECHO in training primary care providers about FASD and other developmental disabilities in pediatrics and opportunities in adult care

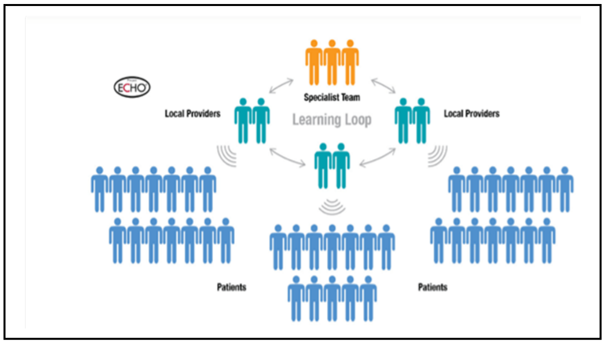
Presentation Summary

Background & Rationale

Fetal Alcohol Spectrum Disorders (FASD) affect an estimated 1.1-5% of the United States (U.S.) school age population [1]. Despite demonstrated importance of FASD diagnosis, most affected individuals experience delayed, missed, or mis-diagnosis, with low professional awareness of FASD and difficulty accessing trained diagnosticians as major contributors [2]. Nationwide shortages of developmental behavioral pediatricians and geneticists, subspecialists who might be uniquely suited to diagnosing FASD, exacerbate the problem [3,4]. Many U.S. states lack a single FASD diagnostic clinic, and those with programs report limited capacity, long wait times, and rare inclusion of adults [5,6,7]

Various approaches to increasing access to FASD diagnosis have been studied in the U.S. and internationally, including mobile teams [8], physician training [9], photographic software [10], and telehealth [11]. All demonstrate some promise, but when viewed through the lens of logistical and financial considerations of the U.S. healthcare system, are insufficient or impractical for expanding capacity to needed levels.

Figure 1.



Because FASD is a complex chronic condition in which inadequate access to diagnosis and care is a widespread problem, flexible professional training and mentoring models adaptable to various geographic regions are needed. As such, Extension for Community Healthcare Outcomes (Project ECHO) was identified as a well-suited approach. Project ECHO, initially designed to build local healthcare capacity and improve for patients with Hepatitis C in rural New Mexico, has since been used to expand access to care for many different conditions, including autism [12,13]. This model focuses on education in best-practice treatment protocols, using case-based learning and co-management via secure, low-cost videoconferencing while developing peer networks, referred to as communities of practice [12].

The primary objective of this project was to develop, pilot, and evaluate feasibility of ECHO FASD, an adaptation of Project ECHO that aimed to train primary care providers and community clinicians in identification, diagnosis and care of children with FASD in their setting. Following the initial pilot, the program was replicated in two additional settings.

Methods (Feasibility Pilot):

The initial feasibility pilot utilized a pre-post design, with evaluation based on Bowen's eight domains of feasibility [14]. A 10-session curriculum (Figure 2) was developed, based upon curriculum guides published by the Centers for Disease Control and Prevention [15] and the Pan-American Health Organization [16], along with the Institute of Medicine (IOM) Updated Guidelines for Diagnosis of FASD [17]. Because a primary goal of the project was to enable participants to establish a FASD diagnosis utilizing a standardized approach, the symptom categories described in the IOM guidelines (alcohol exposure, growth, facial features, neurologic features, and neurobehavioral features) were divided into five separate didactic presentations, followed by five sessions focused on team-identified key components of FASD-informed care.

Figure 2.

Week	Topic	Existing Curricula Alignment
1	Introduction of Hub team & ECHO methodology FASD Overview (types of FASD, prevalence, impacts) Diagnostic Guidelines, Why does Diagnosis matter?	CDC Competencies: I (Goal A,B,C), V(A) PAHO Workbook
2	Introduction to IOM/Hoyme Guidelines Screening and assessing alcohol exposure in different settings and family constellations	CDC Competencies II (A-D), V (A,C), VII (A-C) PAHO Workbook
3	Physical Exam Part 1: Dysmorphology evaluation: measurement of facial features, assessment of common physical findings	CDC Competencies: IV(Goals C,D), V(A,B), PAHO Workbook
4	Physical Exam Part 2: Use of photographic software to assist in facial measurements, Evaluating growth and neurologic features	CDC: IV(Goals C,D), V(A,B), PAHO Workbook
5	Interpreting psychoeducational testing	CDC: V (Goals A,B) PAHO Workbook
6	Putting it all together Part 1: applying IOM guidelines in clinical care with youth of various ages	CDC: V (A,B), VII (A-C) PAHO Workbook
7	Giving feedback to the family Reframing: Supporting families to understand behavior from a brain-based perspective.	CDC Competencies: V (D), VI (A-C), VII (A)
8	FASD-Informed Care: Identifying community resources to support children with FASD and their families	CDC Competencies: V (Goal D), VI (A-C), VII (B,C)
9	Navigating the educational system for children with FASD	CDC: V (Goal D), VI (A-C)
10	Developmental Trauma Disorder: Incorporating trauma-informed care for children with FASD and collaborating with systems of care in infancy through young adulthood	CDC Competencies: V (Goal D), VI (A-C), VII (C)

Next, community clinicians from across Upstate NY, a region with limited diagnostic capacity, targeting recruitment of clinicians in underserved areas and in settings frequented by children at increased risk of FASD. A "hub team" of seven FASD experts located at a university medical center was convened, and included a pediatric nurse practitioner (NP), clinical psychologist, developmental behavioral pediatrician, educator, pediatric social worker, family advocate (caregiver of a teen with FASD), and the project coordinator.

During the intervention phase, the hub team facilitated ten weekly one-hour ECHO FASD Clinics. Each "clinic" utilized secure video conferencing technology to allow participants to interface with the ECHO FASD Hub team and all other participants, view documents, and view videos on screen. The intervention followed standard Project ECHO format, with a targeted didactic presentation lasting approximately 20 minutes, one participant-generated de-identified case presentation, expert feedback, and group discussion. The didactic presentations covered, sequentially, each of the topics on the curriculum, and were presented by various hub team members, including the family advocate. Case presentations by participants allowed application of material to “real life” situations. In each of the case discussion, participants were guided through use of the Hoyme criteria for diagnosis, allowing the participant to either establish a diagnosis or determine the need for additional information gathering. Additional case discussion focused on application of FASD-informed care principles, with both participants and the expert team brainstorming strategies to most effectively support the child and family being discussed.

Results (Feasibility Pilot):

Demand was high, with 21 registrants and 19 clinicians participating in at least one session. The majority (68.4%) of participants were NPs (n=13), followed by physicians (MD and DO, 15.8%, n=3) and clinical psychologists (15.8%, n=3). Participants represented a broad geographic region, including urban, rural, and economically underserved settings and settings serving children at increased risk for FASD. Acceptability, Practicality, and Adaptation domains were rated high by participants. Results from the Knowledge and Confidence surveys from the 6 participants who completed both pre- and post-intervention measures indicate participants showed improvement in FASD knowledge and confidence treating this population. Diagnostic accuracy was assessed post-intervention utilizing a series of five case-based scenarios, with a mean accuracy of 80% (range 60-100%) for participants who completed the measure. A notable finding of this pilot was the interest and engagement from NPs, who are more likely than their physician colleagues to serve rural, minority, disadvantaged, and vulnerable populations (Gigli et al., 2019).

<u>Replication #1:</u>

Following completion of the initial feasibility trial, a collaboration with the Pan American Health Organization (PAHO) allowed for an international replication, utilizing learnings from the initial pilot. In this project, the hub team was modified to accommodate logistic considerations as well as the international nature of the project, with members including a pediatric nurse practitioner, psychologist, geneticist, and Spanish-speaking coordinator from the U.S., along with a Chilean physician with a strong understanding of the local context. Slight modifications to the curriculum were made to reflect regional considerations and all materials were translated into Spanish. Community clinicians from across the country of Chile were invited to participate by a national health minister, who also attempted to assure wide geographic reach.

The intervention followed standard Project ECHO format of introductions, brief didactic, case presentation, and discussion, with simultaneous translation throughout the sessions. Minor logistical modifications were made based upon participant feedback from the first pilot and cultural considerations. For example, the length of sessions was extended from 60 minutes to 90 minutes, and sessions were generally every 2 weeks with an extended break Chile's summer holiday/travel period.

Replication #1 results:

Demand was high, with 49 applicants for 25 spots. Participants included 6 different disciplines (physician, psychologist, nurse, midwife, educator, occupational therapist), and participants reported high levels of satisfaction and utility of the sessions. Intent to use skills within the next three months was high with 40% indicating "often" and 60% indicating "always."

Replication #2:

Due to high demand from clinicians across the U.S., the ECHO FASD leadership team then completed a U.S. replication. Given financial and logistical limitations, the hub team was small (NP, psychologist, geneticist). Recruitment was opened to clinicians across the U.S. The initial curriculum was modified slightly, based upon feedback from participants in the feasibility pilot, though session length was maintained at 60 minutes. Implementation was otherwise consistent with the initial pilot.

Replication #2 results:

Demand was high, with 29 registrants from a wide geographic range, who represented multiple disciplines including NP, physician, and psychologist. Eighteen clinicians engaged in sessions and demonstrated high engagement. Satisfaction was high, and notably, >20% of participants have sought mentoring following the program as they have engaged in diagnosis and FASD-informed care.

Translating Pediatric Work to Adult Populations:

ECHO FASD shows promise as a feasible and scalable method of training community-based clinicians in a wide range of professional settings to diagnose treat children with FASD and future work directed at expanding capacity for adult diagnosis and FASD-informed care is critically needed. There are a number of lessons from our initial work that could be relevant.

The high prevalence of FASD suggests that relying exclusively on FASD specialty clinics will not realistically meet the need. Clinicians in the communities where individuals with FASD are living, and in the settings where they are accessing care need the skills to recognize symptoms, screen, and when appropriate, make straight-forward diagnoses.

Clinicians in community settings have many competing demands for skills and expertise in different areas – they need to know how FASD is relevant to their daily work.

The clinicians who may be the easiest to engage are those who are (a) working in settings where individuals at high risk for FASD receive care, (b) may be feeling less than fully effective with current models of care.

Think creatively about professionals who might be able to be engaged and do the needed work. Nurse practitioners stood out in our work as a key professional group with capacity for this work. There may be others in the adult world – Physician Assistants (PA), substance use counselors, social workers, and others.

Conclusion:

ECHO FASD has shown promise in trials with pediatric community clinicians of being a feasible method to increase knowledge and confidence in diagnosis and treatment of children with FASD, while teaching skills to attain diagnostic accuracy in straightforward cases. Given the overwhelming need for adult diagnostic capacity, a similar model, focusing on adult clinicians in settings where individuals at high risk for FASD receive care may be a path to meet this need. Use of such a model, with case-based learning, ongoing mentoring, and communities of practice may support adult clinicians in applying learned knowledge to practice in the *complex clinical situations* where clinicians may encounter adults who have experienced the impact of prenatal alcohol exposure.

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A3

Follow-up to PC1: The Verdict in in Your Court: Advancing Justice for Individuals with FASD Across Judicial Systems

Peter Choate, Marian Gaston, Corey La Berge

A4

Implementing an FASD Assessment and Strengths and Strategies Approach in a Substance Use Treatment Agency and a Behavioral Health Agency

Dan Dubovsky, Summer Krochta

A5

Practice-Based Evidence FASD Support Groups in Ontario: What Makes Them Work and How Augmenting Groups and Individual Sessions with Acceptance Commitment Training Can Impact Outcomes

Angela Geddes, Shannon Butt

Objectives

As a result of attending this presentation, participants will:

- Express the importance of working alongside individuals with FASD and their caregivers to develop and deliver supports tailored to their needs.
- Understand the importance of partnership alliances with community agencies, sharing expertise and resources, while building skills and capacity.
- Identify key elements of support groups that are considered effective in addressing the wellbeing of individuals with FASD and their caregivers.
- Practice and further discover the elements of Acceptance Commitment Therapy/Training (ACT) within their personal lives and within FASD support group and individual counselling/support activities.

Part 1: Understanding Support Groups in Ontario

- Introduction to the history and evolution of support groups in Ontario.
- Importance of community partnerships and strategies to nurture participant engagement.
- Creating inclusive and supportive environments through collaborative efforts.
- Practical considerations for successful support groups:
  - Safety, dignity, and confidentiality.
  - Inclusion and reducing barriers to service.
  - Volunteer screening and team training.
  - Feedback, evaluation, and continuous improvement.

Part 2: The Role of Acceptance Commitment Therapy (ACT)

- Background on psychological challenges faced by individuals with FASD and their caregivers.
- Introduction to ACT as an intervention:
  - Focus on mindfulness and values-based actions.
  - Addressing shame, guilt, and psychological distress.
- Overview of preliminary research findings on ACT effectiveness.
- Adaptation of ACT for caregivers of individuals with FASD.
- Future directions for ACT research and implementation.

Part 3: Integrating ACT Principles into Practice

- Embracing acceptance: Understanding and acknowledging the realities of FASD without stigma.
- Exploring the core principles of ACT:
  - Present moment awareness.

    - Clarifying personal values.
    - Acceptance and commitment to action.
- Practical strategies for applying ACT principles in daily life:
    - Mindfulness exercises.
    - Identifying and aligning with personal values.
    - Committing to doing things differently and focusing on meaningful actions despite challenges.
- Discussion on the importance of self-compassion and resilience in navigating FASD-related stressors.

Conclusion: Living Our Best Lives

- Recap of key concepts from the workshop.
- Opportunities for participants to learn more and how to apply ACT principles in their personal and professional lives.
- Commitment to ongoing support and collaboration within the FASD community.
- Closing remarks and gratitude for participation.

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A6

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

David Junior Gilbert

SUMMARY SHEET FOR SESSION A6

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

Dr David Junior Gilbert

📖Introduction

Individuals with FASD are overrepresented in the justice system (Popova et al., 2011). Interrogative suggestibility, and confabulation have been reported as prevalent within this population. This session will focus on findings from the recently published experimental study on interrogative suggestibility in adolescents with FASD (Gilbert et al., 2024), alongside findings from the study on confabulation and compliance which are in preparation for publication.

Interrogative suggestibility is the ‘extent to which, within closed social interaction, people come to accept messages communicated during formal questioning, as the result of which their subsequent behavioural response is affected’ (Gudjonsson, 1986, p. 84). Compliance is the tendency to accept a suggestion while privately disagreeing with the content of the suggestion (Gudjonsson, 1989). While closely related to suggestibility, with compliance, the interviewee does not internalize the suggestion. Confabulation on the other hand is defined as “problems in memory processing where people replace gaps in their memory with imaginary experiences that they believe to be true” (Gudjonsson, 2003, p. 364).

The study aimed to investigate interrogative suggestibility, compliance’ and confabulation in adolescents with FASD when compared to a control group. Confabulation and suggestibility were measured immediately and after one week. Findings from this study presents an addition to the existing literature on suggestibility in adults with FASD (Brown et al., 2011) while also supporting qualitative and case study narratives (Gilbert et al., 2023; Greenspan & Driscoll, 2016).

🎯 Objectives of the session

The objectives of the session include to:

i) Present the research findings on interrogative suggestibility in adolescents with FASD (compared to controls) as measured immediately and after one week.

ii) Present findings on the unique patterns of confabulation observed in adolescents with FASD as measured immediately and after one week.

iii) Expand on the types of responses of adolescents with FASD in comparison to controls during interrogative questioning with the implications of the findings

📊 Summary of Findings

1. 📝 **Immediate and Repeat Suggestibility:** Individuals with FASD showed significantly higher total suggestibility compared to controls immediately and after one week.
2. 🔄 **Relationship Between Suggestibility Measures:** a significant relationship between immediate and repeat suggestibility was observed, emphasising the consistency of findings over time.
3. 👮 **Yield and Shift Scores:** The FASD group demonstrated significantly more yield to leading questions and shift in responses upon negative feedback suggesting potential implications for coping strategies during police interviews.
4. 💫 **Confabulation**: The group with FASD developed significantly imaginative stories to support their admissions to false suggestions, while also presenting altered versions of scenarios
5. ⏳ **Compliance**: Self-reported compliance did not show any significant difference between the two groups when measured.
6. 🧠 **Memory, impulsivity and IQ:** Lower memory scores, higher impulsivity and lower average IQ were observed in the FASD group, consistent with literature.
7. ⚖️ **Legal Implications**: Findings suggest individuals with FASD are vulnerable to leading questions and interrogative pressure, with potential implications for legal processes, and understanding rights. Poor memory poses challenges in legal proceedings, potentially leading to self-incrimination.

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B1a

Examination of Epigenetic Profiles Associated with Prenatal Exposure to Alcohol

Aileen Baldwin

B1b

Ultrasound imaging of ciliary arterial blood flow as a potential ocular biomarker for brain effects in adult offspring prenatally exposed to alcohol.

Marisa Pinson

Authors
Marisa R. Pinson[1], Shameena Bake[1,2], Farida Sohrabji[1,2,*], Rajesh C. Miranda[1,2,*]
[1] Department of Neuroscience and Experimental Therapeutics, Texas A&M School of Medicine, Bryan, TX, USA
[2] Women's Health in Neuroscience Program, Texas A&M University School of Medicine, Bryan, TX, USA

Abstract

Background:

Prenatal Alcohol Exposure (PAE) can contribute to cardiovascular, metabolic, and neurological disease risk in adulthood[1,2,3], and to premature mortality[2]. In rodent models, adult PAE offspring exhibit persistent cranial blood flow deficits, and worse neurobehavioral outcomes following acute cerebrovascular ischemic stroke. Neurovascular deficits may contribute to pathogenic effects of PAE in adulthood, but are difficult to assess without sophisticated imaging technology. We hypothesized that ultrasound imaging of ocular blood flow may be a more clinically tractable approach to assess neurovascular function in adults with PAE.

Methods:

Pregnant Sprague Dawley rats were exposed daily to control air or alcohol by vapor inhalation, between gestational day 8 and 19 to model multiple binge exposures during pregnancy. This dose and regimen is shown to result in behavioral deficits in social interaction and cognition. Growth parameters were assessed in both pregnant dams and offspring. At 5 months of age, male and female offspring were assessed by high-resolution ultrasonography, for blood flow parameters in the posterior ciliary arteries, which supply blood to a majority of the eye.

Results:

The alcohol exposure paradigm did not result in significant maternal or neonatal weight loss, though at 5 months of age, there was a sex-independent trend towards decreased brain to bodyweight ratio in PAE offspring. PAE offspring also exhibited significant and sex-independent decrease in ciliary arterial velocity time integral, compared to control offspring.

Conclusions:

PAE at levels that did not result in significant growth deficits, nevertheless resulted in decreased cardiac output to the eye in adult offspring. Ocular blood flow may serve as a proxy biomarker for brain health in adults with PAE.

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B1c

Metabolic and Cardiovascular Diseases in a Retrospective Cohort of Adults with FASD

Olivia Weeks

Authors

Olivia Weeks[1,2,3], Caroline E. Burns[1,2,4], C. Geoffrey Burns[1,2,4,] Wolfram Goessling[2,3,4,5,6,7], CIFASD

[1]Division of Basic and Translational Cardiovascular Research, Department of Cardiology, Boston Children's Hospital, MA, 02115, USA,

[2]Harvard Medical School, Boston, MA, 02115, USA

[3]Division of Genetics, Brigham and Women's Hospital, Boston, MA.

[4]Harvard Stem Cell Institute, Cambridge, MA.

[5]Broad Institute of MIT and Harvard, Cambridge, MA.

[6]Harvard-MIT Division of Health Sciences and Technology, Cambridge, MA.

[7]Division of Gastroenterology, Massachusetts General Hospital, Boston, MA.

Objectives

- Define "retrospective cohort study" along with the benefits and limitations of this type of study.
- Identify metabolic and cardiac health conditions in a cohort of patients with FASDs.
- Discuss the potential implications of findings to patients and providers, as well as where additional research is needed.

Introduction

In the United States, approximately 1 in 20 school age children live with an FASD (1-3). Despite this high prevalence, little is known about long-term health outcomes in FASDs or the overall risk that patients will develop cardiomyopathy, heart failure, and associated cardiometabolic syndrome. Previous reports have documented a staggering number of cardiac anomalies in individuals with FASDs, ranging from up to 70% of patients with FAS to >30% of patients with FASDs (4-6). More recently, children and adolescents with FASD were also found to have a higher incidence of hypertension (7), and in a self-report-based survey, adults with FASDs indicated a higher incidence of CHDs and adult cardiomyopathy than the general population (8). **While these data strongly suggest that cardiovascular abnormalities are a common feature of FASDs, comprehensive studies on lifetime CVD risk in adult cohorts have yet to be performed.** *Inquiry into whether PAE increases the risk for adult CVD would be directly impactful for FASD patients, with the potential to elicit immediate clinical intervention through earlier monitoring or preventative medications*.

Objective 1

Define "retrospective cohort study" along with the benefits and limitations of this type of study.

Cohort studies can be **retrospective** or **prospective**. Retrospective studies are studies that begin in the present and look backward at what has happened to individuals over time. In contrast, prospective studies look forward, beginning in the present and tracking the patients over time as they age. Our study is retrospective, meaning that we identified control and FASD patients and reviewed their medical histories to date as they are available in our electronic medical record data base. One critical advantage of this type of study is that it allows us to examine health outcomes in much older patients than can typically be accomplished with a prospective study. This is especially relevant because we are studying adult-onset conditions which may not appear until an individual is >30 – 65 years of age. The limitations of this type of study include poor control of the exposure, covariates, and other potential confounders. Additionally, a patient may have missing information in their medical records, and everyone has not necessarily been seen by the same doctors and therefore may have had different types of evaluations.

Objective 2

Identify metabolic and cardiac health conditions in a cohort of patients with FASDs.

We previously published a retrospective cross-sectional study examining the incidence of metrics of cardiometabolic health in adults with any FASD diagnosis, including fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defect (ARBD) (9). Using the patient database registry at a large academic health system [Research Patient Data registry of Partners HealthCare System], we identified male and female patients ≥18 years with FASDs (n=208) and controls matched for age, sex, and race/ethnicity (n=208) (9). Patients ranged from ~18-80 years, with a median age of ~30 years. We found that FASD was a risk factor for an overweight/obese phenotype in females (69.0% FASD females vs. 54.3% controls, p=0.04), but not males (60.7% FASD males vs. 73.3% controls, p=0.08) (9). Further, significantly more FASD patients had Type 2 Diabetes Mellitus (11.5% vs. 3.8%, unadj. p-value = 0.003), low high-density lipoprotein (HDL; <40mg/dL; 31.9% vs. 15.4%, p=0.004) and elevated triglycerides (≥150 mg/dL; 34.5% vs. 14.9%, p=0.0009) (9). FASD subjects were also significantly more likely to have ≥2 metabolic abnormalities (46.9% vs. 26.2%, p=0.002) (9). **These findings suggest that PAE is a risk factor for developing features of the metabolic syndrome and led us to hypothesize that FASD patients may also have a high CVD burden, especially given their low HDL levels.**

Utilizing this same patient cohort, we have now turned to examine the incidence of cardiovascular testing and CVDs, including:

- Electrocardiogram (EKG)
- Echocardiogram (ECG)
- Congenital heart defects
- Patent Foramen Ovale
- Hypertension
- Arrythmia
- Atrial Fibrillation
- Cardiomyopathy
- Left atrial enlargement
- Heart Failure (systolic and diastolic)
- Heart valve disease
- Atherosclerosis
- Myocardial Infarction
- Clotting (Cerebrovascular accident/stroke, thrombosis, embolism)
- All-cause mortality

Our preliminary data, which will be presented in this lecture, provide compelling evidence that FASD patients may have a higher incidence of congenital and adult-onset cardiac diseases, especially amongst females.

Objective 3

Discuss the potential implications of findings to patients and providers, as well as where additional research is needed.

Implications

- Our data suggests that males and females with FASDs may have an increased rate of congenital heart defects relative to the general population. The rate is lower than what has been reported in the literature, but nonetheless indicative of the impact of PAE on the developing heart and cardiovascular system.
- Patients with FASDs may be referred for cardiac testing more frequently and may also be more likely to receive significant cardiovascular disease diagnoses.
- Because diastolic dysfunction is easily missed or not diagnosed in the clinic, patients and providers should consider whether targeted evaluations for diastolic dysfunction could be beneficial in symptomatic patients who otherwise have normal ejection fraction or normal baseline echo parameters.

Additional Research Needed

- Prospective cohort studies that perform comprehensive evaluations of systolic function, diastolic function, and global longitudinal strain in patients with FASDs and matched controls.
- Additional longitudinal studies to assess all CVD outcomes in patients with FASDs and matched controls. Ours is only one study, and while we saw increased CVD rates in females with FASDs, it is important to clarify whether this is reproducible in other large cohorts and whether it may also be seen in males from other cohorts.
- Determine whether patients with FASDs who are affected by CVDs have serum biomarkers that indicate cardiac risk.
- Evaluate whether interventions such as exercise, diet, early screening, and/or management of metabolic disease phenotypes can alter the CVD rates in FASD patients.

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B1d

Embryonic Alcohol Exposure in Zebrafish Predisposes Adults to Cardiomyopathy and Diastolic Dysfunction

Olivia Weeks

Authors

Olivia Weeks[1,2],, Xinlei Gao[1,2,] Sandeep Basu[1,2], Kaifu Chen[1,2], C. Geoffrey Burns[1,2], Caroline E. Burns[1,2,3], CIFASD

[1]Division of Basic and Translational Cardiovascular Research, Department of Cardiology, Boston Children's Hospital, MA, 02115, USA
[2]Harvard Medical School, Boston, MA, 02115, USA
[3]Harvard Stem Cell Institute, Cambridge, MA, 02138, USA

Objectives

- Understand how zebrafish can be used as a model for prenatal alcohol exposure, FASDs, and cardiovascular diseases (CVDs).
- Define cardiomyopathy and diastolic heart failure.
- Identify cardiac issues resulting from prenatal alcohol exposure in zebrafish.
- Discover how “biomarkers” may help identify individuals with prenatal alcohol exposure who are at risk for diastolic heart failure and/or cardiomyopathy.

Objective 1

Zebrafish as a tool to study FASDs and CVDs.

Danio rerio, the zebrafish, is a tropical freshwater fish from the Ganges River that is commonly used in scientific and medical research (Fig. 1). Zebrafish are a preferred animal model because they are easily raised in an aquarium setting, lay hundreds of eggs per week, and have an external fertilization process that enables scientists to directly observe development (1). Additionally, there is a high degree of conservation between human and zebrafish on a genomic and physiological level (2). Zebrafish have nearly all the major organs that humans have and present with approximately 84% of the genes known to cause human disease (1, 3).

Zebrafish larvae have been established as a vertebrate model organism for FASD because they are easily exposed to EtOH during development and recapitulate key features of the human syndrome, including developmental delay, short stature, craniofacial anomalies, cardiac defect, organ malformations, and behavioral alterations (4-9). In our model of EAE, larvae are exposed to 0.5 – 1% EtOH from the completion of gastrulation (10 hours post fertilization (hpf)) until cardiac disc formation (~22 somite stage (ss); 20 - 22 hpf) or the formation of the two-chambered heart (48 hpf). The tissue concentration of EtOH in embryos ranges from ~24-37% of external EtOH concentrations; therefore, 0.5 – 1% EtOH exposures are in the range of what would be physiologically relevant for humans with chronic alcohol use disorder (10).

Objective 2

Define cardiomyopathy and diastolic heart failure.

In humans, there are several types of cardiomyopathies, including dilated cardiomyopathy, hypertrophic cardiomyopathy, arrhythmogenic right ventricle dysplasia (rare), and restrictive cardiomyopathy (rare) (11). In dilated cardiomyopathy, the ventricle stretches and becomes enlarged, often weakening its pumping action (Fig. 2). In hypertrophic cardiomyopathy, the wall of the left ventricle becomes thickened and stiff, which also negatively impacts pumping function (Fig. 2). Cardiomyopathy can result from many causes, including high blood pressure, obesity or diabetes, heart attack, heart valve problems, alcohol use disorder, chemotherapy, hemochromatosis, pregnancy complications, and infection (11). Importantly, cardiomyopathy can lead to heart failure.

There are two types of left-sided heart failure: diastolic heart failure and systolic heart failure. For more information on heart failure from the American Heart Association, see: https://www.heart.org/en/health-topics/heart-failure/what-is-heart-failure/types-of-heart-failure. In diastolic heart failure, or heart failure with preserved ejection fraction (HFpEF), there are abnormalities in how the left ventricle fills during diastole. This can happen when the myocardial wall fails to relax properly, preventing the heart from filling with as much blood as it should. Patients often experience symptoms of heart failure, such as shortness of breath, fatigue, exercise intolerance, and peripheral edema. In systolic heart failure, there is a defect in the contractile function of the left ventricle such that it cannot squeeze normally. This results in an inability of the heart to pump with enough force to move blood into circulation. Importantly, there is a quantitative reduction in ejection fraction. Congenital heart defects, which can result from prenatal alcohol exposure, may predispose to heart failure and cardiomyopathy due to structural abnormalities in the heart chambers. Zebrafish can develop features of cardiomyopathy and heart failure, which can be detected by dissection and imaging of the heart, echocardiography, and histopathology of sectioned heart tissue.

Objective 3

Identify cardiac issues resulting from prenatal alcohol exposure in zebrafish.

The heart is the first functional organ to form in the human embryo, making it particularly susceptible to post-conception alcohol exposure before a woman is aware of her pregnancy. To understand how EtOH impacts the earliest stages of cardiac development, we turn to the zebrafish model. Fundamental stages of heart development are conserved across vertebrates, and the zebrafish heart is formed by the same progenitor cell populations that construct the mammalian heart (12, 13). In zebrafish, first heart field (FHF)-derived cardiomyocytes and second heart field (SHF) progenitors migrate from the anterior lateral plate mesoderm (ALPM) to form a cardiac disc (Fig. 3) (13-16). The cardiac disc then undergoes telescoping to create a linear heart tube, and the linear heart tube then completes looping to create a heart with a single ventricle and single atrial chamber (Fig. 3) (14). Defects in the migration of cardiac progenitors and differentiating cardiomyocytes to the midline during cardiac disc formation, along with other downstream events, is expected to cause congenital defects (16).

Prior work by Marrs and others has established the zebrafish as a robust system to model EAE-induced cardiac malformations that include delayed cardiomyocyte migration to the midline, decreased SHF progenitor contribution to the ventricular chamber, and bi-lobed ventricle (5, 17-21). In this presentation, we will confirm these findings and describe how EAE causes the cardiac issues in embryos and adults.

EAE-induced cardiac issues in embryos:

- Impaired cardiac cone and linear heart tube formation
- Abnormal ventricle structure
- Acute reduction in atrial and ventricular systolic function
- Abnormal cardiomyocyte cell size in the ventricle

EAE-induced cardiac issues in adults:

- Cardiomyopathy-like phenotype, characterized by increased atrial size and increased compact myocardial wall thickness in the ventricle
- Increased global longitudinal strain in the ventricle, indicative of increased tissue deformation during heart contraction
- Diastolic dysfunction in the context of preserved systolic function
- Abnormal expression of novel and heart failure associated genes

Objective 4

Discover how "biomarkers" may help identify individuals with prenatal alcohol exposure who are at risk for diastolic heart failure and/or cardiomyopathy.

While a large percentage of individuals have a medical history significant for PAE, obtaining a diagnosis of FASD is often very difficult. Furthermore, there are few molecular means by which we can stratify patients with FASDs based on their risk for developing additional conditions during adulthood, such as cardiovascular diseases. Our goal was to identify cardiac biomarkers (biological molecules found in blood or cardiac tissue) that could indicate whether an individual had PAE and/or had PAE and was at increased risk for developing cardiac complications. To do this, we raised sibling control and embryonic EtOH-exposed embryos to adulthood, isolated their hearts, and looked for biomarkers in the form of mRNA. For a cell to make protein, DNA must first be transcribed into mRNA. The amount of mRNA in a cell at any given time provides an idea of which genes are being expressed in the cell and at what quantity. To identify the amount of RNA that is made from each gene, RNA sequencing is often deployed. Relevant cells are isolated, tissues are homogenized, and RNA is extracted and sequenced. RNA sequencing of the EAE ventricle identified novel and heart failure associated genes whose expression levels were altered across the lifespan or correlated with the degree of diastolic dysfunction detected in adulthood. These results suggest that individuals with PAE may have sustained changes in the molecular signature of their hearts, and that the misexpression of several of these genes may correlate with their likelihood of developing cardiac dysfunction as they age.

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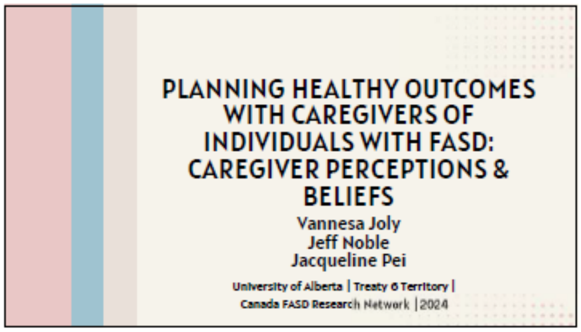
B2a

Planning Healthy Outcomes with Caregivers of Individuals with FASD: Caregiver Perceptions and Beliefs

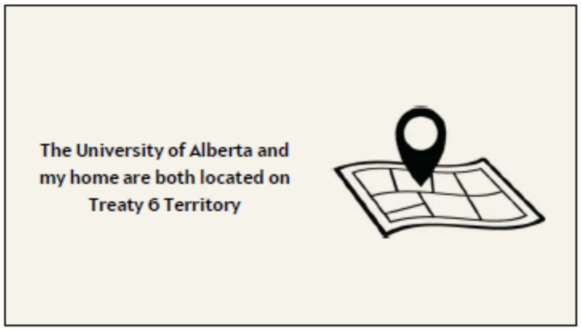
Vannesa Joly



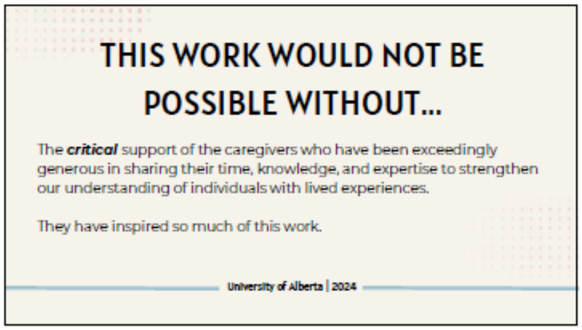
PLANNING HEALTHY OUTCOMES WITH CAREGIVERS OF INDIVIDUALS WITH FASD: CAREGIVER PERCEPTIONS & BELIEFS

Vannesa Joly
Jeff Noble
Jacqueline Pei

University of Alberta | Treaty 6 Territory |
Canada FASD Research Network | 2024



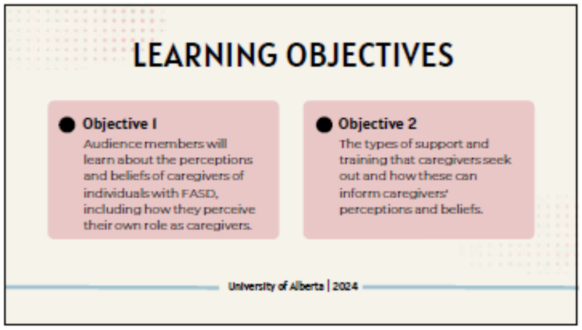
The University of Alberta and my home are both located on Treaty 6 Territory



THIS WORK WOULD NOT BE POSSIBLE WITHOUT…

The ***critical*** support of the caregivers who have been exceedingly generous in sharing their time, knowledge, and expertise to strengthen our understanding of individuals with lived experiences.

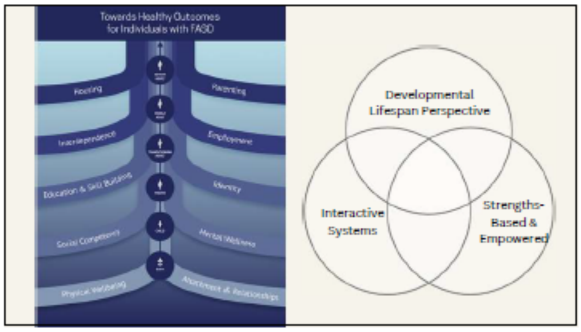
They have inspired so much of this work.

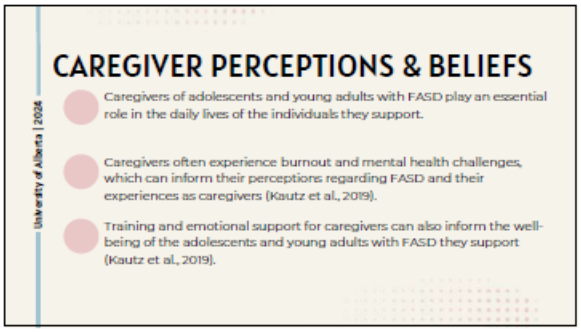


LEARNING OBJECTIVES

Objective 1
Audience members will learn about the perceptions and beliefs of caregivers of individuals with FASD, including how they perceive their own role as caregivers.

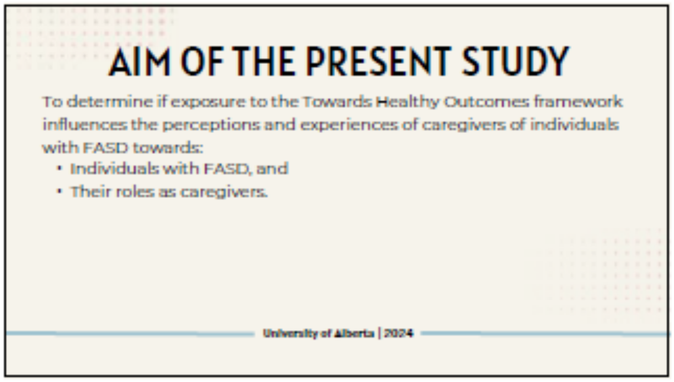
Objective 2
The types of support and training that caregivers seek out and how these can inform caregivers' perceptions and beliefs.





CAREGIVER PERCEPTIONS & BELIEFS

- Caregivers of adolescents and young adults with FASD play an essential role in the daily lives of the individuals they support.
- Caregivers often experience burnout and mental health challenges, which can inform their perceptions regarding FASD and their experiences as caregivers (Kautz et al., 2019).
- Training and emotional support for caregivers can also inform the well-being of the adolescents and young adults with FASD they support (Kautz et al., 2019).



AIM OF THE PRESENT STUDY

To determine if exposure to the Towards Healthy Outcomes framework influences the perceptions and experiences of caregivers of individuals with FASD towards:

- Individuals with FASD, and
- Their roles as caregivers.

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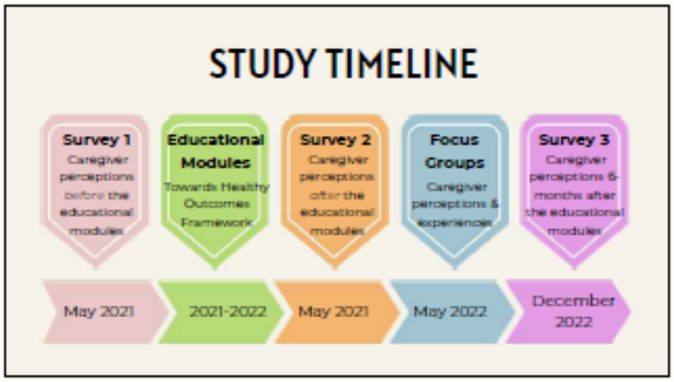


STUDY TIMELINE

Survey 1
Caregiver perceptions before the educational modules

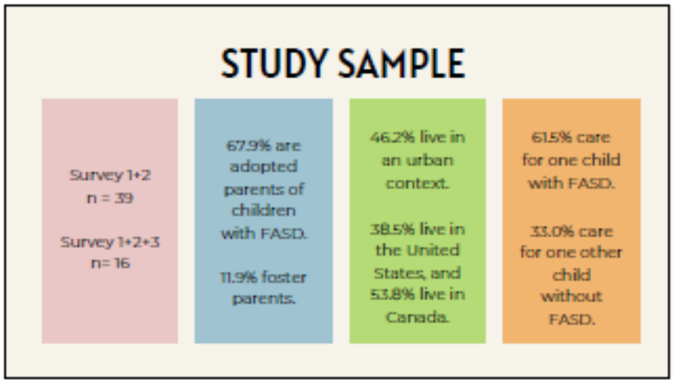
Educational Modules
Towards Healthy Outcomes Framework

Survey 2
Caregiver perceptions after the educational modules

Focus Groups
Caregiver perceptions & experiences

Survey 3
Caregiver perceptions 6-months after the educational modules

May 2021
2021-2022
May 2021
May 2022
December 2022



STUDY SAMPLE

Survey 1+2
n = 39

Survey 1+2+3
n= 16

67.9% are adopted parents of children with FASD.

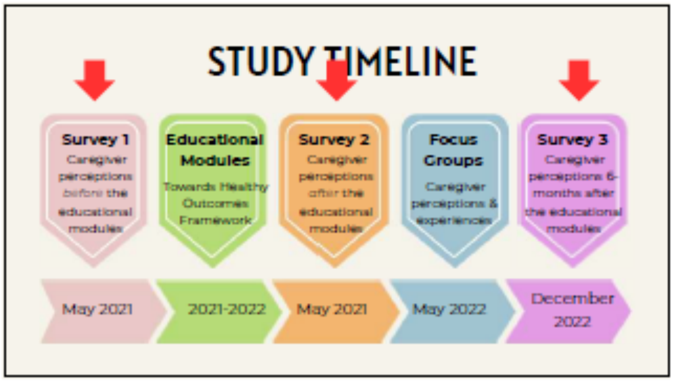
11.9% foster parents.

46.2% live in an urban context.

38.5% live in the United States, and 53.8% live in Canada.

61.5% care for one child with FASD.

33.0% care for one other child without FASD.



STUDY TIMELINE

Survey 1
Caregiver perceptions before the educational modules

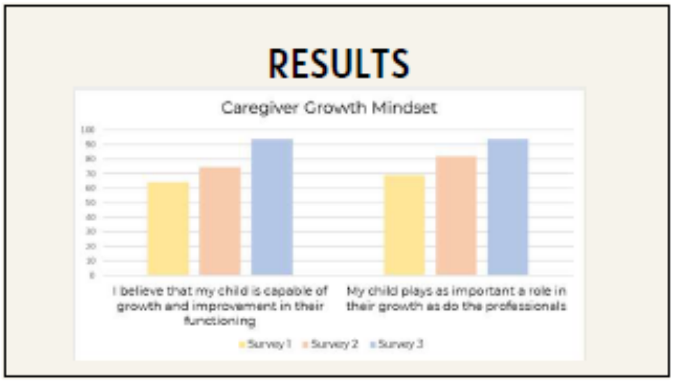
Educational Modules
Towards Healthy Outcomes Framework

Survey 2
Caregiver perceptions after the educational modules

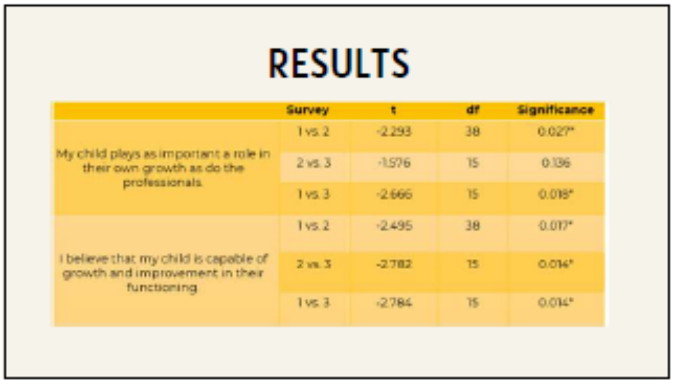
Focus Groups
Caregiver perceptions & experiences

Survey 3
Caregiver perceptions 6-months after the educational modules

May 2021
2021-2022
May 2021
May 2022
December 2022



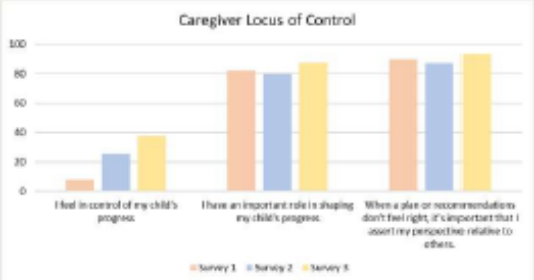
RESULTS



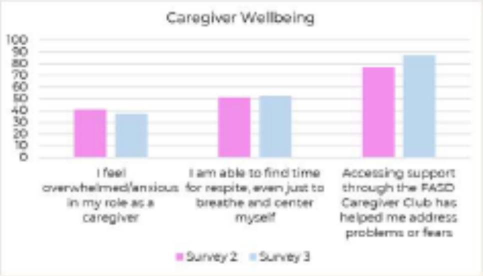
RESULTS

	Survey	t	df	Significance
My child plays as important a role in their own growth as do the professionals	1 vs. 2	-2.293	38	0.027*
	2 vs. 3	-1.576	15	0.136
	1 vs. 3	-2.666	15	0.018*
I believe that my child is capable of growth and improvement in their functioning	1 vs. 2	-2.495	38	0.017*
	2 vs. 3	-2.782	15	0.014*
	1 vs. 3	-2.784	15	0.014*

RESULTS



RESULTS



STUDY TIMELINE

Survey 1
Caregiver perceptions before the educational modules
May 2021

Educational Modules
Towards Healthy Outcomes Framework
2021-2022

Survey 2
Caregiver perceptions after the educational modules
May 2021

Focus Groups
Caregiver perceptions & experiences
May 2022

Survey 3
Caregiver perceptions 6-months after the educational modules
December 2022

RESULTS

Identifying Growth	Planning for the Future
Navigating Complexity	Normalizing Interdependence

KEY TAKEAWAYS

University of Alberta| 2024

UNIVERSITY OF ALBERTA
CanFASD
CANADA FASD RESEARCH NETWORK

THANK YOU

Presented By : Vannesa Joly
vannesa@ualberta.ca

B2b

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

Kara Te Whata-Maynard

B2c

Results from the Randomized Controlled Efficacy Trial of the Families Moving Forward Connect App for Caregivers Raising Children with FASD

Christie Petrenko

Families Moving Forward

CONNECT

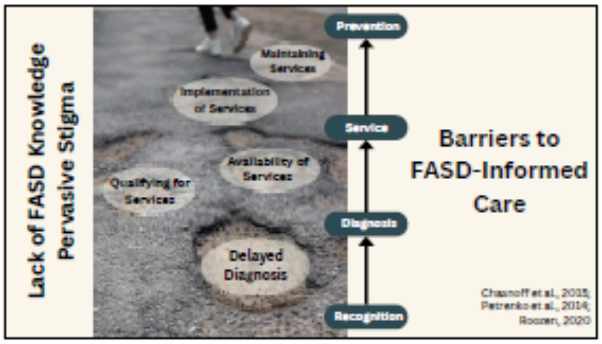
Efficacy Trial Results

Christie L. M. Petrenko Ph.D.

April 12th, 2024

1

2



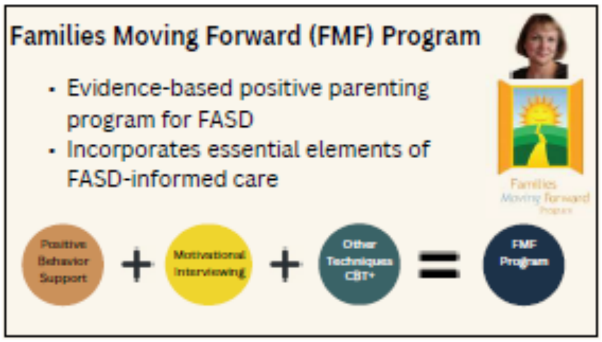
Lack of FASD Knowledge

Pervasive Stigma

Barriers to FASD-Informed Care

Chasnoff et al., 2015; Petrenko et al., 2014; Roozen, 2020

3



Families Moving Forward (FMF) Program

- Evidence-based positive parenting program for FASD
- Incorporates essential elements of FASD-informed care

Positive Behavior Support + Motivational Interviewing + Other Techniques CBT+ = FMF Program

4

CIFASD

The purpose of this consortium is to inform and develop effective interventions and treatment approaches for Fetal Alcohol Spectrum Disorders (FASD) through multidisciplinary research involving basic, behavioral and clinical investigators and projects. We hope to develop an infrastructure to foster collaboration and coordinate basic, clinical and translational research on FASD.

5

The Possibilities of Mobile Health (mHealth)

More than 91% of adults own a smartphone in the US

Good potential for scalability

Information can be accessed at any time

Apps are well suited for:
- Providing information
- Self-monitoring tools
- Goal setting
- Real-time (synchronous) communication

6

Content Development Process

Families Moving Forward (FMF) Program:

Content, principles, methods

- FMF developed by Heather Charmichael Olson and team at UW/SCRI
- Funded by CDC

FMF Connect is a derivative product with unique features

FMF Connect Content

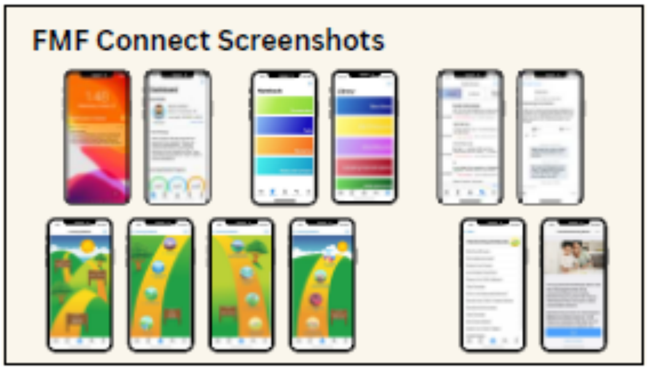
Learning Modules
- 12 core modules, 3 levels
- Educational text and audio
- Exercises to practice content
- Animation and video

Notebook
- User builds personalized section for later reference
- Exercises about child, selected content, tools, notes

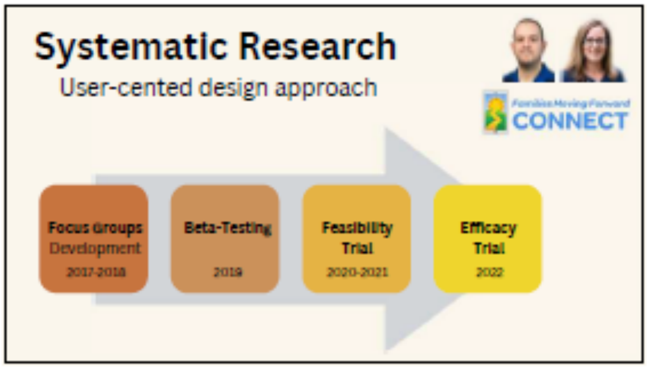
Dashboard
- Summary of progress
- Badges earned, child behavior, ratings, usage metrics

Family Forum
- Users share ideas, ask questions, get support
- Organized in sub forums
- Moderated by trained peers

Library
- Lists of books, websites, other resources
- Optional fact sheets



FMF Connect Screenshots



Systematic Research

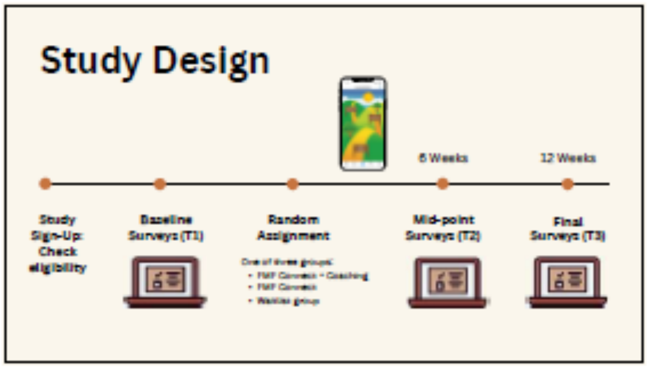
User-cented design approach

Focus Groups
Development
2017-2018

Beta-Testing
2019

Feasibility Trial
2020-2021

Efficacy Trial
2022



Study Design

Study Sign-Up: Check eligibility

Baseline Surveys (T1)

Random Assignment

One of three groups:
- FMF Connect + Coaching
- FMF Connect
- Waitlist group

6 Weeks

Mid-point Surveys (T2)

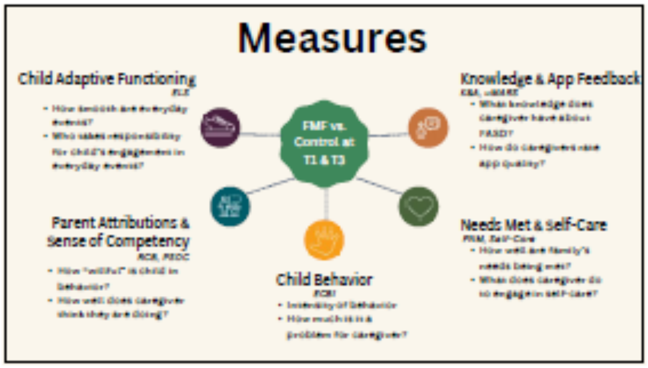
12 Weeks

Final Surveys (T3)

N = 129

Recruitment

32 States Represented



Measures

Child Adaptive Functioning
ELS
- How smooth are everyday events?
- Who takes responsibility for child's engagement in everyday events?

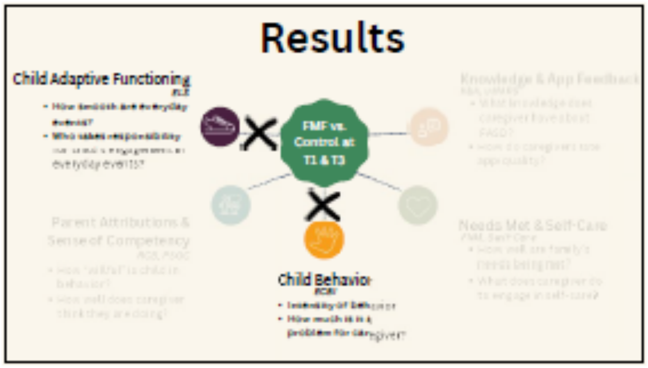
Parent Attributions & Sense of Competency
PCS, PSOC
- How "willful" is child in behavior?
- How well does caregiver think they are doing?

Child Behavior
ECBI
- Intensity of behavior
- How much is it a problem for caregiver?

Knowledge & App Feedback
KBA, uMARS
- What knowledge does caregiver have about FASD?
- How do caregivers rate app quality?

Needs Met & Self-Care
FNM, Self-Care
- How well are family's needs being met?
- What does caregiver do to engage in self-care?

13



Results

Child Adaptive Functioning
ELS
- How smooth are everyday events?
- Who takes responsibility for child's engagement in everyday events?

Parent Attributions & Sense of Competency
PCS, PSOC
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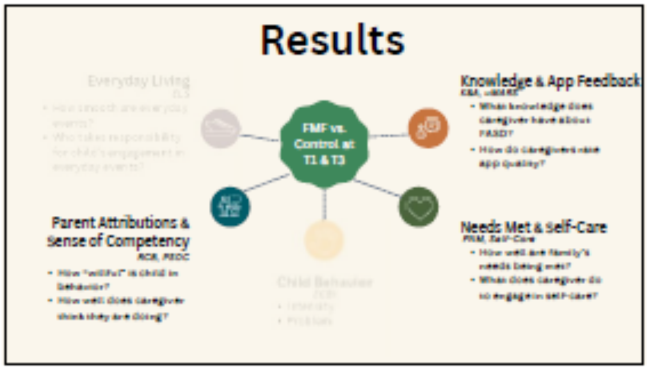
14



Results

Everyday Living
ELS
- How smooth are everyday events?
- Who takes responsibility for child's engagement in everyday events?

Parent Attributions & Sense of Competency
PCS, PSOC
- How "willful" is child in behavior?
- How well does caregiver think they are doing?

Child Behavior
ECBI
- Intensity
- Problem

Knowledge & App Feedback
KBA, uMARS
- What knowledge does caregiver have about FASD?
- How do caregivers rate app quality?

Needs Met & Self-Care
FNM, Self-Care
- How well are family's needs being met?
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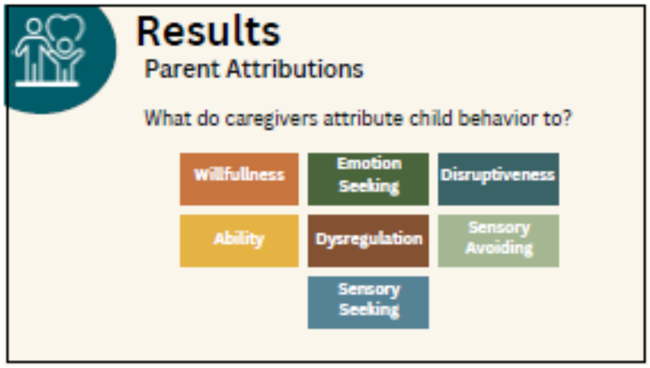
15



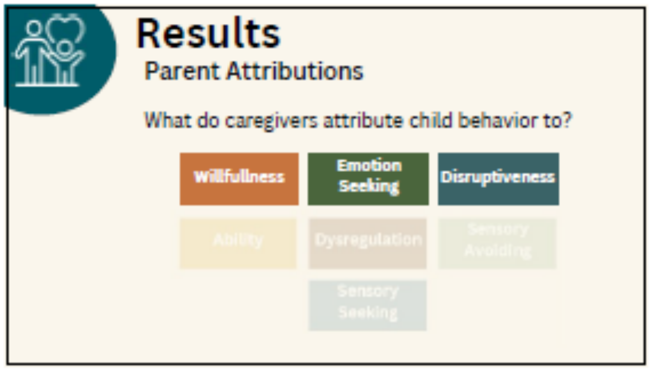
Results

Parent Attributions

What do caregivers attribute child behavior to?

Willfullness	Emotion Seeking	Disruptiveness
Ability	Dysregulation	Sensory Avoiding
	Sensory Seeking	

16



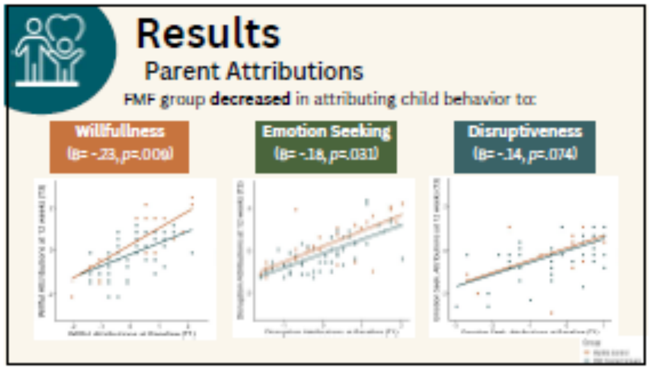
Results

Parent Attributions

What do caregivers attribute child behavior to?

Willfullness	Emotion Seeking	Disruptiveness
Ability	Dysregulation	Sensory Avoiding
	Sensory Seeking	

17



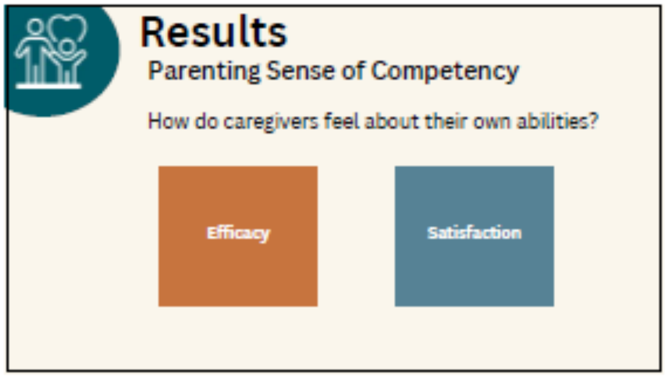
Results

Parent Attributions

FMF group **decreased** in attributing child behavior to:

Willfullness	Emotion Seeking	Disruptiveness
(B= -.23, *p*=.009)	(B= -.18, *p*=.031)	(B= -.14, *p*=.074)

18



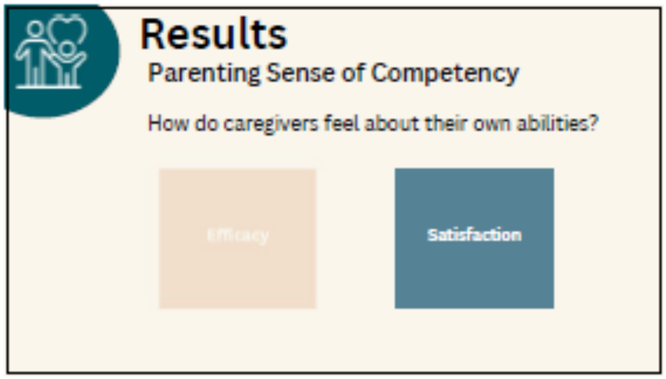
Results

Parenting Sense of Competency

How do caregivers feel about their own abilities?

Efficacy

Satisfaction



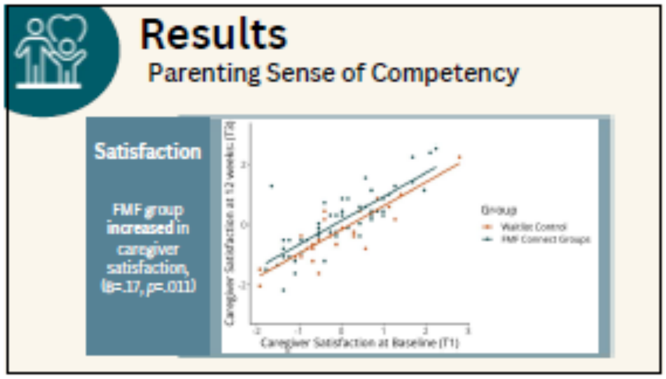
Results

Parenting Sense of Competency

How do caregivers feel about their own abilities?

Efficacy

Satisfaction

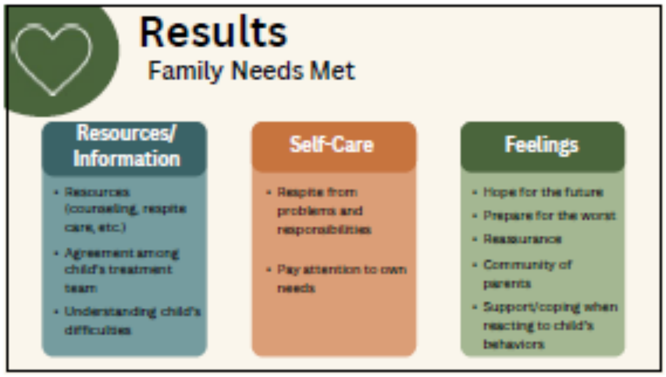


Results

Parenting Sense of Competency

Satisfaction

FMF group increased in caregiver satisfaction, (B=.17, *p*=.011)



Results

Family Needs Met

Resources/ Information

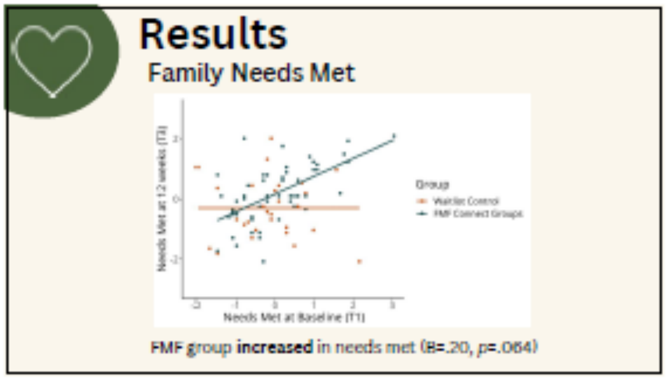
- Resources (counseling, respite care, etc.)
- Agreement among child's treatment team
- Understanding child's difficulties

Self-Care

- Respite from problems and responsibilities
- Pay attention to own needs

Feelings

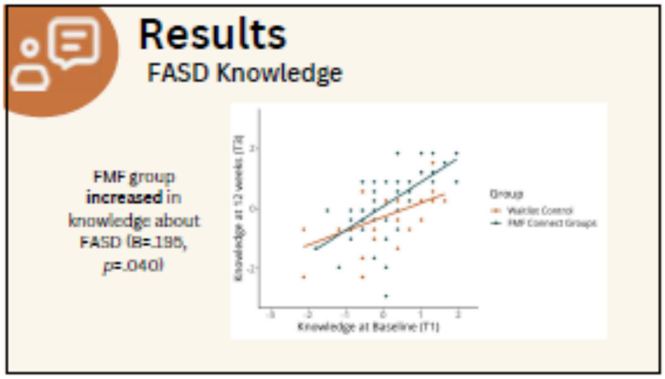
- Hope for the future
- Prepare for the worst
- Reassurance
- Community of parents
- Support/coping when reacting to child's behaviors



Results

Family Needs Met

FMF group **increased** in needs met (B=.20, *p*=.064)



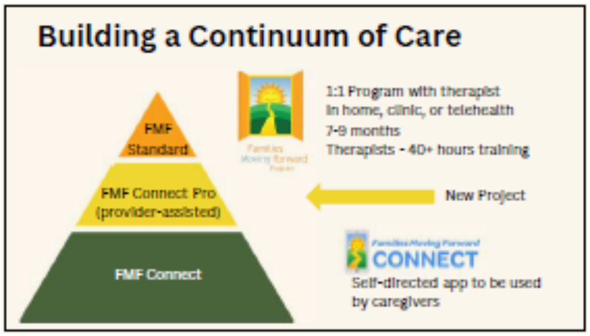
Results

FASD Knowledge

FMF group **increased** in knowledge about FASD (B=.195, *p*=.040)

Families Moving Forward (FMF) Connect

www.fmfconnect.com



Building a Continuum of Care

1:1 Program with therapist
In home, clinic, or telehealth
7-9 months
Therapists - 40+ hours training

New Project

CONNECT
Self-directed app to be used by caregivers

Contact Information

christie_petrenko@urmc.rochester.edu

@clpetrenko

(585) 275 - 2991 x 241

For information on available archived CIFASD data, please visit https://cifasd.org/data-sharing/.

Information on accessing CIFASD research data

B2d

Rural and Remote Programming: Changing Pathways for Youth Living with FASD

Wanda Beland

The NWR FASD Society began supporting individuals, families and community agencies in 2003 in the Mackenzie Region out of the community of High Level, Alberta, Canada. The NWR FASD Society has been operating a Youth Coach and eventually a Youth Transition Coach Program since January of 2011. The original intent of the program was to ensure that youth diagnosed with FASD would be able to take part in the community programming with the level of FASD supports they would need to succeed. By 2011 the number of youth FASD supports outnumbered the staff that could be sent to community programming in the community of High Level. So a program specific for youth diagnosed with FASD was started.

The NWR FASD Youth Coach Program provided afterschool, holiday, and summer programming for youth diagnosed with FASD. The program focused on teaching of communication, social, recreation, and advocacy skills. The intent was to ensure that the youth were taking part in safe, supervised programming while developing these skills.

The growth and development of the youth were tracked in case notes and observations over the years. In 2017, the youth aged, there was a need to develop the next level of support, building on the original objectives of the program. In developing what is now the Youth Transition Program, the youth who were involved in the original program were put into a program which also took older teens and young adults diagnosed with FASD who had never been involved in youth or FASD informed programming. The intent of the pilot of this program was to track and compare education retention and completion, employment, post-secondary education, teen parenting and justice involvement. We wanted to see if the support in the Youth Coach Program from kindergarten and elementary had a significant impact as the youth entered high school and adulthood.

The results are as of January 30, 2020:

Areas Measured	Early Youth Programming (24 youth)	No Early Youth Programming (17 youth)
Graduated or still in School	92%	6%
Employed	35%	6%
Post-Secondary	13%	0%
Parenting	13%	41%
Justice Involvement	8%	29%

The results are as of October 2023: (Youth/adults are 3.75 years older)

Areas Measured	Early Youth Programming (24 youth)	No Early Youth Programming (17 youth)
Graduated or still in School	96%	13%
Employed	52%	25%
Post-Secondary	17%	0%
Parenting	26%	75%
Justice Involvement	8%	50%

The conclusion is that youth involved in early FASD informed programming focusing on communication, social, recreation, and advocacy skills are more likely to complete their high school education, find employment, and less likely to become teen parents or to be involved in the justice system.

The program continues to operate seasonally as community compacity permits. Youth Coach participants have aged (the youngest of this group is now 17 and the oldest is 30 as of October 2023 12 years after the programs start up). Those who were in the Youth Program (61%) continue to regularly access the next level programming as needed. 29% of those who only accessed the transitional program continue to access supports.

B3

Systemic Advocacy: Creating Change through Community Connection and Co-Creation

Samantha Cocker, Myles Himmelreich, Karen Bopp, Dawson Jones

Presenter, Authors and Affiliations

- Myles Himmelreich – FASD Changemaker, Mentor, FASD Consultant, Speaker
- Dawson Jones – Youth research participant
- Samantha Cocker – Deputy Representative, The office of the Representative for Children and Youth of British Columbia, Canada
- Karen Bopp – Executive Advisor for Children and Youth with Disabilities, The office of the Representative for Children and Youth of British Columbia, Canada

Objectives

- Hear from the lived experience of children and youth diagnosed with FASD and how those voices have informed the RCY's systemic advocacy work.
- Identify the different tools to be used in systemic advocacy work and how community-based research uplifts these tools.
- Identify barriers to systemic change.
- Shift patterns in complex systems.

In British Columbia (B.C.), Canada the Representative for Children and Youth (RCY) is mandated to monitor the child and youth serving systems in the province and make comments and recommendations on how these systems can be improved. The RCY takes a global view, well-informed by data and evidence and from Indigenous communities, community service agencies, and what children, youth, young adults, and their families tell the RCY Office about their experiences with the system.

In recent systemic advocacy work for children and youth with FASD and their families, the RCY recognized an absence of child and youth voices in policy development. The RCY also recognized the significant lack of services and supports that are publicly available for children and youth with FASD and their families. To examine the FASD service system in B.C. and to raise the voices of children and youth with lived experience, the RCY partnered with Myles Himmelreich, an adult with FASD. Myles led an extensive engagement project with children and youth with FASD and their families across the province to learn about their daily lives. This research culminated in the report Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families which included recommendations for systems improvement. Since the release of the Excluded, the RCY has continued to monitor and advocate for system improvements for children and youth with FASD and their families and continues to highlight the voices of those with lived experience.

This RCY community-based, lived experience approach has led to many positive results including, (1) a knowledge mobilization campaign that resulted in the creation of Hands, Not Hurdles: Helping Children with FASD and their Families, a condensed and easily digestible version of Excluded that includes tips and other suggested resources for community practitioners, including teachers, counsellors, recreation workers, and clinicians; (2) the dismantling of harmful stigma and false understandings of the realities of children and youth with FASD; (3) the identification of inequalities in service delivery system; (4) recommendations to Government for service and support change; and (5) the creation of a provincial parent advocacy group, Inspire Kids BC, who have now received Government funding.

Most recently, the Office reconnected with the children, youth and families who shared their experiences in the Excluded report and reconnected with families who participated in another RCY report Left Out: Children and youth with special needs in the pandemic. These reconnections resulted in the release of Still Left Out: Children and youth with disabilities in B.C. in November 2023. The RCY continues to actively monitor and advocate for system change as the B.C. government works toward a new system of supports for all children and youth with disabilities.

This presentation will outline the engagement work led by Myles and review how only in depth, lived experience understanding through conversation, connection, and committed relationships with the adolescents and their families can lead to greater outcomes for all.

B4

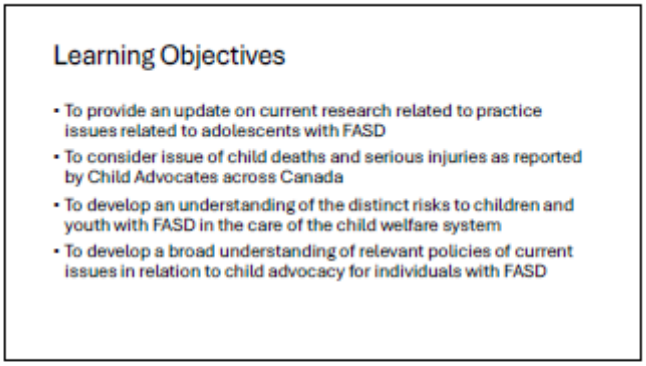
FASD as a Brain/Body Disorder: A Social Determinants of Health Perspective

Peter Choate, Dorothy Badry, Christina Tortorelli

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

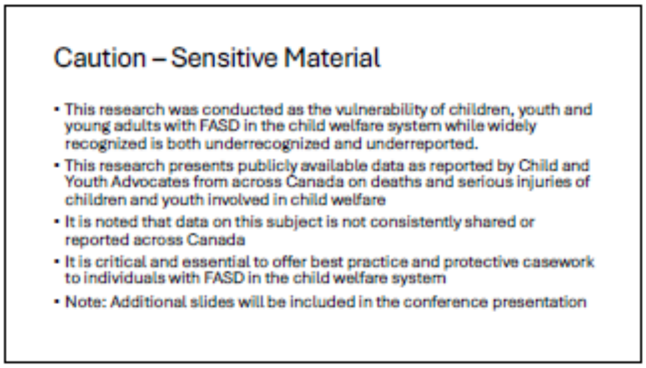
Presentation to the 9th International Research Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorders
Seattle, Washington
April 11-14, 2024

Dorothy Badry, PhD, MSW, RSW, University of Calgary, CanFASD
Peter Choate, PhD, RSW, Mount Royal University
Chris Tortorelli, MA, RSW, Mount Royal University
Kirsten Morrison, Research Assistant, CanFASD Research Network



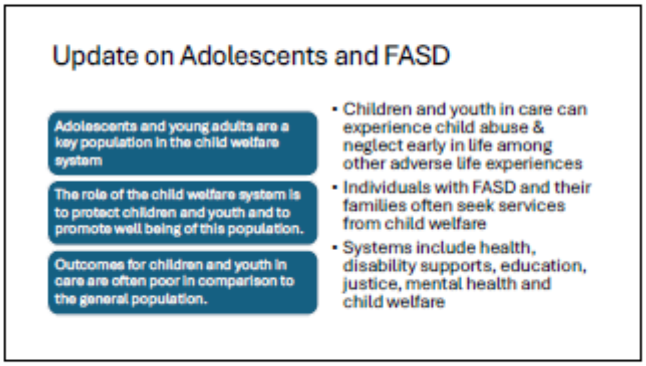
Learning Objectives

- To provide an update on current research related to practice issues related to adolescents with FASD
- To consider issue of child deaths and serious injuries as reported by Child Advocates across Canada
- To develop an understanding of the distinct risks to children and youth with FASD in the care of the child welfare system
- To develop a broad understanding of relevant policies of current issues in relation to child advocacy for individuals with FASD



Caution – Sensitive Material

- This research was conducted as the vulnerability of children, youth and young adults with FASD in the child welfare system while widely recognized is both underrecognized and underreported.
- This research presents publicly available data as reported by Child and Youth Advocates from across Canada on deaths and serious injuries of children and youth involved in child welfare
- It is noted that data on this subject is not consistently shared or reported across Canada
- It is critical and essential to offer best practice and protective casework to individuals with FASD in the child welfare system
- Note: Additional slides will be included in the conference presentation



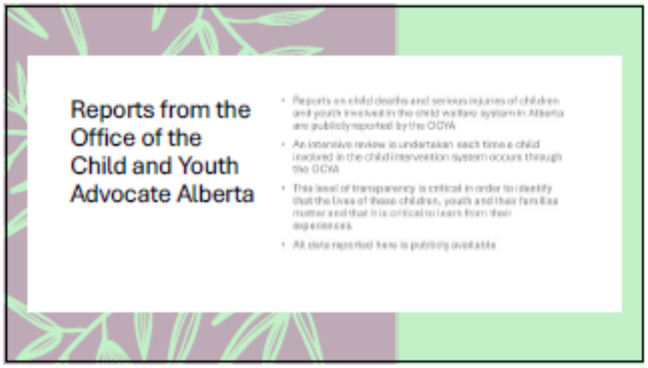
Update on Adolescents and FASD

Adolescents and young adults are a key population in the child welfare system

The role of the child welfare system is to protect children and youth and to promote well being of this population.

Outcomes for children and youth in care are often poor in comparison to the general population.

- Children and youth in care can experience child abuse & neglect early in life among other adverse life experiences
- Individuals with FASD and their families often seek services from child welfare
- Systems include health, disability supports, education, justice, mental health and child welfare



Reports from the Office of the Child and Youth Advocate Alberta

- Reports on child deaths and serious injuries of children and youth involved in the child welfare system in Alberta are publicly reported by the OCYA
- An intensive review is undertaken each time a child involved in the child intervention system occurs through the OCYA
- This level of transparency is critical in order to identify that the lives of these children, youth and their families matter and that it is critical to learn from their experiences.
- All data reported here is publicly available

Challenges for youth with FASD in the child welfare system

Service providers may not be disability informed and have no knowledge of FASD

Given children and youth with FASD are more likely to intersect with the child welfare system a alack of knowledge of FASD is a risk

Children and youth with disabilities are at higher risk of abuse than other children

Children and youth with disabilities are at greater vulnerability to the impacts of adversity

Meeting the complex and varied needs of child and youth with FASD is a challenge for the child welfare system

Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada

- Report on the deaths of nine youth involved in Child Intervention Services in Alberta
- Five of these young people were identified to have prenatal alcohol exposure
- Children and youth with FASD are at risk
- Concerns include health vulnerabilities associated with prenatal alcohol exposure
- Engagement in risk taking behavior by adolescents
- Long family history of trauma present
- Report available at https://www.ocya.alberta.ca/wp-content/uploads/2023/11/MandRev_April-Sept2018v3.pdf

Child and Youth Advocates in Canada

ALBERTA	BRITISH COLUMBIA	MANITOBA
Office of the Child and Youth Advocate (OCYA)	Representative for Children and Youth	Children's Advocate
NEW BRUNSWICK	NEWFOUNDLAND AND LABRADOR	NORTHWEST TERRITORIES
Office of the Child, Youth and Seniors Advocate	Child and Youth Advocate	No independent child advocate
NOVA SCOTIA	NUNAVUT	ONTARIO
Office of the Ombudsman (The Office of the Ombudsman has a child and youth mandate)	Representative for Children and Youth	No independent child advocate
PRINCE EDWARD ISLAND	QUEBEC	SASKATCHEWAN
No independent child advocate	Commission des droits de la personne et des droits de la jeunesse	Advocate for Children and Youth
YUKON		
Yukon Child and Youth Advocate Office		

Child and youth advocates in canada

Play a key role in highlighting problems for children and youth with FASD engaged in the child welfare systems

Youth with FASD often "crossover" between the child welfare and justice systems

Child advocates often document the deaths of children with FASD in the child welfare system of Canada

What does exist in public policy in Canada

A national review of each province and territory and relevant child welfare legislation was reviewed as well as any reports relevant to FASD across Canada

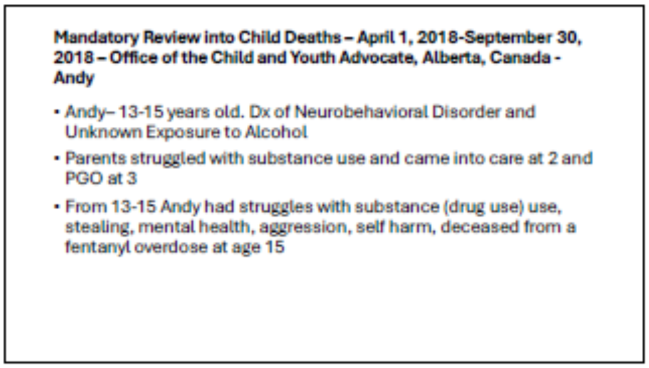
Reports from Child Advocates across Canada often identify the challenges children, youth and adults with FASD face in the child welfare system and in transitioning to adulthood

The child welfare research portal canada

- The child welfare research portal offers an entry point to reviewing relevant child welfare policy and legislation across Canada
- https://cwrp.ca/

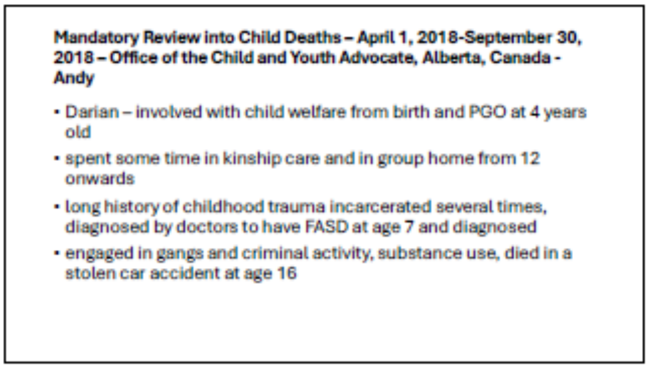
Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Sophia

- Sophia – 3 months old at time of death. Had both alcohol and drug exposure and experience NOW (Neonatal Opioid Withdrawal).
- Mom was in care under PGO and living in a group home. Child in care by agreement.
- Sophia had multiple health problems and complex needs.
- Was found unresponsive in her crib by foster carer



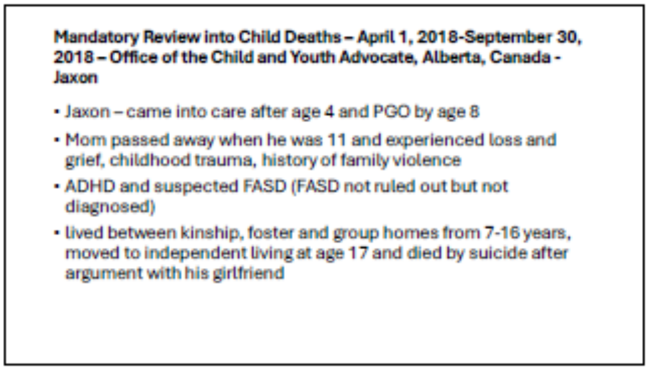
Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Andy

- Andy– 13-15 years old. Dx of Neurobehavioral Disorder and Unknown Exposure to Alcohol
- Parents struggled with substance use and came into care at 2 and PGO at 3
- From 13-15 Andy had struggles with substance (drug use) use, stealing, mental health, aggression, self harm, deceased from a fentanyl overdose at age 15



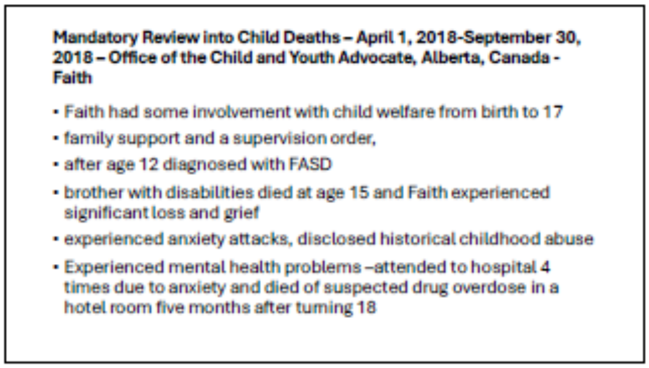
Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Andy

- Darian – involved with child welfare from birth and PGO at 4 years old
- spent some time in kinship care and in group home from 12 onwards
- long history of childhood trauma incarcerated several times, diagnosed by doctors to have FASD at age 7 and diagnosed
- engaged in gangs and criminal activity, substance use, died in a stolen car accident at age 16



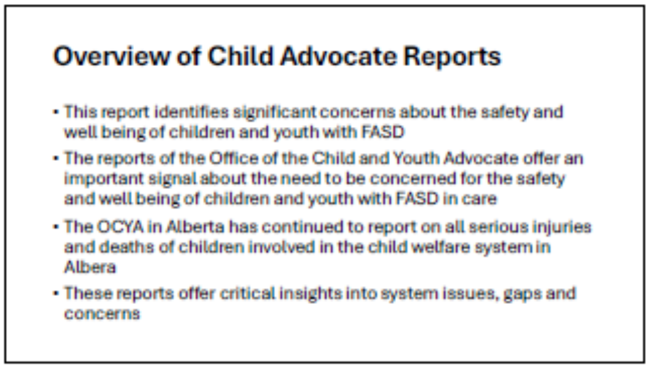
Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Jaxon

- Jaxon – came into care after age 4 and PGO by age 8
- Mom passed away when he was 11 and experienced loss and grief, childhood trauma, history of family violence
- ADHD and suspected FASD (FASD not ruled out but not diagnosed)
- lived between kinship, foster and group homes from 7-16 years, moved to independent living at age 17 and died by suicide after argument with his girlfriend



Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Faith

- Faith had some involvement with child welfare from birth to 17
- family support and a supervision order,
- after age 12 diagnosed with FASD
- brother with disabilities died at age 15 and Faith experienced significant loss and grief
- experienced anxiety attacks, disclosed historical childhood abuse
- Experienced mental health problems –attended to hospital 4 times due to anxiety and died of suspected drug overdose in a hotel room five months after turning 18

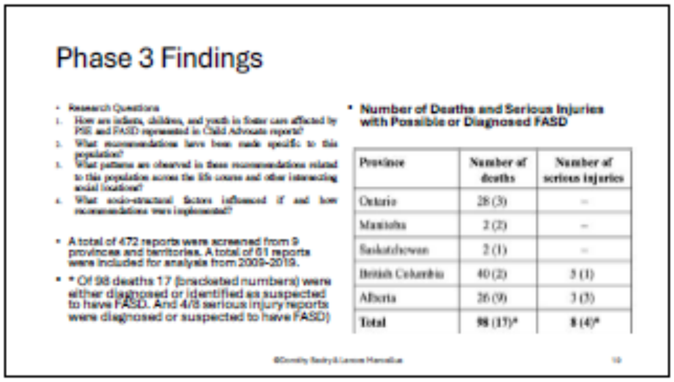


Overview of Child Advocate Reports

- This report identifies significant concerns about the safety and well being of children and youth with FASD
- The reports of the Office of the Child and Youth Advocate offer an important signal about the need to be concerned for the safety and well being of children and youth with FASD in care
- The OCYA in Alberta has continued to report on all serious injuries and deaths of children involved in the child welfare system in Albera
- These reports offer critical insights into system issues, gaps and concerns

Research Activities

- Phase 1 research in 2017 – rapid evidence assessment of best practice literature on the care of infants with prenatal substance exposure in foster care by Dr. Lenora Marcellus, University of Victoria
- Phase 2 research in 2017 – scoping literature review of care of children and youth with prenatal substance exposure in child welfare
- Phase 3 – Publication of Research of all Child & Youth Advocate reports across Canada
- **Badry**, D., Marcellus, L., & Choate, P. (2022). An Intersectionality-Based Policy Analysis of Canadian Child Advocate Reviews of Infants, Children and Youth with Prenatal Substance Exposure and Fetal Alcohol Spectrum Disorder in Child Welfare Care. *Journal of Fetal Alcohol Spectrum Disorder*, 4(SP1), e91–e115.



Phase 3 Findings

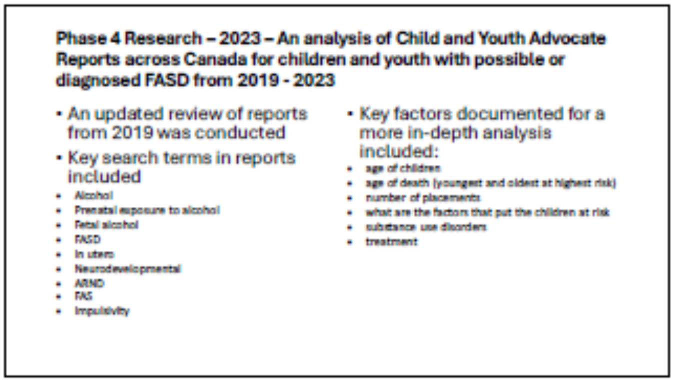
- Research Questions
1. How are infants, children, and youth in foster care affected by PSE and FASD represented in Child Advocate reports?
2. What recommendations have been made specific to this population?
3. What patterns are observed in these recommendations related to this population across the life course and other intersecting social locations?
4. What socio-structural factors influenced if and how recommendations were implemented?

- A total of 472 reports were screened from 9 provinces and territories. A total of 61 reports were included for analysis from 2009-2019.
- * Of 98 deaths 17 (bracketed numbers) were either diagnosed or identified as suspected to have FASD. And 4/8 serious injury reports were diagnosed or suspected to have FASD)

- **Number of Deaths and Serious Injuries with Possible or Diagnosed FASD**

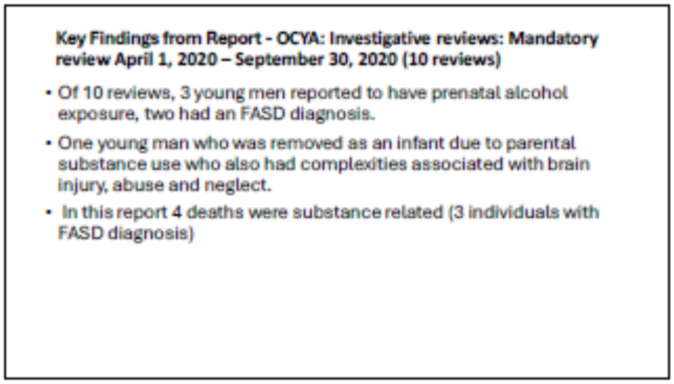
Province	Number of deaths	Number of serious injuries
Ontario	28 (3)	–
Manitoba	2 (2)	–
Saskatchewan	2 (1)	–
British Columbia	40 (2)	5 (1)
Alberta	26 (9)	3 (3)
Total	**98** (17)*	**8** (4)*

©Dorothy Badry & Lenora Marcellus



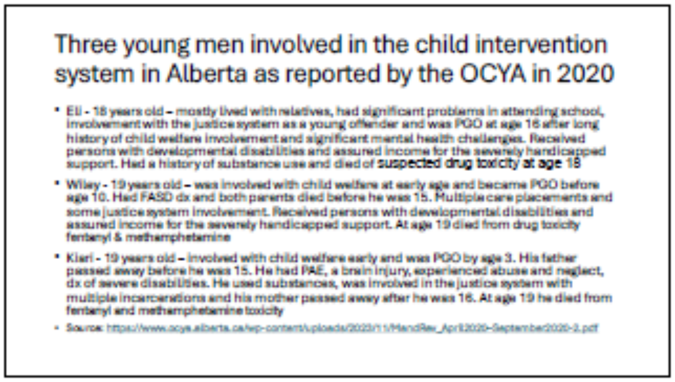
Phase 4 Research – 2023 – An analysis of Child and Youth Advocate Reports across Canada for children and youth with possible or diagnosed FASD from 2019 - 2023

- An updated review of reports from 2019 was conducted
- Key search terms in reports included
  - Alcohol
  - Prenatal exposure to alcohol
  - Fetal alcohol
  - FASD
  - In utero
  - Neurodevelopmental
  - ARND
  - FAS
  - Impulsivity
- Key factors documented for a more in-depth analysis included:
  - age of children
  - age of death (youngest and oldest at highest risk)
  - number of placements
  - what are the factors that put the children at risk
  - substance use disorders
  - treatment



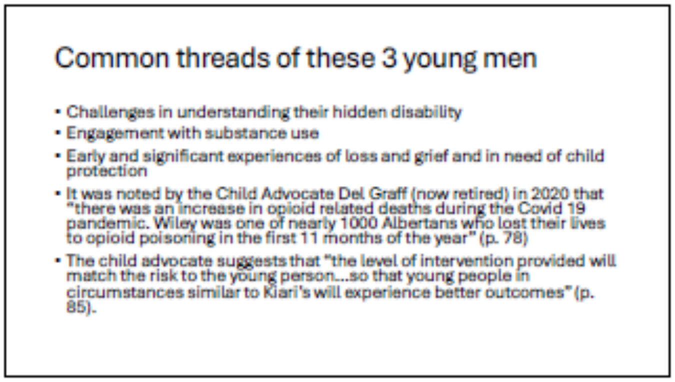
Key Findings from Report - OCYA: Investigative reviews: Mandatory review April 1, 2020 – September 30, 2020 (10 reviews)

- Of 10 reviews, 3 young men reported to have prenatal alcohol exposure, two had an FASD diagnosis.
- One young man who was removed as an infant due to parental substance use who also had complexities associated with brain injury, abuse and neglect.
- In this report 4 deaths were substance related (3 individuals with FASD diagnosis)



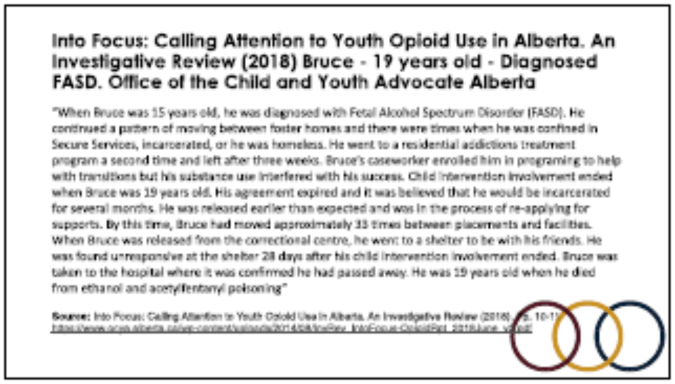
Three young men involved in the child intervention system in Alberta as reported by the OCYA in 2020

- Eli - 18 years old – mostly lived with relatives, had significant problems in attending school, involvement with the justice system as a young offender and was PGO at age 16 after long history of child welfare involvement and significant mental health challenges. Received persons with developmental disabilities and assured income for the severely handicapped support. Had a history of substance use and died of suspected drug toxicity at age 18
- Wiley - 19 years old – was involved with child welfare at early age and became PGO before age 10. Had FASD dx and both parents died before he was 15. Multiple care placements and some justice system involvement. Received persons with developmental disabilities and assured income for the severely handicapped support. At age 19 died from drug toxicity fentanyl & methamphetamine
- Kiari - 19 years old – involved with child welfare early and was PGO by age 3. His father passed away before he was 15. He had PAE, a brain injury, experienced abuse and neglect, dx of severe disabilities. He used substances, was involved in the justice system with multiple incarcerations and his mother passed away after he was 16. At age 19 he died from fentanyl and methamphetamine toxicity
- Source: https://www.ocya.alberta.ca/wp-content/uploads/2020/11/MandRev_April2020-September2020-2.pdf



Common threads of these 3 young men

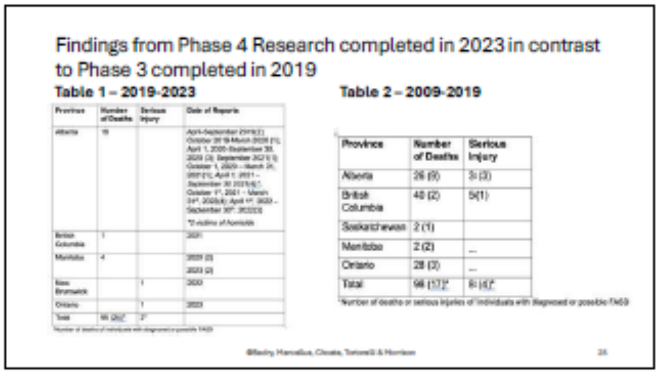
- Challenges in understanding their hidden disability
- Engagement with substance use
- Early and significant experiences of loss and grief and in need of child protection
- It was noted by the Child Advocate Del Graff (now retired) in 2020 that "there was an increase in opioid related deaths during the Covid 19 pandemic. Wiley was one of nearly 1000 Albertans who lost their lives to opioid poisoning in the first 11 months of the year" (p. 78)
- The child advocate suggests that "the level of intervention provided will match the risk to the young person…so that young people in circumstances similar to Kiari's will experience better outcomes" (p. 85).



Into Focus: Calling Attention to Youth Opioid Use in Alberta. An Investigative Review (2018) Bruce - 19 years old - Diagnosed FASD. Office of the Child and Youth Advocate Alberta

"When Bruce was 15 years old, he was diagnosed with Fetal Alcohol Spectrum Disorder (FASD). He continued a pattern of moving between foster homes and there were times when he was confined in Secure Services, incarcerated, or he was homeless. He went to a residential addictions treatment program a second time and left after three weeks. Bruce's caseworker enrolled him in programing to help with transitions but his substance use interfered with his success. Child Intervention involvement ended when Bruce was 19 years old. His agreement expired and it was believed that he would be incarcerated for several months. He was released earlier than expected and was in the process of re-applying for supports. By this time, Bruce had moved approximately 33 times between placements and facilities. When Bruce was released from the correctional centre, he went to a shelter to be with his friends. He was found unresponsive at the shelter 28 days after his child intervention involvement ended. Bruce was taken to the hospital where it was confirmed he had passed away. He was 19 years old when he died from ethanol and acetylfentanyl poisoning"

Source: Into Focus: Calling Attention to Youth Opioid Use in Alberta. An Investigative Review (2018), pp. 10-11
https://www.ocya.alberta.ca/wp-content/uploads/2014/08/InvRev_IntoFocus-OpioidRpt_2018June_v2.pdf



Findings from Phase 4 Research completed in 2023 in contrast to Phase 3 completed in 2019

Table 1 – 2019-2023

Province	Number of Deaths	Serious Injury	Date of Reports
Alberta	15		[illegible] *2 victims of homicide
British Columbia	1		2021
Manitoba	4		2022 (2) 2023 (2)
New Brunswick		1	2020
Ontario		1	2023
Total	[illegible]	2*	

*Number of deaths of individuals with diagnosed or possible FASD

Table 2 – 2009-2019

Province	Number of Deaths	Serious Injury
Alberta	26 (9)	3 (3)
British Columbia	40 (2)	5(1)
Saskatchewan	2 (1)	
Manitoba	2 (2)	_
Ontario	28 (3)	_
Total	98 (17)*	8 (4)*

*Number of deaths or serious injuries of individuals with diagnosed or possible FASD

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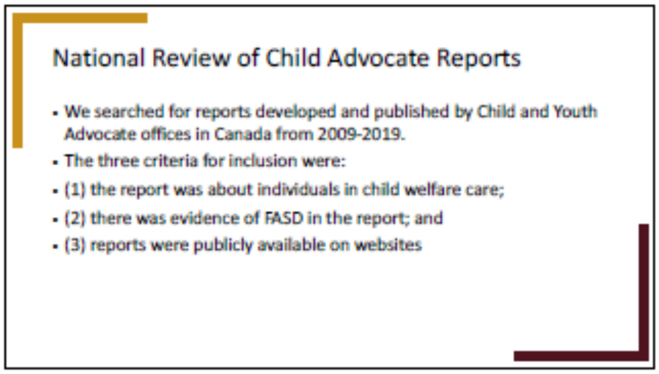

National Review of Child Advocate Reports

- We searched for reports developed and published by Child and Youth Advocate offices in Canada from 2009-2019.
- The three criteria for inclusion were:
- (1) the report was about individuals in child welfare care;
- (2) there was evidence of FASD in the report; and
- (3) reports were publicly available on websites

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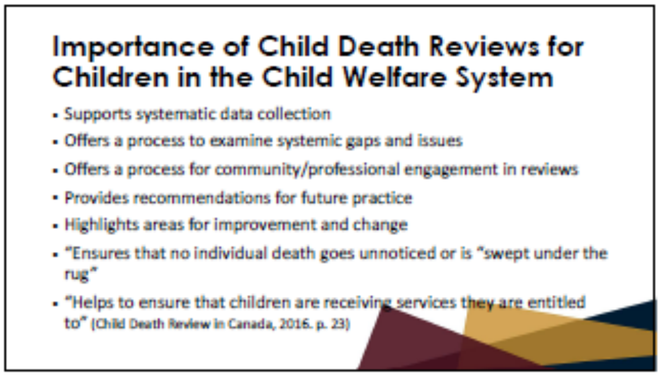

Importance of Child Death Reviews for Children in the Child Welfare System

- Supports systematic data collection
- Offers a process to examine systemic gaps and issues
- Offers a process for community/professional engagement in reviews
- Provides recommendations for future practice
- Highlights areas for improvement and change
- "Ensures that no individual death goes unnoticed or is "swept under the rug"
- "Helps to ensure that children are receiving services they are entitled to" (Child Death Review in Canada, 2016. p. 23)

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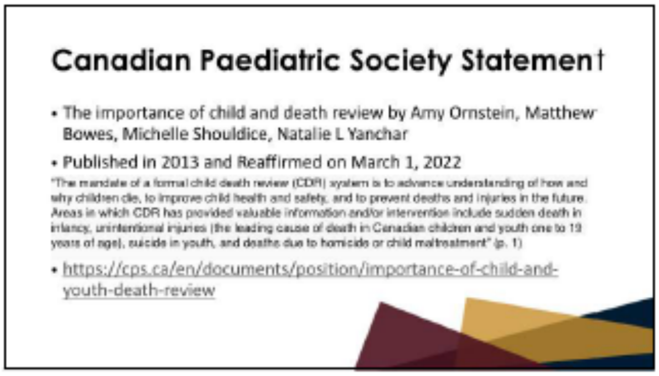

Canadian Paediatric Society Statement

- The importance of child and death review by Amy Ornstein, Matthew Bowes, Michelle Shouldice, Natalie L Yanchar
- Published in 2013 and Reaffirmed on March 1, 2022

"The mandate of a formal child death review (CDR) system is to advance understanding of how and why children die, to improve child health and safety, and to prevent deaths and injuries in the future. Areas in which CDR has provided valuable information and/or intervention include sudden death in infancy, unintentional injuries (the leading cause of death in Canadian children and youth one to 19 years of age), suicide in youth, and deaths due to homicide or child maltreatment" (p. 1)

- https://cps.ca/en/documents/position/importance-of-child-and-youth-death-review

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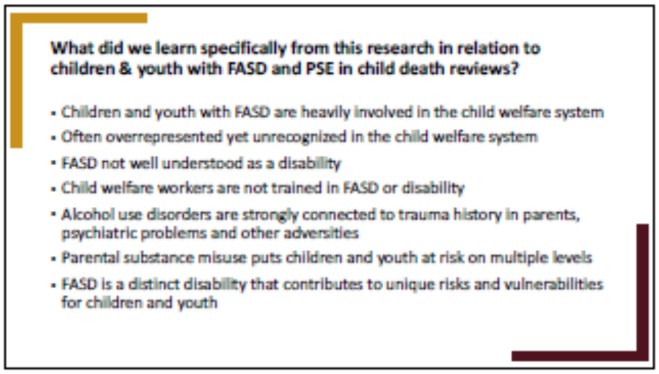

What did we learn specifically from this research in relation to children & youth with FASD and PSE in child death reviews?

- Children and youth with FASD are heavily involved in the child welfare system
- Often overrepresented yet unrecognized in the child welfare system
- FASD not well understood as a disability
- Child welfare workers are not trained in FASD or disability
- Alcohol use disorders are strongly connected to trauma history in parents, psychiatric problems and other adversities
- Parental substance misuse puts children and youth at risk on multiple levels
- FASD is a distinct disability that contributes to unique risks and vulnerabilities for children and youth

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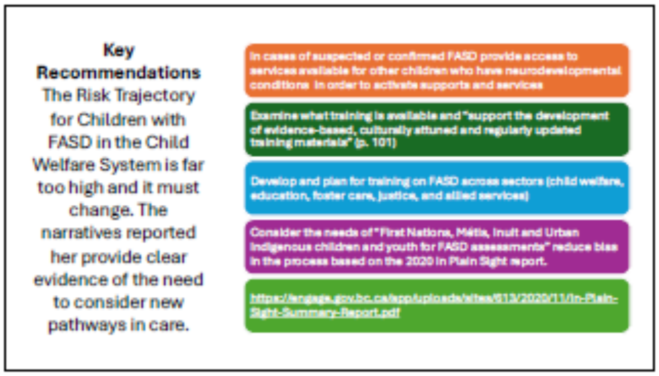

Key Recommendations

The Risk Trajectory for Children with FASD in the Child Welfare System is far too high and it must change. The narratives reported her provide clear evidence of the need to consider new pathways in care.

In cases of suspected or confirmed FASD provide access to services available for other children who have neurodevelopmental conditions in order to activate supports and services

Examine what training is available and "support the development of evidence-based, culturally attuned and regularly updated training materials" (p. 101)

Develop and plan for training on FASD across sectors (child welfare, education, foster care, justice, and allied services)

Consider the needs of "First Nations, Métis, Inuit and Urban Indigenous children and youth for FASD assessments" reduce bias in the process based on the 2020 In Plain Sight report.

https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Summary-Report.pdf

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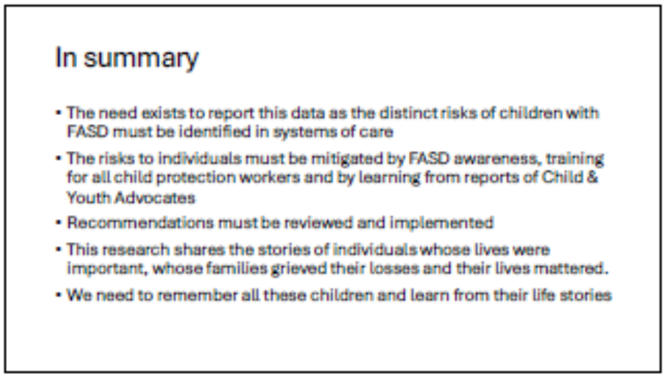
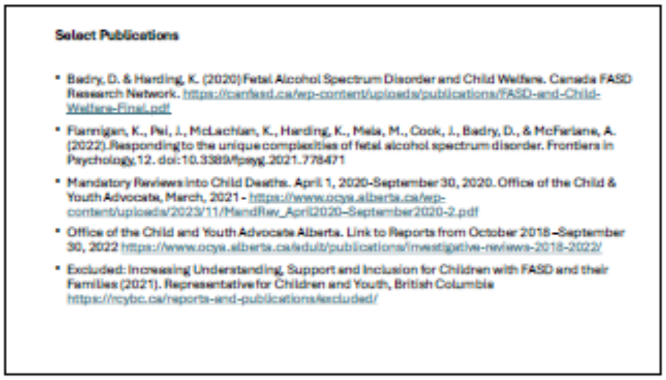


In summary

- The need exists to report this data as the distinct risks of children with FASD must be identified in systems of care
- The risks to individuals must be mitigated by FASD awareness, training for all child protection workers and by learning from reports of Child & Youth Advocates
- Recommendations must be reviewed and implemented
- This research shares the stories of individuals whose lives were important, whose families grieved their losses and their lives mattered.
- We need to remember all these children and learn from their life stories

Select publications

- Badry, D., Marcellus, L., & Choate, P. (2022). An Intersectionality-Based Policy Analysis of Canadian Child Advocate Reviews of Infants, Children and Youth with Prenatal Substance Exposure and Fetal Alcohol Spectrum Disorder in Child Welfare Care. *Journal of Fetal Alcohol Spectrum Disorder*, 4(SP1), e91-e115.
- Flannigan, McMorris, C., Ewasiuk, A., Badry, D., Mela, M., Ben Gibbard, W., Unsworth, K., Cook, J., &Harding, K. D. (2021). Suicidality and Associated Factors Among Individuals Assessed for Fetal Alcohol Spectrum Disorder Across the Lifespan in Canada. Canadian Journal of Psychiatry, 70674372110532–7067437211053288. https://doi.org/10.1177/07067437211053288
- Burns, J., . Badry, D., Harding, K., Roberts, N., Unsworth, K. & Cook, JL. (17 October 2020). Comparing Outcomes of Children and Youth with Fetal Alcohol Spectrum Disorder (FASD) in the Child Welfare System to those in Other Living Situations in Canada: Results from the Canadian National FASD Database. Child: care, health and development. Vol.47 (1), p.77-84 https://doi.org/10.1111/cch.12817
- Missing in Inaction: Misty's Story. April 13, 2023. Ombudsman, Ontario
- [illegible]



Select Publications

- Badry, D. & Harding, K. (2020) Fetal Alcohol Spectrum Disorder and Child Welfare. Canada FASD Research Network. https://canfasd.ca/wp-content/uploads/publications/FASD-and-Child-Welfare-Final.pdf
- Flannigan, K., Pei, J., McLachlan, K., Harding, K., Mela, M., Cook, J., Badry, D., & McFarlane, A. (2022).Respondingto the unique complexities of fetal alcohol spectrum disorder. Frontiers in Psychology.12. doi:10.3389/fpsyg.2021.778471
- Mandatory Reviews into Child Deaths. April 1, 2020-September 30, 2020. Office of the Child & Youth Advocate, March, 2021 - https://www.ocya.alberta.ca/wp-content/uploads/2023/11/MandRev_April2020–September2020-2.pdf
- Office of the Child and Youth Advocate Alberta. Link to Reports from October 2018 –September 30, 2022 https://www.ocya.alberta.ca/adult/publications/investigative-reviews-2018-2022/
- Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families (2021). Representative for Children and Youth, British Columbia https://rcybc.ca/reports-and-publications/excluded/

CanFASD
CANADA FASD RESEARCH NETWORK

Thank you. For further information contact: badry@ucalgary.ca

B5

FASD and Policy Implications Among Offenders in a Federal Psychiatric Facility

Mansfield Mela

B6

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

Dan Dubovsky, Brenda Knight

Evidence from the Atlanta and Seattle Research Study Sites

Claire Coles

Evidence from the Canadian Research Study Site

Charlis Raineki

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

Farida Sohrabji

Objectives

The talk will cover the following points:

1. An overview of chronic diseases that may occur at a *higher frequency* or are *more severe* in adulthood due to prenatal exposure to ethanol (PAE).
2. Focus on ischemic stroke: what is ischemic stroke, the known consequences of stroke, and risk factors for this disease.
3. Studying the effect of PAE in an animal model: challenges and advantages
4. Important lessons learnt:
    a. PAE alters the immune environment, which can affect the progression of many diseases in the central nervous system as well as other end organs such as the endocrine system, musculoskeletal, cardiovascular systems.
    b. PAE affects specific behaviors related to cognition and depression differently in males and females.
    c. PAE increases the severity of stroke outcomes in adulthood and middle age.
    d. In a model Alzheimer's disease, PAE affects spatial memory and associative learning. FASD is an umbrella term used to describe a range of lifelong, diagnosable, medical and mental health disorders that can occur in a person prenatally exposed to alcohol, regardless of the timing or amount of exposure, including prior to recognition of the pregnancy. These can occur with distinctive facial features, but most commonly do not.

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

Julie Kable

A Systematic and Person-Centered Harmonizing Framework for Housing Individual with FASD: Experiences and Translational Resources

Jacqueline Pei, Eizabeth Carlson

Please see this link to review the *Creating Intersections* guide (2018): https://canfasd.ca/wp-content/uploads/2019/10/FASD-X-Housing-Pei-2018_Amended-March-04-2019-dl.pdf

In our presentation, we will speak about the research process, our learnings and the translational resources we created from those learnings. All references are included in the guide.

The learning objectives for our presentation are as follows:

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

Progress Report from The International Consensus Committee on the Research Classification of FASD

Michael Charness

C1a

Recommendations Towards Neuropsychological Assessment, Therapy and Post-Diagnostic Activities Based on Proposition of Polish Diagnostic Guidelines of FASD

Magdalena Borkowska

C1b

Can Dysmorphology Examinations at Midlife Detect Physical Differences Between Adults With and Without Prenatal Alcohol Exposure?

Susan Stoner

Authors

Susan A. Stoner, Emmy Smith-Stewart, Margaret L. P. Adam, Tamara S. Bodnar, Charlis Raineki, Parker J. Holman, Julie A. Kable, Alexandra Perez, Tim F. Oberlander, Christine Loock, Kenneth L. Jones, Miguel Del Campo, Joanne Weinberg, Claire D. Coles and the Collaborative Initiative on Fetal Alcohol Spectrum Disorders.

Objectives

- Identify the three cardinal physical features of fetal alcohol spectrum disorders
- Describe physical features associated with prenatal alcohol exposure at midlife

Purpose: Dysmorphology examinations have established that fetal alcohol spectrum disorders (FASD) are associated with several characteristic physical features early in life. Cardinal facial features include relatively shorter palpebral fissures, smoother philtrum, and thinner vermilion border of the upper lip. As the aging process gradually changes many physical features, it is possible that differences in these features are attenuated over time. Thus, the purpose of this study was to determine whether the features that are characteristic of FASD in childhood continue to be so at midlife.

Methods: Subjects (N=192) were recruited from two longitudinal cohorts in Seattle and Atlanta and from the general community in Vancouver, British Columbia. About two-thirds (n=132) had an FASD or previously documented prenatal alcohol exposure (PAE). A standard dysmorphology examination was conducted in person by expert dysmorphologists and research staff trained by expert dysmorphologists who were blinded to the subjects' documented FASD or PAE status. One-sided t-tests were used to compare physical characteristics between those with and without PAE.

Results: Subjects' mean (SD) age was 35.6 (11.3). 56% were female, 18.2% were American Indian/Alaska Native/Indigenous/Aboriginal, 22.4% were Black/African American, 47.4% were White/Caucasian, 4.2% were Hispanic, and 10.4% were more than one race. Collapsing across gender, race, and ethnicity, we found significant differences according to PAE status in the following measures: occipito-frontal circumference, t(190)=2.212, p=.014; palpebral fissure length, t(190)=3.102, p=.001; hypoplastic midface, t(134.8)=-3.258, p=.001; anteverted nares, t(180.5)=-2.244, p=.013; philtrum lipometer, t(188)=-3.702, p=.001; vermilion border lipometer, t(188)=-3.213, p=.001; camptodactyly, t(131.0)=-4.548, p=.001; and difficulty with pronation/supination of elbows, t(169.6)=-2.109, p=0.018.

Implications: Individual differences in physical characteristics according to PAE status continue to be observable at midlife in the three cardinal features of FASD, as well as other secondary physical? features. Dysmorphology examination could thus continue to be useful in the identification of FASD later in life.

References

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Del Campo, M., Kable, J. A., Coles, C. D., Suttie, M., Chambers, C. D., & Bandoli, G. (2024). Secondary physical features in children with FASD. European Journal of Medical Genetics, 67, 104890.

C1c

Caregiver perspectives on the stressors and successes of life transitions among adolescents and adults with FASD

Katherine Flannigan, Dorothy Reid

C1d

Healthcare Utilization and Characteristics of Individuals with FAS: A descriptive population-based cohort study in Ontario

Danijela Dozet

C2

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

Dan Dubovsky, Brenda Knight

C4

‘8 Keys for Adults with FASD’: Seven adults with fetal alcohol spectrum disorders telling their stories, challenges, strengths, and strategies for success.

Teri Tibbett, Gina Schumaker, Assorted Panelists

I. INTRODUCTION of the Film - Moderators: Teri Tibbett and Gina Schumaker
Teri and Gina will introduce Janice, executive director, acknowledge contributors, and introduce the film's co-producers, Deb Evensen and Marilyn Pierce-Bulger, who will speak on the history and making of the film, and how the adults featured in the film developed the film's content.

II. SHOW THE FILM: "8 Keys for Adults with FASD" (31 minutes).

III. PANEL - Moderator: Gina Schumaker

Panelists: Gina Schumaker (film cast member), Deb Evensen (film co-producer), Marilyn Pierce-Bulger (film co-producer), Karen Lomack) (self-advocate/parent/navigator), Mary Katasse (parent/advocate). Teri and Janice will be the mic runners for Q&A.

IV. CLOSING - Moderators: Gina Schumaker and Teri Tibbett *(with panelists still on the stage)*

RESOURCES: Alaska Center for FASD's "8 Keys for Adults with FASD" and 9 Core Messages: What Everyone Should Know About Prenatal Alcohol Exposure.

C5

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

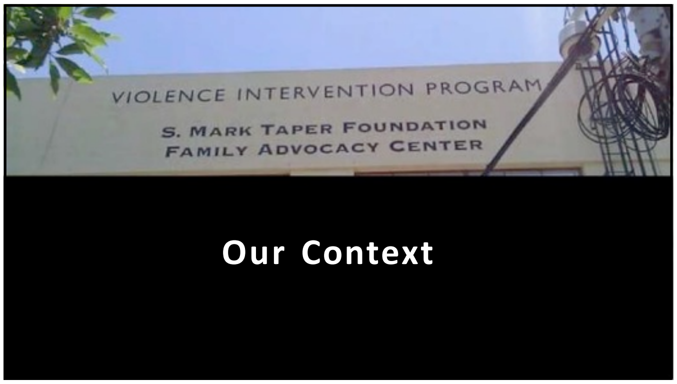
Janis Yue, Jessica Frausto

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

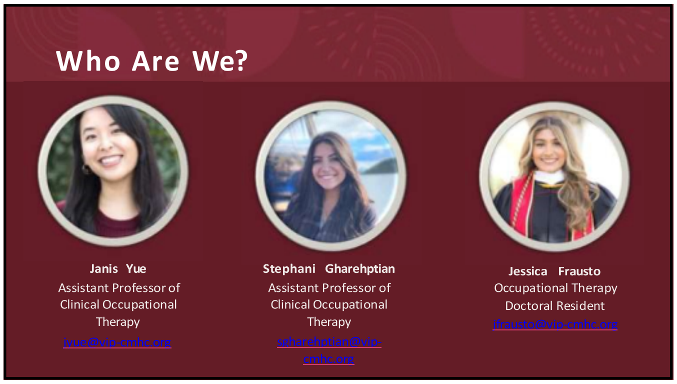
Janis Yue, OTD, OTR/L
Stephani Gharehptian, OTD, OTR/L
Jessica Frausto, MA, OTR/L

Learning Objectives

- Identify specific challenges to occupational engagement and participation that adolescents with FASD often experience
- Apply occupational therapy-based strategies to holistically support the development of adolescents with FASD



Our Context

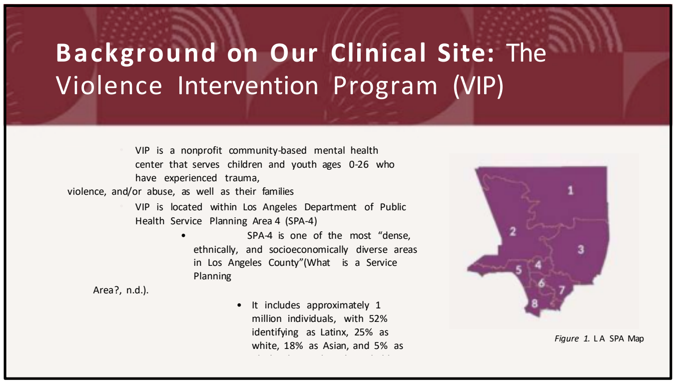


Who Are We?

Janis Yue
Assistant Professor of Clinical Occupational Therapy
jyue@vip-cmhc.org

Stephani Gharehptian
Assistant Professor of Clinical Occupational Therapy
sgharehptian@vip-cmhc.org

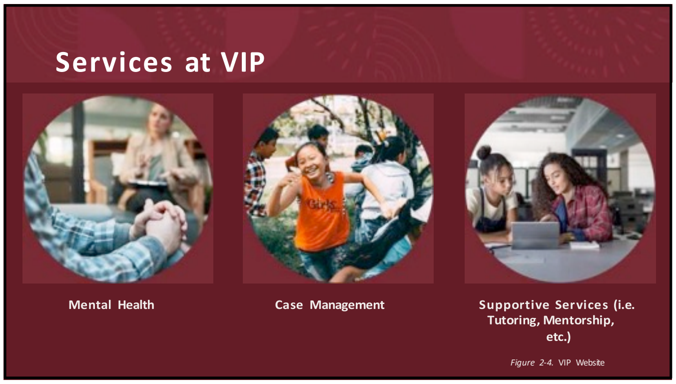
Jessica Frausto
Occupational Therapy Doctoral Resident
jfrausto@vip-cmhc.org



Background on Our Clinical Site: The Violence Intervention Program (VIP)

- VIP is a nonprofit community-based mental health center that serves children and youth ages 0-26 who have experienced trauma, violence, and/or abuse, as well as their families
- VIP is located within Los Angeles Department of Public Health Service Planning Area 4 (SPA-4)
  - SPA-4 is one of the most "dense, ethnically, and socioeconomically diverse areas in Los Angeles County"(What is a Service Planning Area?, n.d.).
  - It includes approximately 1 million individuals, with 52% identifying as Latinx, 25% as white, 18% as Asian, and 5% as

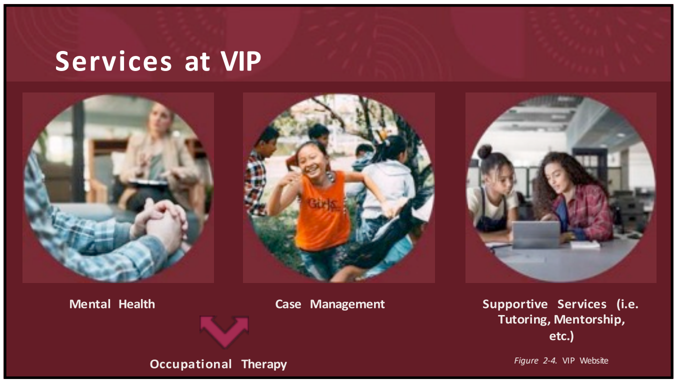
Figure 1. LA SPA Map



Services at VIP

- Mental Health
- Case Management
- Supportive Services (i.e. Tutoring, Mentorship, etc.)

Figure 2-4. VIP Website



Services at VIP

Mental Health

Occupational Therapy

Case Management

Supportive Services (i.e. Tutoring, Mentorship, etc.)

Figure 2-4. VIP Website

What is Occupational Therapy?

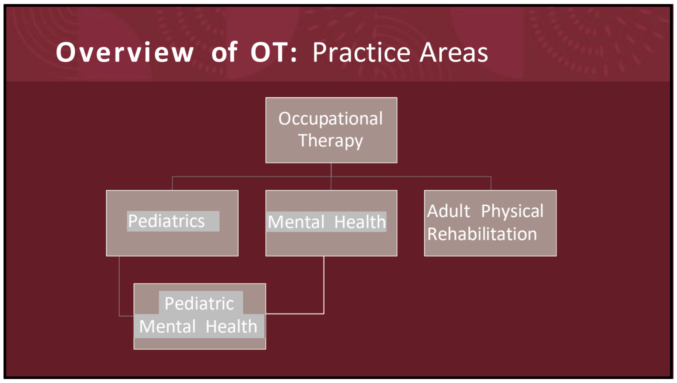
Overview of OT:
Definition

***Occupation**: Meaningful activities that OCCUPY one's time throughout the day*

***Occupational Therapists**: Help people across the lifespan to do the things they want and need to do through the therapeutic use of daily activities (occupations).*

"Occupational therapy practitioners enable people of

Figure 5. FreePik



Overview of OT: Practice Areas

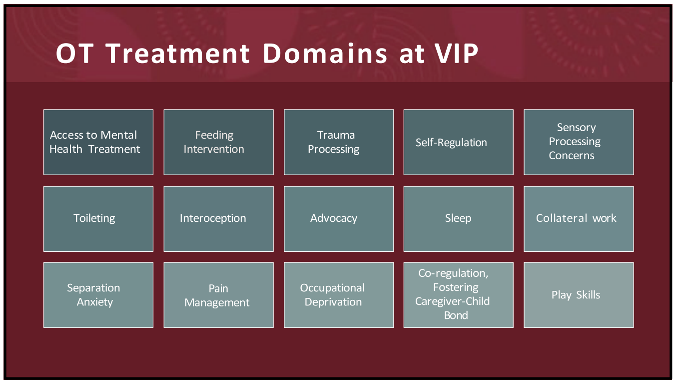
Occupational Therapy

Pediatrics

Mental Health

Adult Physical Rehabilitation

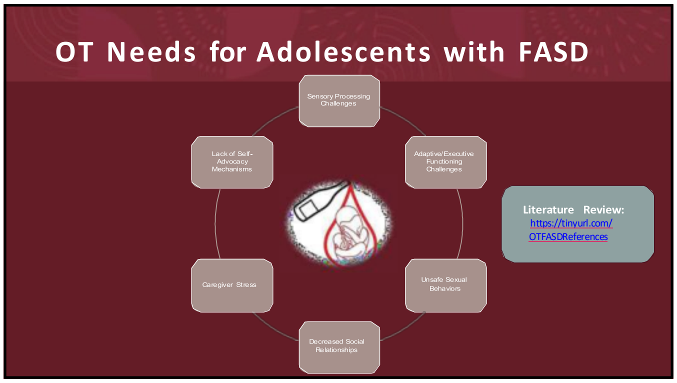
Pediatric Mental Health



OT Treatment Domains at VIP

Access to Mental Health Treatment	Feeding Intervention	Trauma Processing	Self-Regulation	Sensory Processing Concerns
Toileting	Interoception	Advocacy	Sleep	Collateral work
Separation Anxiety	Pain Management	Occupational Deprivation	Co-regulation, Fostering Caregiver-Child Bond	Play Skills

OT & FASD:
Establishing Connections



OT Needs for Adolescents with FASD

Sensory Processing Challenges

Adaptive/Executive Functioning Challenges

Unsafe Sexual Behaviors

Decreased Social Relationships

Caregiver Stress

Lack of Self-Advocacy Mechanisms

Literature Review: https://tinyurl.com/OTFASDReferences

Sensory Processing Challenges

Lack of Self-Advocacy Mechanisms

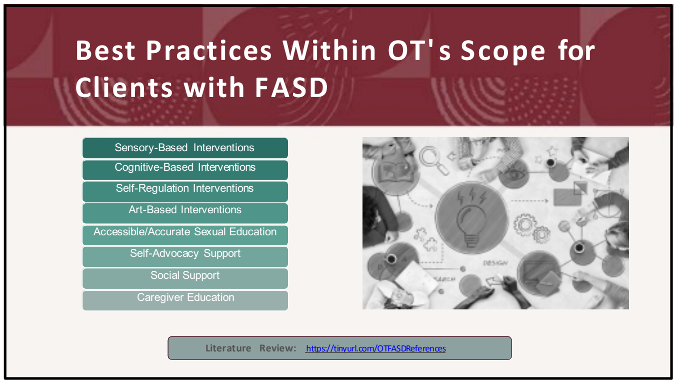
Adaptive/Executive Functioning Challenges

Decreased Social Relationships & Unsafe Sexual Behavior

Caregiver Stress

How have you seen these needs come up for teens with FASD in your lived

Small Group Share



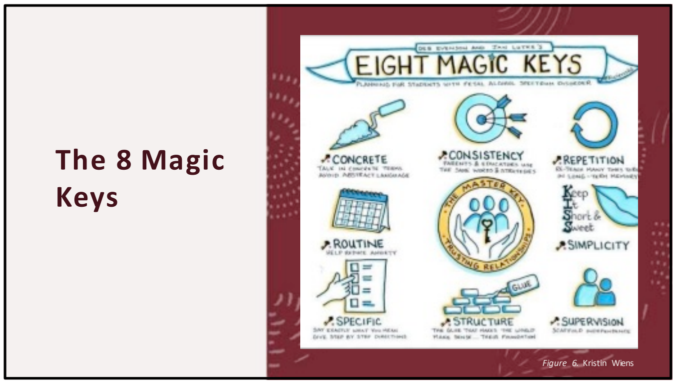
Best Practices Within OT's Scope for Clients with FASD

- Sensory-Based Interventions
- Cognitive-Based Interventions
- Self-Regulation Interventions
- Art-Based Interventions
- Accessible/Accurate Sexual Education
- Self-Advocacy Support
- Social Support
- Caregiver Education

Literature Review: https://tinyurl.com/OTFASDReferences

General Best Practices for Clients with FASD

No Blame, No Shame	**Strengths-Based Approach**	**8 Magic Keys**
(Zizzo & Racine, 2017)	(Flannigan et al., 2018)	(Everson & Lutke, 1997)



The 8 Magic Keys

Figure 6. Kristin Wiens

Holistic Supports:

1) Disability Processing

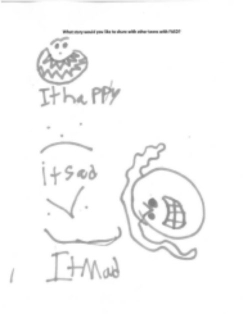
Needs Addressed

- Sensory Processing Challenges
- Decreased Social Relationships
- Caregiver Stress
- Lack of Self-Advocacy Mechanisms
- Unsafe Sexual Behavior
- Adaptive/Executive Functioning Challenges

Best Practices Used

- Sensory-Based Interventions
- Cognitive-Based Interventions
- Self-Regulation Interventions
- Accessible/Accurate Sexual Education
- Self-Advocacy Support
- Social Support
- Caregiver Education

FASD Storytelling Group: Background



FASD Storytelling Group: Curriculum

- WEEK 1: INTRODUCTIONS & STRENGTHS-BASED CHARACTER DESIGN
- WEEK 2: SETTINGS & SENSORY ELEMENTS
- WEEK 3: PLOT-CONFLICT
- WEEK 4: PLOT-RESOLUTION & RESILIENCE
- WEEK 5: POETRY
- WEEK 6: IN-PERSON WORKSHOP
- WEEK 7: IN-PERSON WORKSHOP
- WEEK 8: CLOSING AND CELEBRATION

FASD Storytelling Group: Activity Example

Setting Activity

Use drawing or writing to create a setting for your character!

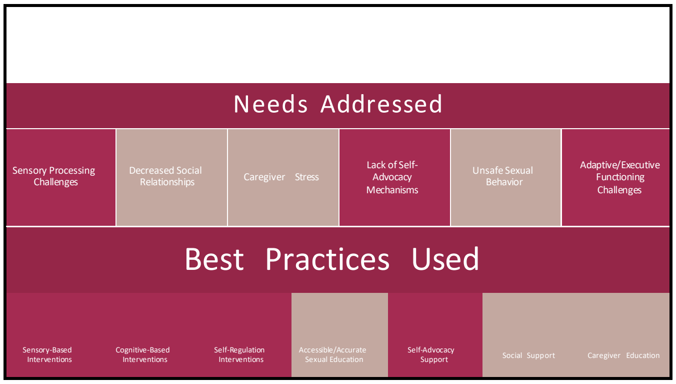
What **supports** your character in the environment? What is a **barrier**?

Describe the **sensory details** (visuals, sounds, smells, taste, textures) in the **setting** you created!

FASD Storytelling Group: Strengths and Future Directions

Strengths	Future Directions to Explore

Holistic Supports:
2) Relationship-Building

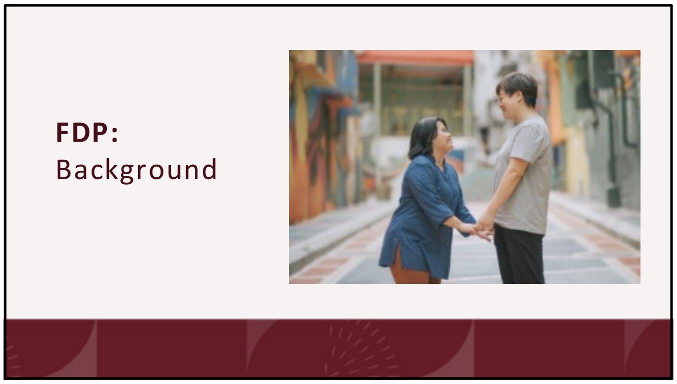


Needs Addressed

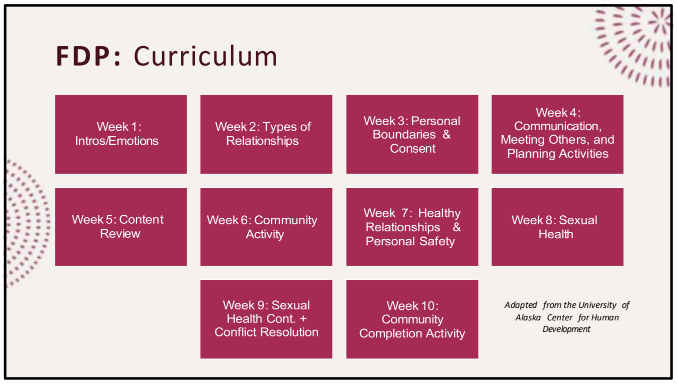
Sensory Processing Challenges
Decreased Social Relationships
Caregiver Stress
Lack of Self-Advocacy Mechanisms
Unsafe Sexual Behavior
Adaptive/Executive Functioning Challenges

Best Practices Used

Sensory-Based Interventions
Cognitive-Based Interventions
Self-Regulation Interventions
Accessible/Accurate Sexual Education
Self-Advocacy Support
Social Support
Caregiver Education



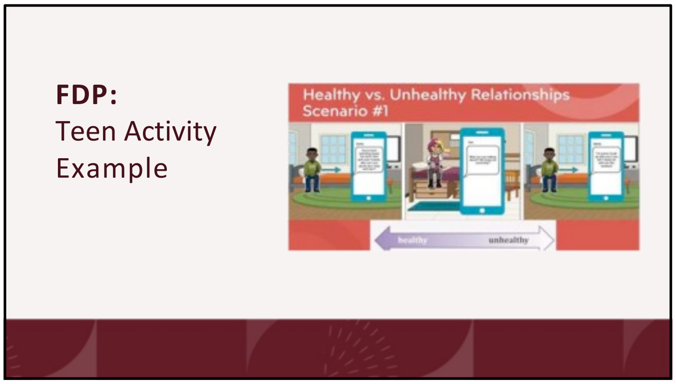
FDP: Background



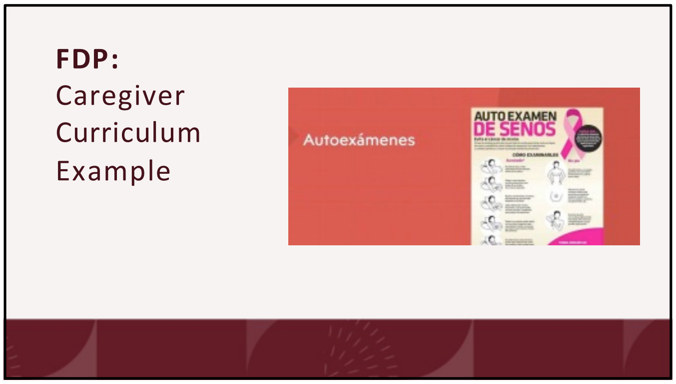
FDP: Curriculum

Week 1: Intros/Emotions
Week 2: Types of Relationships
Week 3: Personal Boundaries & Consent
Week 4: Communication, Meeting Others, and Planning Activities
Week 5: Content Review
Week 6: Community Activity
Week 7: Healthy Relationships & Personal Safety
Week 8: Sexual Health
Week 9: Sexual Health Cont. + Conflict Resolution
Week 10: Community Completion Activity

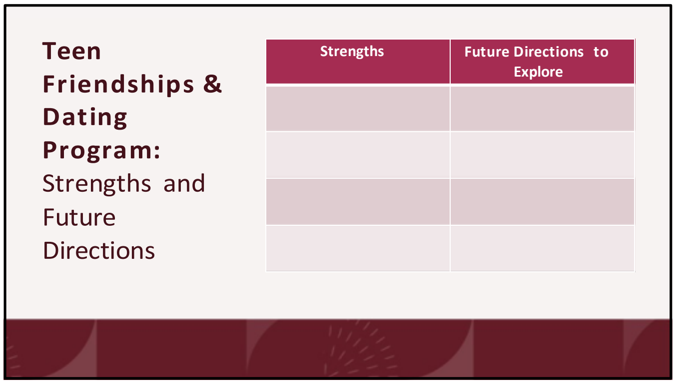
Adapted from the University of Alaska Center for Human Development



FDP: Teen Activity Example



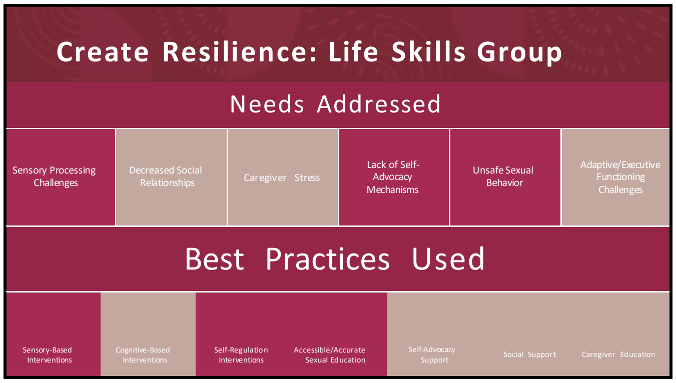
FDP: Caregiver Curriculum Example



Teen Friendships & Dating Program: Strengths and Future Directions

Strengths	Future Directions to Explore

Holistic Supports:
3) Adaptive Living Skills



Create Resilience: Life Skills Group

Needs Addressed

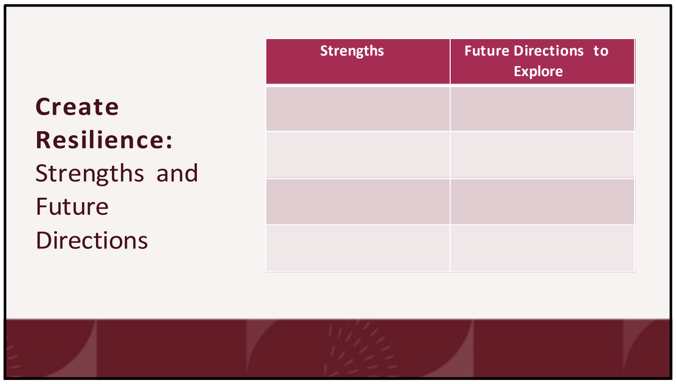
Sensory Processing Challenges	Decreased Social Relationships	Caregiver Stress	Lack of Self-Advocacy Mechanisms	Unsafe Sexual Behavior	Adaptive/Executive Functioning Challenges

Best Practices Used

Sensory-Based Interventions	Cognitive-Based Interventions	Self-Regulation Interventions	Accessible/Accurate Sexual Education	Self-Advocacy Support	Social Support	Caregiver Education

Figure 7. UC Davis

Create Resilience: Life Skills Curriculum



Create Resilience: Strengths and Future Directions

Strengths	Future Directions to Explore

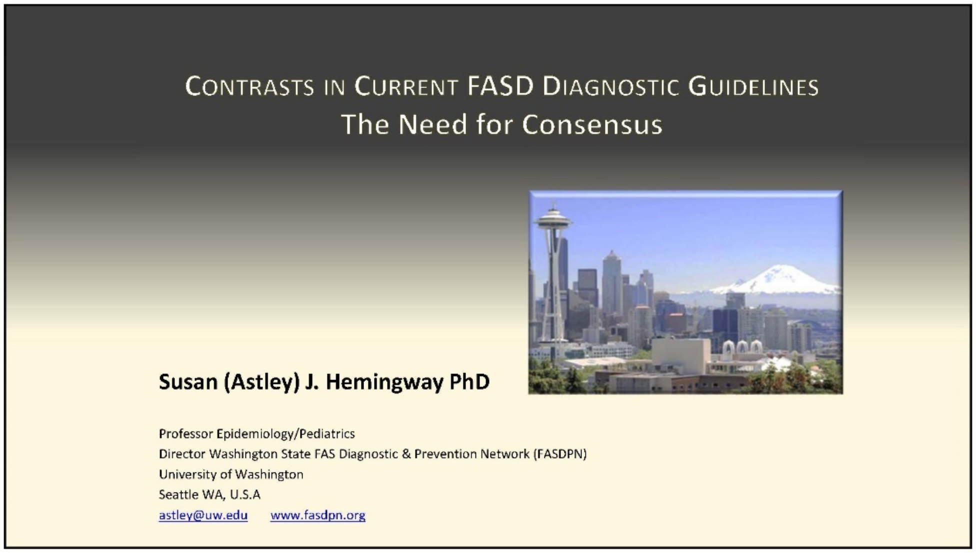
Citations

- Flannigan, K., Harding, K., Reid, D., & Family Advisory Committee. (2018). Strengths among individuals with FASD. *Canada FASD Research Network*, 1–4.
- Supplement to Community Health Assessment. (2014). Service Planning Area 4: Metro [PDF file]. Retrieved from http://publichealth.lacounty.gov/plan/docs/SPA4Supplement.pdf
- What is a Service Planning Area? (n.d.). Retrieved April 4th, 2023 from http://www.copalm.org/spa-4.html
- Wiens, K. (n.d.). *8 magic keys*. POPFASD - Fetal Alcohol Spectrum Disorder (FASD) Resource for Educators. Retrieved April 4, 2023, from https://www.fasdoutreach.ca/resources/all/0-9/8-magic-keys#:~:text=The%208%20Magic%20Keys%20are,repitition%2C%20simplicity%2C%20and%20relationship.
- Zizzo, N., Racine, E. Ethical challenges in FASD prevention: Scientific uncertainty, stigma, and respect for women's autonomy. *Can J Public Health* **108**, 414–417 (2017). https://doi.org/10.17269/CJPH.108.6048

C6

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

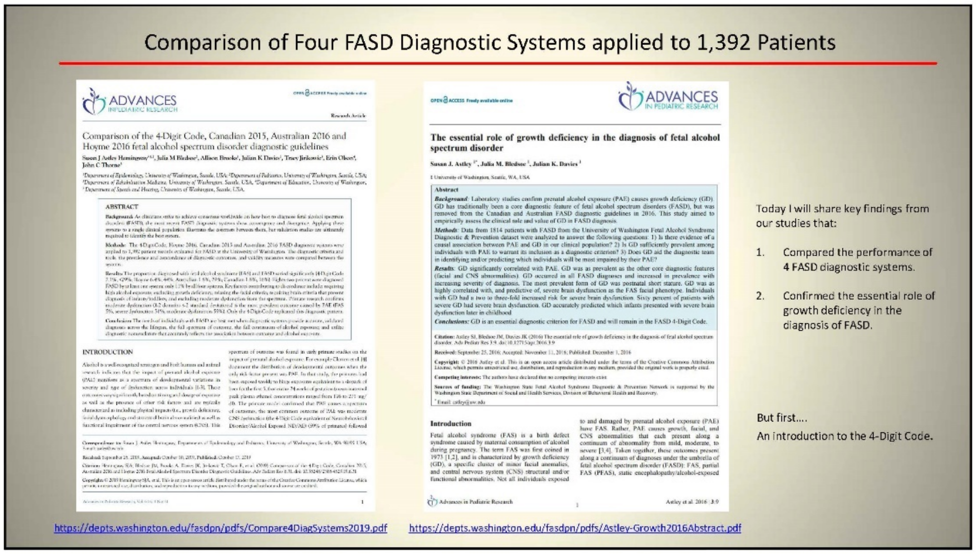
Susan Hemingway



CONTRASTS IN CURRENT FASD DIAGNOSTIC GUIDELINES
The Need for Consensus

Susan (Astley) J. Hemingway PhD

Professor Epidemiology/Pediatrics
Director Washington State FAS Diagnostic & Prevention Network (FASDPN)
University of Washington
Seattle WA, U.S.A
astley@uw.edu www.fasdpn.org



Comparison of Four FASD Diagnostic Systems applied to 1,392 Patients

ADVANCES IN PEDIATRIC RESEARCH

Research Article

Comparison of the 4-Digit Code, Canadian 2015, Australian 2016 and Hoyme 2016 fetal alcohol spectrum disorder diagnostic guidelines

Susan J Astley Hemingway, Julia M Bledsoe, Allison Brooks, Julian K Davies, Tracy Jirikowic, Erin Olson, John C Thorne

OPEN ACCESS Freely available online

ADVANCES IN PEDIATRIC RESEARCH

The essential role of growth deficiency in the diagnosis of fetal alcohol spectrum disorder

Susan J. Astley [1*], Julia M. Bledsoe [1], Julian K. Davies [1]

1 University of Washington, Seattle, WA, USA

Abstract

Background: Laboratory studies confirm prenatal alcohol exposure (PAE) causes growth deficiency (GD). GD has traditionally been a core diagnostic feature of fetal alcohol spectrum disorders (FASD), but was removed from the Canadian and Australian FASD diagnostic guidelines in 2016. This study aimed to empirically assess the clinical role and value of GD in FASD diagnosis.

Methods: Data from 1814 patients with FASD from the University of Washington Fetal Alcohol Syndrome Diagnostic & Prevention dataset were analyzed to answer the following questions: 1) Is there evidence of a causal association between PAE and GD in our clinical population? 2) Is GD sufficiently prevalent among individuals with PAE to warrant its inclusion as a diagnostic criterion? 3) Does GD aid the diagnostic team in identifying and/or predicting which individuals will be most impaired by their PAE?

Results: GD significantly correlated with PAE. GD was as prevalent as the other core diagnostic features (facial and CNS abnormalities). GD occurred in all FASD diagnoses and increased in prevalence with increasing severity of diagnosis. The most prevalent form of GD was postnatal short stature. GD was as highly correlated with, and predictive of, severe brain dysfunction as the FAS facial phenotype. Individuals with GD had a two to three-fold increased risk for severe brain dysfunction. Sixty percent of patients with severe GD had severe brain dysfunction. GD accurately predicted which infants presented with severe brain dysfunction later in childhood.

Conclusions: GD is an essential diagnostic criterion for FASD and will remain in the FASD 4-Digit Code.

Citation: Astley SJ, Bledsoe JM, Davies JK (2016) The essential role of growth deficiency in the diagnosis of fetal alcohol spectrum disorder. Adv Pediatr Res 3:9. doi:10.12715/apr.2016.3.9

Received: September 25, 2016; **Accepted:** November 11, 2016; **Published:** December 1, 2016

Competing interests: The authors have declared that no competing interests exist.

Sources of funding: The Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network is supported by the Washington State Department of Social and Health Services, Division of Behavioral Health and Recovery.

* Email: astley@uw.edu

Introduction

Fetal alcohol syndrome (FAS) is a birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The term FAS was first coined in 1973 [1,2], and is characterized by growth deficiency (GD), a specific cluster of minor facial anomalies, and central nervous system (CNS) structural and/or functional abnormalities. Not all individuals exposed to and damaged by prenatal alcohol exposure (PAE) have FAS. Rather, PAE causes growth, facial, and CNS abnormalities that each present along a continuum of abnormality from mild, moderate, to severe [3,4]. Taken together, these outcomes present along a continuum of diagnoses under the umbrella of fetal alcohol spectrum disorder (FASD): FAS, partial FAS (PFAS), static encephalopathy/alcohol-exposed

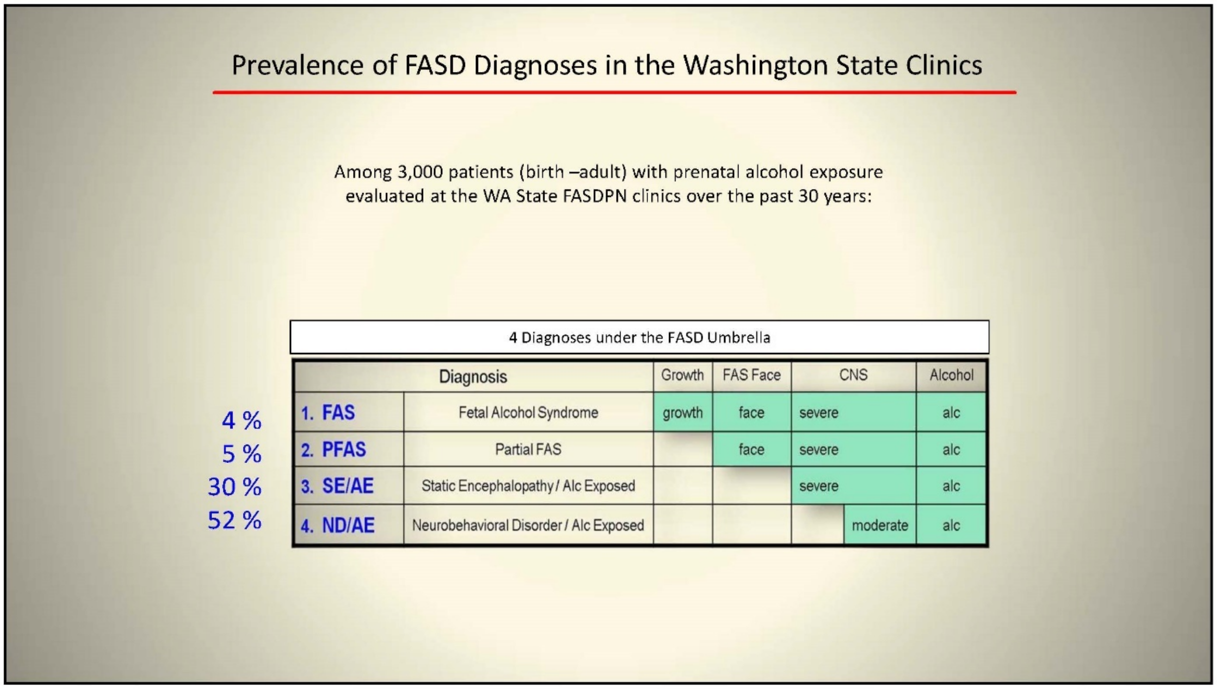
Advances in Pediatric Research 1 Astley et al. 2016 | 3:9

https://depts.washington.edu/fasdpn/pdfs/Compare4DiagSystems2019.pdf https://depts.washington.edu/fasdpn/pdfs/Astley-Growth2016Abstract.pdf

Today I will share key findings from our studies that:

1. Compared the performance of 4 FASD diagnostic systems.
2. Confirmed the essential role of growth deficiency in the diagnosis of FASD.

But first….
An introduction to the 4-Digit Code.

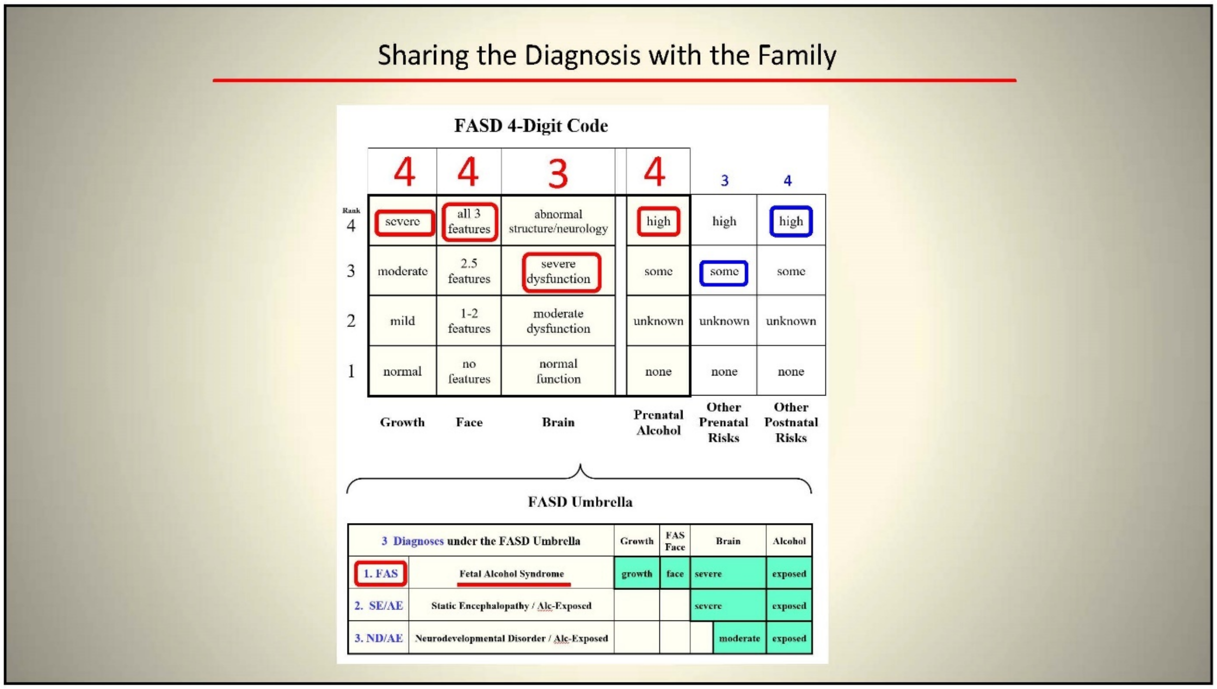


Prevalence of FASD Diagnoses in the Washington State Clinics

Among 3,000 patients (birth –adult) with prenatal alcohol exposure evaluated at the WA State FASDPN clinics over the past 30 years:

4 Diagnoses under the FASD Umbrella

	Diagnosis		Growth	FAS Face	CNS	Alcohol
4 %	1. FAS	Fetal Alcohol Syndrome	growth	face	severe	alc
5 %	2. PFAS	Partial FAS		face	severe	alc
30 %	3. SE/AE	Static Encephalopathy / Alc Exposed			severe	alc
52 %	4. ND/AE	Neurobehavioral Disorder / Alc Exposed			moderate	alc



Sharing the Diagnosis with the Family

FASD 4-Digit Code

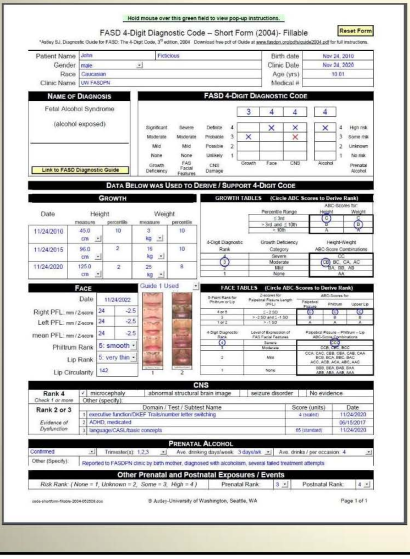
Rank	4	4	3	4	3	4
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none
	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks

FASD Umbrella

3 Diagnoses under the FASD Umbrella		Growth	FAS Face	Brain	Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe	exposed
2. SE/AE	Static Encephalopathy / Alc-Exposed			severe	exposed
3. ND/AE	Neurodevelopmental Disorder / Alc-Exposed			moderate	exposed

Surveys of over 1300 clinicians using the 4-Digit Code:

96% describe it as simple to use. 100% recommend it to others.



Hold mouse over this green field to view pop-up instructions.

FASD 4-Digit Diagnostic Code – Short Form (2004)- Fillable

Reset Form

*Astley SJ. Diagnostic Guide for FASD: The 4-Digit Code, 3rd edition, 2004 Download free pdf of Guide at www.fasdpn.org/pdfs/guide2004.pdf for full instructions.

Patient Name	John	Ficticious	Birth date	Nov 24, 2010
Gender	male		Clinic Date	Nov 24, 2020
Race	Caucasian		Age (yrs)	10.01
Clinic Name	UW FASDPN		Medical #	

NAME OF DIAGNOSIS

Fetal Alcohol Syndrome

(alcohol exposed)

Link to FASD Diagnostic Guide

FASD 4-DIGIT DIAGNOSTIC CODE

				Growth	Face	CNS	Alcohol		
				3	4	4	4		
Significant	Severe	Definite	4		X	X	X	4	High risk
Moderate	Moderate	Probable	3	X		X		3	Some risk
Mild	Mild	Possible	2					2	Unknown
None	None	Unlikely	1					1	No risk
Growth Deficiency	FAS Facial Features	CNS Damage		Growth	Face	CNS	Alcohol		Prenatal Alcohol

DATA BELOW WAS USED TO DERIVE / SUPPORT 4-DIGIT CODE

GROWTH

Date	Height measure	Height percentile	Weight measure	Weight percentile
11/24/2010	45.0 cm	10	3 kg	10
11/24/2015	96.0 cm	2	16 kg	10
11/24/2020	125.0 cm	2	25 kg	8

GROWTH TABLES (Circle ABC Scores to Derive Rank)

Percentile Range	ABC-Scores for: Height	Weight
≤ 3rd	[✓ C]	C
> 3rd and ≤ 10th	B	[✓ B]
> 10th	A	A

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
[✓ 3]	Moderate	[✓ CB], BC, CA, AC
2	Mild	BA, BB, AB
1	None	AA

FACE

Guide 1 Used

Date	11/24/2022	
Right PFL: mm / Z-score	24	-2.5
Left PFL: mm / Z-score	24	-2.5
mean PFL: mm / Z-score	24	-2.5
Philtrum Rank	5: smooth	
Lip Rank	5: very thin	
Lip Circularity	142	

1 2

FACE TABLES (Circle ABC Scores to Derive Rank)

5-Point Rank for Philtrum or Lip	Z-scores for Palpebral Fissure Length (PFL)	ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	[✓ C]	[✓ C]	[✓ C]
3	> -2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
[✓ 4]	Severe	[✓ CCC]
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

CNS

Rank 4 *Check 1 or more*	✓	microcephaly	abnormal structural brain image		seizure disorder		No evidence
	Other (specify):						

Rank 2 or 3 *Evidence of Dysfunction*		Domain / Test / Subtest Name	Score (units)	Date
	1	executive function/DKEF Trails/number letter switching	4 (scaled)	11/24/2020
	2	ADHD, medicated		06/15/2017
	3	language/CASL/basic concepts	65 (standard)	11/24/2020

PRENATAL ALCOHOL

Confirmed | Trimester(s): 1,2,3 | Ave. drinking days/week: 3 days/wk | Ave. drinks / per occasion: 4

Other (Specify): Reported to FASDPN clinic by birth mother, diagnosed with alcoholism, several failed treatment attempts

Other Prenatal and Postnatal Exposures / Events

Risk Rank: (None = 1, Unknown = 2, Some = 3, High = 4) Prenatal Rank: 3 Postnatal Rank: 4

code-shortform-fillable-2004-052508.doc © Astley-University of Washington, Seattle, WA Page 1 of 1

The Code can be administered using nothing more than:

1. Our 1-page diagnostic form programmed to derive the 4-Digit Code from the data you enter. (Download free from www.fasdpn.org)
2. And free digital Lip-Philtrum Guides on your cell phone. (obtain from astley@uw.edu

FAS Facial Software: Used to screen and diagnose facial features

Fully validated. Takes 5 minutes to measure the 2D photos. Your cell phone is your camera.
Over 2,000 copies distributed to 38 countries. Software is free. Current version: 2.1, 2016

FAS Facial Photographic Analysis Software

Susan Astley, Ph.D.
Fetal Alcohol Syndrome Diagnostic & Prevention Network
University of Washington, Seattle, WA

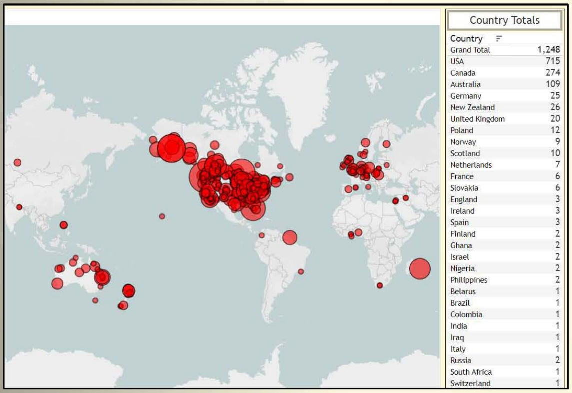
www.fasdpn.org
Version 2.0.0
Copyright 2012

FAS Facial Photographic Analysis Software

Version 2.0 (2012)

Trained over 150 diagnostic teams and thousands of clinicians in 38 countries.

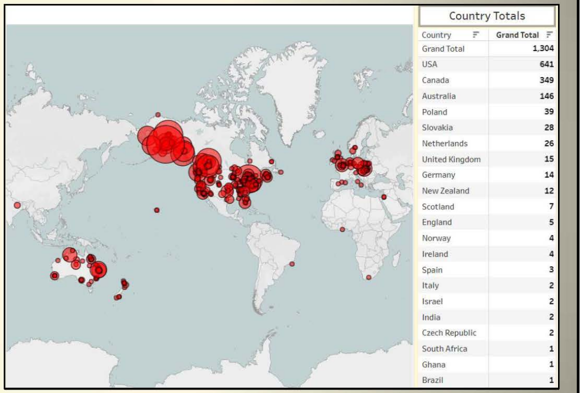
FAS Facial Photographic Analysis Software



Country Totals

Country	
Grand Total	1,248
USA	715
Canada	274
Australia	109
Germany	25
New Zealand	26
United Kingdom	20
Poland	12
Norway	9
Scotland	10
Netherlands	7
France	6
Slovakia	6
England	3
Ireland	3
Spain	3
Finland	2
Ghana	2
Israel	2
Nigeria	2
Philippines	2
Belarus	1
Brazil	1
Colombia	1
India	1
Iraq	1
Italy	1
Russia	2
South Africa	1
Switzerland	1

4-Digit Code Online Course



Country Totals

Country	Grand Total
Grand Total	1,304
USA	641
Canada	349
Australia	146
Poland	39
Slovakia	28
Netherlands	26
United Kingdom	15
Germany	14
New Zealand	12
Scotland	7
England	5
Norway	4
Ireland	4
Spain	3
Italy	2
Israel	2
India	2
Czech Republic	2
South Africa	1
Ghana	1
Brazil	1

https://depts.washington.edu/fasdpn/htmls/Tableau-FASDPN.htm

Comparison of 4 FASD Diagnostic Systems

Four FASD diagnostic systems were applied to 1,392 patients (birth to adult):

- 4-Digit Code 2004
- Australian 2016
- Canadian 2015
- Hoyme et al Revised IOM 2016

Results: The proportion diagnosed with FAS and FASD varied significantly

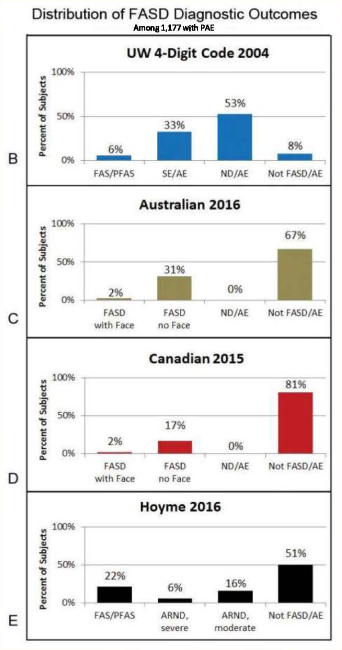
	FAS	FASD
4-Digit Code	2.1 %	79 %
Australian	1.8 %	29 %
Canadian	1.8 %	16 %
Hoyme	6.4 %	44 %

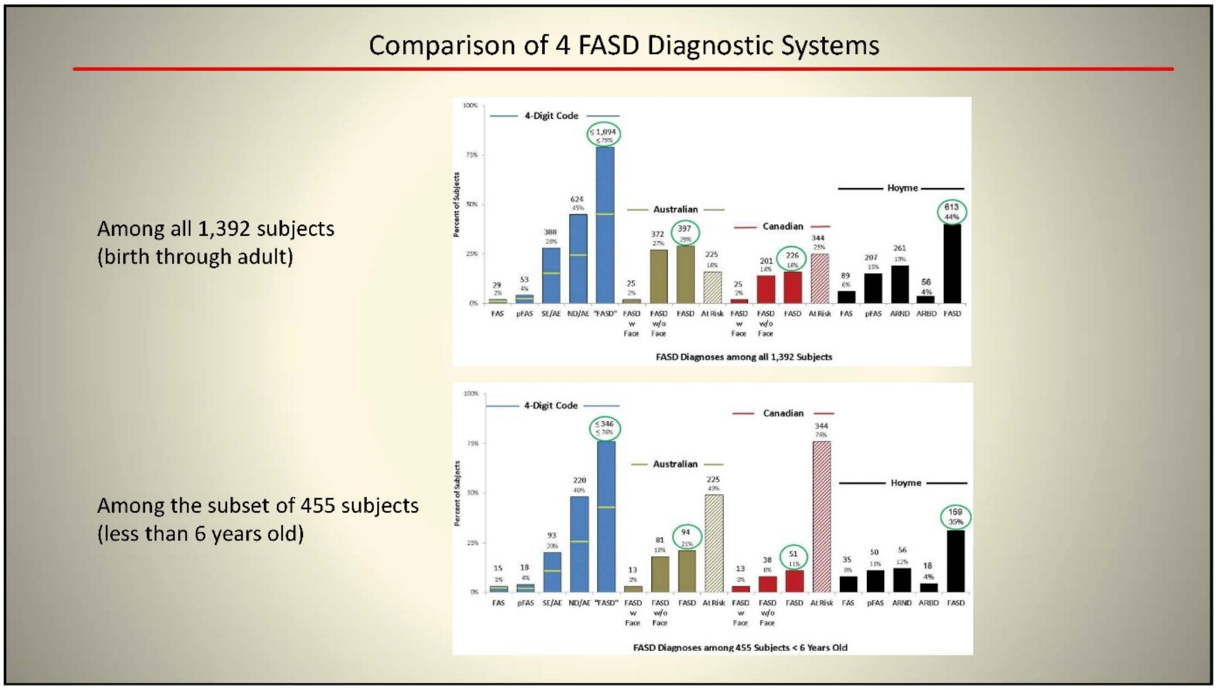
82% were diagnosed FASD by at least one system; only 11% by all four systems.

Key factors contributing to discordance include:

1. Excluding moderate dysfunction (ND/AE) from the spectrum.
2. Requiring a threshold of alcohol exposure.
3. Requiring evidence of significant brain dysfunction that prevents diagnosis of infants/toddlers too young to assess brain function.
4. Excluding growth deficiency.
5. Relaxing the facial criteria.
6. Collapsing continuous outcomes into dichotomous (present/absent) categories.

Important note: the 4-Digit Code ND/AE (*Neurobehavioral Disorder/Alcohol Exposed*) diagnosis is NOT the same as the DSM-5 ND-PAE (*Neurodevelopmental Disorder –Prenatal Alcohol Exposed*) diagnosis. The DSM-5 ND-PAE is not being reviewed in this presentation.



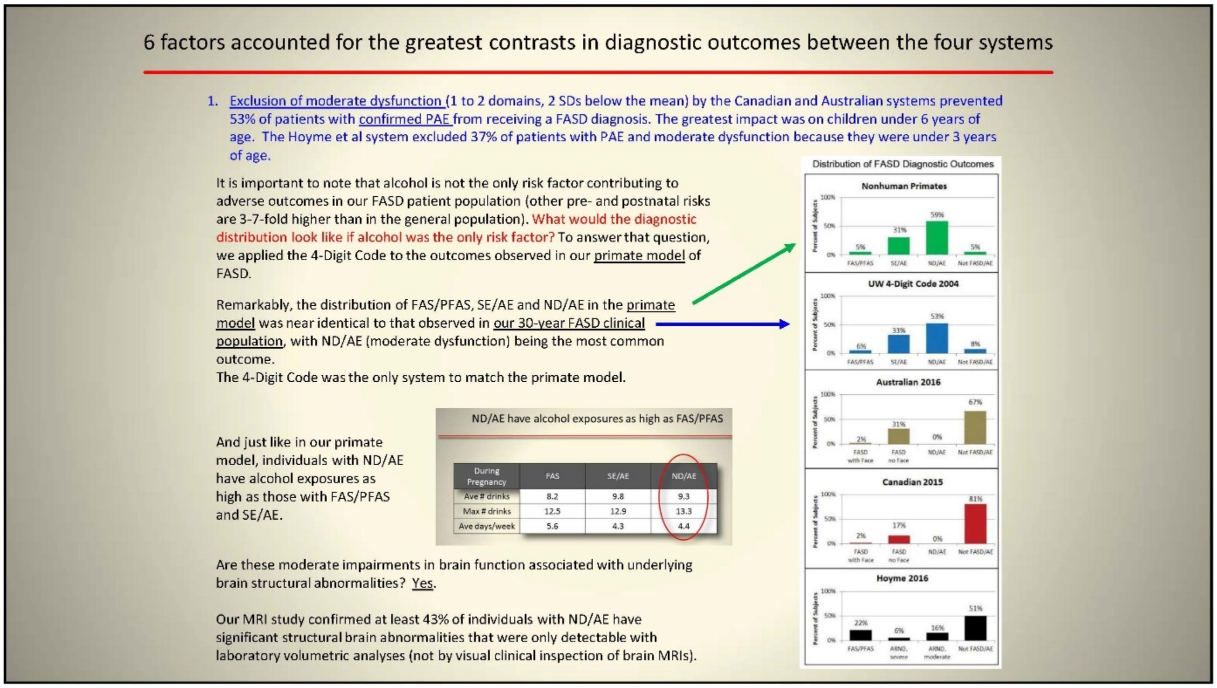


Comparison of 4 FASD Diagnostic Systems

Among all 1,392 subjects
(birth through adult)

Among the subset of 455 subjects
(less than 6 years old)

11



6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

1. Exclusion of moderate dysfunction (1 to 2 domains, 2 SDs below the mean) by the Canadian and Australian systems prevented 53% of patients with confirmed PAE from receiving a FASD diagnosis. The greatest impact was on children under 6 years of age. The Hoyme et al system excluded 37% of patients with PAE and moderate dysfunction because they were under 3 years of age.

It is important to note that alcohol is not the only risk factor contributing to adverse outcomes in our FASD patient population (other pre- and postnatal risks are 3-7-fold higher than in the general population). What would the diagnostic distribution look like if alcohol was the only risk factor? To answer that question, we applied the 4-Digit Code to the outcomes observed in our primate model of FASD.

Remarkably, the distribution of FAS/PFAS, SE/AE and ND/AE in the primate model was near identical to that observed in our 30-year FASD clinical population, with ND/AE (moderate dysfunction) being the most common outcome.
The 4-Digit Code was the only system to match the primate model.

And just like in our primate model, individuals with ND/AE have alcohol exposures as high as those with FAS/PFAS and SE/AE.

ND/AE have alcohol exposures as high as FAS/PFAS

During Pregnancy	FAS	SE/AE	ND/AE
Ave # drinks	8.2	9.8	9.3
Max # drinks	12.5	12.9	13.3
Ave days/week	5.6	4.3	4.4

Are these moderate impairments in brain function associated with underlying brain structural abnormalities? Yes.

Our MRI study confirmed at least 43% of individuals with ND/AE have significant structural brain abnormalities that were only detectable with laboratory volumetric analyses (not by visual clinical inspection of brain MRIs).

Distribution of FASD Diagnostic Outcomes

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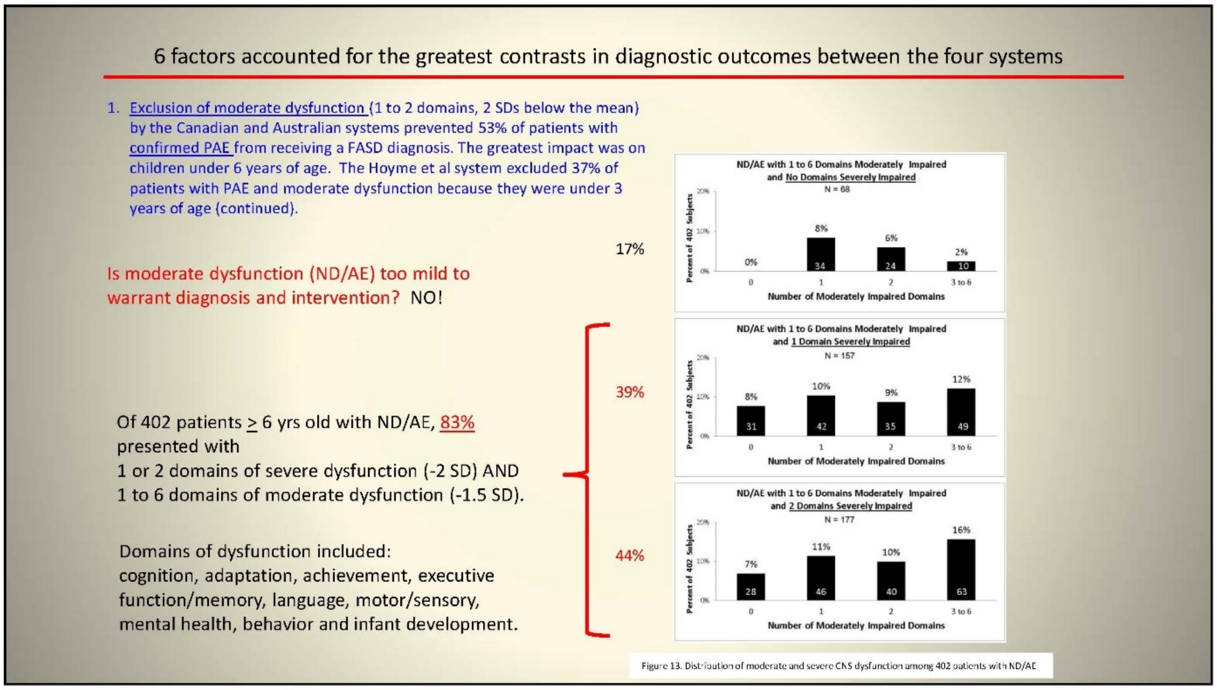

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Is moderate dysfunction (ND/AE) too mild to warrant diagnosis and intervention? NO!

Of 402 patients > 6 yrs old with ND/AE, 83% presented with
1 or 2 domains of severe dysfunction (-2 SD) AND
1 to 6 domains of moderate dysfunction (-1.5 SD).

Domains of dysfunction included:
cognition, adaptation, achievement, executive function/memory, language, motor/sensory, mental health, behavior and infant development.

17%

39%

44%

Figure 13. Distribution of moderate and severe CNS dysfunction among 402 patients with ND/AE

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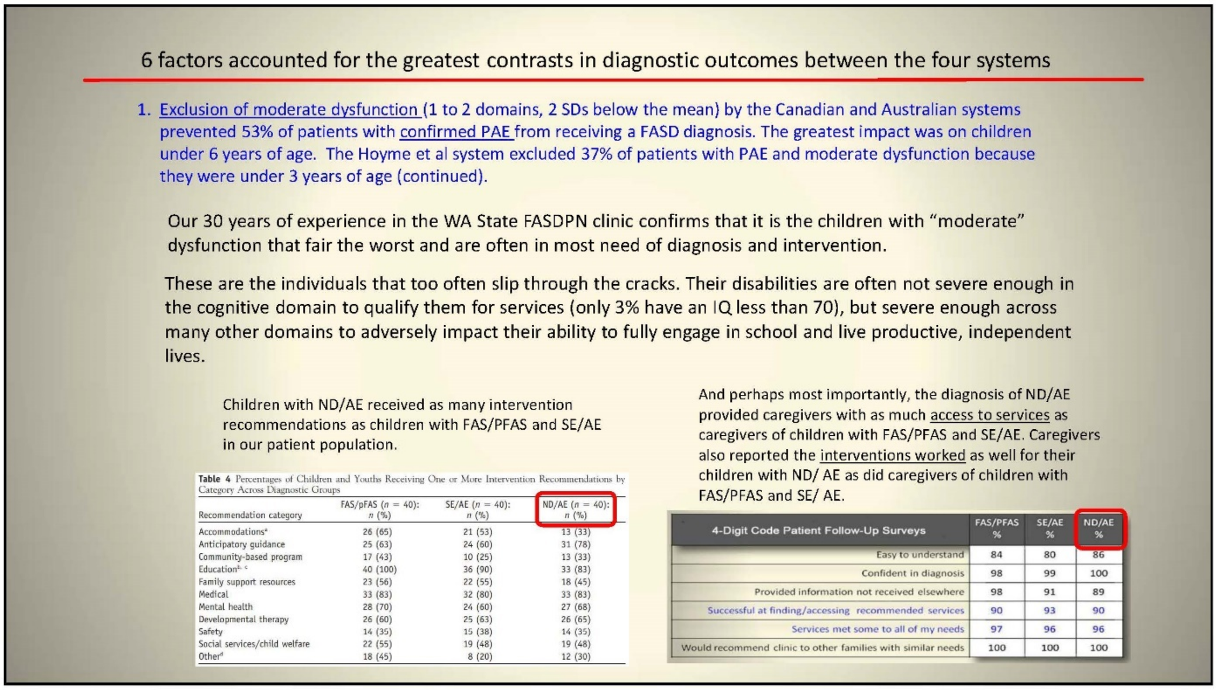

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Our 30 years of experience in the WA State FASDPN clinic confirms that it is the children with "moderate" dysfunction that fair the worst and are often in most need of diagnosis and intervention.

These are the individuals that too often slip through the cracks. Their disabilities are often not severe enough in the cognitive domain to qualify them for services (only 3% have an IQ less than 70), but severe enough across many other domains to adversely impact their ability to fully engage in school and live productive, independent lives.

Children with ND/AE received as many intervention recommendations as children with FAS/PFAS and SE/AE in our patient population.

Table 4 Percentages of Children and Youths Receiving One or More Intervention Recommendations by Category Across Diagnostic Groups

Recommendation category	FAS/pFAS (n = 40): n (%)	SE/AE (n = 40): n (%)	ND/AE (n = 40): n (%)
Accommodations[a]	26 (65)	21 (53)	13 (33)
Anticipatory guidance	25 (63)	24 (60)	31 (78)
Community-based program	17 (43)	10 (25)	13 (33)
Education[b, c]	40 (100)	36 (90)	33 (83)
Family support resources	23 (56)	22 (55)	18 (45)
Medical	33 (83)	32 (80)	33 (83)
Mental health	28 (70)	24 (60)	27 (68)
Developmental therapy	26 (60)	25 (63)	26 (65)
Safety	14 (35)	15 (38)	14 (35)
Social services/child welfare	22 (55)	19 (48)	19 (48)
Other[d]	18 (45)	8 (20)	12 (30)

And perhaps most importantly, the diagnosis of ND/AE provided caregivers with as much access to services as caregivers of children with FAS/PFAS and SE/AE. Caregivers also reported the interventions worked as well for their children with ND/ AE as did caregivers of children with FAS/PFAS and SE/ AE.

4-Digit Code Patient Follow-Up Surveys	FAS/PFAS %	SE/AE %	ND/AE %
Easy to understand	84	80	86
Confident in diagnosis	98	99	100
Provided information not received elsewhere	98	91	89
Successful at finding/accessing recommended services	90	93	90
Services met some to all of my needs	97	96	96
Would recommend clinic to other families with similar needs	100	100	100

14

6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

2. The more stringent Hoyme et al and Canadian alcohol exposure criteria prevented 47%-59% of patients with confirmed prenatal alcohol exposure (PAE) from receiving a diagnosis of FASD.

In a clinical setting, one never knows how accurate the exposure was recalled and reported. Setting a threshold implies the details of all reported exposures are accurate and no fetus can be harmed by exposures below the threshold. Neither of these statements is true and the latter sends a confusing public health message that lower levels are safe. Recognizing this, the 4-Digit Code requires a confirmed exposure, but does not set a threshold.

4-Digit Code	Hoyme et al 2016	Canadian 2015	Australian 2016
Confirmed Exposure (at any level) or Unknown Exposure (if 4-Digit Code FAS face is present)	Confirmed High Exposure >6 drinks/week for > 2 weeks >3 drinks/occasion on >2 occasions or Unknown Exposure (if Hoyme et al FAS Face is present)	Confirmed High Exposure >7 drinks/week for > 2 weeks >4 drinks/occasion on >2 occasions or Unknown Exposure (if 4-Digit Code FAS face is present)	Confirmed Exposure (at any level) or Unknown Exposure (if 4-Digit Code FAS face is present)

A Canadian clinical team (Petryk et al 2018) reported similar findings when they assessed the impact of applying the more stringent 2015 Canadian guidelines to 79 patients with confirmed PAE that were diagnosed with FASD using the 2005 Canadian guidelines. The more stringent Canadian exposure criteria would have caused 71% of these individuals to lose their FASD diagnosis because their reported exposure would not have met the required threshold.

Among the 1st 1,400 patients with confirmed exposure diagnosed in the WA State clinics, **less than 50%** had details like quantity /frequency /duration available.

Alcohol Use "Reported" During Pregnancy among 1,400 Patients

Reported Drinking Pattern during Pregnancy	FAS (n=154)	SE/AE (n=334)	ND/AE (n = 722)
Quantity: Max drinks per occasion mean (range) N	13 (1-60) 56	13 (1-72) 169	13 (1-128) 275
Frequency: Days per week mean (range) N	5.6 (1-7) 81	4.3 (1-7) 227	4.4 (1-7) 409
Duration: Trimesters 1st only (1st + 2nd) all 3, %	14 (14) 72	17 (12) 67	12 (11) 72

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6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

2. The more stringent Hoyme et al and Canadian alcohol exposure criteria prevented 47%-59% of patients with confirmed PAE from receiving a diagnosis of FASD (continued).

Alcoholism: Clinical and Experimental Research

Are Low-to-Moderate Average Alcohol Consumption and Isolated Episodes of Binge Drinking in Early Pregnancy Associated with Facial Features Related to Fetal Alcohol Syndrome in 5-Year-Old Children?

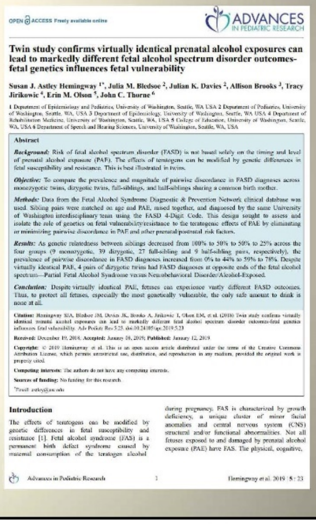
Ulrik Schiøler Kesmodel, Siv Steffen Nygaard, Erik Lykke Mortensen, Jacquelyn Bertrand, Clark H. Denny, Alex Glidewell, and Susan Astley Hemingway

Low levels of alcohol exposure do place some fetuses at risk:

Kesmodel et al 2019 confirmed 1-2 drinks/week increased the risk of the 4-Digit Code FAS facial phenotype 8.5-fold.

Astley 2019 reported 1 out of every 14 patients with FAS report no more than 1 drink/day. (well below the *'safe'* thresholds set by Canada and Hoyme et al.) Were these fetuses especially vulnerable to low levels or were the reported exposures inaccurate?

Setting thresholds also fails to acknowledge that risk is not just dependent on the quantity/frequency/timing of exposure. Our large twin study (Hemingway et al., 2019) confirmed that fetal genetics influences risk. Genetically identical twins with identical exposures experienced identical FASD outcomes. Genetically nonidentical twins experienced discordant FASD outcomes 44% of the time despite identical exposures. The exposure that caused moderate dysfunction (ND/PAE) in one twin caused severe dysfunction (PFAS) in the other.



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ADVANCES IN PEDIATRIC RESEARCH

Twin study confirms virtually identical prenatal alcohol exposures can lead to markedly different fetal alcohol spectrum disorder outcomes-fetal genetics influences fetal vulnerability

Susan J. Astley Hemingway 1*, Julia M. Bledsoe 2, Julian K. Davies 2, Allison Brooks 3, Tracy Jirikowic 4, Erin M. Olson 5, John C. Thorne 6

1 Department of Epidemiology and Pediatrics, University of Washington, Seattle, WA USA 2 Department of Pediatrics, University of Washington, Seattle, WA, USA 3 Department of Epidemiology, University of Washington, Seattle, WA USA 4 Department of Rehabilitation Medicine, University of Washington, Seattle, WA, USA 5 College of Education, University of Washington, Seattle, WA, USA 6 Department of Speech and Hearing Sciences, University of Washington, Seattle, WA, USA

Abstract

Background: Risk of fetal alcohol spectrum disorder (FASD) is not based solely on the timing and level of prenatal alcohol exposure (PAE). The effects of teratogens can be modified by genetic differences in fetal susceptibility and resistance. This is best illustrated in twins.

Objective: To compare the prevalence and magnitude of pairwise discordance in FASD diagnoses across monozygotic twins, dizygotic twins, full-siblings, and half-siblings sharing a common birth mother.

Methods: Data from the Fetal Alcohol Syndrome Diagnostic & Prevention Network clinical database was used. Sibling pairs were matched on age and PAE, raised together, and diagnosed by the same University of Washington interdisciplinary team using the FASD 4-Digit Code. This design sought to assess and isolate the role of genetics on fetal vulnerability/resistance to the teratogenic effects of PAE by eliminating or minimizing pairwise discordance in PAE and other prenatal/postnatal risk factors.

Results: As genetic relatedness between siblings decreased from 100% to 50% to 50% to 25% across the four groups (9 monozygotic, 39 dizygotic, 27 full-sibling and 9 half-sibling pairs, respectively), the prevalence of pairwise discordance in FASD diagnoses increased from 0% to 44% to 59% to 78%. Despite virtually identical PAE, 4 pairs of dizygotic twins had FASD diagnoses at opposite ends of the fetal alcohol spectrum—Partial Fetal Alcohol Syndrome versus Neurobehavioral Disorder/Alcohol-Exposed.

Conclusion: Despite virtually identical PAE, fetuses can experience vastly different FASD outcomes. Thus, to protect all fetuses, especially the most genetically vulnerable, the only safe amount to drink is none at all.

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Competing interests: The authors do not have any competing interests.

Sources of funding: No funding for this research.

Introduction

The effects of teratogens can be modified by genetic differences in fetal susceptibility and resistance [1]. Fetal alcohol syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of the teratogen alcohol during pregnancy. FAS is characterized by growth deficiency, a unique cluster of minor facial anomalies and central nervous system (CNS) structural and/or functional abnormalities. Not all fetuses exposed to and damaged by prenatal alcohol exposure (PAE) have FAS. The physical, cognitive,

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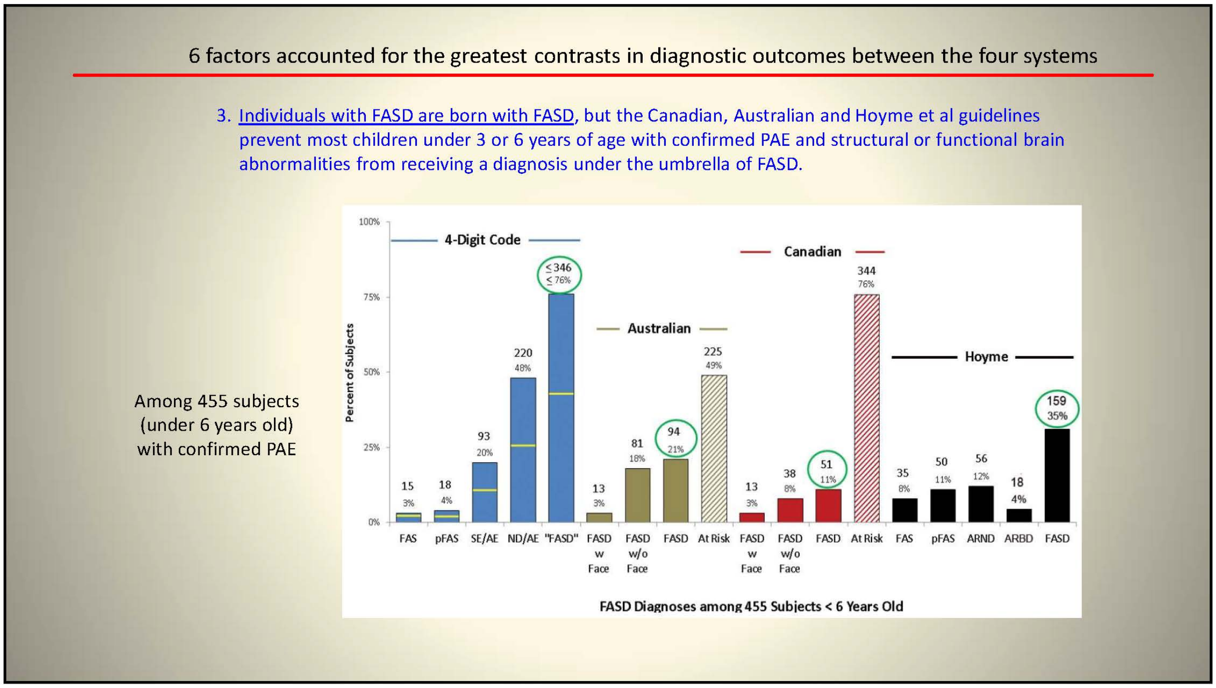
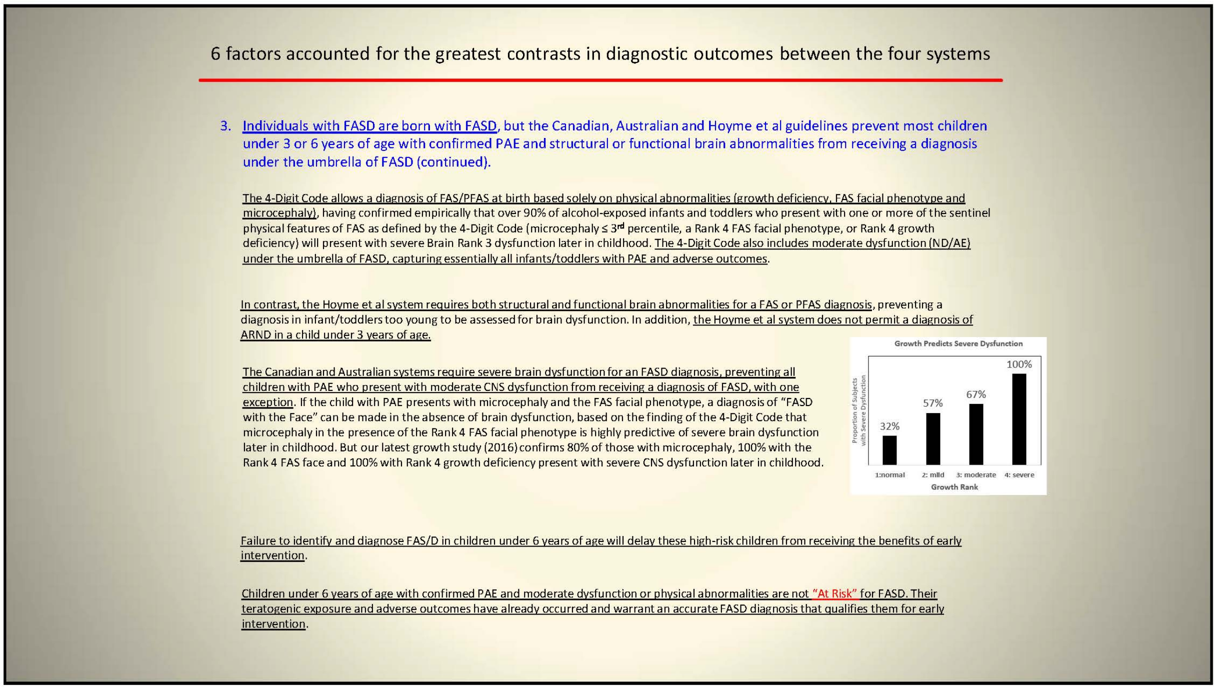


6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

3. Individuals with FASD are born with FASD, but the Canadian, Australian and Hoyme et al guidelines prevent most children under 3 or 6 years of age with confirmed PAE and structural or functional brain abnormalities from receiving a diagnosis under the umbrella of FASD.

Among 455 subjects (under 6 years old) with confirmed PAE

FASD Diagnoses among 455 Subjects < 6 Years Old



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3. Individuals with FASD are born with FASD, but the Canadian, Australian and Hoyme et al guidelines prevent most children under 3 or 6 years of age with confirmed PAE and structural or functional brain abnormalities from receiving a diagnosis under the umbrella of FASD (continued).

The 4-Digit Code allows a diagnosis of FAS/PFAS at birth based solely on physical abnormalities (growth deficiency, FAS facial phenotype and microcephaly), having confirmed empirically that over 90% of alcohol-exposed infants and toddlers who present with one or more of the sentinel physical features of FAS as defined by the 4-Digit Code (microcephaly ≤ 3rd percentile, a Rank 4 FAS facial phenotype, or Rank 4 growth deficiency) will present with severe Brain Rank 3 dysfunction later in childhood. The 4-Digit Code also includes moderate dysfunction (ND/AE) under the umbrella of FASD, capturing essentially all infants/toddlers with PAE and adverse outcomes.

In contrast, the Hoyme et al system requires both structural and functional brain abnormalities for a FAS or PFAS diagnosis, preventing a diagnosis in infant/toddlers too young to be assessed for brain dysfunction. In addition, the Hoyme et al system does not permit a diagnosis of ARND in a child under 3 years of age.

The Canadian and Australian systems require severe brain dysfunction for an FASD diagnosis, preventing all children with PAE who present with moderate CNS dysfunction from receiving a diagnosis of FASD, with one exception. If the child with PAE presents with microcephaly and the FAS facial phenotype, a diagnosis of "FASD with the Face" can be made in the absence of brain dysfunction, based on the finding of the 4-Digit Code that microcephaly in the presence of the Rank 4 FAS facial phenotype is highly predictive of severe brain dysfunction later in childhood. But our latest growth study (2016) confirms 80% of those with microcephaly, 100% with the Rank 4 FAS face and 100% with Rank 4 growth deficiency present with severe CNS dysfunction later in childhood.

Failure to identify and diagnose FAS/D in children under 6 years of age will delay these high-risk children from receiving the benefits of early intervention.

Children under 6 years of age with confirmed PAE and moderate dysfunction or physical abnormalities are not "At Risk" for FASD. Their teratogenic exposure and adverse outcomes have already occurred and warrant an accurate FASD diagnosis that qualifies them for early intervention.

6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

4. The Canadian and Australian systems removed growth deficiency as a criterion for FASD despite the fact that growth deficiency is significantly associated with PAE, is more prevalent than the FAS facial features and microcephaly and is highly predictive of severe brain dysfunction among infants/toddlers with PAE.

The Canadian guidelines offered the following rationale for removing growth as a diagnostic criterion.

- "In North America, FAS was "discovered" because a group of children were referred to a clinic for growth deficiency, and later found to have the other features of what is now known as FAS. At that time, growth deficiency became one of the defining features of FAS." This is a legitimate concern. A growth deficiency clinic is not a representative sample from which to derive diagnostic criteria. But this can be easily resolved by looking at the prevalence of growth deficiency in a more representative sample (e.g., Canadian FASD dataset or Washington State FASD dataset). Our Washington State dataset of 3,000 cases with PAE compiled over 30 years documents 32% have growth deficiency ≤ 10th percentile, more than the other core diagnostic features of FASD combined (FAS facial phenotype 9% and microcephaly 12%) and 3-fold more prevalent than in the general population. **These findings do not support removing growth deficiency as a diagnostic criterion.**

- "The predictive value of growth deficiency especially in the absence of documented prenatal alcohol exposure has been queried." Predictive of what? PAE? FAS/D? Our empirical analysis of growth (Hemingway 2016) conducted on 1,814 patients with PAE found growth deficiency (GD) to be ASTOUNDINGLY predictive of severe brain dysfunction among infants with PAE that will manifest later in childhood when they are old enough to assess brain function. GD was as highly correlated with, and predictive of, severe brain dysfunction as the FAS facial phenotype. Individuals with GD had a 3-fold increased risk for severe brain dysfunction. Sixty percent of patients with severe GD had severe brain dysfunction. **Again, these findings do not support removing growth as a diagnostic criterion.**

- "Recent evidence [O'Leary et al., 2008], plus clinical experience suggest that growth is neither sensitive nor sufficiently specific to indicate an FASD diagnosis." FASD guidelines require evidence of prenatal and/or postnatal growth deficiency. O'Leary only looked at prenatal growth and found a significant association between PAE and preterm birth but not birth weight. Birth weight appeared more strongly associated with maternal smoking. Our growth study assessed prenatal AND postnatal growth. Our prenatal results were identical to O'Leary's (PAE was associated with preterm birth and smoking was associated with low birth weight). Our assessment of postnatal growth, however, discovered a highly significant association between PAE and postnatal short stature. **Once again, these findings do not support removing growth as a criterion.**

- The Canadian guidelines state "growth is neither sensitive nor sufficiently specific to indicate an FASD diagnosis". This is true. But neither is microcephaly. Neither is brain dysfunction (memory, cognition, language, motor, executive function, attention, etc). Should these features be removed as criteria? No. Sensitivity and specificity are not the correct metrics for determining inclusion or exclusion of diagnostic criteria. Prevalence, correlation with PAE and intercorrelations with one another are the proper metrics.

6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

4. The Canadian and Australian systems removed growth deficiency as a criterion for FASD despite the fact that growth deficiency is significantly associated with PAE, is more prevalent than the FAS facial features and microcephaly and is highly predictive of severe brain dysfunction among infants/toddlers with PAE (continued).

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ADVANCES IN PEDIATRIC RESEARCH

The essential role of growth deficiency in the diagnosis of fetal alcohol spectrum disorder

Susan J. Astley [1*], Julia M. Bledsoe [1], Julian K. Davies [1]

1 University of Washington, Seattle, WA, USA

Abstract

Background: Laboratory studies confirm prenatal alcohol exposure (PAE) causes growth deficiency (GD). GD has traditionally been a core diagnostic feature of fetal alcohol spectrum disorders (FASD), but was removed from the Canadian and Australian FASD diagnostic guidelines in 2016. This study aimed to empirically assess the clinical role and value of GD in FASD diagnosis.

Methods: Data from 1814 patients with FASD from the University of Washington Fetal Alcohol Syndrome Diagnostic & Prevention dataset were analyzed to answer the following questions: 1) Is there evidence of a causal association between PAE and GD in our clinical population? 2) Is GD sufficiently prevalent among individuals with PAE to warrant its inclusion as a diagnostic criterion? 3) Does GD aid the diagnostic team in identifying and/or predicting which individuals will be most impaired by their PAE?

Results: GD significantly correlated with PAE. GD was as prevalent as the other core diagnostic features (facial and CNS abnormalities). GD occurred in all FASD diagnoses and increased in prevalence with increasing severity of diagnosis. The most prevalent form of GD was postnatal short stature. GD was as highly correlated with, and predictive of, severe brain dysfunction as the FAS facial phenotype. Individuals with GD had a two to three-fold increased risk for severe brain dysfunction. Sixty percent of patients with severe GD had severe brain dysfunction. GD accurately predicted which infants presented with severe brain dysfunction later in childhood

Conclusions: GD is an essential diagnostic criterion for FASD and will remain in the FASD 4-Digit Code.

Citation: Astley SJ, Bledsoe JM, Davies JK (2016) The essential role of growth deficiency in the diagnosis of fetal alcohol spectrum disorder. Adv Pediatr Res 3:9. doi:10.12715/apr.2016.3.9

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Competing interests: The authors have declared that no competing interests exist.

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[*] Email: astley@uw.edu

Introduction

Fetal alcohol syndrome (FAS) is a birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The term FAS was first coined in 1973 [1,2], and is characterized by growth deficiency (GD), a specific cluster of minor facial anomalies, and central nervous system (CNS) structural and/or functional abnormalities. Not all individuals exposed to and damaged by prenatal alcohol exposure (PAE) have FAS. Rather, PAE causes growth, facial, and CNS abnormalities that each present along a continuum of abnormality from mild, moderate, to severe [3,4]. Taken together, these outcomes present along a continuum of diagnoses under the umbrella of fetal alcohol spectrum disorder (FASD): FAS, partial FAS (PFAS), static encephalopathy/alcohol-exposed

Advances in Pediatric Research 1 Astley et al. 2016 | 3:9

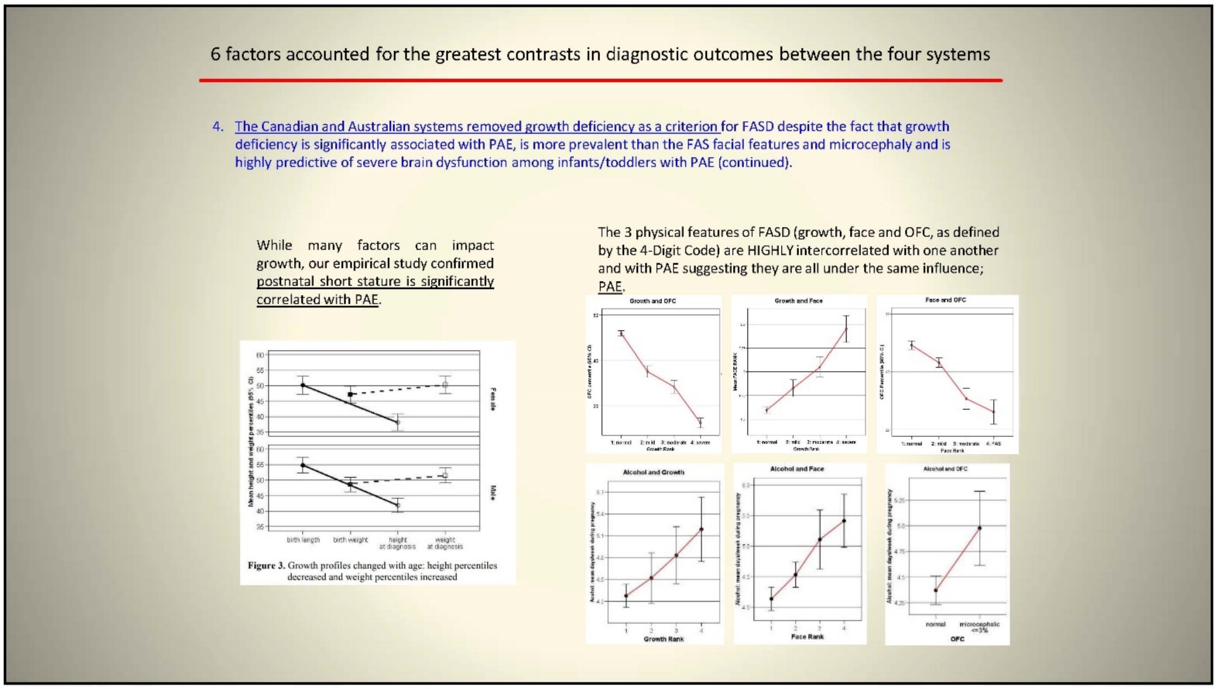
The importance of using empirical data to make diagnostic decisions cannot be over emphasized.

Decades of laboratory studies have unequivocally confirmed that PAE causes growth deficiency (GD).

In our empirical study of 1,814 patients with PAE:

GD significantly correlated with PAE. GD was more prevalent than the other core diagnostic features (facial and CNS abnormalities). GD occurred in all FASD diagnoses and increased in prevalence with increasing severity of diagnosis. The most prevalent form of GD was postnatal short stature. GD was as highly correlated with, and predictive of, severe brain dysfunction as the FAS facial phenotype. Individuals with GD had a two to three-fold increased risk for severe brain dysfunction. Sixty percent of patients with severe GD had severe brain dysfunction. GD accurately predicted which infants presented with severe brain dysfunction later in childhood

GD is an essential diagnostic criterion for FASD
and remains in the FASD 4-Digit Code



6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

4. The Canadian and Australian systems removed growth deficiency as a criterion for FASD despite the fact that growth deficiency is significantly associated with PAE, is more prevalent than the FAS facial features and microcephaly and is highly predictive of severe brain dysfunction among infants/toddlers with PAE (continued).

While many factors can impact growth, our empirical study confirmed postnatal short stature is significantly correlated with PAE.

Figure 3. Growth profiles changed with age: height percentiles decreased and weight percentiles increased

The 3 physical features of FASD (growth, face and OFC, as defined by the 4-Digit Code) are HIGHLY intercorrelated with one another and with PAE suggesting they are all under the same influence; PAE.

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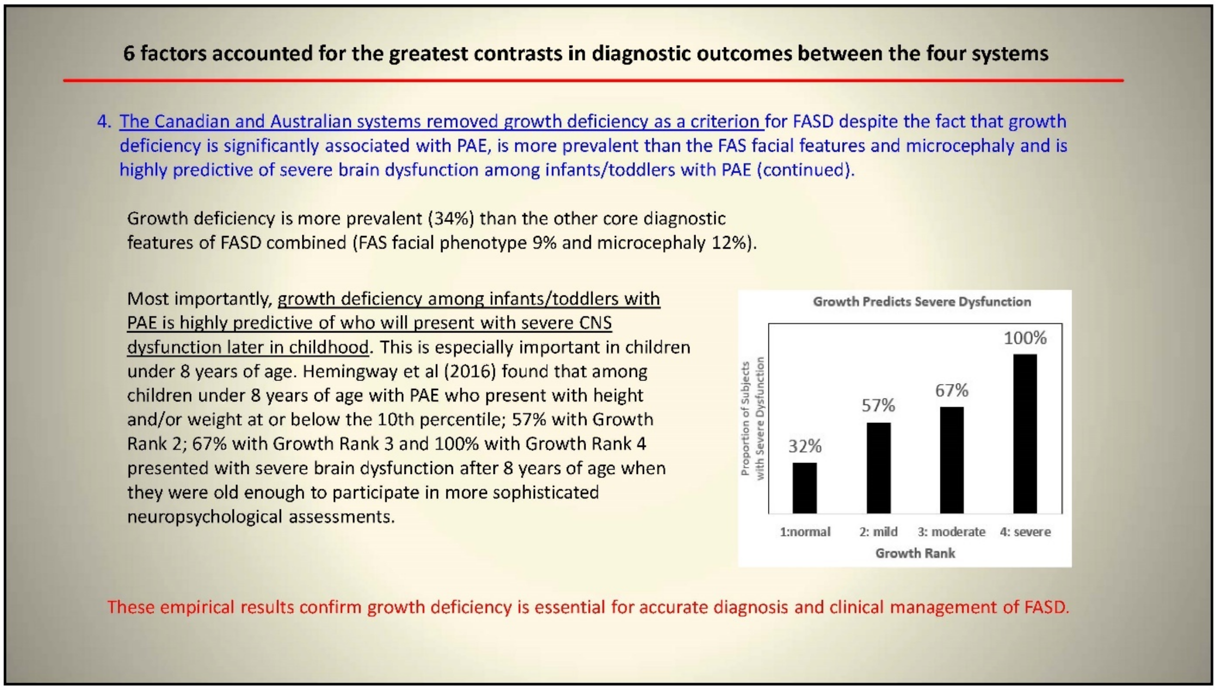

6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

4. The Canadian and Australian systems removed growth deficiency as a criterion for FASD despite the fact that growth deficiency is significantly associated with PAE, is more prevalent than the FAS facial features and microcephaly and is highly predictive of severe brain dysfunction among infants/toddlers with PAE (continued).

Growth deficiency is more prevalent (34%) than the other core diagnostic features of FASD combined (FAS facial phenotype 9% and microcephaly 12%).

Most importantly, growth deficiency among infants/toddlers with PAE is highly predictive of who will present with severe CNS dysfunction later in childhood. This is especially important in children under 8 years of age. Hemingway et al (2016) found that among children under 8 years of age with PAE who present with height and/or weight at or below the 10th percentile; 57% with Growth Rank 2; 67% with Growth Rank 3 and 100% with Growth Rank 4 presented with severe brain dysfunction after 8 years of age when they were old enough to participate in more sophisticated neuropsychological assessments.

These empirical results confirm growth deficiency is essential for accurate diagnosis and clinical management of FASD.

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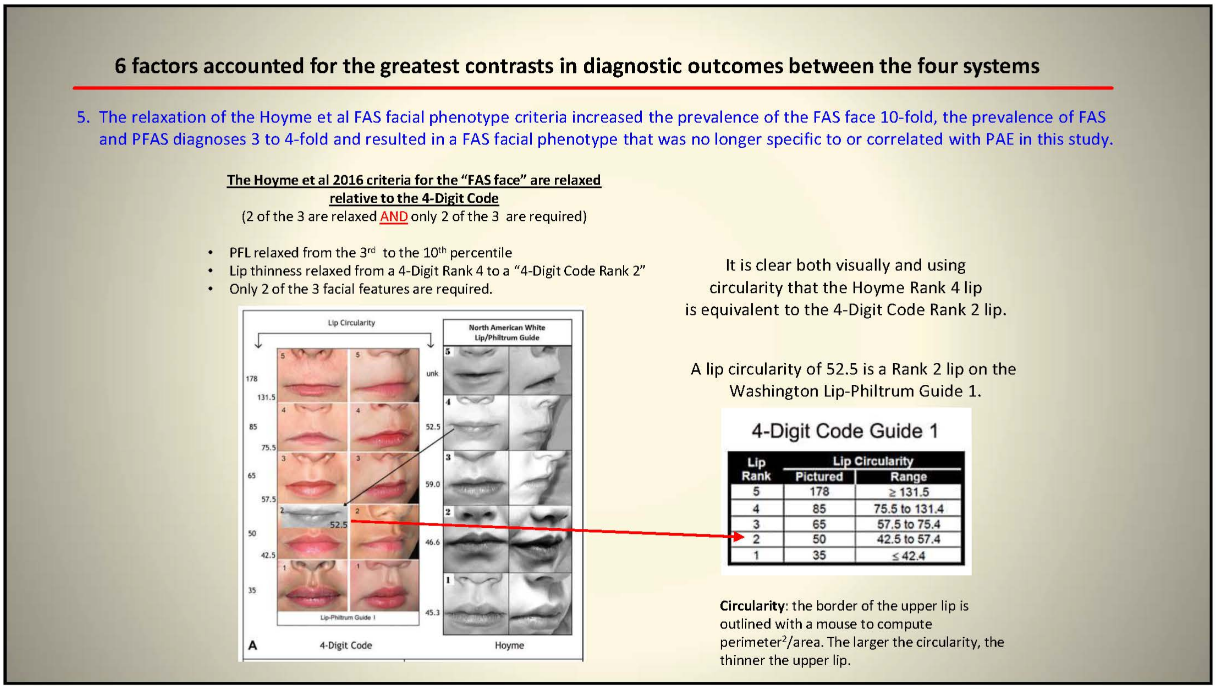

6 factors accounted for the greatest contrasts in diagnostic outcomes between the four systems

5. The relaxation of the Hoyme et al FAS facial phenotype criteria increased the prevalence of the FAS face 10-fold, the prevalence of FAS and PFAS diagnoses 3 to 4-fold and resulted in a FAS facial phenotype that was no longer specific to or correlated with PAE in this study.

The Hoyme et al 2016 criteria for the "FAS face" are relaxed relative to the 4-Digit Code

(2 of the 3 are relaxed AND only 2 of the 3 are required)

- PFL relaxed from the 3rd to the 10th percentile
- Lip thinness relaxed from a 4-Digit Rank 4 to a "4-Digit Code Rank 2"
- Only 2 of the 3 facial features are required.

It is clear both visually and using circularity that the Hoyme Rank 4 lip is equivalent to the 4-Digit Code Rank 2 lip.

A lip circularity of 52.5 is a Rank 2 lip on the Washington Lip-Philtrum Guide 1.

4-Digit Code Guide 1

Lip Rank	Lip Circularity	
	Pictured	Range
5	178	≥ 131.5
4	85	75.5 to 131.4
3	65	57.5 to 75.4
2	50	42.5 to 57.4
1	35	≤ 42.4

Circularity: the border of the upper lip is outlined with a mouse to compute perimeter^2/area. The larger the circularity, the thinner the upper lip.

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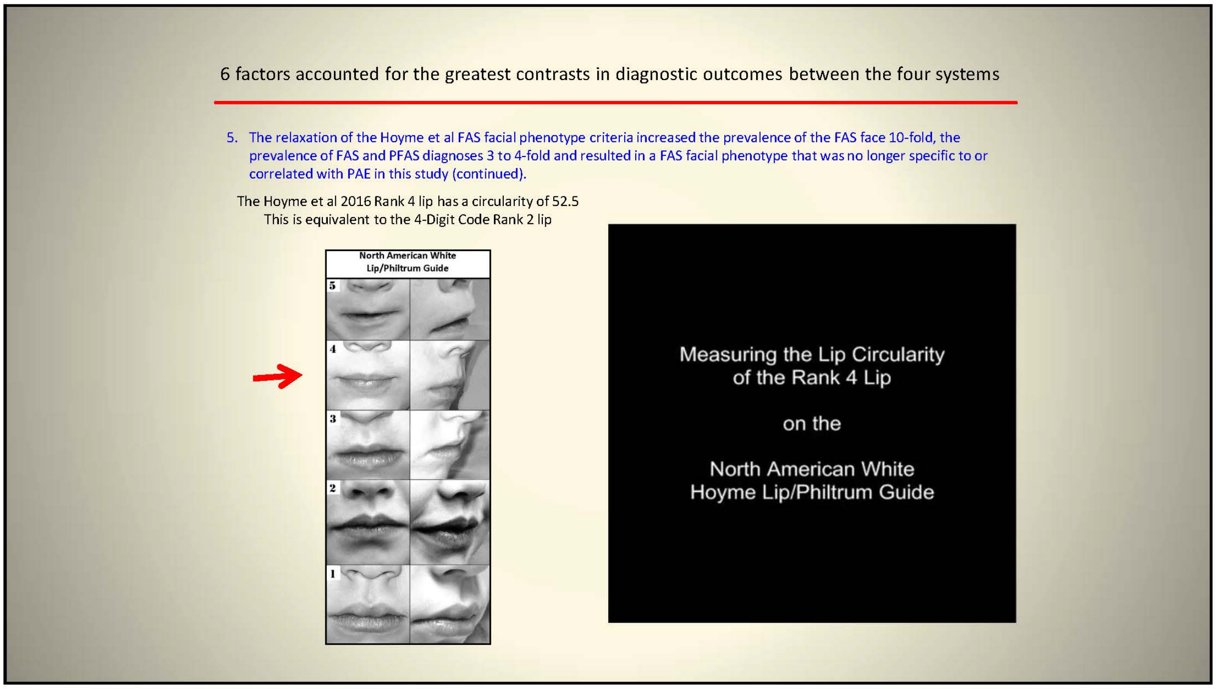

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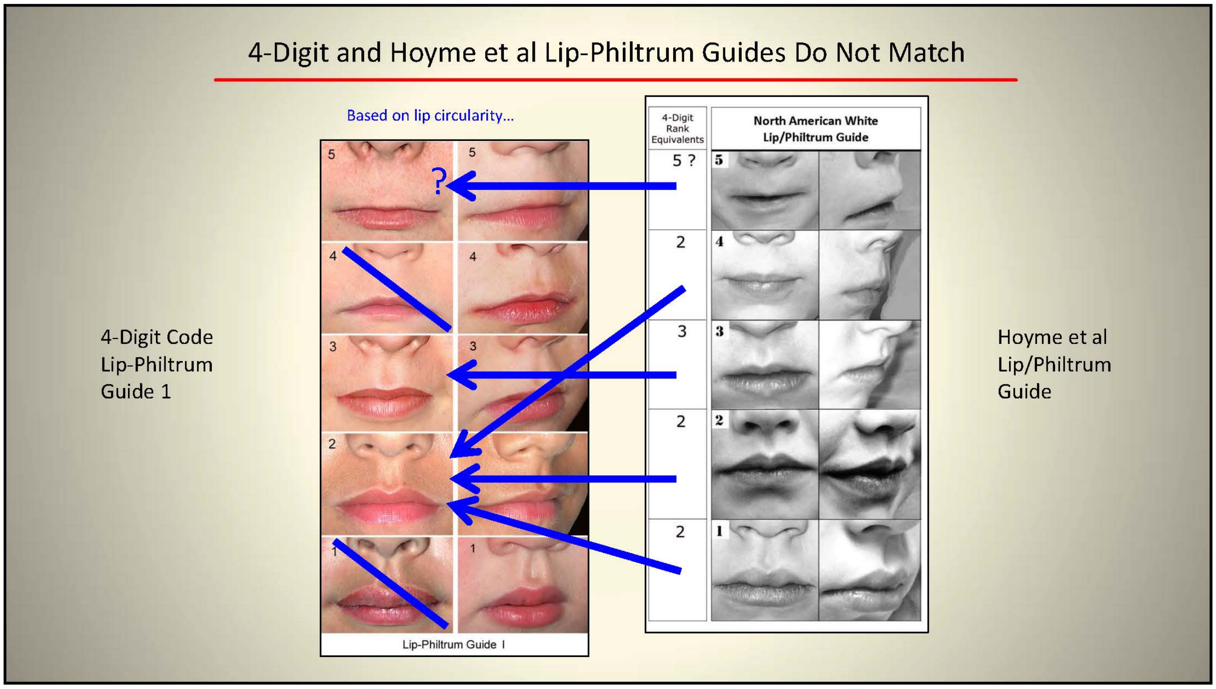
The Hoyme et al 2016 Rank 4 lip has a circularity of 52.5
This is equivalent to the 4-Digit Code Rank 2 lip

Measuring the Lip Circularity of the Rank 4 Lip

on the

North American White Hoyme Lip/Philtrum Guide

24

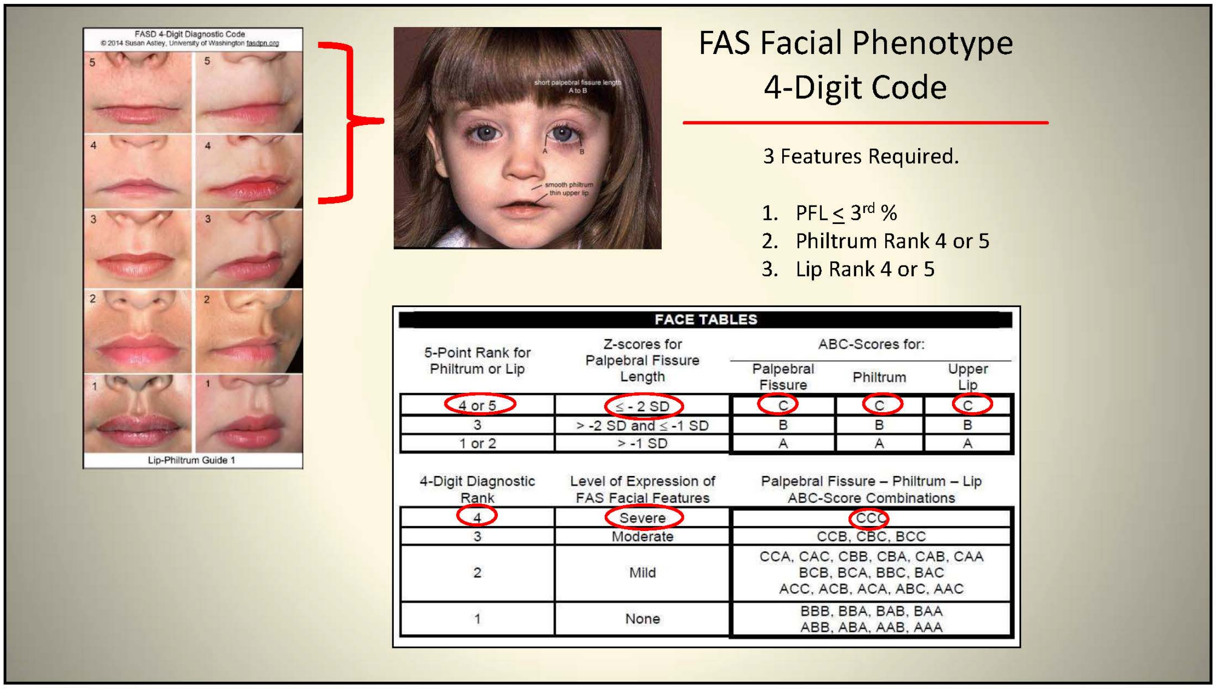


4-Digit and Hoyme et al Lip-Philtrum Guides Do Not Match

Based on lip circularity…

4-Digit Code Lip-Philtrum Guide 1

Hoyme et al Lip/Philtrum Guide



FAS Facial Phenotype 4-Digit Code

3 Features Required.

1. PFL ≤ 3rd %
2. Philtrum Rank 4 or 5
3. Lip Rank 4 or 5

FACE TABLES

5-Point Rank for Philtrum or Lip	Z-scores for Palpebral Fissure Length	ABC-Scores for: Palpebral Fissure	ABC-Scores for: Philtrum	ABC-Scores for: Upper Lip
4 or 5	≤ - 2 SD	C	C	C
3	> -2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

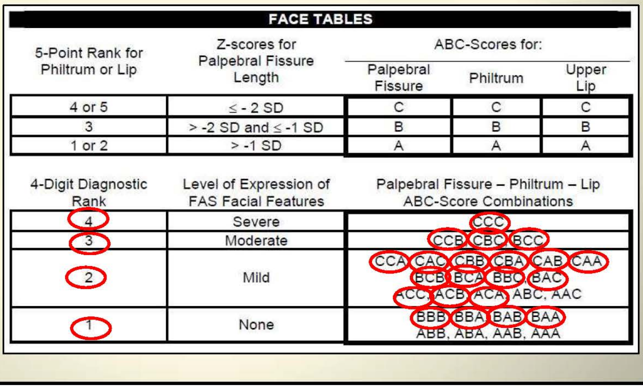
FAS Facial Phenotype
Hoyme et al 2016

Hoyme et al
Lip Ranks 4-5
equivalent to
4-Digit
Lip Ranks 2-5

Hoyme et al., 2016

Only 2 features required and
2 of the 3 relaxed from 4-Digit Code.

1. PFL ≤ 10th %
2. Philtrum Rank 4 or 5
3. 4-Digit Lip Ranks 2-5



FACE TABLES

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4 or 5	≤ - 2 SD	C	C	C
3	> -2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

Hoyme et al FAS facial
phenotype relaxed all the
way into the
4-Digit Code normal range
(Face Rank 1)

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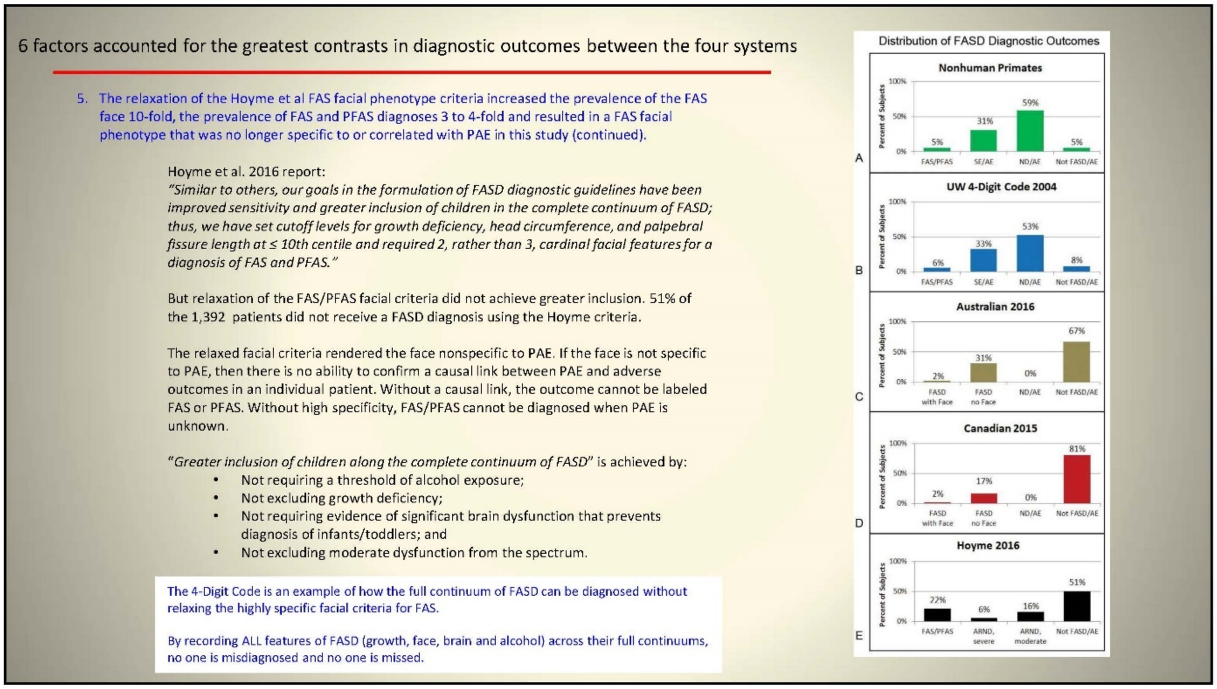
5. The relaxation of the Hoyme et al FAS facial phenotype criteria increased the prevalence of the FAS face 10-fold, the prevalence of FAS and PFAS diagnoses 3 to 4-fold and resulted in a FAS facial phenotype that was no longer specific to or correlated with PAE in this study (continued).

A. The Hoyme system classified 10 times more individuals with the FAS facial phenotype (n=552) than the 4-Digit Code (n=54).

B. The Hoyme system produced 14 times more FAS/PFAS diagnoses with unknown alcohol exposure (n=111) than the 4-Digit Code (n=6). This is particularly concerning because 68 (61%) of these patients had 4-Digit Code Rank 1 or Rank 2 facial phenotypes that are, by our definition, clinically "normal". The Rank 1 and 2 phenotypes have no specificity to PAE and therefore cannot be used to confirm PAE when the history of exposure is unknown.

C. 70% of the 296 Hoyme FAS/PFAS cases had "normal" facial phenotypes (4-Digit Code Face Ranks 1 or 2).

D. 43% of the 552 patients with the Hoyme FAS face did not receive a diagnosis under the umbrella of FASD using the Hoyme system. In contrast, all 54 individuals with the 4-Digit Code Rank 4 FAS face met criteria for a diagnosis under the umbrella of FASD using the 4-Digit Code.



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Hoyme et al. 2016 report:
"Similar to others, our goals in the formulation of FASD diagnostic guidelines have been improved sensitivity and greater inclusion of children in the complete continuum of FASD; thus, we have set cutoff levels for growth deficiency, head circumference, and palpebral fissure length at ≤ 10th centile and required 2, rather than 3, cardinal facial features for a diagnosis of FAS and PFAS."

But relaxation of the FAS/PFAS facial criteria did not achieve greater inclusion. 51% of the 1,392 patients did not receive a FASD diagnosis using the Hoyme criteria.

The relaxed facial criteria rendered the face nonspecific to PAE. If the face is not specific to PAE, then there is no ability to confirm a causal link between PAE and adverse outcomes in an individual patient. Without a causal link, the outcome cannot be labeled FAS or PFAS. Without high specificity, FAS/PFAS cannot be diagnosed when PAE is unknown.

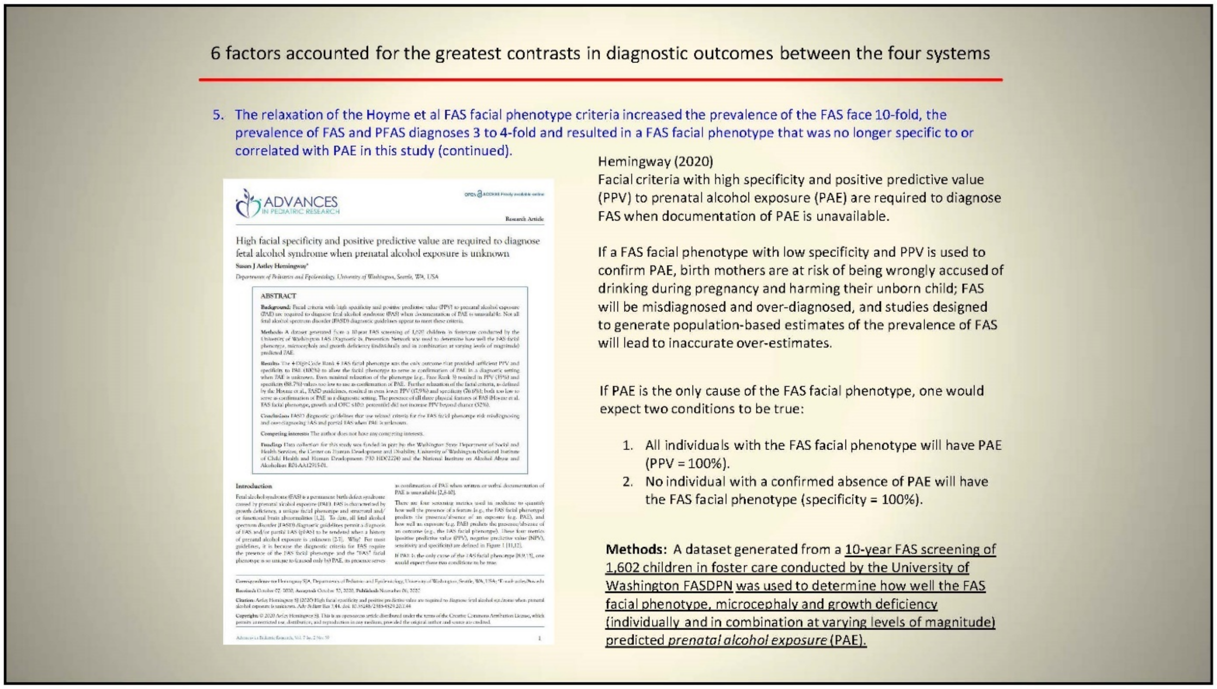
"*Greater inclusion of children along the complete continuum of FASD*" is achieved by:

- Not requiring a threshold of alcohol exposure;
- Not excluding growth deficiency;
- Not requiring evidence of significant brain dysfunction that prevents diagnosis of infants/toddlers; and
- Not excluding moderate dysfunction from the spectrum.

The 4-Digit Code is an example of how the full continuum of FASD can be diagnosed without relaxing the highly specific facial criteria for FAS.

By recording ALL features of FASD (growth, face, brain and alcohol) across their full continuums, no one is misdiagnosed and no one is missed.

Distribution of FASD Diagnostic Outcomes



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ADVANCES IN PEDIATRIC RESEARCH

Research Article

High facial specificity and positive predictive value are required to diagnose fetal alcohol syndrome when prenatal alcohol exposure is unknown

Susan J Astley Hemingway*

Department of Pediatrics and Epidemiology, University of Washington, Seattle, WA, USA

ABSTRACT

Hemingway (2020)
Facial criteria with high specificity and positive predictive value (PPV) to prenatal alcohol exposure (PAE) are required to diagnose FAS when documentation of PAE is unavailable.

If a FAS facial phenotype with low specificity and PPV is used to confirm PAE, birth mothers are at risk of being wrongly accused of drinking during pregnancy and harming their unborn child; FAS will be misdiagnosed and over-diagnosed, and studies designed to generate population-based estimates of the prevalence of FAS will lead to inaccurate over-estimates.

If PAE is the only cause of the FAS facial phenotype, one would expect two conditions to be true:

1. All individuals with the FAS facial phenotype will have PAE (PPV = 100%).
2. No individual with a confirmed absence of PAE will have the FAS facial phenotype (specificity = 100%).

Methods: A dataset generated from a 10-year FAS screening of 1,602 children in foster care conducted by the University of Washington FASDPN was used to determine how well the FAS facial phenotype, microcephaly and growth deficiency (individually and in combination at varying levels of magnitude) predicted *prenatal alcohol exposure* (PAE).

University of Washington FASDPN Website
www.fasdpn.org

FAS DPN: established 1993
Center on Human Development & Disability
University of Washington, Seattle WA

VALIDATION of the FASD 4-Digit Code

- Free Lip-Philtrum Guides with 3/4 views for iPhone/Tablet
- (2017) Comparison of 4-Digit Code & Hoyme Diag Systems
- (2016) Growth deficiency essential in FASD Diagnosis
- (2016) Updated FAS Facial Analysis Software
- Video introduction to FAS Facial Photo Analysis Software
- (2015) AAP recognizes FASDPN as national/international leader
- (2014) FASD Recommendations to WA Legislature
- (2014) Astley testimony to WA Legislature on FASD
- (2014) Value of a FASD Diagnosis: 20 yrs of Parent Surveys
- (2013) Validation of the FASD 4-Digit Code
- (2010) Profile of 1,400 WA FAS DPN Patients with FASD
- When is a philtrum Rank 4 or Rank 5?
- Animated Facial Photography and Measurement Instruction
- (2004) 4-Digit Diagnostic Code
- FASD Prevention: Evidence of Success
- 4-Digit Code Online Course (over 1000 graduates)
- Palpebral fissure length measurement accuracy.
- PFL Z-score Calculator & Which Norms to Use

Interact with FASDPN Tableau Dashboards

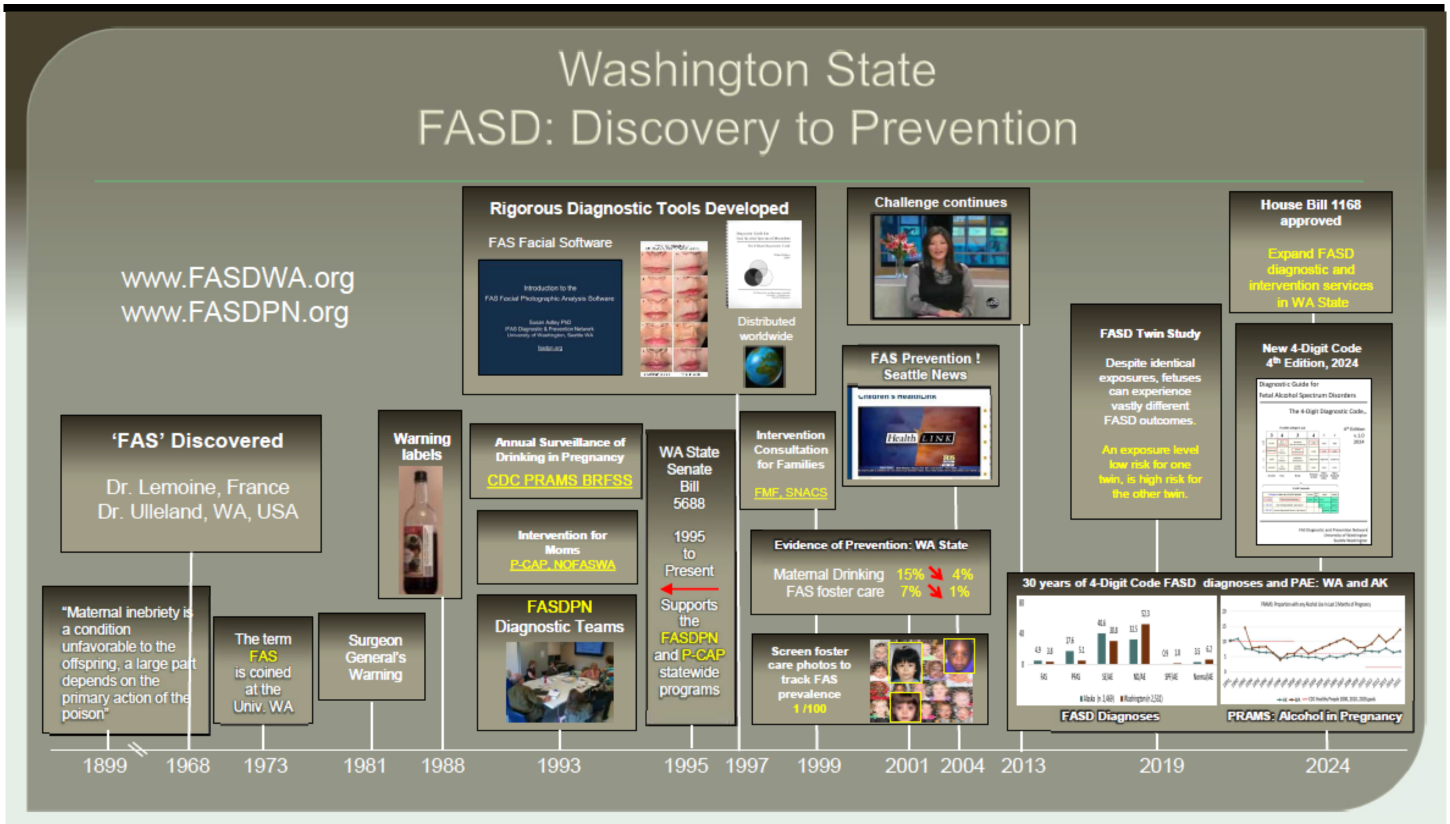
Interact with our FASDPN Tableau Dashboards

http://depts.washington.edu/fasdpn/htmls/Tableau-FASDPN.htm

C6

FASD in Washington State: A 50-Year Reflection

Susan Hemingway



Washington State
FASD: Discovery to Prevention

www.FASDWA.org
www.FASDPN.org

‘FAS’ Discovered
Dr. Lemoine, France
Dr. Ulleland, WA, USA

“Maternal inebriety is a condition unfavorable to the offspring, a large part depends on the primary action of the poison”

The term FAS is coined at the Univ. WA

Surgeon General’s Warning

Warning labels

Annual Surveillance of Drinking in Pregnancy
CDC PRAMS BRFSS

Intervention for Moms
P-CAP, NOFASWA

FASDPN Diagnostic Teams

Rigorous Diagnostic Tools Developed
FAS Facial Software

Introduction to the
FAS Facial Photographic Analysis Software
Susan Astley PhD
FAS Diagnostic & Prevention Network
University of Washington, Seattle WA

Distributed worldwide

WA State Senate Bill 5688
1995 to Present
Supports the FASDPN and P-CAP statewide programs

Intervention Consultation for Families
FMF, SNACS

Challenge continues

FAS Prevention ! Seattle News

Evidence of Prevention: WA State
Maternal Drinking 15% ↘ 4%
FAS foster care 7% ↘ 1%

Screen foster care photos to track FAS prevalence 1 /100

FASD Twin Study
Despite identical exposures, fetuses can experience vastly different FASD outcomes.
An exposure level low risk for one twin, is high risk for the other twin.

House Bill 1168 approved
Expand FASD diagnostic and intervention services in WA State

New 4-Digit Code 4th Edition, 2024

Diagnostic Guide for
Fetal Alcohol Spectrum Disorders
The 4-Digit Diagnostic Code
4th Edition
v.1.0
2024

30 years of 4-Digit Code FASD diagnoses and PAE: WA and AK

FASD Diagnoses

PRAMS: Alcohol in Pregnancy

D1b

FASD in Canadian Criminal Cases: A Case Law Review

Kaitlyn McLachlan

D1c

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

Dorothy Reid

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

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

CanFASD

1

THE UNIVERSITY OF BRITISH COLUMBIA

8th International Research Conference on Adolescents and Adults with FASD

Review, Respond and Relate

Integrating Research, Policy and Practice Around the World

April 18-21, 2018

The Hyatt Regency Vancouver
Vancouver, BC, Canada

Presented by

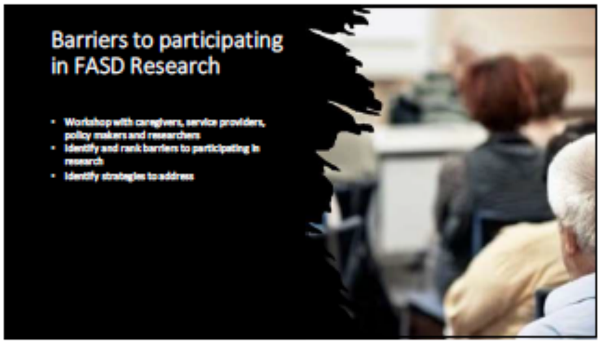
It all started in 2018

2

Our team

- Dorothy Reid
  - CanFASD Family Advisory Committee
- Michelle Stewart
  - University of Regina
  - CanFASD Justice lead
- Lisa Brownstone
  - CanFASD Board of Directors
- Niall Schofield
  - CanFASD Adult Expert Collaboration Team

3



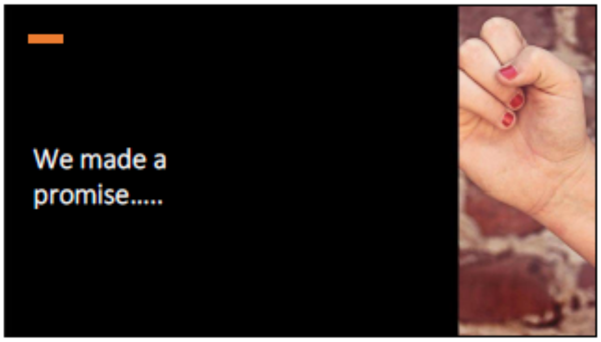
Barriers to participating in FASD Research

- Workshop with caregivers, service providers, policy makers and researchers
- Identify and rank barriers to participating in research
- Identify strategies to address

4

- Workshop with the adults adolescents attending the conference
- What are the barriers from their perspective
- How can those barriers be overcome
- What are their priorities for FASD research

5



We made a promise.....

6

Since then.....

Journal of Fetal Alcohol Spectrum Disorder

Intervention, Prevention, Diagnosis, Welfare and Justice

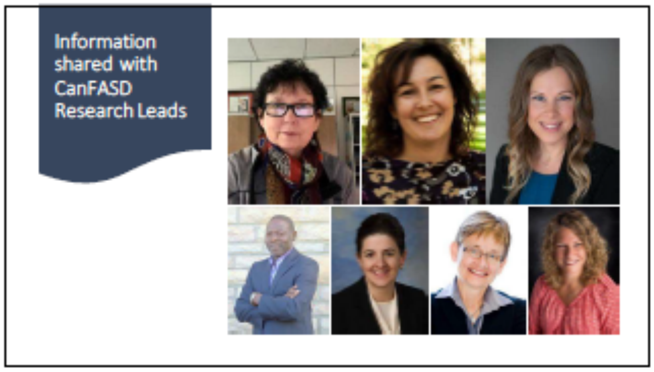
ORIGINAL ARTICLE
DOI:10.22374/jfasrp.v4iSP1.14

NOTHING ABOUT US WITHOUT US: ESSENTIAL CONSIDERATIONS FOR COLLABORATIVE FASD RESEARCH

Dorothy Reid[1*], Lisa Brownstone[2], Michelle Stewart[3], Niall Schofield[4], Robyn Pitawanakwat[5]

[1]Co-Chair of the CanFASD Family Advisory Committee
[2]Occupational Therapist (retired)
[3]Associate Professor, Department of Gender, Religion and Critical Studies; University of Regina
[4]Project manager for BMX track build Saskatoon, Motivational Speaker, Clothing Designer
[5]Integrated Justice Program, FASD Network of Saskatchewan

*Corresponding Author: Dorothy Reid: reidwellness@gmail.com

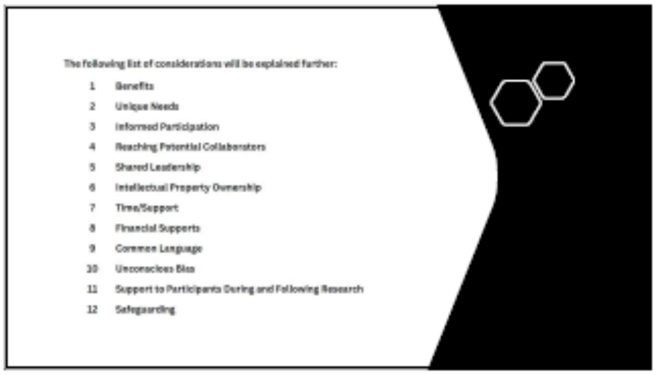


Information shared with CanFASD Research Leads

Knowledge mobilization

Considerations When Planning Collaborative Research in FASD

Information for Research Teams



The following list of considerations will be explained further:

1 Benefits
2 Unique Needs
3 Informed Participation
4 Reaching Potential Collaborators
5 Shared Leadership
6 Intellectual Property Ownership
7 Time/Support
8 Financial Supports
9 Common Language
10 Unconscious Bias
11 Support to Participants During and Following Research
12 Safeguarding

benefits

1 Benefits

- Have you considered any potential benefits for the collaborators?
- Can you describe the potential benefits (and risks) in an understandable way?
- Are the benefits of participation worth it? For example, will the outcome support the advocacy for more services or supports?
- Have you conversed with collaborators about what would make research participation worth it for them? For example, collaborators [illegible]

Shared Leadership

Collaboration requires shared leadership through all the stages of the research.

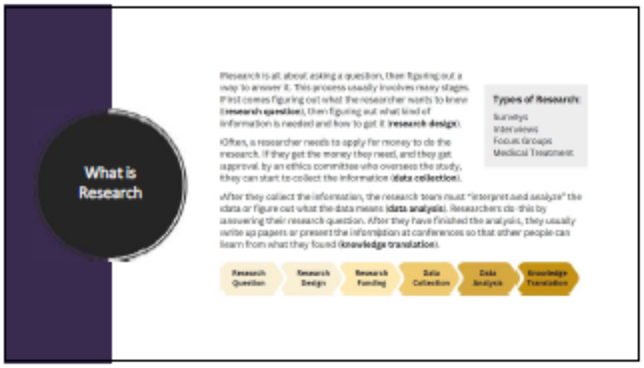
- How are you fully incorporating the voice of individuals with lived experience in your research plan? Keep in mind that fully incorporating collaborators' voices means addressing collaborator priorities in your research questions/objectives.
- Are there opportunities for people with lived experience to help shape your research question, methods, and/or knowledge translation?
- Have you had conversations with collaborators to understand their expectations with respect to shared leadership?
- How are you providing space for collaborators to share their knowledge and expertise throughout the research process?


2023

Guide for individuals with FASD and Caregivers

When You are Asked to Take Part in Research

CanFASD


What is Research

Research is all about asking a question, then figuring out a way to answer it. This process usually involves many stages. First comes figuring out what the researcher wants to know (**research question**), then figuring out what kind of information is needed and how to get it (**research design**).

Often, a researcher needs to apply for money to do the research. If they get the money they need, and they get approval by an ethics committee who oversees the study, they can start to collect the information (**data collection**).

After they collect the information, the research team must "interpret and analyze" the data or figure out what the data means (**data analysis**). Researchers do this by answering their research question. After they have finished the analysis, they usually write up papers or present the information at conferences so that other people can learn from what they found (**knowledge translation**).

Types of Research:
Surveys
Interviews
Focus Groups
Medical Treatment

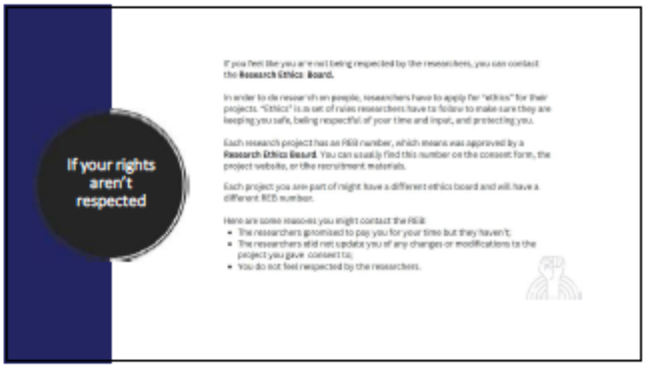

How Can You be Involved in Research?

There are two main ways of being involved in research.

1. **As a Participant:**
   - The researcher does all the work setting up the re
They might ask you to participate in a project as a
2. **As a Collaborator:**
   - The researcher meets with people with FASD and
to help create the research project. For example,
ask for your help in deciding what topic area to e:
for your advice on what the research question sh


Key considerations

Respect and Dignity
Support
Written Description of Research
Informed Consent
Agreeing to Take Part in Research
Payment
Description of the Researcher


If your rights aren't respected

If you feel like you are not being respected by the researchers, you can contact the **Research Ethics Board.**

In order to do research on people, researchers have to apply for "ethics" for their projects. "Ethics" is a set of rules researchers have to follow to make sure they are keeping you safe, being respectful of your time and input, and protecting you.

Each research project has an REB number, which means was approved by a **Research Ethics Board**. You can usually find this number on the consent form, the project website, or the recruitment materials.

Each project you are part of might have a different ethics board and will have a different REB number.

Here are some reasons you might contact the REB:
- The researchers promised to pay you for your time but they haven't;
- The researchers did not update you of any changes or modifications to the project you gave consent to;
- You do not feel respected by the researchers.


Checklist

☐ **I know what this research is about**

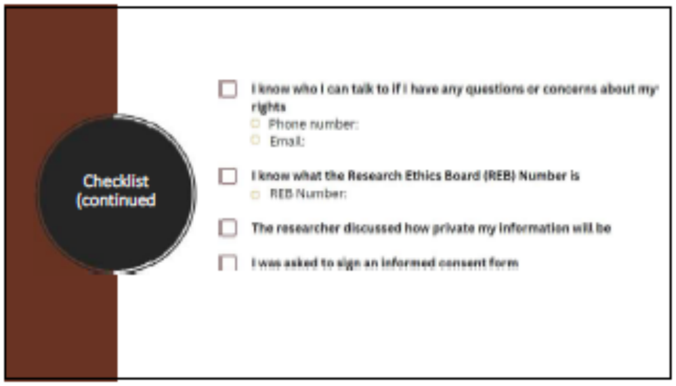
☐ **I know who the researcher(s) is and their background**
- Name of researcher(s):

☐ **I know how I will participate in this research**

☐ **I know approximately how long the research will take**
- Timeline:

☐ **I know what the risk are to me if I do this research**
- Risks:

☐ **I have asked what money I will get for being part of this research**
- Payment/compensation:



Checklist (continued

☐ I know who I can talk to if I have any questions or concerns about my rights
  - Phone number:
  - Email:

☐ I know what the Research Ethics Board (REB) Number is
  - REB Number:

☐ The researcher discussed how private my information will be

☐ I was asked to sign an informed consent form

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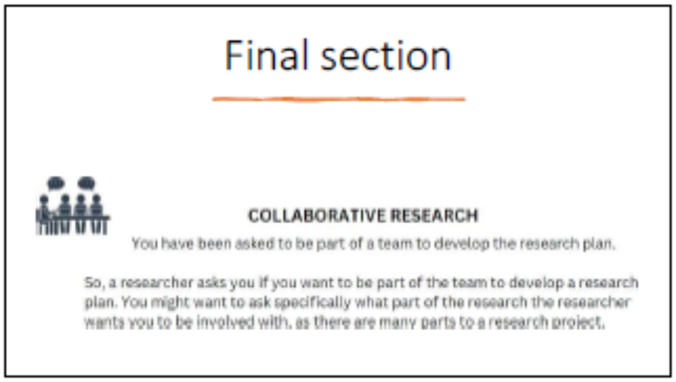

Final section

COLLABORATIVE RESEARCH

You have been asked to be part of a team to develop the research plan.

So, a researcher asks you if you want to be part of the team to develop a research plan. You might want to ask specifically what part of the research the researcher wants you to be involved with, as there are many parts to a research project.

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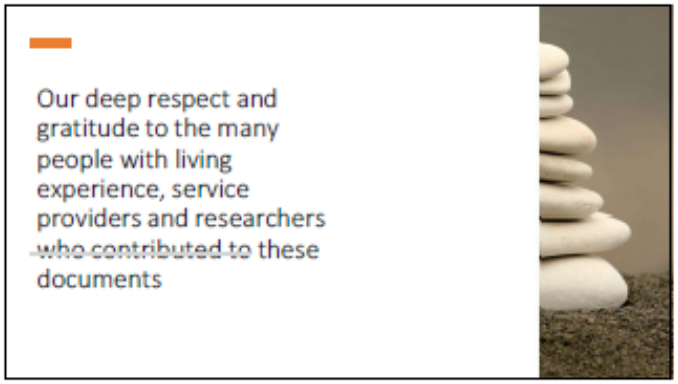

Our deep respect and gratitude to the many people with living experience, service providers and researchers who contributed to these documents

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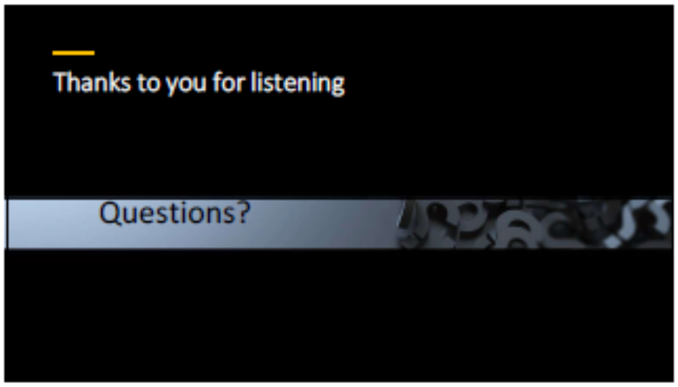

Thanks to you for listening

Questions?

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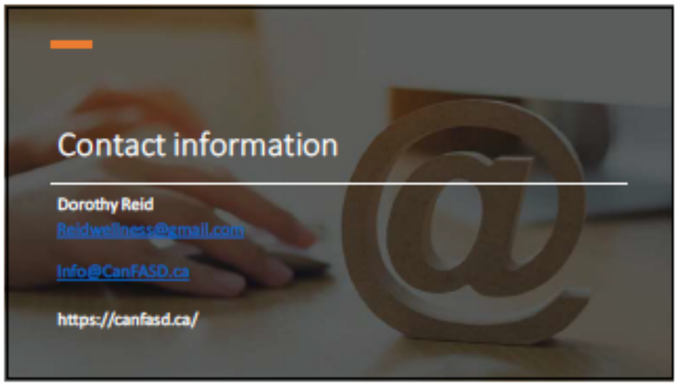

Contact information

Dorothy Reid

Reidwellness@gmail.com

Info@CanFASD.ca

https://canfasd.ca/

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D1d

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

Christina Tortorelli

D2

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

Katherine Fitzpatrick, Dan Dubovsky

It is well recognized that individuals with FASD may have co-occurring mental health issues. We know that the earlier these are recognized and treated properly, the better the long term outcomes. However, many times, the FASD people is not recognized and either the individual receives mental health diagnoses that are inaccurate or, even if accurate, the treatment is not modified taking into account the FASD. In either of these instances, the treatment provided is not optimal.

The State of Michigan recognized the need to correctly identify youth with FASD in order to provide the best services to them and their families. As a result, the Department of Health and Human Services initiated an FASD Initiative. The focus of this initiative has been to develop a screening, assessment, and intervention protocol that can be implemented county by county throughout the state. A quick screen of 5 to 6 questions was developed that could be asked by any trained community mental health provider. If the screen is positive, an assessment (based on the Life History Screen) for children who are birth to 5 years old or 6-21 years old is completed by an FASD informed clinician. A strengths assessment is also completed. Both the assessment and the strengths assessment are completed by both the youth 12-21 years old and their caregivers (separately) when appropriate for the youth's functioning. If the assessment is positive, the family is referred to an intervention approach. This protocol has been implemented in a number of counties in the state so far.

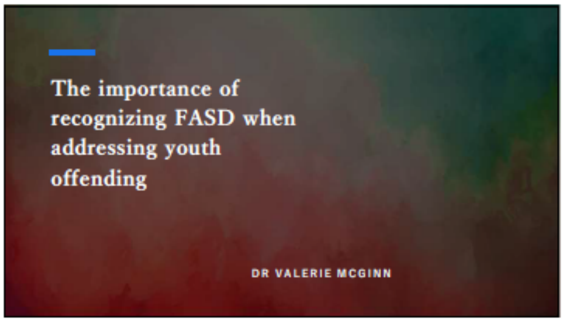
This session details the process of developing and implementing the FASD initiative in the state as well as the screening, assessment, and intervention protocol. Findings thus far, along with a discussion of barriers throughout the process and attempts to overcome them are examined. Discussion about the importance of this protocol and how it can be implemented in other settings is encouraged.

D3

A Community Initiative to Increase Well-being and Reduce Recidivism in Youth Offenders with FASD

Sam Galloway, Maria Pecotić, Valerie McGinn

START TARANAKI
Seattle FASD
Conference 2024
PRESENTATION

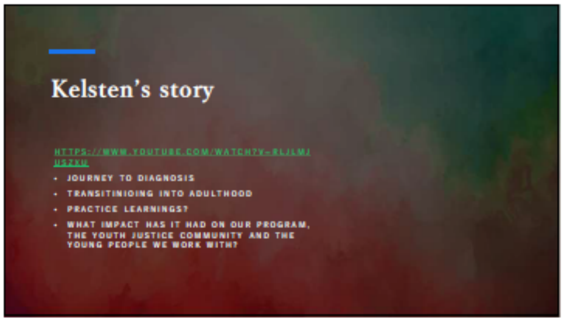


The importance of recognizing FASD when addressing youth offending

DR VALERIE MCGINN

What is S.T.A.R.T Taranaki

- HISTORY
- PROGRAMMES
- FASD INFORMED APPROACH
- EDUCATION, STORIES, RESOURCES AND FUNDING MODELS



Kelsten's story

HTTPS://WWW.YOUTUBE.COM/WATCH?V=RLJLMJUSZXU

- JOURNEY TO DIAGNOSIS
- TRANSITINIOING INTO ADULTHOOD
- PRACTICE LEARNINGS?
- WHAT IMPACT HAS IT HAD ON OUR PROGRAM, THE YOUTH JUSTICE COMMUNITY AND THE YOUNG PEOPLE WE WORK WITH?

D4

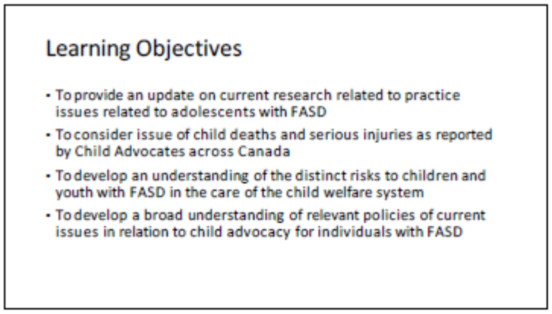
FASD Across the Lifespan Research Including a Report on Adolescent Deaths and Serious Injuries with Prenatal Substance Exposure/FASD in Child Advocate Reports in Canada: A Systematic Review

Dorothy Badry

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

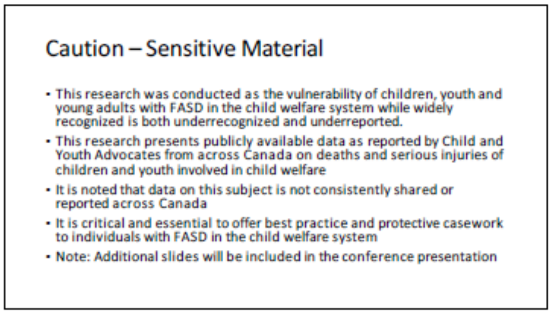
Presentation to the 9th International Research Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorders
Seattle, Washington
April 11-14, 2024

Dorothy Badry, PhD, MSW, RSW, University of Calgary, CanFASD
Peter Choate, PhD, RSW, Mount Royal University
Chris Tortorelli, MA, RSW, Mount Royal University
Kirsten Morrison, Research Assistant, CanFASD Research Network



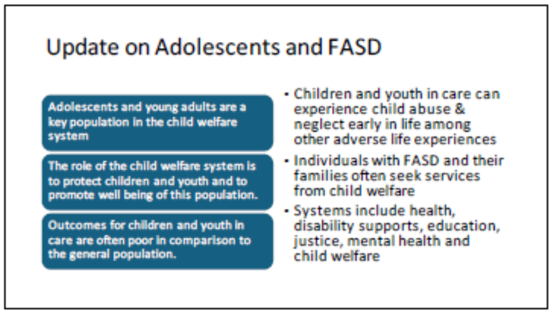
Learning Objectives

- To provide an update on current research related to practice issues related to adolescents with FASD
- To consider issue of child deaths and serious injuries as reported by Child Advocates across Canada
- To develop an understanding of the distinct risks to children and youth with FASD in the care of the child welfare system
- To develop a broad understanding of relevant policies of current issues in relation to child advocacy for individuals with FASD



Caution – Sensitive Material

- This research was conducted as the vulnerability of children, youth and young adults with FASD in the child welfare system while widely recognized is both underrecognized and underreported.
- This research presents publicly available data as reported by Child and Youth Advocates from across Canada on deaths and serious injuries of children and youth involved in child welfare
- It is noted that data on this subject is not consistently shared or reported across Canada
- It is critical and essential to offer best practice and protective casework to individuals with FASD in the child welfare system
- Note: Additional slides will be included in the conference presentation



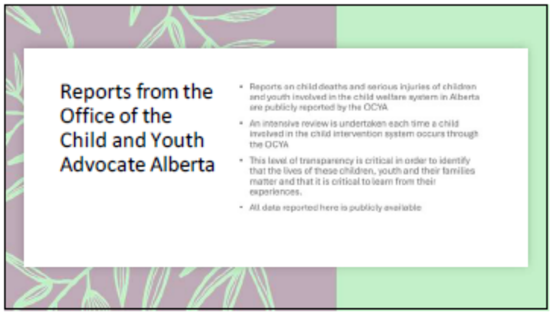
Update on Adolescents and FASD

Adolescents and young adults are a key population in the child welfare system

The role of the child welfare system is to protect children and youth and to promote well being of this population.

Outcomes for children and youth in care are often poor in comparison to the general population.

- Children and youth in care can experience child abuse & neglect early in life among other adverse life experiences
- Individuals with FASD and their families often seek services from child welfare
- Systems include health, disability supports, education, justice, mental health and child welfare



Reports from the Office of the Child and Youth Advocate Alberta

- Reports on child deaths and serious injuries of children and youth involved in the child welfare system in Alberta are publicly reported by the OCYA
- An intensive review is undertaken each time a child involved in the child intervention system occurs through the OCYA
- This level of transparency is critical in order to identify that the lives of these children, youth and their families matter and that it is critical to learn from their experiences.
- All data reported here is publicly available

Challenges for youth with FASD in the child welfare system

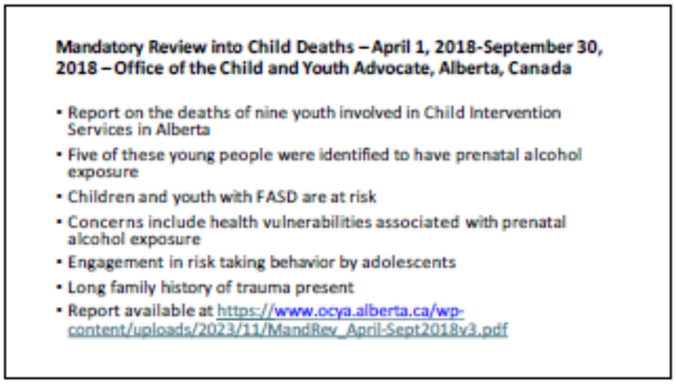
Service providers may not be disability informed and have no knowledge of FASD

Given children and youth with FASD are more likely to intersect with the child welfare system a alack of knowledge of FASD is a risk

Children and youth with disabilities are at higher risk of abuse than other children

Children and youth with disabilities are at greater vulnerability to the impacts of adversity

Meeting the complex and varied needs of child and youth with FASD is a challenge for the child welfare system



Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada

- Report on the deaths of nine youth involved in Child Intervention Services in Alberta
- Five of these young people were identified to have prenatal alcohol exposure
- Children and youth with FASD are at risk
- Concerns include health vulnerabilities associated with prenatal alcohol exposure
- Engagement in risk taking behavior by adolescents
- Long family history of trauma present
- Report available at https://www.ocya.alberta.ca/wp-content/uploads/2023/11/MandRev_April-Sept2018v3.pdf

Child and Youth Advocates in Canada

ALBERTA	BRITISH COLUMBIA	MANITOBA
Office of the Child and Youth Advocate (OCYA)	Representative for Children and Youth	Children's Advocate
NEW BRUNSWICK	NEWFOUNDLAND AND LABRADOR	NORTHWEST TERRITORIES
Office of the Child, Youth and Seniors Advocate	Child and Youth Advocate	No independent child advocate
NOVA SCOTIA	NUNAVUT	ONTARIO
Office of the Ombudsman (The Office of the Ombudsman has a child and youth mandate)	Representative for Children and Youth	No independent child advocate
PRINCE EDWARD ISLAND	QUEBEC	SASKATCHEWAN
No independent child advocate	Commission des droits de la personne et des droits de la jeunesse	Advocate for Children and Youth
YUKON		
Yukon Child and Youth Advocate Office		

Child and youth advocates in canada

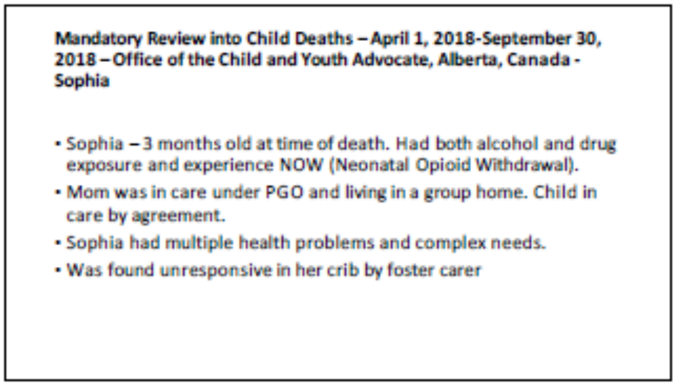
- Play a key role in highlighting problems for children and youth with FASD engaged in the child welfare systems
- Youth with FASD often "crossover" between the child welfare and justice systems
- Child advocates often document the deaths of children with FASD in the child welfare system of Canada

What does exist in public policy in Canada

- A national review of each province and territory and relevant child welfare legislation was reviewed as well as any reports relevant to FASD across Canada
- Reports from Child Advocates across Canada often identify the challenges children, youth and adults with FASD face in the child welfare system and in transitioning to adulthood

The child welfare research portal canada

- The child welfare research portal offers an entry point to reviewing relevant child welfare policy and legislation across Canada
- https://cwrp.ca/



Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Sophia

- Sophia – 3 months old at time of death. Had both alcohol and drug exposure and experience NOW (Neonatal Opioid Withdrawal).
- Mom was in care under PGO and living in a group home. Child in care by agreement.
- Sophia had multiple health problems and complex needs.
- Was found unresponsive in her crib by foster carer

Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Andy

- Andy– 13-15 years old. Dx of Neurobehavioral Disorder and Unknown Exposure to Alcohol
- Parents struggled with substance use and came into care at 2 and PGO at 3
- From 13-15 Andy had struggles with substance (drug use) use, stealing, mental health, aggression, self harm, deceased from a fentanyl overdose at age 15

Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Andy

- Darian – involved with child welfare from birth and PGO at 4 years old
- spent some time in kinship care and in group home from 12 onwards
- long history of childhood trauma incarcerated several times, diagnosed by doctors to have FASD at age 7 and diagnosed
- engaged in gangs and criminal activity, substance use, died in a stolen car accident at age 16

Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Jaxon

- Jaxon – came into care after age 4 and PGO by age 8
- Mom passed away when he was 11 and experienced loss and grief, childhood trauma, history of family violence
- ADHD and suspected FASD (FASD not ruled out but not diagnosed)
- lived between kinship, foster and group homes from 7-16 years, moved to independent living at age 17 and died by suicide after argument with his girlfriend

Mandatory Review into Child Deaths – April 1, 2018-September 30, 2018 – Office of the Child and Youth Advocate, Alberta, Canada - Faith

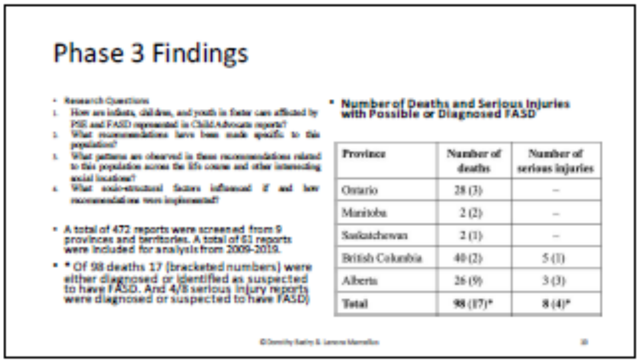
- Faith had some involvement with child welfare from birth to 17
- family support and a supervision order,
- after age 12 diagnosed with FASD
- brother with disabilities died at age 15 and Faith experienced significant loss and grief
- experienced anxiety attacks, disclosed historical childhood abuse
- Experienced mental health problems –attended to hospital 4 times due to anxiety and died of suspected drug overdose in a hotel room five months after turning 18

Overview of Child Advocate Reports

- This report identifies significant concerns about the safety and well being of children and youth with FASD
- The reports of the Office of the Child and Youth Advocate offer an important signal about the need to be concerned for the safety and well being of children and youth with FASD in care
- The OCYA in Alberta has continued to report on all serious injuries and deaths of children involved in the child welfare system in Alberta
- These reports offer critical insights into system issues, gaps and concerns

Research Activities

- Phase 1 research in 2017 – rapid evidence assessment of best practice literature on the care of infants with prenatal substance exposure in foster care by Dr. Lenora Marcellus, University of Victoria
- Phase 2 research in 2017 – scoping literature review of care of children and youth with prenatal substance exposure in child welfare
- Phase 3 – Publication of Research of all Child & Youth Advocate reports across Canada
- **Badry, D.**, Marcellus, L., & Choate, P. (2022). An Intersectionality-Based Policy Analysis of Canadian Child Advocate Reviews of Infants, Children and Youth with Prenatal Substance Exposure and Fetal Alcohol Spectrum Disorder in Child Welfare Care. *Journal of Fetal Alcohol Spectrum Disorder*, 4(SP1), e91-e115.



Phase 3 Findings

- Research Questions
1. How are infants, children, and youth in foster care affected by PSE and FASD represented in Child Advocate reports?
2. What recommendations have been made specific to this population?
3. What patterns are observed in these recommendations related to this population across the life course and other intersecting social locations?
4. What socio-structural factors influenced if and how recommendations were implemented?

- A total of 472 reports were screened from 9 provinces and territories. A total of 61 reports were included for analysis from 2009-2019.
- * Of 98 deaths 17 (bracketed numbers) were either diagnosed or identified as suspected to have FASD. And 4/8 serious injury reports were diagnosed or suspected to have FASD)

- **Number of Deaths and Serious Injuries with Possible or Diagnosed FASD**

Province	Number of deaths	Number of serious injuries
Ontario	28 (3)	–
Manitoba	2 (2)	–
Saskatchewan	2 (1)	–
British Columbia	40 (2)	5 (1)
Alberta	26 (9)	3 (3)
Total	**98 (17)***	**8 (4)***

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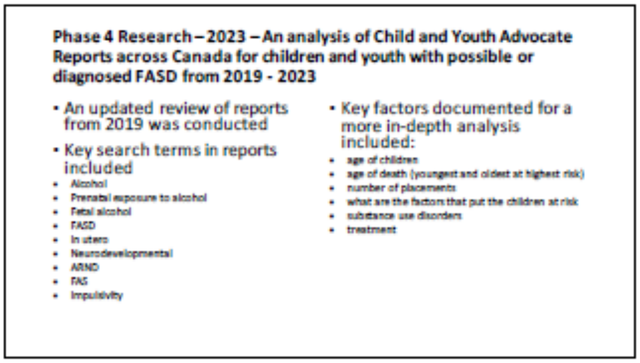

Phase 4 Research – 2023 – An analysis of Child and Youth Advocate Reports across Canada for children and youth with possible or diagnosed FASD from 2019 - 2023

- An updated review of reports from 2019 was conducted
- Key search terms in reports included
  - Alcohol
  - Prenatal exposure to alcohol
  - Fetal alcohol
  - FASD
  - In utero
  - Neurodevelopmental
  - ARND
  - FAS
  - Impulsivity
- Key factors documented for a more in-depth analysis included:
  - age of children
  - age of death (youngest and oldest at highest risk)
  - number of placements
  - what are the factors that put the children at risk
  - substance use disorders
  - treatment

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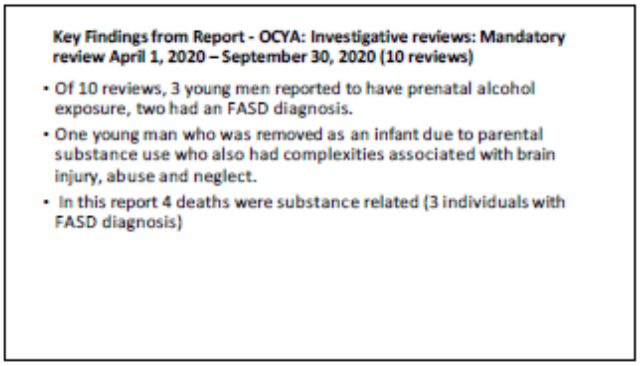

Key Findings from Report - OCYA: Investigative reviews: Mandatory review April 1, 2020 – September 30, 2020 (10 reviews)

- Of 10 reviews, 3 young men reported to have prenatal alcohol exposure, two had an FASD diagnosis.
- One young man who was removed as an infant due to parental substance use who also had complexities associated with brain injury, abuse and neglect.
- In this report 4 deaths were substance related (3 individuals with FASD diagnosis)

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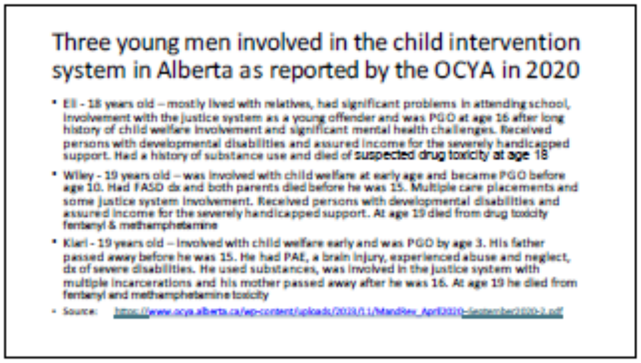

Three young men involved in the child intervention system in Alberta as reported by the OCYA in 2020

- Eli - 18 years old – mostly lived with relatives, had significant problems in attending school, involvement with the justice system as a young offender and was PGO at age 16 after long history of child welfare involvement and significant mental health challenges. Received persons with developmental disabilities and assured income for the severely handicapped support. Had a history of substance use and died of suspected drug toxicity at age 18
- Wiley - 19 years old – was involved with child welfare at early age and became PGO before age 10. Had FASD dx and both parents died before he was 15. Multiple care placements and some justice system involvement. Received persons with developmental disabilities and assured income for the severely handicapped support. At age 19 died from drug toxicity fentanyl & methamphetamine
- Kiari - 19 years old – involved with child welfare early and was PGO by age 3. His father passed away before he was 15. He had PAE, a brain injury, experienced abuse and neglect, dx of severe disabilities. He used substances, was involved in the justice system with multiple incarcerations and his mother passed away after he was 16. At age 19 he died from fentanyl and methamphetamine toxicity
- Source: https://www.ocya.alberta.ca/wp-content/uploads/2020/11/MandRev_April2020-September2020-2.pdf

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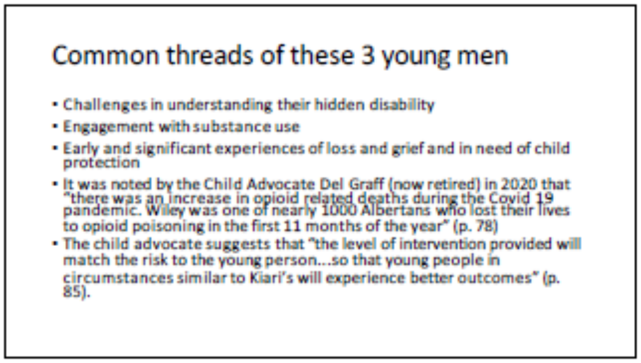

Common threads of these 3 young men

- Challenges in understanding their hidden disability
- Engagement with substance use
- Early and significant experiences of loss and grief and in need of child protection
- It was noted by the Child Advocate Del Graff (now retired) in 2020 that "there was an increase in opioid related deaths during the Covid 19 pandemic. Wiley was one of nearly 1000 Albertans who lost their lives to opioid poisoning in the first 11 months of the year" (p. 78)
- The child advocate suggests that "the level of intervention provided will match the risk to the young person…so that young people in circumstances similar to Kiari's will experience better outcomes" (p. 85).

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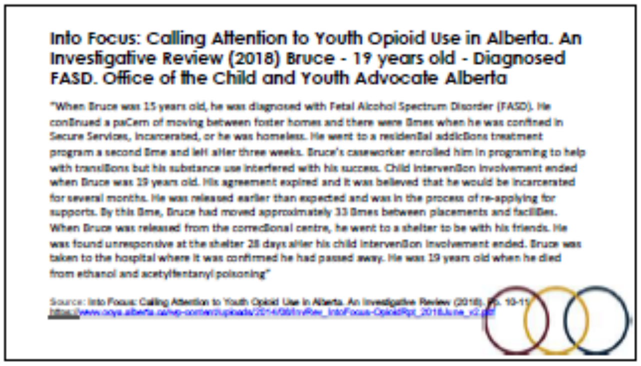

Into Focus: Calling Attention to Youth Opioid Use in Alberta. An Investigative Review (2018) Bruce - 19 years old - Diagnosed FASD. Office of the Child and Youth Advocate Alberta

"When Bruce was 15 years old, he was diagnosed with Fetal Alcohol Spectrum Disorder (FASD). He continued a pattern of moving between foster homes and there were times when he was confined in Secure Services, incarcerated, or he was homeless. He went to a residential addictions treatment program a second time and left after three weeks. Bruce's caseworker enrolled him in programing to help with transitions but his substance use interfered with his success. Child intervention involvement ended when Bruce was 19 years old. His agreement expired and it was believed that he would be incarcerated for several months. He was released earlier than expected and was in the process of re-applying for supports. By this time, Bruce had moved approximately 33 times between placements and facilities. When Bruce was released from the correctional centre, he went to a shelter to be with his friends. He was found unresponsive at the shelter 28 days after his child intervention involvement ended. Bruce was taken to the hospital where it was confirmed he had passed away. He was 19 years old when he died from ethanol and acetylfentanyl poisoning"

Source: Into Focus: Calling Attention to Youth Opioid Use in Alberta. An Investigative Review (2018), pp. 10-11
https://www.ocya.alberta.ca/wp-content/uploads/2014/08/InvRev_IntoFocus-OpioidRpt_2018June_v2.pdf

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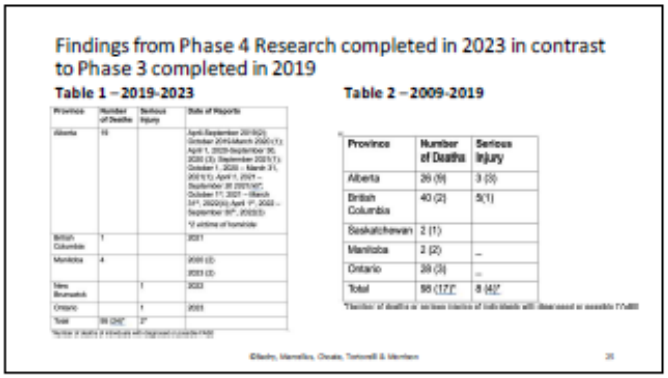

Findings from Phase 4 Research completed in 2023 in contrast to Phase 3 completed in 2019

Table 1 – 2019-2023

Province	Number of Deaths	Serious Injury	Date of Reports
Alberta	15		[illegible] *2 victims of homicide
British Columbia	1		2021
Manitoba	4		2020 (2) 2023 (2)
New Brunswick		1	2023
Ontario		1	2023
Total	[illegible]	2*	

*Number of deaths of individuals with diagnosed or possible FASD

Table 2 – 2009-2019

Province	Number of Deaths	Serious Injury
Alberta	26 (9)	3 (3)
British Columbia	40 (2)	5(1)
Saskatchewan	2 (1)	
Manitoba	2 (2)	_
Ontario	28 (3)	_
Total	98 (17)*	8 (4)*

*Number of deaths or serious injuries of individuals with diagnosed or possible FASD

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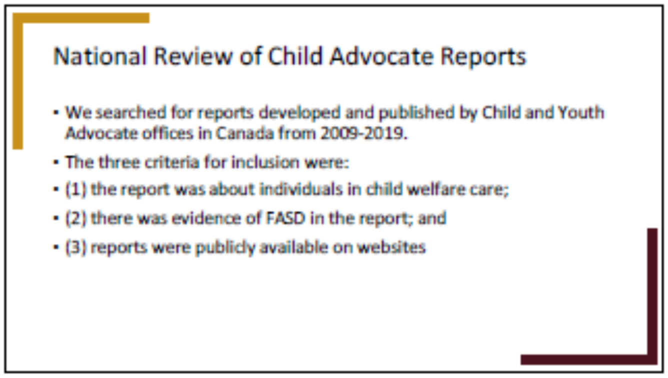
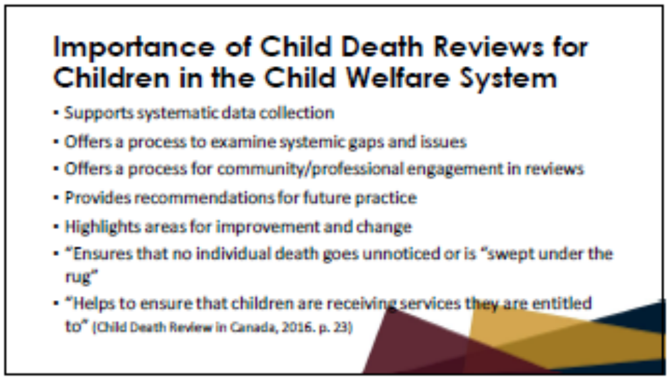


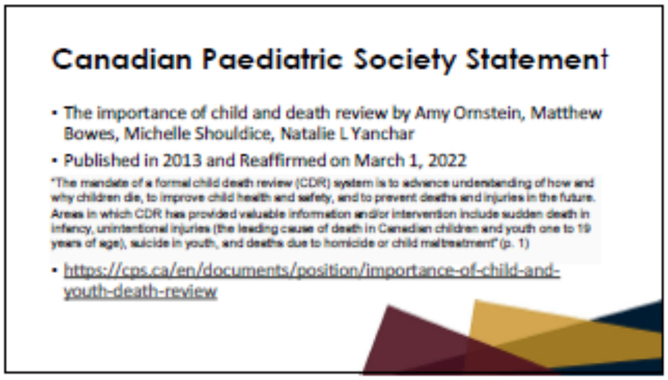
National Review of Child Advocate Reports

- We searched for reports developed and published by Child and Youth Advocate offices in Canada from 2009-2019.
- The three criteria for inclusion were:
- (1) the report was about individuals in child welfare care;
- (2) there was evidence of FASD in the report; and
- (3) reports were publicly available on websites



Importance of Child Death Reviews for Children in the Child Welfare System

- Supports systematic data collection
- Offers a process to examine systemic gaps and issues
- Offers a process for community/professional engagement in reviews
- Provides recommendations for future practice
- Highlights areas for improvement and change
- "Ensures that no individual death goes unnoticed or is "swept under the rug"
- "Helps to ensure that children are receiving services they are entitled to" (Child Death Review in Canada, 2016. p. 23)

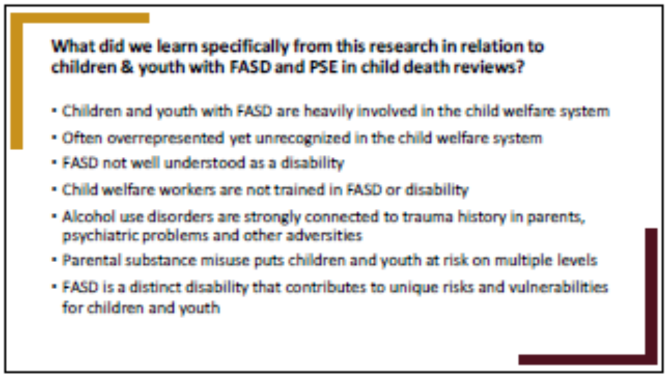


Canadian Paediatric Society Statement

- The importance of child and death review by Amy Ornstein, Matthew Bowes, Michelle Shouldice, Natalie L Yanchar
- Published in 2013 and Reaffirmed on March 1, 2022

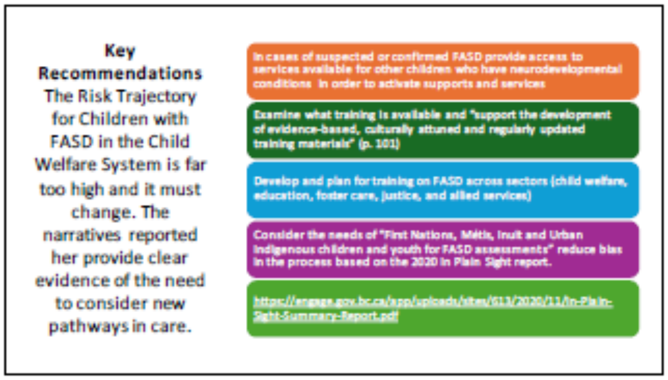
"The mandate of a formal child death review (CDR) system is to advance understanding of how and why children die, to improve child health and safety, and to prevent deaths and injuries in the future. Areas in which CDR has provided valuable information and/or intervention include sudden death in infancy, unintentional injuries (the leading cause of death in Canadian children and youth one to 19 years of age), suicide in youth, and deaths due to homicide or child maltreatment" (p. 1)

- https://cps.ca/en/documents/position/importance-of-child-and-youth-death-review



What did we learn specifically from this research in relation to children & youth with FASD and PSE in child death reviews?

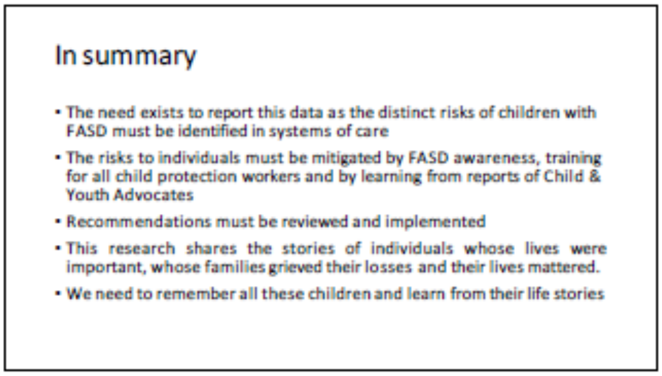
- Children and youth with FASD are heavily involved in the child welfare system
- Often overrepresented yet unrecognized in the child welfare system
- FASD not well understood as a disability
- Child welfare workers are not trained in FASD or disability
- Alcohol use disorders are strongly connected to trauma history in parents, psychiatric problems and other adversities
- Parental substance misuse puts children and youth at risk on multiple levels
- FASD is a distinct disability that contributes to unique risks and vulnerabilities for children and youth



Key Recommendations

The Risk Trajectory for Children with FASD in the Child Welfare System is far too high and it must change. The narratives reported her provide clear evidence of the need to consider new pathways in care.

- In cases of suspected or confirmed FASD provide access to services available for other children who have neurodevelopmental conditions in order to activate supports and services
- Examine what training is available and "support the development of evidence-based, culturally attuned and regularly updated training materials" (p. 101)
- Develop and plan for training on FASD across sectors (child welfare, education, foster care, justice, and allied services)
- Consider the needs of "First Nations, Métis, Inuit and Urban Indigenous children and youth for FASD assessments" reduce bias in the process based on the 2020 In Plain Sight report.
- https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Summary-Report.pdf



In summary

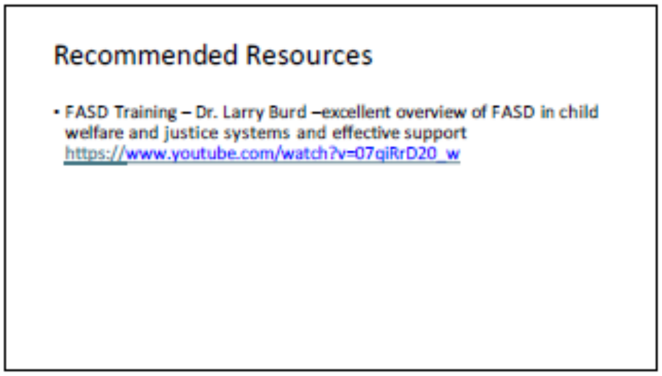
- The need exists to report this data as the distinct risks of children with FASD must be identified in systems of care
- The risks to individuals must be mitigated by FASD awareness, training for all child protection workers and by learning from reports of Child & Youth Advocates
- Recommendations must be reviewed and implemented
- This research shares the stories of individuals whose lives were important, whose families grieved their losses and their lives mattered.
- We need to remember all these children and learn from their life stories

Select publications

- Badry, D., Marcellus, L., & Choate, P. (2022). An Intersectionality-Based Policy Analysis of Canadian Child Advocate Reviews of Infants, Children and Youth with Prenatal Substance Exposure and Fetal Alcohol Spectrum Disorder in Child Welfare Care. *Journal of Fetal Alcohol Spectrum Disorder*, 4(SP1), e91–e115.
- Flannigan, McMorris, C., Ewasiuk, A., Badry, D., Mela, M., Ben Gibbard, W., Unsworth, K., Cook, J., &Harding, K. D. (2021). Suicidality and Associated Factors Among Individuals Assessed for Fetal Alcohol Spectrum Disorder Across the Lifespan in Canada. Canadian Journal of Psychiatry, 70674372110532–7067437211053288. https://doi.org/10.1177/07067437211053288
- Burns, J., . Badry, D., Harding, K., Roberts, N., Unsworth, K. & Cook, JL. (17 October 2020). Comparing Outcomes of Children and Youth with Fetal Alcohol Spectrum Disorder (FASD) in the Child Welfare System to those in Other Living Situations in Canada: Results from the Canadian National FASD Database. Child: care, health and development. Vol.47 (1), p.77-84 https://doi.org/10.1111/cch.12817
- Missing in Inaction: Misty's Story. April 13, 2023. Ombudsman, Ontario
- https://www.ombudsman.on.ca/resources/reports,-cases-and-submissions/reports-on-investigations/2023/missing-in-inaction-misty%E2%80%99s-story

Select Publications

- Badry, D. & Harding, K. (2020) Fetal Alcohol Spectrum Disorder and Child Welfare. Canada FASD Research Network. https://canfasd.ca/wp-content/uploads/publications/FASD-and-Child-Welfare-Final.pdf
- Flannigan, K., Pei, J., McLachlan, K., Harding, K., Mela, M., Cook, J., Badry, D., & McFarlane, A. (2022).Responding to the unique complexities of fetal alcohol spectrum disorder. Frontiers in Psychology,12. doi:10.3389/fpsyg.2021.778471
- Mandatory Reviews into Child Deaths. April 1, 2020-September 30, 2020. Office of the Child & Youth Advocate, March, 2021 - https://www.ocya.alberta.ca/wp-content/uploads/2023/11/MandRev_April2020-September2020-2.pdf
- Office of the Child and Youth Advocate Alberta. Link to Reports from October 2018 –September 30, 2022 https://www.ocya.alberta.ca/adult/publications/investigative-reviews-2018-2022/
- Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families (2021). Representative for Children and Youth, British Columbia https://rcybc.ca/reports-and-publications/excluded/



Recommended Resources

- FASD Training – Dr. Larry Burd –excellent overview of FASD in child welfare and justice systems and effective support https://www.youtube.com/watch?v=07qiRrD20_w

CanFASD
CANADA FASD RESEARCH NETWORK

Thank you. For further information contact: badry@ucalgary.ca

D5

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

Christie Petrenko, Christiano Tapparello, Emily Speybroeck, Maggie May, Emily Hargrove

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My Health Coach App: Partnering with Adults with FASD to Support Health and Quality of Life

Leads: Christie Petrenko & Cristiano Tapparello
Staff: Emily Speybroeck & Cody Romanos
Advisory Board: International Adult Leadership Collaborative

Mt. HOPE family center
UNIVERSITY of ROCHESTER

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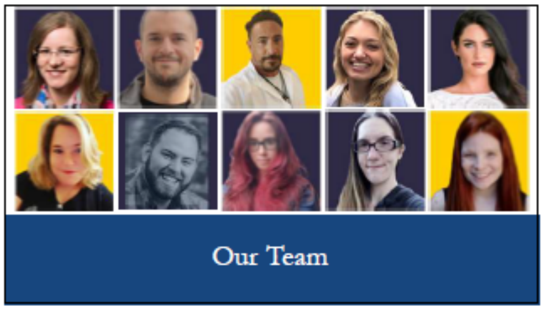

Our Team

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Session Outline

- Background
- App development
- Focus group
- Survey
- App Version 1 Demo
- Feasibility Trial

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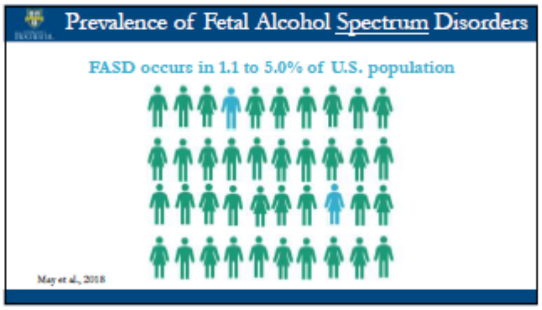

Prevalence of Fetal Alcohol Spectrum Disorders

FASD occurs in 1.1 to 5.0% of U.S. population

May et al., 2018

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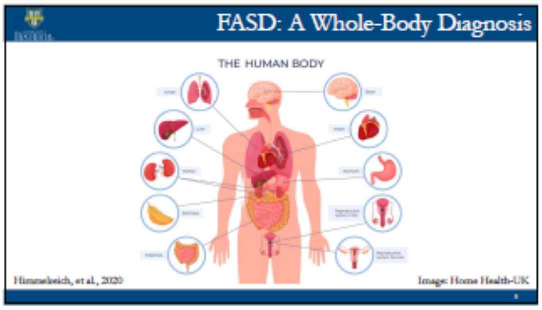

FASD: A Whole-Body Diagnosis

Himmelreich, et al., 2020

Image: Home Health-UK

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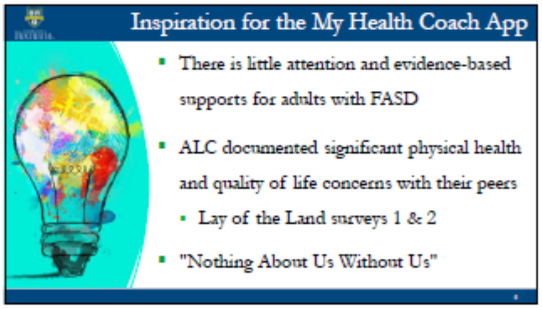

Inspiration for the My Health Coach App

- There is little attention and evidence-based supports for adults with FASD
- ALC documented significant physical health and quality of life concerns with their peers
  - Lay of the Land surveys 1 & 2
- "Nothing About Us Without Us"

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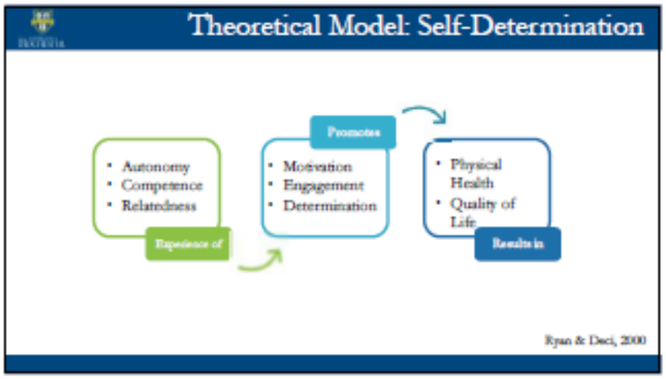

Theoretical Model: Self-Determination

- Autonomy
- Competence
- Relatedness

Experience of

Promotes

- Motivation
- Engagement
- Determination

- Physical Health
- Quality of Life

Results in

Ryan & Deci, 2000

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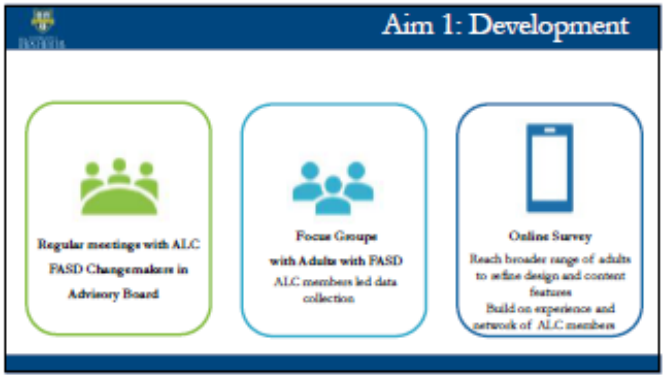

Aim 1: Development

Regular meetings with ALC FASD Changemakers in Advisory Board

Focus Groups

with Adults with FASD

ALC members led data collection

Online Survey

Reach broader range of adults to refine design and content features

Build on experience and network of ALC members

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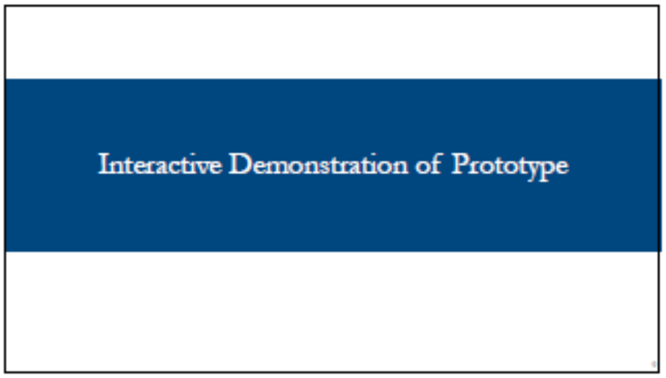

Interactive Demonstration of Prototype

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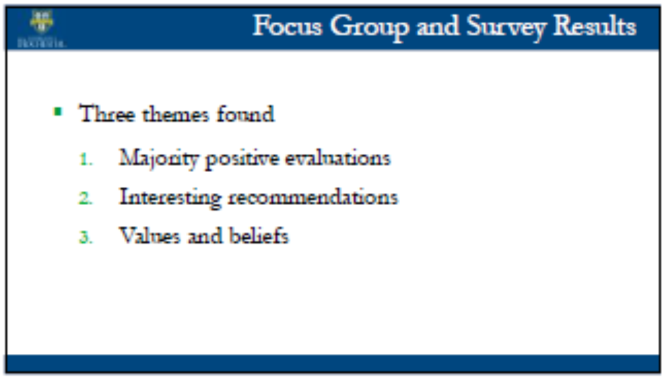

Focus Group and Survey Results

- Three themes found
  1. Majority positive evaluations
  2. Interesting recommendations
  3. Values and beliefs

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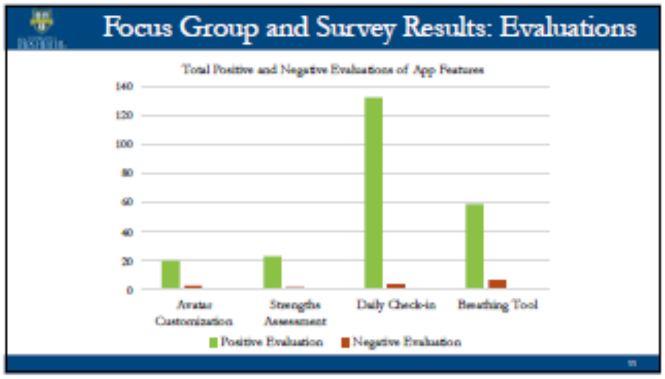
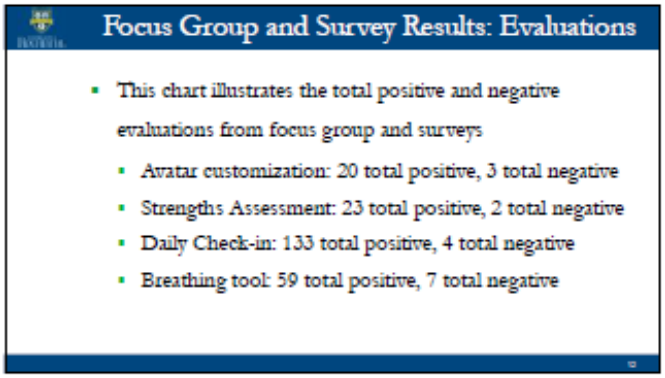


Focus Group and Survey Results: Evaluations

Total Positive and Negative Evaluations of App Features

11



Focus Group and Survey Results: Evaluations

- This chart illustrates the total positive and negative evaluations from focus group and surveys
  - Avatar customization: 20 total positive, 3 total negative
  - Strengths Assessment: 23 total positive, 2 total negative
  - Daily Check-in: 133 total positive, 4 total negative
  - Breathing tool: 59 total positive, 7 total negative

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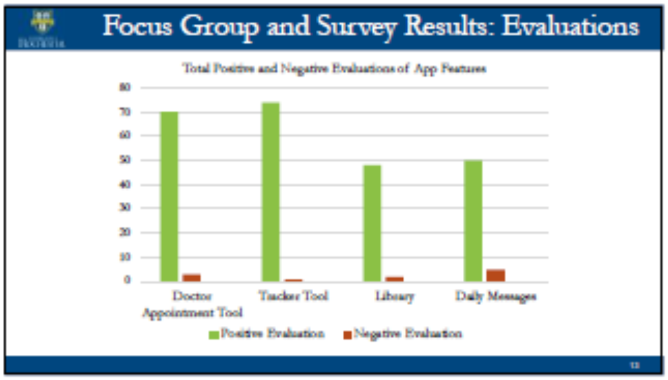
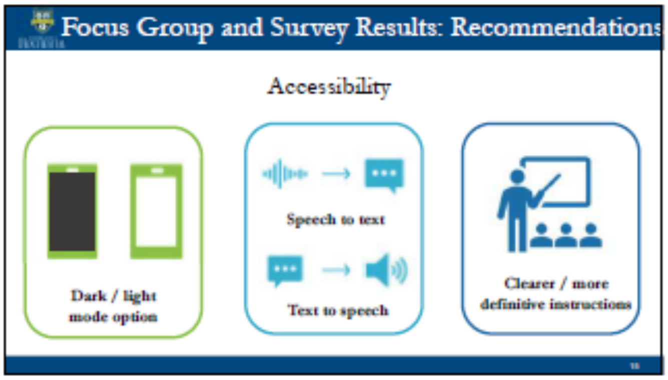


Focus Group and Survey Results: Evaluations

Focus Group and Survey Results: Evaluations

- This chart illustrates the total positive and negative evaluations from focus group and surveys
  - Doctor Appointment Tool: 70 total positive, 3 total negative
  - Tracker Tool: 74 total positive, 1 total negative
  - Library: 48 total positive, 2 total negative
  - Daily Messages: 50 total positive, 5 total negative



Focus Group and Survey Results: Recommendations

Accessibility

Dark / light mode option

Speech to text

Text to speech

Clearer / more definitive instructions

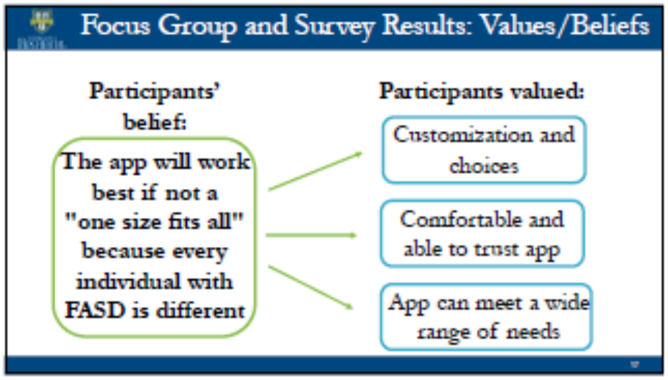
Focus Group and Survey Results: Recommendations

Accountability

Shareable

Time management tools

Notification type and amount



Focus Group and Survey Results: Values/Beliefs

Participants' belief:

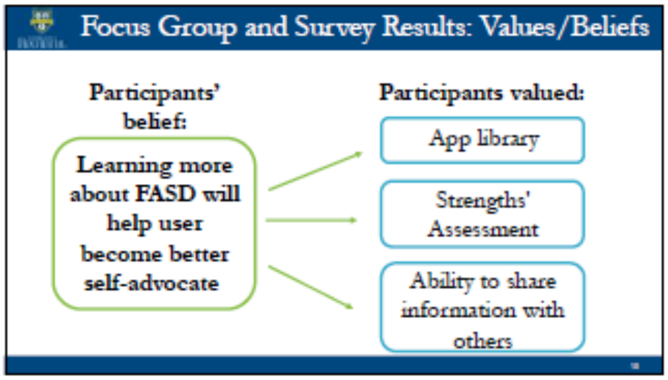
The app will work best if not a "one size fits all" because every individual with FASD is different

Participants valued:

Customization and choices

Comfortable and able to trust app

App can meet a wide range of needs



Focus Group and Survey Results: Values/Beliefs

Participants' belief:

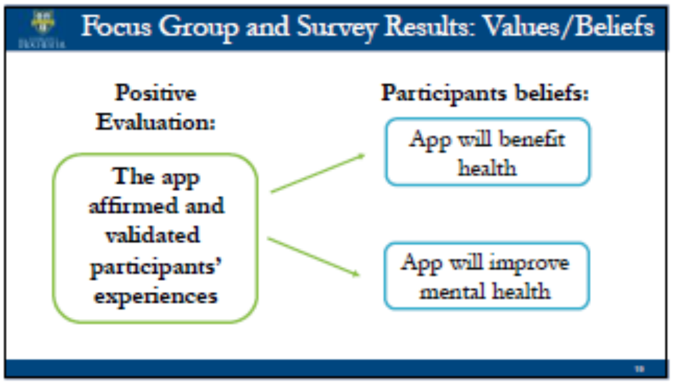
Learning more about FASD will help user become better self-advocate

Participants valued:

App library

Strengths' Assessment

Ability to share information with others



Focus Group and Survey Results: Values/Beliefs

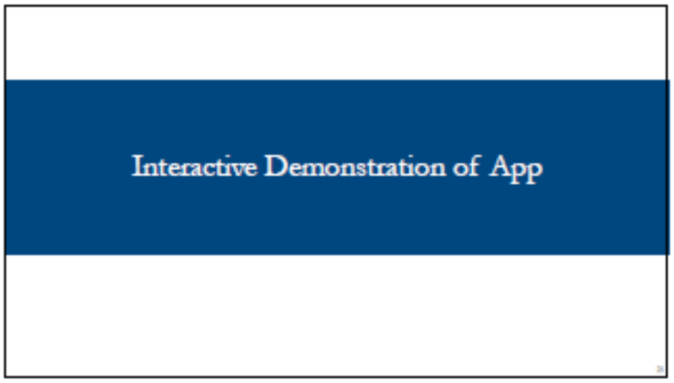
Positive Evaluation:

The app affirmed and validated participants' experiences

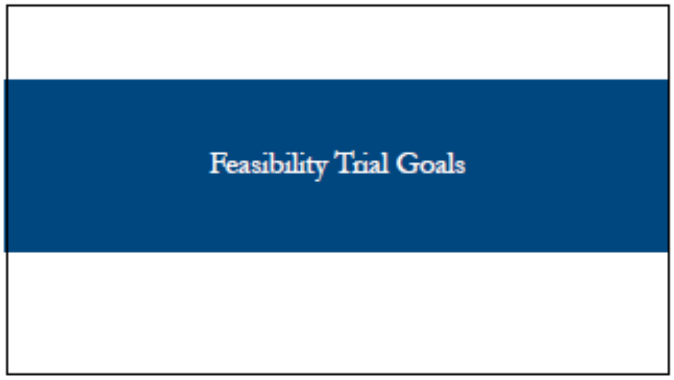
Participants beliefs:

- App will benefit health
- App will improve mental health

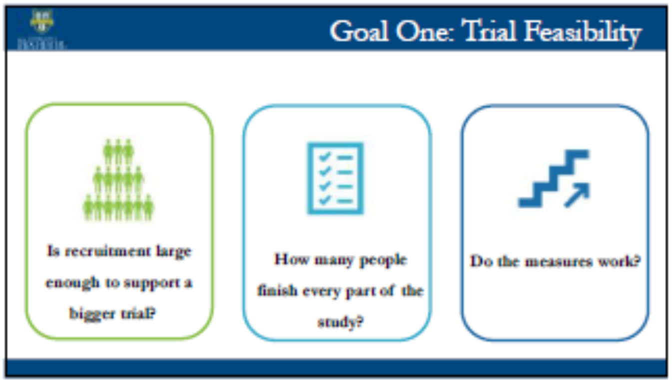
Aim 2: Feasibility Study



Interactive Demonstration of App



Feasibility Trial Goals

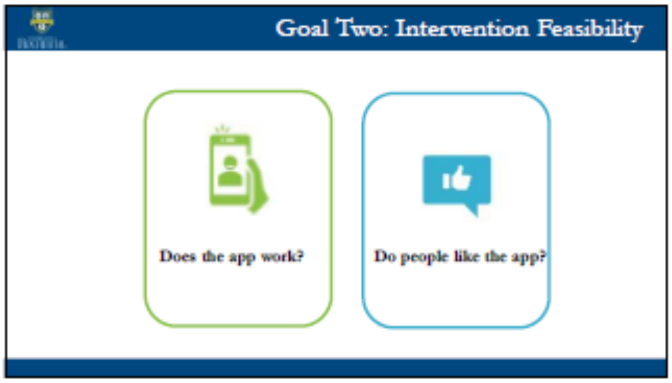


Goal One: Trial Feasibility

Is recruitment large enough to support a bigger trial?

How many people finish every part of the study?

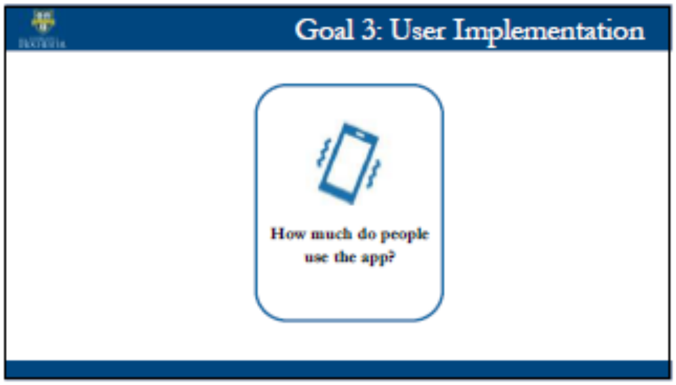
Do the measures work?



Goal Two: Intervention Feasibility

Does the app work?

Do people like the app?



Goal 3: User Implementation

How much do people use the app?

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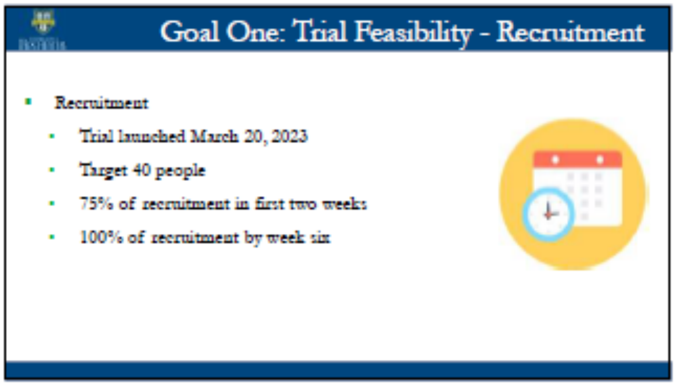

Goal One: Trial Feasibility - Recruitment

- Recruitment
  - Trial launched March 20, 2023
  - Target 40 people
  - 75% of recruitment in first two weeks
  - 100% of recruitment by week six

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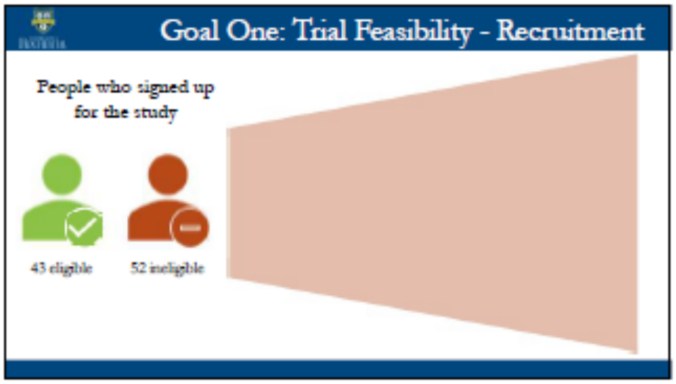


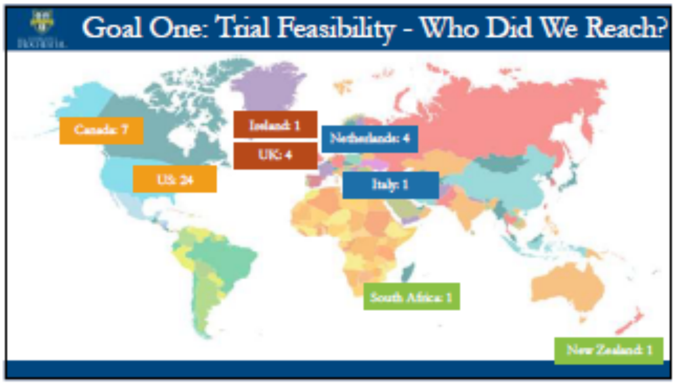
Goal One: Trial Feasibility - Recruitment

People who signed up for the study

43 eligible

52 ineligible

27



Goal One: Trial Feasibility - Who Did We Reach?

Canada: 7

Ireland: 1

UK: 4

Netherlands: 4

US: 24

Italy: 1

South Africa: 1

New Zealand: 1

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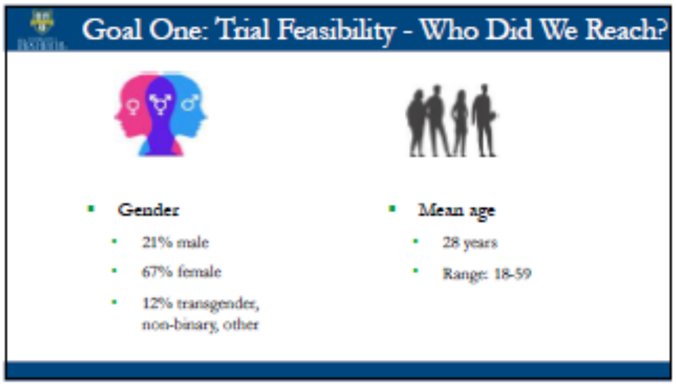

Goal One: Trial Feasibility - Who Did We Reach?

- Gender
  - 21% male
  - 67% female
  - 12% transgender, non-binary, other
- Mean age
  - 28 years
  - Range: 18-59

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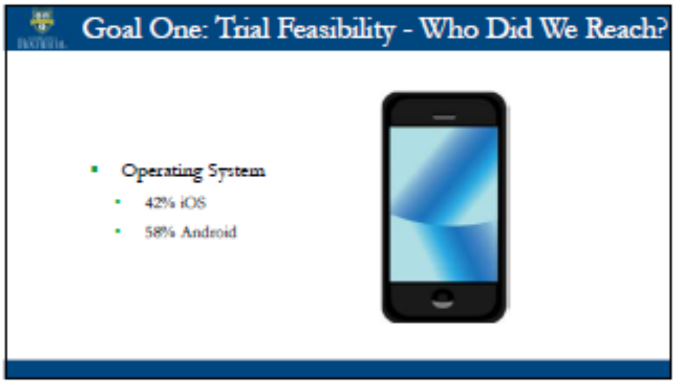

Goal One: Trial Feasibility - Who Did We Reach?

- Operating System
  - 42% iOS
  - 58% Android

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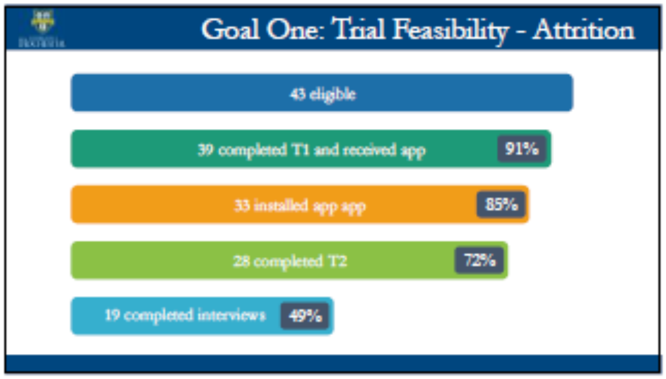

Goal One: Trial Feasibility - Attrition

- 43 eligible
- 39 completed T1 and received app — 91%
- 33 installed app app — 85%
- 28 completed T2 — 72%
- 19 completed interviews — 49%

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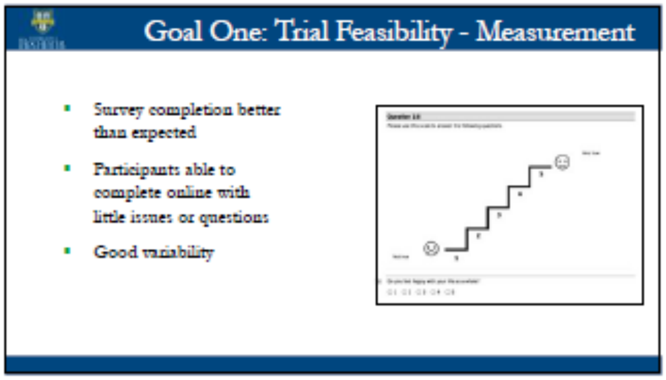

Goal One: Trial Feasibility - Measurement

- Survey completion better than expected
- Participants able to complete online with little issues or questions
- Good variability

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Goal One: Trial Feasibility - Measurement

Easy to complete

"Simple" P004

"Smooth" P009

Accessible

"I liked that you could save them and come back later" P046

"I love the fact that you had the audio to read it to you, that really helped me" P035

Informative

"They were quite comprehensive, I really appreciated that." P016

"It was interesting to see where you were at on the scales." P024

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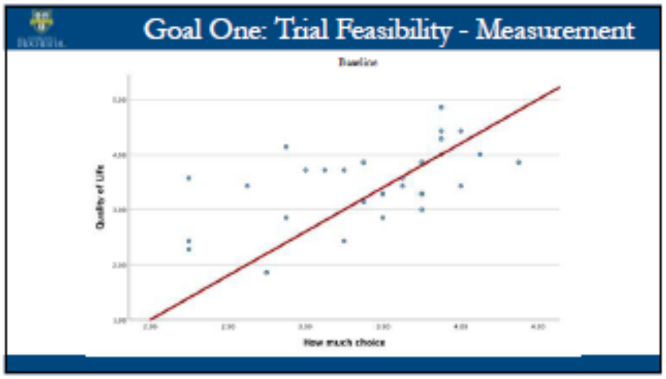

Goal One: Trial Feasibility - Measurement

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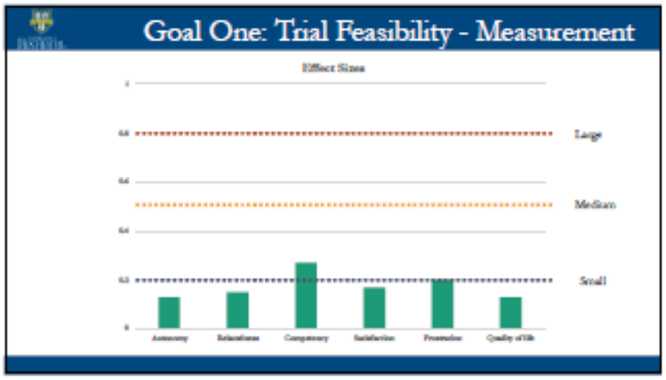

Goal One: Trial Feasibility - Measurement

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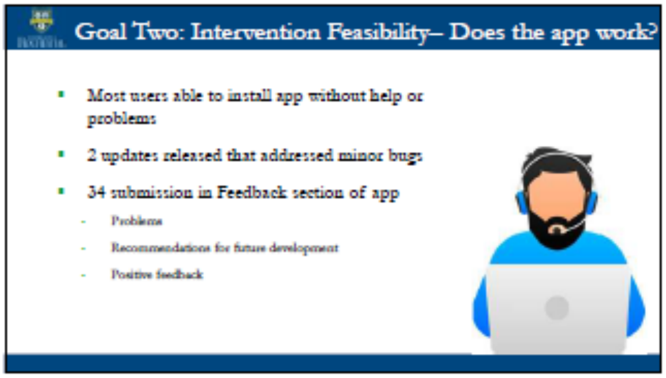

Goal Two: Intervention Feasibility– Does the app work?

- Most users able to install app without help or problems
- 2 updates released that addressed minor bugs
- 34 submission in Feedback section of app
  - Problems
  - Recommendations for future development
  - Positive feedback

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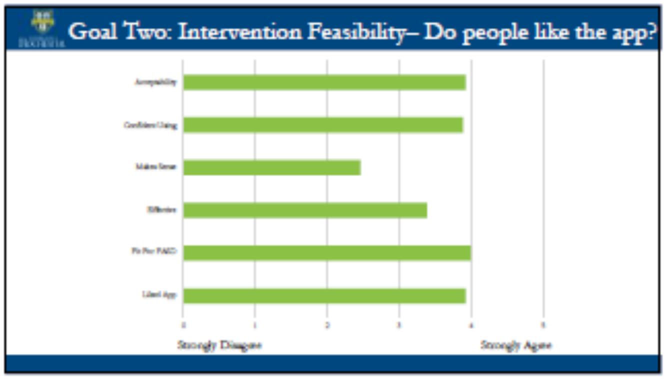
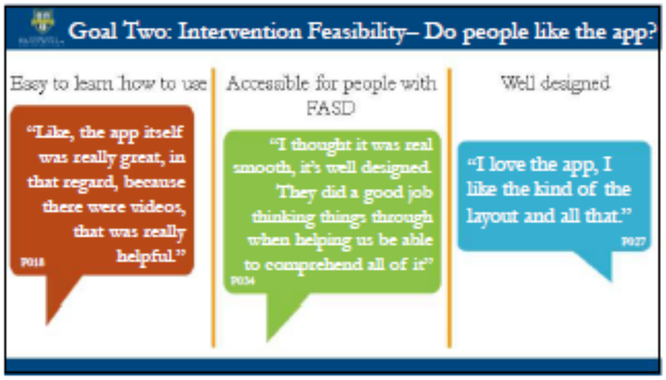


Goal Two: Intervention Feasibility– Do people like the app?



Goal Two: Intervention Feasibility– Do people like the app?

Easy to learn how to use

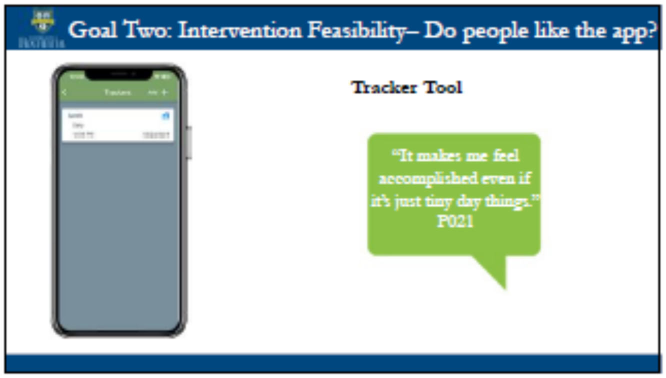
"Like, the app itself was really great, in that regard, because there were videos, that was really helpful."
P018

Accessible for people with FASD

"I thought it was real smooth, it's well designed. They did a good job thinking things through when helping us be able to comprehend all of it"
P034

Well designed

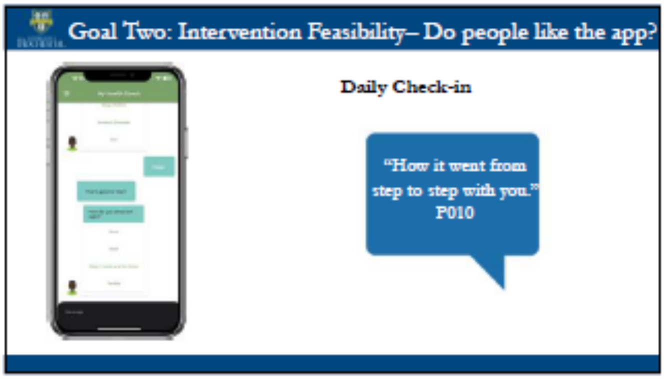
"I love the app, I like the kind of the layout and all that."
P027



Goal Two: Intervention Feasibility– Do people like the app?

Tracker Tool

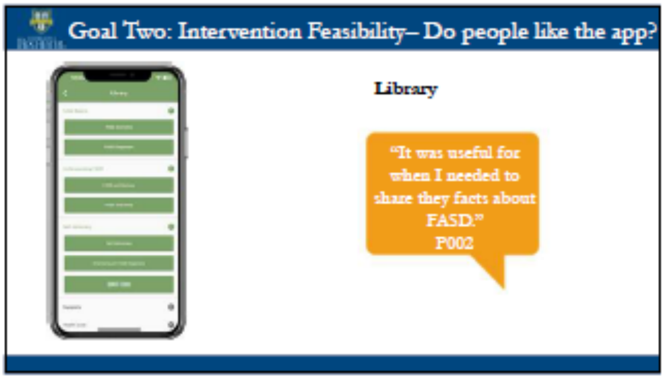
"It makes me feel accomplished even if it's just tiny day things."
P021



Goal Two: Intervention Feasibility– Do people like the app?

Daily Check-in

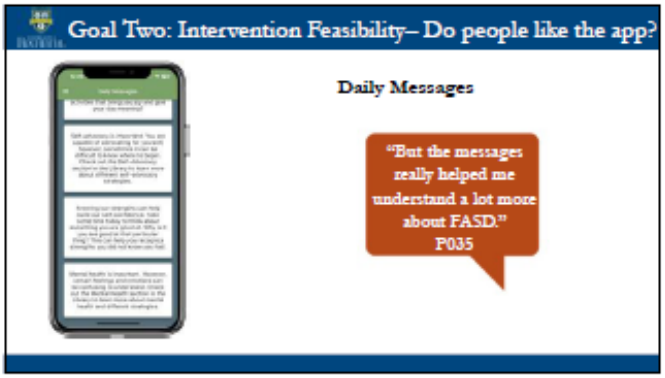
"How it went from step to step with you."
P010



Goal Two: Intervention Feasibility– Do people like the app?

Library

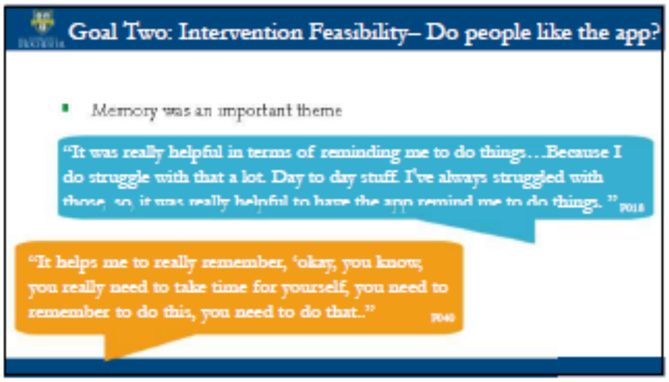
"It was useful for when I needed to share they facts about FASD."
P002



Goal Two: Intervention Feasibility– Do people like the app?

Daily Messages

"But the messages really helped me understand a lot more about FASD."
P035

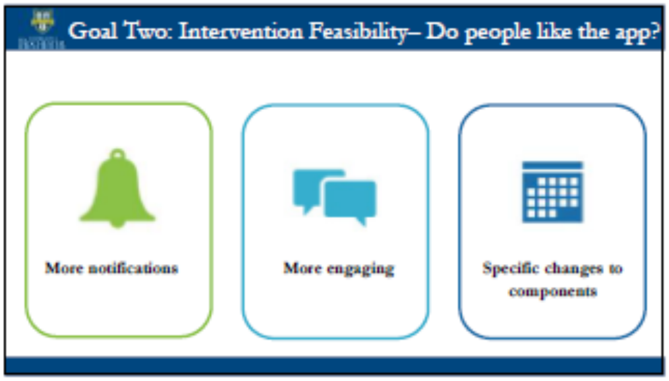


Goal Two: Intervention Feasibility– Do people like the app?

- Memory was an important theme

"It was really helpful in terms of reminding me to do things…Because I do struggle with that a lot. Day to day stuff. I've always struggled with those, so, it was really helpful to have the app remind me to do things." P018

"It helps me to really remember, 'okay, you know, you really need to take time for yourself, you need to remember to do this, you need to do that.." P040

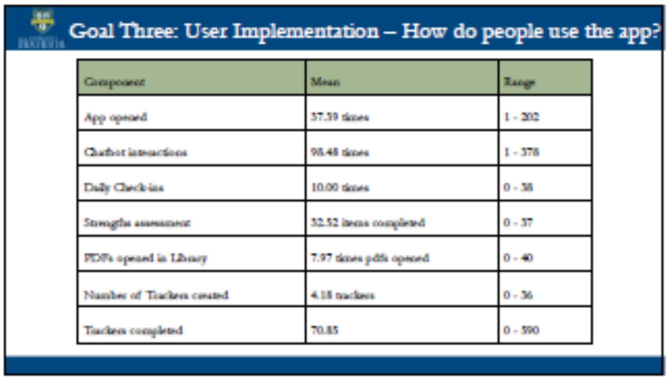


Goal Two: Intervention Feasibility– Do people like the app?

More notifications

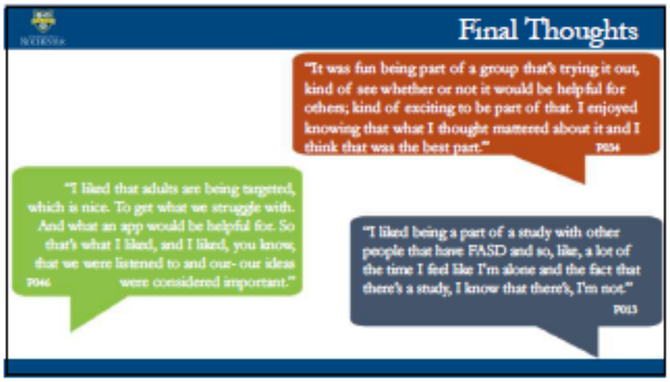
More engaging

Specific changes to components



Goal Three: User Implementation – How do people use the app?

Component	Mean	Range
App opened	37.39 times	1 - 202
Chatbot interactions	98.48 times	1 - 378
Daily Check-ins	10.00 times	0 - 38
Strengths assessment	32.52 items completed	0 - 37
PDFs opened in Library	7.97 times pdfs opened	0 - 40
Number of Trackers created	4.18 trackers	0 - 36
Trackers completed	70.85	0 - 590

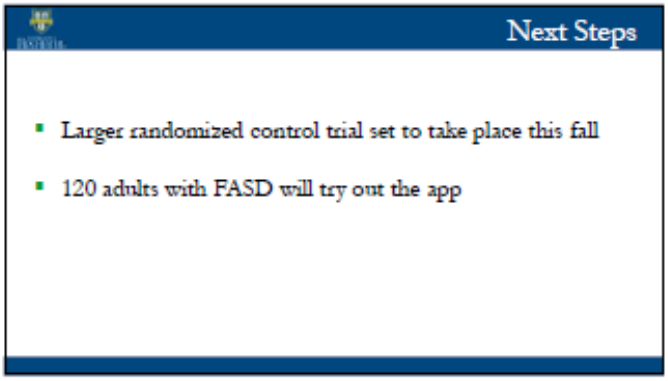


Final Thoughts

"It was fun being part of a group that's trying it out, kind of see whether or not it would be helpful for others; kind of exciting to be part of that. I enjoyed knowing that what I thought mattered about it and I think that was the best part." P034

"I liked that adults are being targeted, which is nice. To get what we struggle with. And what an app would be helpful for. So that's what I liked, and I liked, you know, that we were listened to and our- our ideas were considered important." P046

"I liked being a part of a study with other people that have FASD and so, like, a lot of the time I feel like I'm alone and the fact that there's a study, I know that there's, I'm not." P013



Next Steps

- Larger randomized control trial set to take place this fall
- 120 adults with FASD will try out the app

THANK YOU!

- Thank you to NIAAA and CIFASD for supporting this work
  - UH2 AA029050
- We also appreciate the generous support of Jay and Constance Mazelsky

NIH National Institute on Alcohol Abuse and Alcoholism

CIFASD is supported by NIAAA

Questions

THANK YOU AND CONTACT INFORMATION

@FASDChangeMakrs

@Clpetrenko

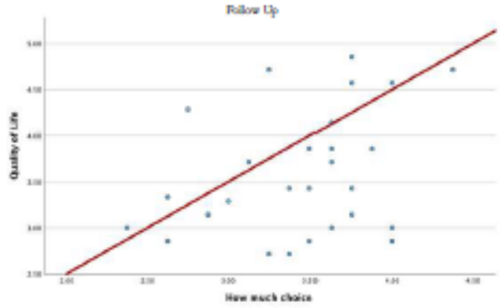
FASDChangemakers@gmail.com

Christie_Petrenko@urmc.rochester.edu

@fasdchangemakers.alc

Emily_Speybroeck@urmc.rochester.edu

Goal One: Trial Feasibility - Measurement



D6

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

Elizabeth Elliott, Claire Coles, Christine Loock

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

- Overall objective: To provide updated information on prevalence, contexts, and current state of play regarding FASD in Australia, Canada and USA, the challenges we face in each country, and solutions that have been developed to address these challenges.

Life Experience of those with FASD in a Rural South African Context

Leana Olivier

The Lasting Legacy of Dr. Ann Streissguth: Wide-Ranging Work on FASD

Susan Stoner

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

Alexandre Lussier

EPIGENETIC SIGNATURES OF DEVELOPMENTAL ADVERSITY: IMPLICATIONS FOR RISK AND RESILIENCE IN FASD

Alexandre Lussier, PhD
Pronouns: he/him/his
Instructor in Investigation, Massachusetts General Hospital
Instructor in Psychology, Department of Psychiatry, Harvard Medical School
April 14, 2024

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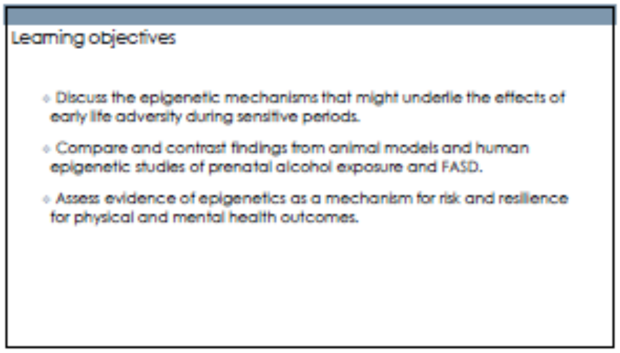

Learning objectives

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

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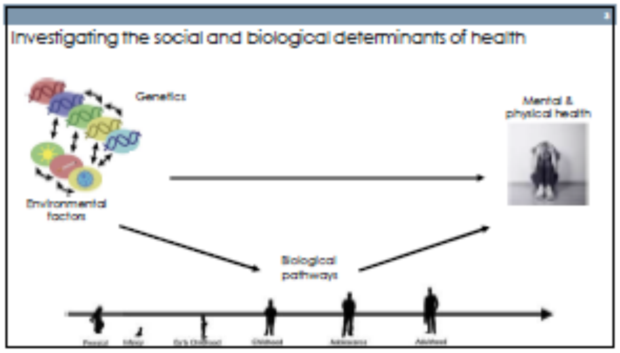

Investigating the social and biological determinants of health

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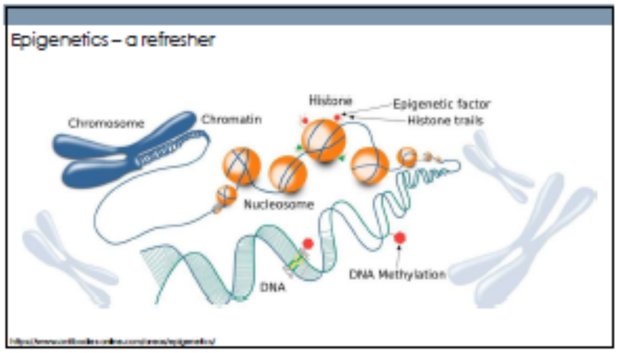

Epigenetics – a refresher

https://www.antibodies-online.com/areas/epigenetics/

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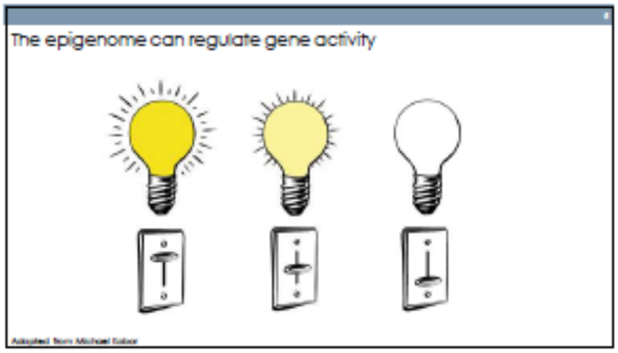

The epigenome can regulate gene activity

Adapted from Michael Kobor

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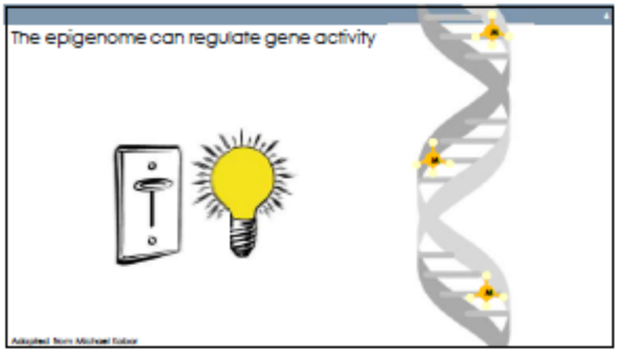

The epigenome can regulate gene activity

Adapted from Michael Kobor

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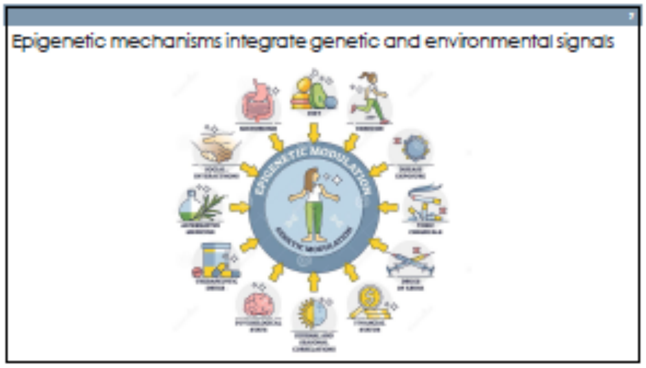

Epigenetic mechanisms integrate genetic and environmental signals

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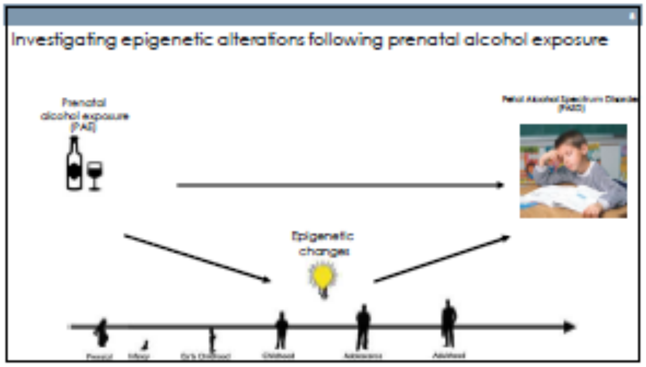


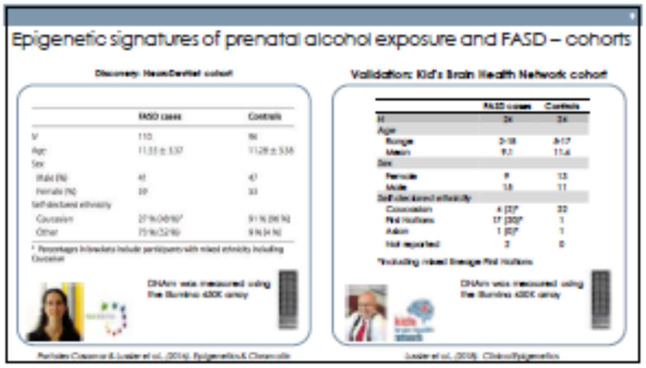
Investigating epigenetic alterations following prenatal alcohol exposure

Prenatal
alcohol exposure
(PAE)

Fetal Alcohol Spectrum Disorder
(FASD)

Epigenetic
changes

8



Epigenetic signatures of prenatal alcohol exposure and FASD – cohorts

Discovery: NeuroDevNet cohort

	FASD cases	Controls
N	110	96
Age	11.33 ± 3.37	11.28 ± 3.38
Sex		
Male (%)	61	67
Female (%)	39	33
Self-declared ethnicity		
Caucasian	27% (48%)*	91% (96%)
Other	73% (52%)	9% (4%)

* Percentages in brackets include participants with mixed ethnicity including Caucasian

DNAm was measured using the Illumina 450K array

Validation: Kid's Brain Health Network cohort

	FASD cases	Controls
N	24	24
Age		
Range	3-18	8-17
Mean	9.1	11.4
Sex		
Female	9	13
Male	15	11
Self-declared ethnicity		
Caucasian	4 [3]*	22
First Nations	17 [20]*	1
Asian	1 [0]*	1
Not reported	2	0

*Including mixed lineage First Nations

DNAm was measured using the Illumina 450K array

Portales-Casamar & Lussier et al. (2016). Epigenetics & Chromatin

Lussier et al. (2018). Clinical Epigenetics

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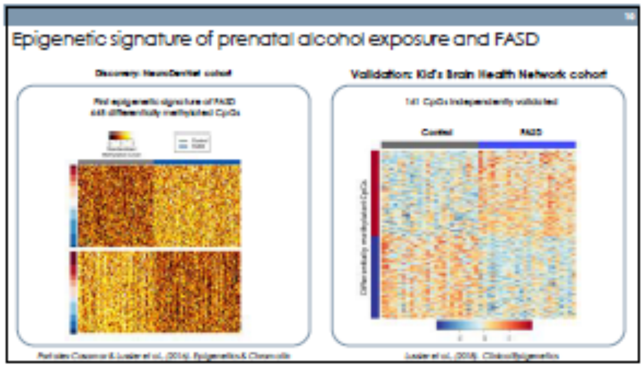

Epigenetic signature of prenatal alcohol exposure and FASD

Discovery: NeuroDevNet cohort

First epigenetic signature of FASD
648 differentially methylated CpGs

Validation: Kid's Brain Health Network cohort

141 CpGs independently validated

Portales-Casamar & Lussier et al. (2016). Epigenetics & Chromatin

Lussier et al. (2018). Clinical Epigenetics

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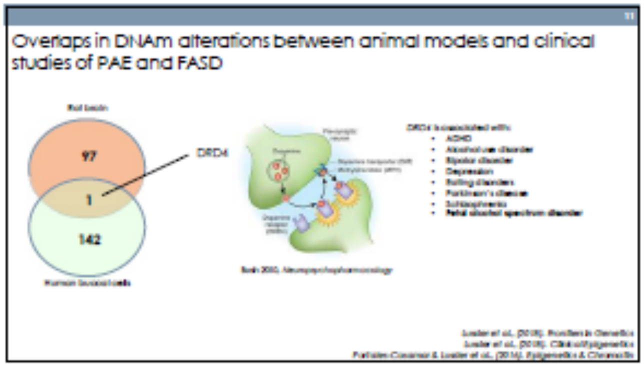

Overlaps in DNAm alterations between animal models and clinical studies of PAE and FASD

Bush 2010, Neuropsychopharmacology

DRD4 is associated with:
- ADHD
- Alcohol use disorder
- Bipolar disorder
- Depression
- Eating disorders
- Parkinson's disease
- Schizophrenia
- **Fetal alcohol spectrum disorder**

Lussier et al. (2018). Frontiers in Genetics
Lussier et al. (2018). Clinical Epigenetics
Portales-Casamar & Lussier et al. (2016). Epigenetics & Chromatin

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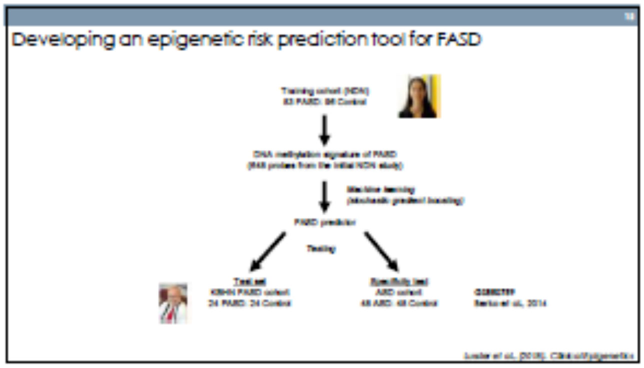

Developing an epigenetic risk prediction tool for FASD

Training cohort (NDN)
83 FASD: 96 Control

DNA methylation signature of FASD
(648 probes from the initial NDN study)

Machine learning
(stochastic gradient boosting)

FASD predictor

Testing

Test set
KBHN FASD cohort
24 FASD: 24 Control

Specificity test
ASD cohort
48 ASD: 48 Control

GSE50759
Berko et al., 2014

Lussier et al. (2018). Clinical Epigenetics

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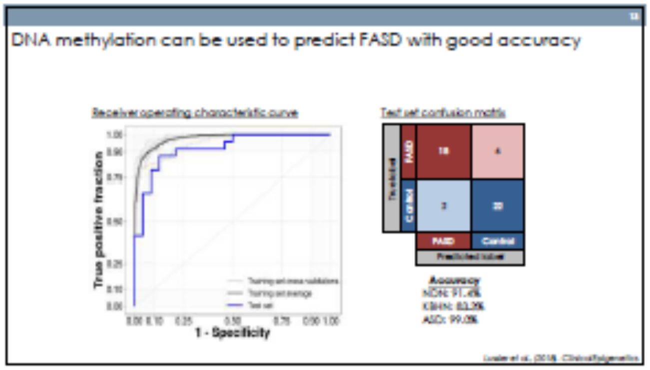
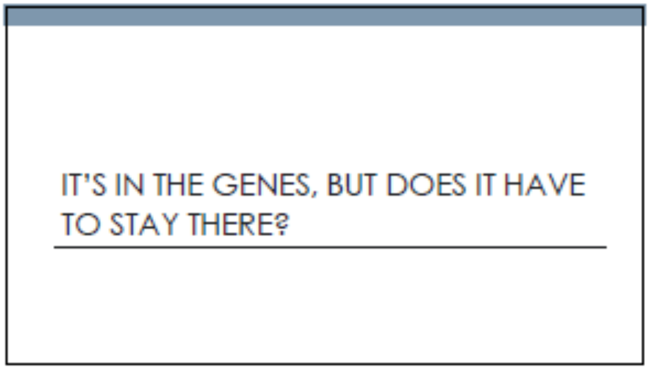


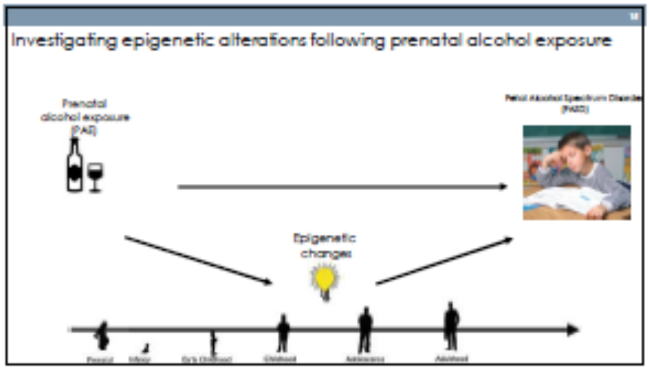
DNA methylation can be used to predict FASD with good accuracy

Accuracy
NDN: 91.4%
KBHN: 83.3%
ASD: 99.0%

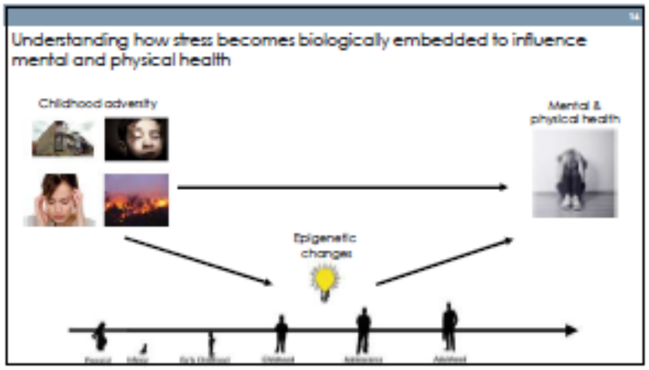
Lussier et al. (2018). Clinical Epigenetics



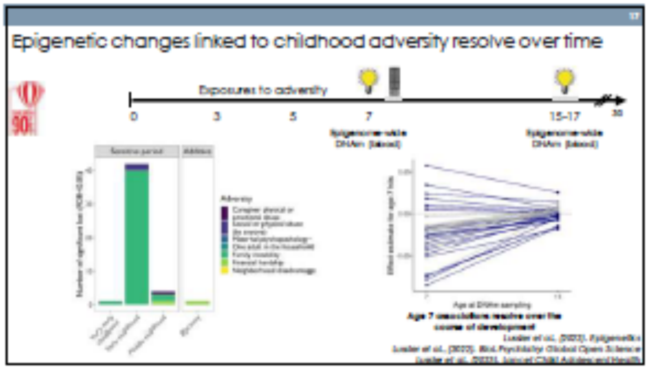
IT'S IN THE GENES, BUT DOES IT HAVE TO STAY THERE?



Investigating epigenetic alterations following prenatal alcohol exposure



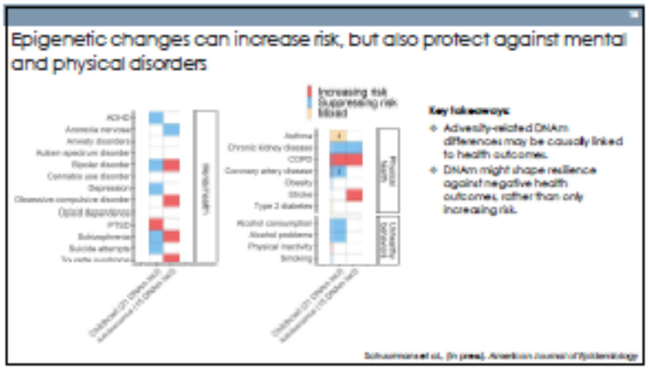
Understanding how stress becomes biologically embedded to influence mental and physical health



Epigenetic changes linked to childhood adversity resolve over time

Age 7 associations resolve over the course of development

Lussier et al. (2023). Epigenetics
Lussier et al. (2022). Biol. Psychiatry Global Open Science
Lussier et al. (2023). Lancet Child Adolescent Health



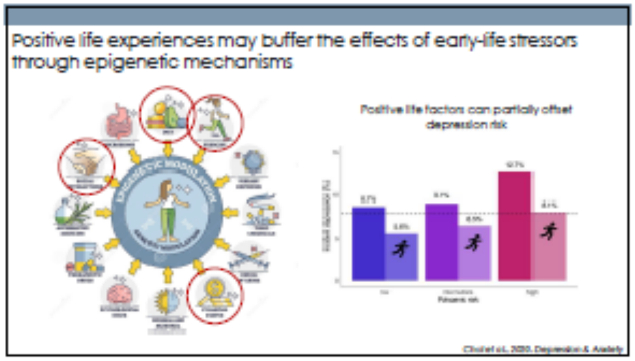
Epigenetic changes can increase risk, but also protect against mental and physical disorders

Key takeaways:

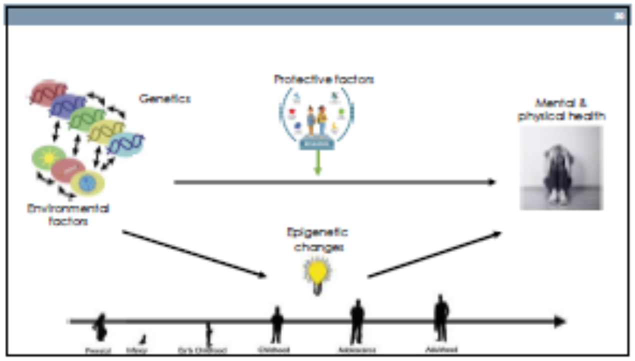
- Adversity-related DNAm differences may be causally linked to health outcomes.
- DNAm might shape resilience against negative health outcomes, rather than only increasing risk.

Schuurmans et al. (in press). American Journal of Epidemiology

Positive life experiences may buffer the effects of early-life stressors through epigenetic mechanisms



Choi et al. 2020. Depression & Anxiety



Conclusions

- FASD is associated with distinct epigenetic signatures
- DNA methylation may be used as biomarkers to predict FASD risk

However,

- Epigenetic changes are not set for life and may resolve over time
- Epigenetic differences related to developmental adversity may have protective effects on health outcomes, or represent resilient processes
- Positive environments or lifestyles may help resolve epigenetic differences

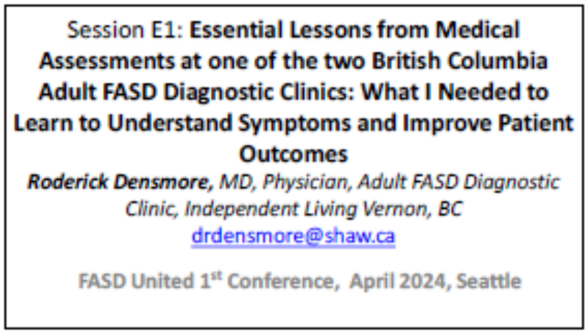
Early Life Experience and Developmental Vulnerability: Adversity, Outcomes and Intervention

James Reynolds

E1

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

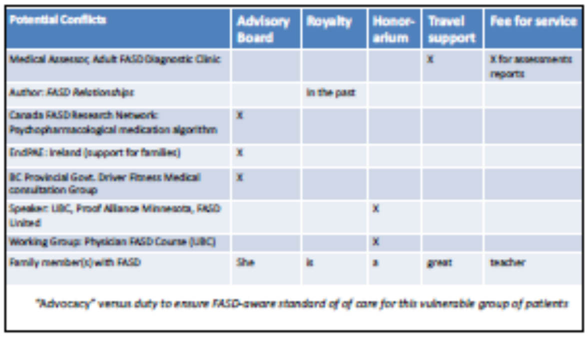
Roderick Densmore



Session E1: **Essential Lessons from Medical Assessments at one of the two British Columbia Adult FASD Diagnostic Clinics: What I Needed to Learn to Understand Symptoms and Improve Patient Outcomes**

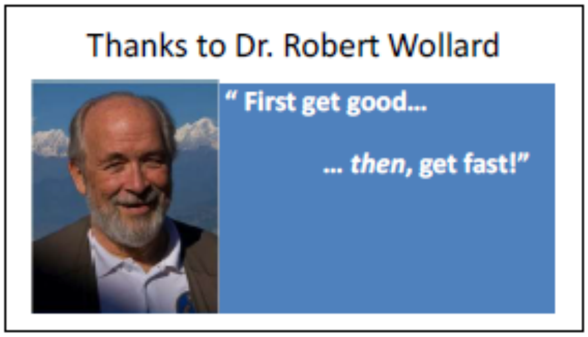
***Roderick Densmore**, MD, Physician, Adult FASD Diagnostic Clinic, Independent Living Vernon, BC*
drdensmore@shaw.ca

FASD United 1st Conference, April 2024, Seattle



Potential Conflicts	Advisory Board	Royalty	Honor-arium	Travel support	Fee for service
Medical Assessor, Adult FASD Diagnostic Clinic				X	X for assessments reports
Author: *FASD Relationships*		In the past			
Canada FASD Research Network: Psychopharmacological medication algorithm	X				
EndPAE : Ireland (support for families)	X				
BC Provincial Govt. Driver Fitness Medical consultation Group	X				
Speaker: UBC, Proof Alliance Minnesota, FASD United			X		
Working Group: Physician FASD Course (UBC)			X		
Family member(s) with FASD	She	is	a	great	teacher

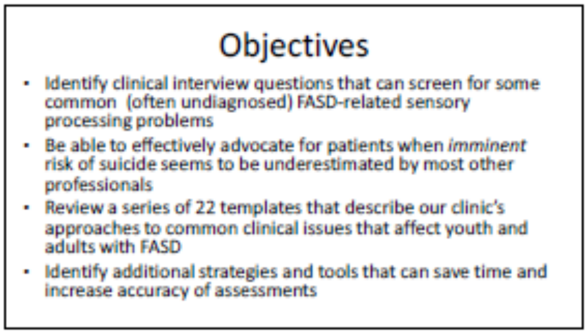
"Advocacy" versus duty to ensure FASD-aware standard of of care for this vulnerable group of patients



Thanks to Dr. Robert Wollard

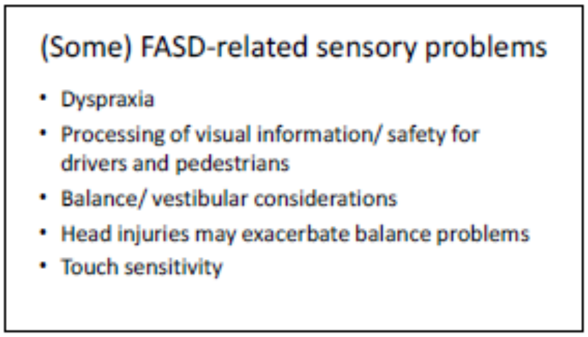
" First get good…

… *then*, get fast!"



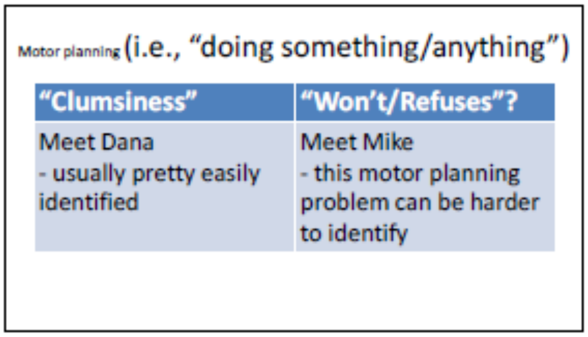
Objectives

- Identify clinical interview questions that can screen for some common (often undiagnosed) FASD-related sensory processing problems
- Be able to effectively advocate for patients when *imminent* risk of suicide seems to be underestimated by most other professionals
- Review a series of 22 templates that describe our clinic's approaches to common clinical issues that affect youth and adults with FASD
- Identify additional strategies and tools that can save time and increase accuracy of assessments



(Some) FASD-related sensory problems

- Dyspraxia
- Processing of visual information/ safety for drivers and pedestrians
- Balance/ vestibular considerations
- Head injuries may exacerbate balance problems
- Touch sensitivity



Motor planning (i.e., "doing something/anything")

"Clumsiness"	"Won't/Refuses"?
Meet Dana - usually pretty easily identified	Meet Mike - this motor planning problem can be harder to identify

Motor planning 3: Dana, 19, with Developmental Coordination Disorder who was labelled as having Munchausen Syndrome

- MABC-2 (Movement Assessment Battery for Children) testing (manual dexterity, aiming and catching, and balance) ***scoring at the 1st or 2nd percentile at age 9***
- Beery Visual-Motor Integration: *minus one standard deviation*
- Grooved Pegboard Test (fine motor dexterity with the left non-dominant hand) score results: ***Exceptionally Low limits***
- Neurologist: subtle reflex abnormalities (Hoffman present left side; absent right side)
CT: ***partial agenesis of corpus callosum***

Refer to physiatrist/ rehab specialist

Mike: putting cream in his coffee

- Doc: "I'm tried want a coffee at Macs?"
- Mike: "Sure"
- Doc: "I will push this button to put cream in"
- Mike: no action
- Doc: "Want cream?
- Mike: "Yep" (but no action)
- Doc (lying): "I want more cream in my coffee…I will push this button… again"
- Mike: can't put cream in coffee, but plays guitar beautifully!
- Now…Urgent: see new office for housing
- **Where is the lesion, what is the diagnosis, what is the plan?**

Motor Planning: Mike … what contributes to this? How to address it.

- Can't do new things esp. if upset, but can play Dark Side of The Moon in any key you want…
- He needs housing… needs to go to an office downtown… plan?

Praxis: Theresa May Benson: is ***Our ability to do the things we want to do***
- Our ability to adapt to our environment; to meet environmental demands
- To be able to plan and organize and come up with ideas for our motor actions
- Praxis is social… it is the basis on which we interact with others

Praxis Requires:
- 1) a repertoire of practiced skills (e.g. tying shoelaces) which we can call on and adapt to a new situation (e.g. lacing up skates)
- 2) the ability to *form a representation* of how to do a new task and then
- 3) the ability to execute the sequence of movements needed to do that task

Mike: *Ideational* Dyspraxia

- Difficulties forming **representations** of a **sequence of actions**, then **planning** those actions and then **executing** the actions accurately and in the right order.
- But habits/overlearned actions (lateral temporal lobe) are often fine
- NOVEL tasks (hippocampus) are the big issue

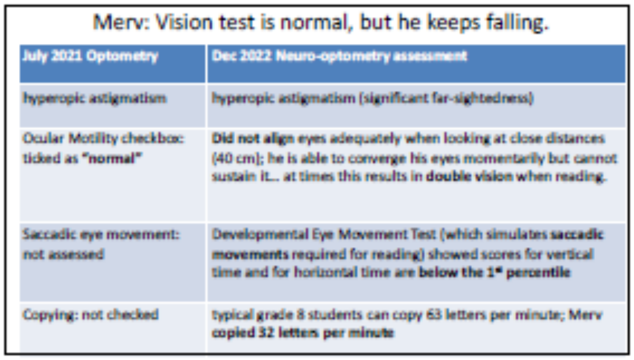
Merv (and Ms. A): The vision test is normal, but the patient cannot take notes from the board and keeps falling

- **PLEASE**
- **Ask, " When you are reading or writing notes, when you look up to the board where the teacher is writing do you see double or is it fuzzy?"**
- **Follow up: fuzzy… how long until it clears?, and when you look back down at your notebook how long until that image is clear?**
- **Follow up: double… just two images or more? Are the two images horizontal , vertical or on an angle?, how long do they last until there is just one image? and when you look back down at your notebook how long until there is just a single image?**
- **YOU WILL BE SURPRISED!**

Merv: falling and ~~won't~~ can't follow recipes

Examination:

Falls: BALANCE…Need at least 2 of 3 of:
1) Vestibular function
2) Proprioceptive function
3) Visual feedback
….. To be intact and accurate



Merv: Vision test is normal, but he keeps falling.

July 2021 Optometry	Dec 2022 Neuro-optometry assessment
hyperopic astigmatism	hyperopic astigmatism (significant far-sightedness)
Ocular Motility checkbox: ticked as **"normal"**	**Did not align** eyes adequately when looking at close distances (40 cm); he is able to converge his eyes momentarily but cannot sustain it… at times this results in **double vision** when reading.
Saccadic eye movement: not assessed	Developmental Eye Movement Test (which simulates **saccadic movements** required for reading) showed scores for vertical time and for horizontal time are **below the 1st percentile**
Copying: not checked	typical grade 8 students can copy 63 letters per minute; Merv **copied 32 letters per minute**

OK: Accurate visual feedback is used to monitor and correct movements in real time… but deeper level is that *intact vestibular function* sets up accurate vision

- Dr. Art Mallinson, Neurophysiolgist, Dept. Otolaryngology, UBC. https://art.mallinson.ca/
- Vestibular system "is always on" first: orient head w.r.t. gravity, then "foveate" (i.e., look at object in central vision), then plan and monitor movements

Head injuries… often associated with vestibular injury…

- Visual/vestibular "mismatch" (Mallinson) less security in movements, less able to accommodate quickly and accurately, for example, to unanticipated movements on a bus when you cannot see what is coming (for example a pot hole or a curve or a stop sign)

Adam: What vocational accommodations are needed?

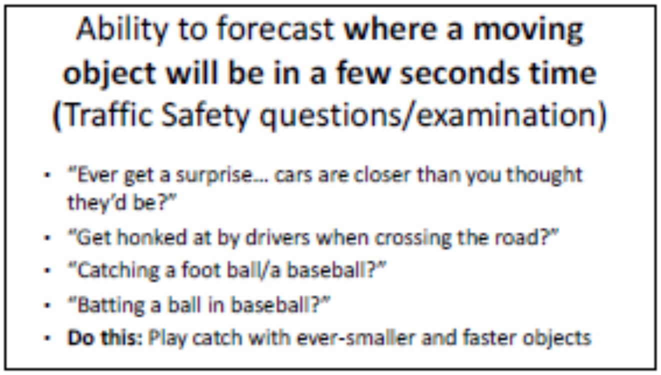
- **FASD, previous head injuries**, IQ 78, incarcerated (first offense), will be discharged in 3 years
- What questions and examinations are needed?

Adam: what is wrong/where is the lesion?

- Rhomberg:
- Walk in line eyes open:
- Walk in line eyes closed:
- Post-rotary nystagmus pattern:

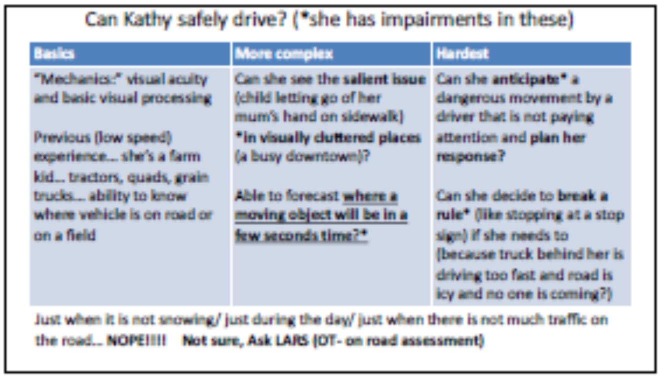
Adam: Dr. Mallinson

- Vestibular organs: Over sensitive to stimuli, made worse by recent concussions; unlikely to recover further
- **No ladders or roofing or work at heights**
- He has to concentrate a lot more than average people to maintain balance (less able to multitask because working memory preoccupied with task of maintaining balance)



Ability to forecast **where a moving object will be in a few seconds time** (Traffic Safety questions/examination)

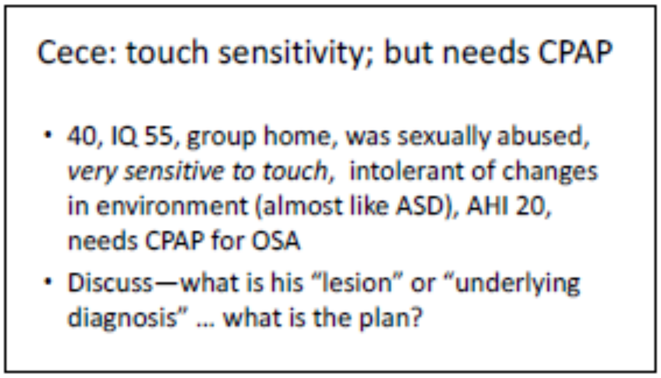
- "Ever get a surprise… cars are closer than you thought they'd be?"
- "Get honked at by drivers when crossing the road?"
- "Catching a foot ball/a baseball?"
- "Batting a ball in baseball?"
- **Do this:** Play catch with ever-smaller and faster objects



Can Kathy safely drive? (*she has impairments in these)

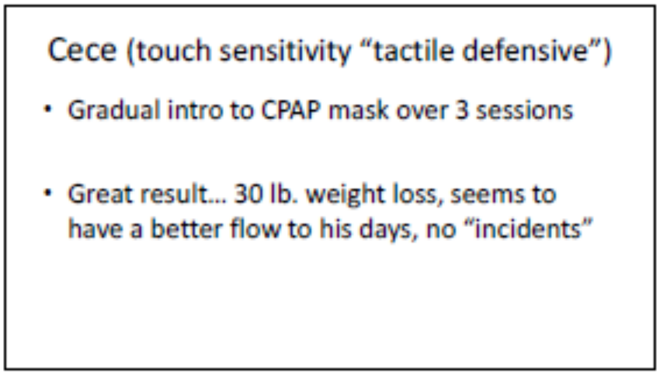
Basics	More complex	Hardest
"Mechanics:" visual acuity and basic visual processing Previous (low speed) experience… she's a farm kid… tractors, quads, grain trucks… ability to know where vehicle is on road or on a field	Can she see the **salient issue** (child letting go of her mum's hand on sidewalk) ***in visually cluttered places** (a busy downtown)? Able to forecast **where a moving object will be in a few seconds time?***	Can she **anticipate*** a dangerous movement by a driver that is not paying attention and **plan her response?** Can she decide to **break a rule*** (like stopping at a stop sign) if she needs to (because truck behind her is driving too fast and road is icy and no one is coming?)

Just when it is not snowing/ just during the day/ just when there is not much traffic on the road… **NOPE!!!!** **Not sure, Ask LARS (OT- on road assessment)**



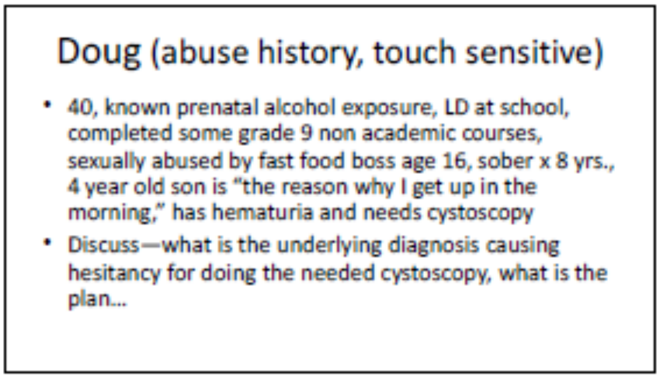
Cece: touch sensitivity; but needs CPAP

- 40, IQ 55, group home, was sexually abused, *very sensitive to touch*, intolerant of changes in environment (almost like ASD), AHI 20, needs CPAP for OSA
- Discuss—what is his "lesion" or "underlying diagnosis" … what is the plan?



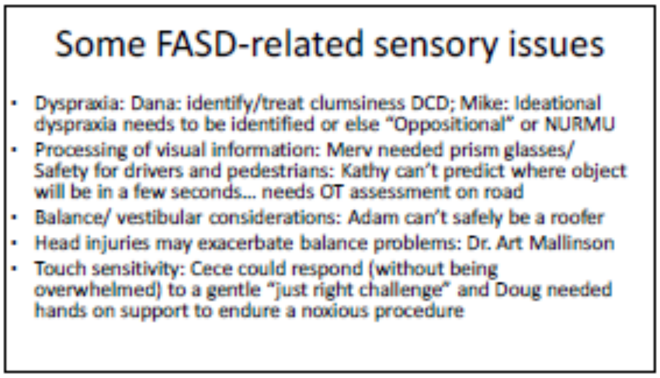
Cece (touch sensitivity "tactile defensive")

- Gradual intro to CPAP mask over 3 sessions
- Great result… 30 lb. weight loss, seems to have a better flow to his days, no "incidents"



Doug (abuse history, touch sensitive)

- 40, known prenatal alcohol exposure, LD at school, completed some grade 9 non academic courses, sexually abused by fast food boss age 16, sober x 8 yrs., 4 year old son is "the reason why I get up in the morning," has hematuria and needs cystoscopy
- Discuss—what is the underlying diagnosis causing hesitancy for doing the needed cystoscopy, what is the plan…

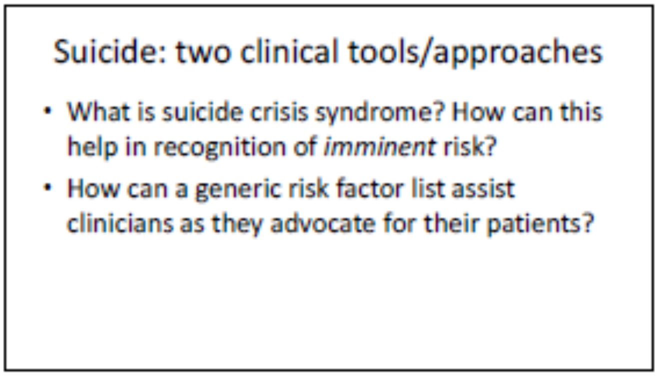


Some FASD-related sensory issues

- Dyspraxia: Dana: identify/treat clumsiness DCD; Mike: Ideational dyspraxia needs to be identified or else "Oppositional" or NURMU
- Processing of visual information: Merv needed prism glasses/ Safety for drivers and pedestrians: Kathy can't predict where object will be in a few seconds… needs OT assessment on road
- Balance/ vestibular considerations: Adam can't safely be a roofer
- Head injuries may exacerbate balance problems: Dr. Art Mallinson
- Touch sensitivity: Cece could respond (without being overwhelmed) to a gentle "just right challenge" and Doug needed hands on support to endure a noxious procedure

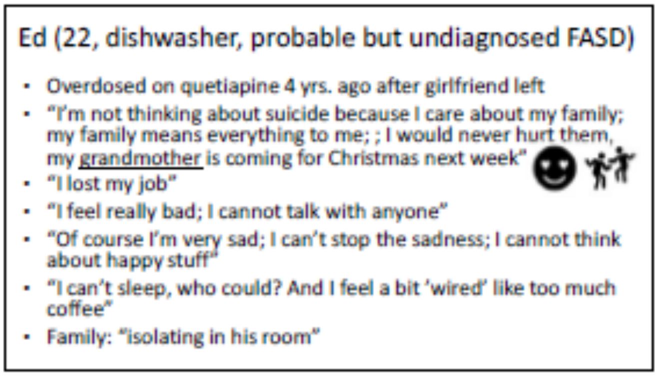
Suicide: the need for excellent care for patients with FASD

- *N=54 teens. Prevalence of suicidal behaviors in this sample was high with 35.2% of teens reporting incidences of suicidal ideation and 13.0% reporting at least one serious suicide attempt in the past year. This finding is in contrast to the 17.2% and 2.4% for ideation and serious attempts, respectively, reported in the general U.S. adolescent population.*
  (Ref: O'Connor MJ, Portnoff LC, Lebsack-Coleman M, Dipple KM. *Suicide risk in adolescents with fetal alcohol spectrum disorders.* Birth Defects Res. 2019 Jul 15;111(12):822-828. doi: 10.1002/bdr2.1465. Epub 2019 Jan 24. PMID: 30677250)
- *In our sample of 796 participants (M_{age} = 17.7 years, range = 6–59; 57.6% male) assessed for FASD, 25.9% were reported to experience suicidal ideation/attempts.*
  (Ref: Flannigan K, McMorris C, Ewasiuk A, Badry D, Mela M, Ben Gibbard W, Unsworth K, Cook J, Harding KD. ***Suicidality and Associated Factors Among Individuals Assessed for Fetal Alcohol Spectrum Disorder Across the Lifespan in Canada.*** Can J Psychiatry. 2022 May;67(5):361-370. doi: 10.1177/07067437211053288.)



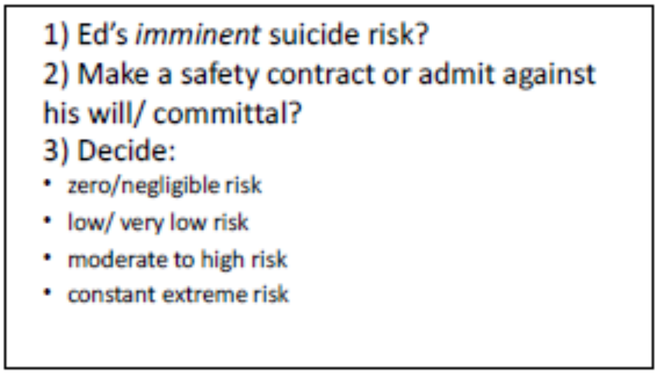
Suicide: two clinical tools/approaches

- What is suicide crisis syndrome? How can this help in recognition of *imminent* risk?
- How can a generic risk factor list assist clinicians as they advocate for their patients?



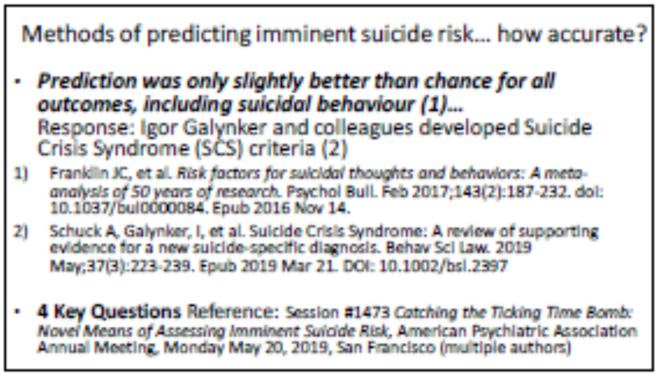
Ed (22, dishwasher, probable but undiagnosed FASD)

- Overdosed on quetiapine 4 yrs. ago after girlfriend left
- "I'm not thinking about suicide because I care about my family; my family means everything to me; ; I would never hurt them, my grandmother is coming for Christmas next week"
- "I lost my job"
- "I feel really bad; I cannot talk with anyone"
- "Of course I'm very sad; I can't stop the sadness; I cannot think about happy stuff"
- "I can't sleep, who could? And I feel a bit 'wired' like too much coffee"
- Family: "isolating in his room"



1) Ed's *imminent* suicide risk?
2) Make a safety contract or admit against his will/ committal?
3) Decide:

- zero/negligible risk
- low/ very low risk
- moderate to high risk
- constant extreme risk

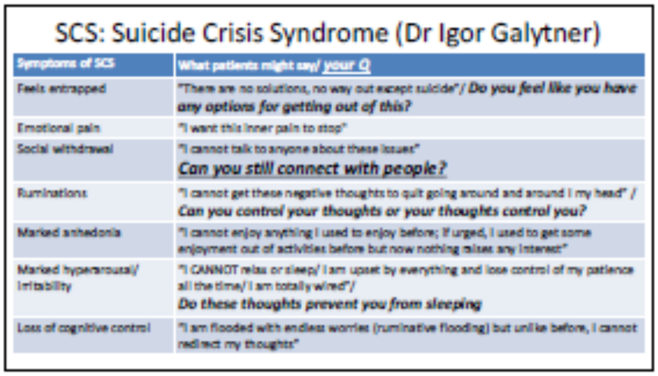


Methods of predicting imminent suicide risk… how accurate?

- ***Prediction was only slightly better than chance for all outcomes, including suicidal behaviour (1)…***
  Response: Igor Galynker and colleagues developed Suicide Crisis Syndrome (SCS) criteria (2)

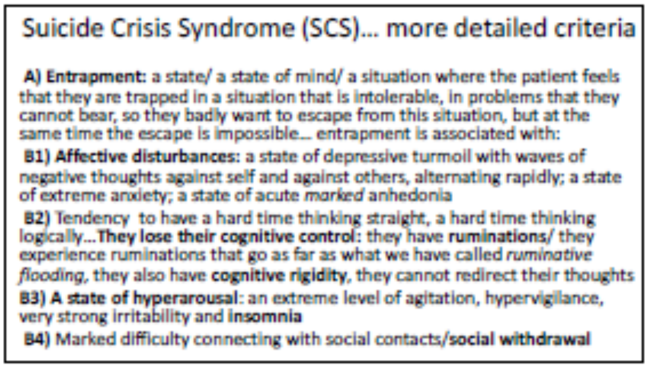
1) Franklin JC, et al. *Risk factors for suicidal thoughts and behaviors: A meta-analysis of 50 years of research.* Psychol Bull. Feb 2017;143(2):187-232. doi: 10.1037/bul0000084. Epub 2016 Nov 14.
2) Schuck A, Galynker, I, et al. Suicide Crisis Syndrome: A review of supporting evidence for a new suicide-specific diagnosis. Behav Sci Law. 2019 May;37(3):223-239. Epub 2019 Mar 21. DOI: 10.1002/bsl.2397

- **4 Key Questions** Reference: Session #1473 *Catching the Ticking Time Bomb: Novel Means of Assessing Imminent Suicide Risk*, American Psychiatric Association Annual Meeting, Monday May 20, 2019, San Francisco (multiple authors)



SCS: Suicide Crisis Syndrome (Dr Igor Galytner)

Symptoms of SCS	What patients might say/ your Q
Feels entrapped	"There are no solutions, no way out except suicide"/ ***Do you feel like you have any options for getting out of this?***
Emotional pain	"I want this inner pain to stop"
Social withdrawal	"I cannot talk to anyone about these issues" ***Can you still connect with people?***
Ruminations	"I cannot get these negative thoughts to quit going around and around I my head" / ***Can you control your thoughts or your thoughts control you?***
Marked anhedonia	"I cannot enjoy anything I used to enjoy before; If urged, I used to get some enjoyment out of activities before but now nothing raises any interest"
Marked hyperarousal/ Irritability	"I CANNOT relax or sleep/ I am upset by everything and lose control of my patience all the time/ I am totally wired"/ ***Do these thoughts prevent you from sleeping***
Loss of cognitive control	"I am flooded with endless worries (ruminative flooding) but unlike before, I cannot redirect my thoughts"



Suicide Crisis Syndrome (SCS)… more detailed criteria

A) Entrapment: a state/ a state of mind/ a situation where the patient feels that they are trapped in a situation that is intolerable, in problems that they cannot bear, so they badly want to escape from this situation, but at the same time the escape is impossible… entrapment is associated with:

B1) Affective disturbances: a state of depressive turmoil with waves of negative thoughts against self and against others, alternating rapidly; a state of extreme anxiety; a state of acute *marked* anhedonia

B2) Tendency to have a hard time thinking straight, a hard time thinking logically…**They lose their cognitive control**: they have **ruminations**/ they experience ruminations that go as far as what we have called *ruminative flooding*, they also have **cognitive rigidity**, they cannot redirect their thoughts

B3) A state of hyperarousal: an extreme level of agitation, hypervigilance, very strong irritability and **insomnia**

B4) Marked difficulty connecting with social contacts/**social withdrawal**

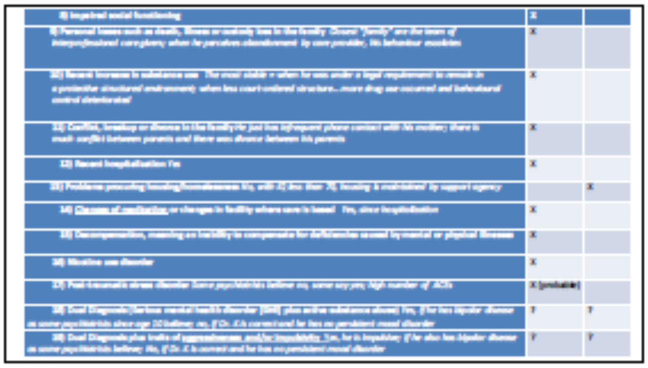
Ed: what's his risk of imminent self-harm?

History/ symptom	Risk/ Consistent with SCS?
Probable FASD/ adolescent	Higher risk of **impulsive** self-harm
OD after split with GF	Previous attempts increase risk ++
No suicidal ideation	Could be denial… or avoidant: hates hospital food! But also could be unaware
Lost job	This is a big life stressor
Feels bad; feels like he can't talk with anyone	Social isolation/ ***can't connect with people***/ **cognitive distortion/entrapment**
Sad, *cannot redirect or stop negative* thoughts	Thoughts control him; **ruminative flood**
Can't sleep/ feels wired/ argumentative	State of **hyperarousal**

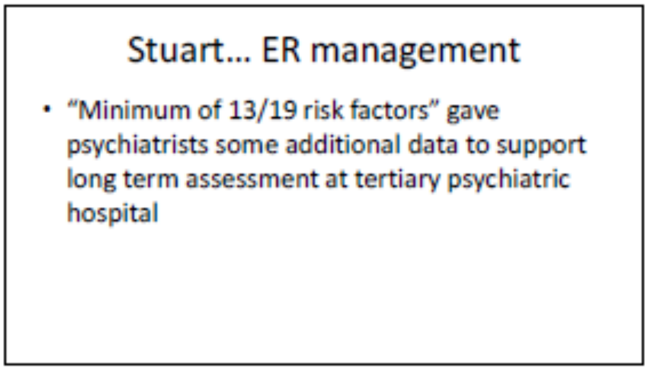
"Stuart has some self-harm by history but is not acutely suicidal" List is from Drs. Shar, Ghani, and Henchen: Sessions SCR08 and S63 of the 2016 American Psychiatric Association Annual Meeting.

(X indicates Stuart's situation as explained by his care providers December 2021)

Trait/Risk Factor for Suicidality	Yes	No
1) Severe and persistent mental illness (SMI) (major depressive disorder, bipolar disorder or schizophrenia/schizoaffective disorder) *Dr. K (psychiatry) says no persistent depressive illness, though other psychiatrists have diagnosed bipolar disorder*	? (probably)	?
2) Previous suicide attempt	X	
3) Two or more previous suicide attempts *an episode of trying to choke himself with a t-shirt, an intentional overdose with risperidone, an attempted self-choking incident and a number of presentations to hospital for making suicidal threats*	X	
4) Access to weapons *Care providers say he is not very interested in knives though he has been found with one on occasion and he did use one in an aggressive act as a teen*	X	
5) Non-adherence to medication and other treatments for mental health problems *Non-compliance with medications and psychological treatments is noted in his files*	X	
6) Not allowing family to be involved in planning treatment follow-up after an acute event such as a hospitalization *Hard to assess as his family is at a distance (1200 km) and has not been involved in decision making recently to my knowledge*		X (probably)
7) Impaired cognition/low I.Q. *Low IQ (72) and lower executive function, and adaptive function scores*	X	

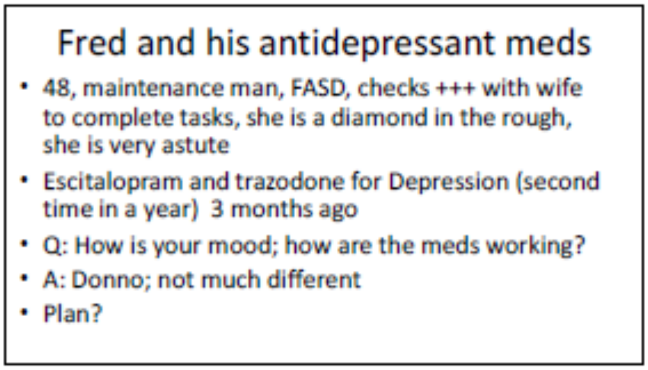


8) Impaired social functioning	X	
9) Personal losses such as death, illness or custody loss in the family *Stuart "family" are the team of interprofessional caregivers; when he perceives abandonment by care provider, his behaviour escalates*	X	
10) Recent increase in substance use *The most stable = when he was under a legal requirement to remain in a protective structured environment; when less court-ordered structure…more drug use occurred and behavioural control deteriorated*	X	
11) Conflict, breakup or divorce in the family *He just has infrequent phone contact with his mother; there is much conflict between parents and there was divorce between his parents*	X	
12) Recent hospitalization *Yes*	X	
13) Problems procuring housing/homelessness *No, with IQ less than 70, housing is maintained by support agency*		X
14) <u>Change of medication</u> or changes in facility where care is based *Yes, since hospitalization*	X	
15) Decompensation, meaning an inability to compensate for deficiencies caused by mental or physical illnesses	X	
16) Nicotine use disorder	X	
17) Post-traumatic stress disorder *Some psychiatrists believe no, some say yes; high number of ACEs*	X (probable)	
18) Dual Diagnosis (Serious mental health disorder (SMI) plus active substance abuse) *Yes, if he has bipolar disease as some psychiatrists since age 10 believe; no, if Dr. K is correct and he has no persistent mood disorder*	?	?
19) Dual Diagnosis plus traits of <u>aggressiveness and/or impulsivity</u> *Yes, he is impulsive; if he also has bipolar disease as some psychiatrists believe; No, if Dr. K is correct and he has no persistent mood disorder*	?	?



Stuart… ER management

- "Minimum of 13/19 risk factors" gave psychiatrists some additional data to support long term assessment at tertiary psychiatric hospital



Fred and his antidepressant meds

- 48, maintenance man, FASD, checks +++ with wife to complete tasks, she is a diamond in the rough, she is very astute
- Escitalopram and trazodone for Depression (second time in a year) 3 months ago
- Q: How is your mood; how are the meds working?
- A: Donno; not much different
- Plan?

Fred

- Q. for wife: How is Fred's mood; how are the meds working?
- Wife: Interacting great with the kids, better at work… "I got my husband back and it's not just the sex"
- **Comment: get collateral history or die!**

So far

- Cece: Sensory oversensitivity but graduated "just right challenge" worked
- Doug: Trusting therapeutic relationship let him go "where he could never go before"
- Merv: More detailed visual processing tests were needed
- Mike: Could not do certain *new* tasks (was not oppositional)
- Kathy: Concerns re ability to forecast trajectory of moving objects
- Adam: Had vestibular injury which added to effort needed to see clearly
- Ed: Look for SCS symptoms
- Stuart: Consider the 19 suicide risk factors
- Fred: get collateral history "or die!"

- Most "Disruptive Physician" colleagues and some medical administrators: "Donno, this looks like 'enabling'…unsustainable mollycoddling!"

Nope… it ain't mollycoddling!

- **FYI:** Sullivan WF, et al. *Primary care of adults with intellectual and developmental disabilities: 2018 Canadian Consensus Guidelines*, Canadian Family Physician Vol. 64: April 2018 pages 254-279
- Response to "mollycoddling" accusations: **If you look at the above comprehensive reference, now in its second edition, you will see that the approaches described above are *simply evidence-based care for this surprisingly big population of patients*…**
- Intellectual and developmental disabilities: 7-8%+ *of the overall population*

Sullivan, et al.

- Develop a mutually respectful doctor-patient relationship
- Allow sufficient time; ensure patients can make their concerns and perspectives understood
- Getting collateral history is essential
- The cause of the intellectual or developmental disability is important because it can inform specifics of preventive care, support and treatment decisions
- Anticipate and look for often missed but common health issues including dental problems, reflux, aspiration (sometimes "silent"), and seizures; be aware that routine cancer screening, and routine preventive health care such as vaccinations, blood pressure checks, cholesterol and diabetes screening are often overlooked "because of all the drama!"

Templates: Thanks to Dr Barry Fogel, Nov 2022

Holistic and Sustainable Management of Complex Neuropsychiatric Patients

Barry S. Fogel, M.D.
Center for Brain-Mind Medicine
Brigham and Women's Hospital

Dr. Fogel, Neuropsychiatry, Boston

- " Without involvement of somebody that a) *has the **capacity*** to understand health matters and organize health planning and b) has the time and ***availability*** to do these tasks, it is NOT a matter of "if," it is simply a question of "when" the patient's mental health and physical health will deteriorate to a point where urgent interventions (emergency care) are needed."
- "Sustainability Should Not Rely on Clinicians Being Masochists, Saints or Clinical Superheros (The Supply is Limited)"

Templates 1-5 (Patients we have discussed or will discuss*)

1) FASD and Head Injuries (*Mike)
2) FASD and applications for Disability Tax Credit and other support programs; information families can provide regarding patient function assists professionals completing these applications
3) FASD and Suicide: 1) Risk Factors for suicide (*Stuart), 2) Notes on Suicide Crisis Syndrome (*Ed)
4) FASD: A grid that assists with assessing several options *prior* to making a decision for patients smaller working memory capacity and impaired impulse control (*Judy)
5) FASD: Problems "doing things" … Motor planning difficulties that look like noncompliance or willful resistance (*Dana, Mike, Merv, Adam)

Templates 6-11

6) A call for inclusion of strengths in FASD assessments
7) The cognitive behavioural phenotype of FASD
8) Use of Dr Burd's Alcohol Related Neurodevelopmental Disorder Behavioral Checklist (ABC) to determine likelihood of prenatal alcohol exposure
9) PTSD leads to impaired control over drinking/ treating PTSD reduces the risk of impaired control over drinking: what evidence supports these statements? The case of Ms. T
10) Criteria required to establish a diagnosis of fetal alcohol spectrum disorder in Canada
11) FASD/estimating quantities /math skills (*Gerry)

Templates 12-16

12) Adverse childhood experiences (ACEs) and FASD/ Adverse experiences that continue into adulthood
13) The essence of how FASD affects people in my experience
14) Unrecognized impaired capacity: the "*Tyranny of Autonomy*" can harm some intellectually disabled patients with FASD
15) FASD and Ophthalmological problems (*Merv, Ms. A)
16) Physician services fees and diagnostic codes regarding FASD

Templates 17-22 (under development)

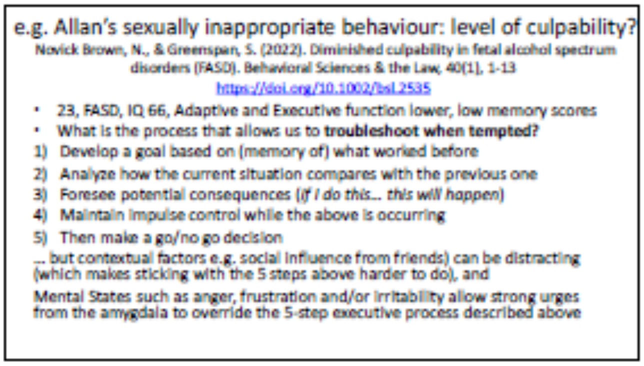
17) (Some references relevant to) … *FASD and accuracy of performance validity tests… the case of my patient, Mr. T*
18) (Some reference articles that describe assessment of) … *Parenting capacity in FASD*
19) (Some references relevant to) … *Can a personality disorder be diagnosed in patients with FASD and an intellectual disability?*
20) (References relevant to) … *Can FASD be diagnosed when prenatal alcohol intake is not confirmed but prenatal cocaine use is confirmed?*
21) (References relevant to) … *The evaluation of Moral Injury in FASD*
22) (References relevant to) … *Brain inflammation and FASD*

Tools/ideas that can assist

1) Dr Natalie Novick-Brown's: a) List of processes that allow us to troubleshoot when tempted, (Allen) b) Ways to identify "Counterfeit Deviance" (Norm)
2) Grid to provide structure for decision making if ↶ working memory (Judy)
3) College of Optometrists in Vision Development questionnaire regarding visual processing problems (Ms. A)
4) Screening questions that can identify problems with estimation of quantities (Gerry)
5) List of medications that can be taken in an easier way than "pills"
6) Dr Daniel Amen's: List of common concussion-related symptoms (Mike)
7) FYI: Memory helper for physical issues often associated with prenatal alcohol exposure

Re Allan: Impairments in which cognitive processes cause *Inappropriate Behaviour?*

- Could be *anything*: inappropriate sexual behaviour, theft, overspending, etc. The issue is ***ability to troubleshoot and weigh consequences in a moment of temptation***



e.g. Allan's sexually inappropriate behaviour: level of culpability?

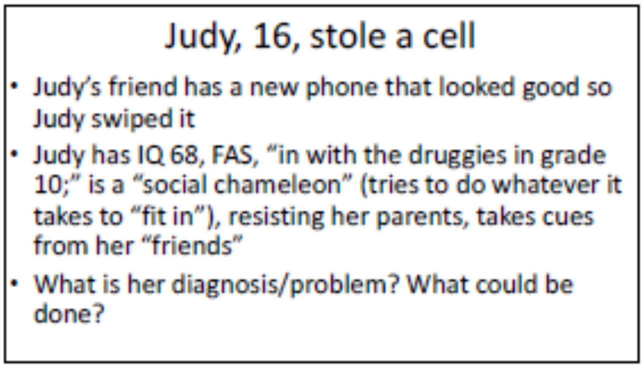
Novick Brown, N., & Greenspan, S. (2022). Diminished culpability in fetal alcohol spectrum disorders (FASD). Behavioral Sciences & the Law, 40(1), 1-13
https://doi.org/10.1002/bsl.2535

- 23, FASD, IQ 66, Adaptive and Executive function lower, low memory scores
- What is the process that allows us to **troubleshoot when tempted?**

1) Develop a goal based on (memory of) what worked before
2) Analyze how the current situation compares with the previous one
3) Foresee potential consequences (*if I do this… this will happen*)
4) Maintain impulse control while the above is occurring
5) Then make a go/no go decision

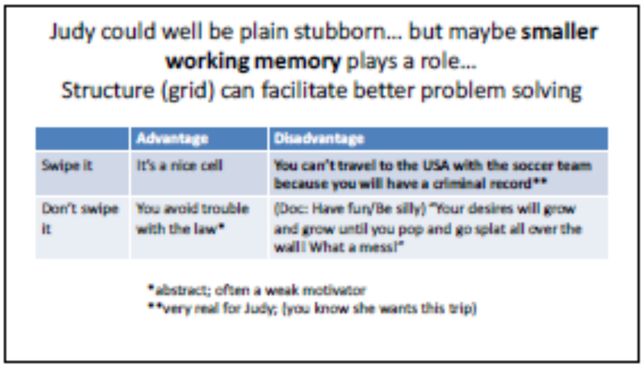
… but contextual factors e.g. social influence from friends) can be distracting (which makes sticking with the 5 steps above harder to do), and

Mental States such as anger, frustration and/or irritability allow strong urges from the amygdala to override the 5-step executive process described above



Judy, 16, stole a cell

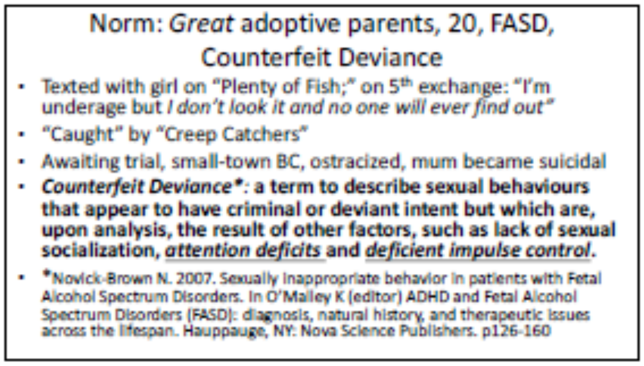
- Judy's friend has a new phone that looked good so Judy swiped it
- Judy has IQ 68, FAS, "in with the druggies in grade 10;" is a "social chameleon" (tries to do whatever it takes to "fit in"), resisting her parents, takes cues from her "friends"
- What is her diagnosis/problem? What could be done?



Judy could well be plain stubborn… but maybe **smaller working memory** plays a role…
Structure (grid) can facilitate better problem solving

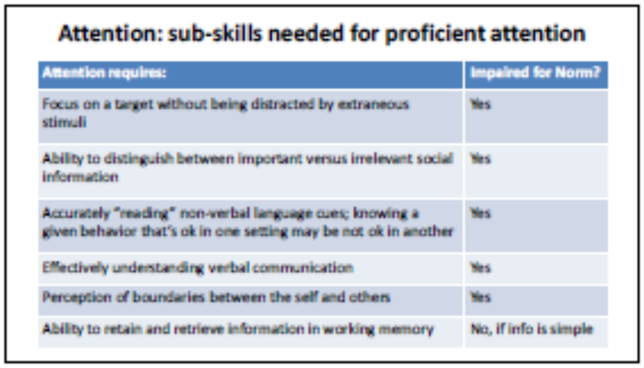
	Advantage	Disadvantage
Swipe it	It's a nice cell	**You can't travel to the USA with the soccer team because you will have a criminal record****
Don't swipe it	You avoid trouble with the law*	(Doc: Have fun/Be silly) "Your desires will grow and grow until you pop and go splat all over the wall! What a mess!"

*abstract; often a weak motivator
**very real for Judy; (you know she wants this trip)



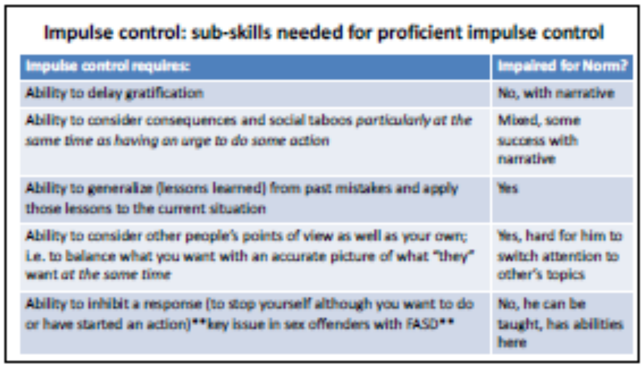
Norm: *Great* adoptive parents, 20, FASD, Counterfeit Deviance

- Texted with girl on "Plenty of Fish;" on 5th exchange: "I'm underage but *I don't look it and no one will ever find out*"
- "Caught" by "Creep Catchers"
- Awaiting trial, small-town BC, ostracized, mum became suicidal
- ***Counterfeit Deviance**: a term to describe sexual behaviours that appear to have criminal or deviant intent but which are, upon analysis, the result of other factors, such as lack of sexual socialization, *attention deficits* and *deficient impulse control*.**
- *Novick-Brown N. 2007. Sexually inappropriate behavior in patients with Fetal Alcohol Spectrum Disorders. In O'Malley K (editor) ADHD and Fetal Alcohol Spectrum Disorders (FASD): diagnosis, natural history, and therapeutic issues across the lifespan. Hauppauge, NY: Nova Science Publishers. p126-160



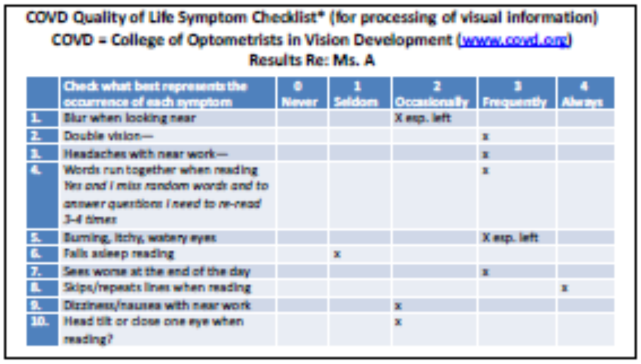
Attention: sub-skills needed for proficient attention

Attention requires:	Impaired for Norm?
Focus on a target without being distracted by extraneous stimuli	Yes
Ability to distinguish between important versus irrelevant social information	Yes
Accurately "reading" non-verbal language cues; knowing a given behavior that's ok in one setting may be not ok in another	Yes
Effectively understanding verbal communication	Yes
Perception of boundaries between the self and others	Yes
Ability to retain and retrieve information in working memory	No, if info is simple



Impulse control: sub-skills needed for proficient impulse control

Impulse control requires:	Impaired for Norm?
Ability to delay gratification	No, with narrative
Ability to consider consequences and social taboos *particularly at the same time as having an urge to do some action*	Mixed, some success with narrative
Ability to generalize (lessons learned) from past mistakes and apply those lessons to the current situation	Yes
Ability to consider other people's points of view as well as your own; i.e. to balance what you want with an accurate picture of what "they" want *at the same time*	Yes, hard for him to switch attention to other's topics
Ability to inhibit a response (to stop yourself although you want to do or have started an action)**key issue in sex offenders with FASD**	No, he can be taught, has abilities here



COVD Quality of Life Symptom Checklist* (for processing of visual information)
COVD = College of Optometrists in Vision Development (www.covd.org)
Results Re: Ms. A

	Check what best represents the occurrence of each symptom	0 Never	1 Seldom	2 Occasionally	3 Frequently	4 Always
1.	Blur when looking near			X esp. left		
2.	Double vision—				x	
3.	Headaches with near work—				x	
4.	Words run together when reading *Yes and I miss random words and to answer questions I need to re-read 3-4 times*				x	
5.	Burning, itchy, watery eyes				X esp. left	
6.	Falls asleep reading		x			
7.	Sees worse at the end of the day				x	
8.	Skips/repeats lines when reading					x
9.	Dizziness/nausea with near work			x		
10.	Head tilt or close one eye when reading?			x		

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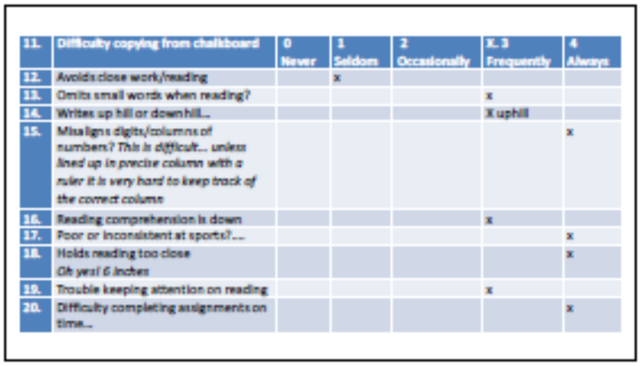

11.	Difficulty copying from chalkboard	0 Never	1 Seldom	2 Occasionally	X. 3 Frequently	4 Always
12.	Avoids close work/reading		x			
13.	Omits small words when reading?				x	
14.	Writes up hill or down hill…				X uphill	
15.	Misaligns digits/columns of numbers? *This is difficult… unless lined up in precise column with a ruler it is very hard to keep track of the correct column*					x
16.	Reading comprehension is down				x	
17.	Poor or inconsistent at sports?…					x
18.	Holds reading too close *Oh yes! 6 inches*					x
19.	Trouble keeping attention on reading				x	
20.	Difficulty completing assignments on time…					x

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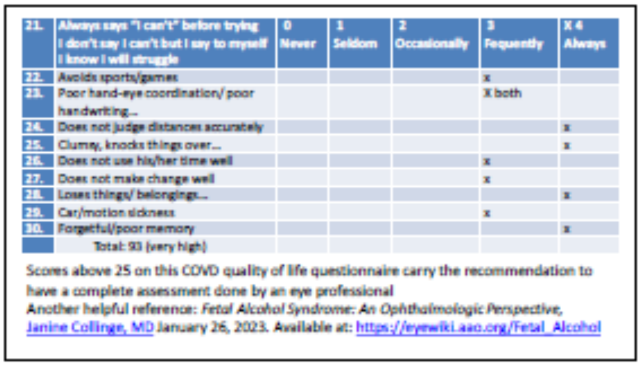

21.	Always says "I can't" before trying **I don't say I can't but I say to myself I know I will struggle**	0 Never	1 Seldom	2 Occasionally	3 Fequently	X 4 Always
22.	Avoids sports/games				x	
23.	Poor hand-eye coordination/ poor handwriting…				X both	
24.	Does not judge distances accurately					x
25.	Clumsy, knocks things over…					x
26.	Does not use his/her time well				x	
27.	Does not make change well				x	
28.	Loses things/ belongings…					x
29.	Car/motion sickness				x	
30.	Forgetful/poor memory					x
	Total: 93 (very high)					

Scores above 25 on this COVD quality of life questionnaire carry the recommendation to have a complete assessment done by an eye professional
Another helpful reference: *Fetal Alcohol Syndrome: An Ophthalmologic Perspective,* Janine Collinge, MD January 26, 2023. Available at: https://eyewiki.aao.org/Fetal_Alcohol

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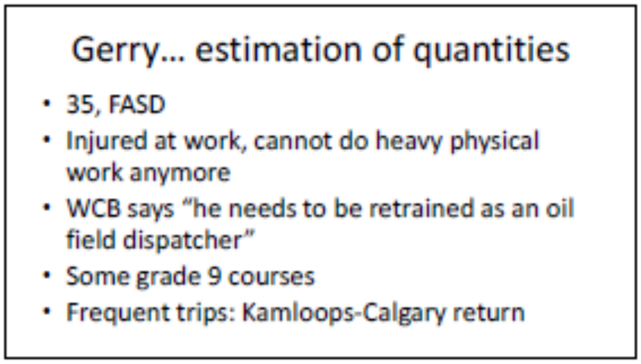

Gerry… estimation of quantities

- 35, FASD
- Injured at work, cannot do heavy physical work anymore
- WCB says "he needs to be retrained as an oil field dispatcher"
- Some grade 9 courses
- Frequent trips: Kamloops-Calgary return

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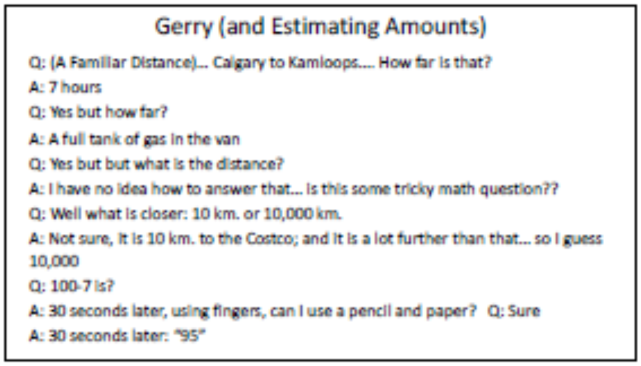

Gerry (and Estimating Amounts)

Q: (A Familiar Distance)… Calgary to Kamloops…. How far is that?
A: 7 hours
Q: Yes but how far?
A: A full tank of gas in the van
Q: Yes but but what is the distance?
A: I have no idea how to answer that… is this some tricky math question??
Q: Well what is closer: 10 km. or 10,000 km.
A: Not sure, it is 10 km. to the Costco; and it is a lot further than that… so I guess 10,000
Q: 100-7 is?
A: 30 seconds later, using fingers, can I use a pencil and paper? Q: Sure
A: 30 seconds later: "95"

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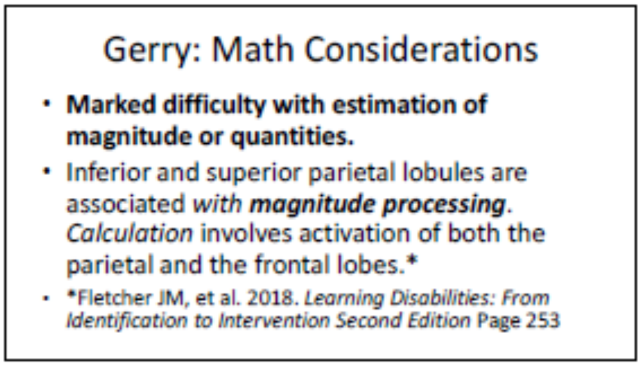

Gerry: Math Considerations

- **Marked difficulty with estimation of magnitude or quantities.**
- Inferior and superior parietal lobules are associated *with* ***magnitude processing***. *Calculation* involves activation of both the parietal and the frontal lobes.*
- *Fletcher JM, et al. 2018. *Learning Disabilities: From Identification to Intervention Second Edition* Page 253

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- **FYI Gerry Math:** “Some kids for a variety of reasons have difficulty developing **‘number sense,’** and we often see them have difficulties developing multiple representations of numbers early on (preschool/K)—that a number can be represented by a symbolic numeral, sets of objects, etc., and we often see problematic counting strategies early on (see examples of problematic counting strategies and how to improve them here, plus other math intervention resources; helpful in providing **big ideas about math intervention and instruction:** https://intensiveintervention.org/intervention-resources/mathematics-strategies-support-intensifying-interventions ”
- Sterett Mercer Ph.D., R. Psych. Chris Spencer Foundation Professor in Dyslexia, U.B.C. Vancouver

“Forgettable” treatments… think: if it is hard to remember pills … could there be alternative methods of drug delivery?

- IV Iron for iron deficiency anemia
- IUD
- Depo shots for birth control and antipsychotic

Mike (pre-treatment): *angry, irritable, **seething***

- In and out of prison for the past decade
- Volatile, but needed disability applications to be completed so we had several meetings
- He came to think I was OK because we are both musicians
- Eventually I wrote out how to ask his mum re PAE* and concussions

1) Before aware of pregnancy: pattern of use of cigarettes, cannabis, alcohol, other drugs?
2) Once became aware of being pregnant: pattern of use of cigarettes, cannabis, alcohol, other drugs?
3) How far along was your mum when she knew she was pregnant?

Mike: “You’d better sit down!”

- Yes, drank heavily at least once a week before and after pregnancy recognized
- When I was 4 months old my stupid father—home on leave from the Navy (Esquimalt) shook me till I shut up

Dr. Daniel Amen’s Concussion Questions for Mike

1) Seldom 2) A little bit 3) Quite a bit 4) Extremely

- Short fuse/ lose temper with minimal provocation?….4
- Tends to misinterpret comments as negative?….4
- History of head injury?….4
- “ADHD” but Ritalin, etc. does not work?….4 <u>**Average 3.6**</u>
- Depression but SSRI make me feel “not myself” or worse?….3
- Dark Thoughts?….3 “yes, like a horror movie”
- Unstable/unpredictable moods?….3
- “See” or “hear” things that are not really there esp. if tried/stressed?….3
- Déjà vu?….4
- Headaches and/or abdominal pain?….3
- Loss of consciousness/ concussions: see stars, nausea, hard to walk/dizzy?…. “yes…lots”….4

Mike… mood stabilizer lamotrigine… then, “I wrote my landlord a letter!”…after that…

- Rosacea: minocycline
- Fights/knifings → PTSD: “Don’t spazz, take a prazz!” (prazosin)
- Met Amie in a rock band… they live together… (diamond in the rough like Gracie Heavy Hand from CBC Dead Dog Café)
- Successfully dealt with neurosurgery on his neck
- Very serious Fender base player… Amie is the drummer
- Exercise: 3 Paper routes
- No jail or trouble with the law for over a decade
- “I like my little life”

- Allen: had low scores in working memory … he could not be expected to manage the 5 steps required to troubleshoot when tempted
- Norm: Counterfeit Deviance is more likely than criminal intent
- Judy: small working memory: use a "Grid"
- Ms. A had high scores on COVD checklist… sent her to optometrist with American Academy of Ophthalmology article… prism glasses
- Gerry cannot estimate quantities: budgeting/ proportional consequences??
- The best meds are "forgettable"… esp. if "high stakes" (low iron, or in need of contraception) consider "non pill" possibilities
- Mike: High score on Dr. Amen's questions; TBI-hostility improved with lamotrigine; also, he had rosacea… minocycline helped skin and mood/flow (brain inflammation)

Physical Issues with FASD A-Z; A little Memory Helper

- A) Allergy/ Anaphylaxis /Asthma/ Acne, if present, can be treated with minocycline
- B) Breast Cancer
- C) Constipation/Celiac/ Circadian Rhythm/High Cholesterol/ Choline/ Congenital heart / "Counterfeit Deviance" (Natalie Novick-Brown)
- D) Dental decay/abscess and denial of pain/ Dental crowding and small upper jaw and issues breathing at night with increased mouth breathing and lower oxygen levels during sleep…Orthodontists may say, "mid face deficiency and myofunctional disorders"
- E) Ear infections

Physical Issues with FASD A-Z

- F) Furuncles/Folate/Frontal Lobe Paradox (better performance in calm organized environments versus busy classrooms/ workplaces)
- G) Gastric reflux (GERD…it hurts teeth too)/ Gluconeogenesis altered
- H) Hypotonia…lax muscles when breathing… increases sleep apnea
- I) Infections (easier to get) / Iron/ Insulin resistance
- J) Joints: "double jointed" is common
- K) Kidney infections/horseshoe kidney/ duplex ureters
- L) Liver (Fatty Liver)…high triglycerides/ Ligamentous laxity/flat feet
- M) Metabolic syndrome

Physical Issues with FASD A-Z

- N) Nutrients: Deficiencies of zinc, Vitamin A, Folic Acid, Iron/ Neuroimmune issues: excessive pro-inflammatory cytokines and inflammation cells in the brain
- O) Obesity (esp. females esp. pFAS; not FAS)/ Osteopenia (due to immune changes)
- P) Pneumonia (relates to immune compromise)
- Q) QT Prolongation
- R) Restless legs…often associated with low iron/ Rosacea, if present, can be treated with minocycline
- S) Suicide risk can be underestimated/ Spondylolisthesis Seizures/ Sensory processing differences/ Suggestibility

Physical Issues with FASD A-Z

- T) Trauma/ TBI/ Traffic safety (play catch to see if patients can forecast where a moving object will be in 2-3 seconds)
- U) Ureters can be double (duplex ureters are prone to "backflow"… leads to kidney infection risk)
- V) Visual changes (double vision/focus issues/ anticipating where moving objects will be in a few seconds [traffic safety])
- W) Whole Body…as Myles, CJ and Emily (FASD Changemakers) say: FASD affects the whole body, not just the brain
- X) X-ray the lower back (rule out or treat spondylolisthesis)
- Y) Dr. Mark Ylvasaker: " In absence of meaningful engagement in chosen pursuits, all interventions ultimately fail"
- Z) Zits! Remember minocycline can also help brain inflammation

THANKS FOR YOUR INTEREST AND ATTENTION

Questions? drdensmore@shaw.ca

E2

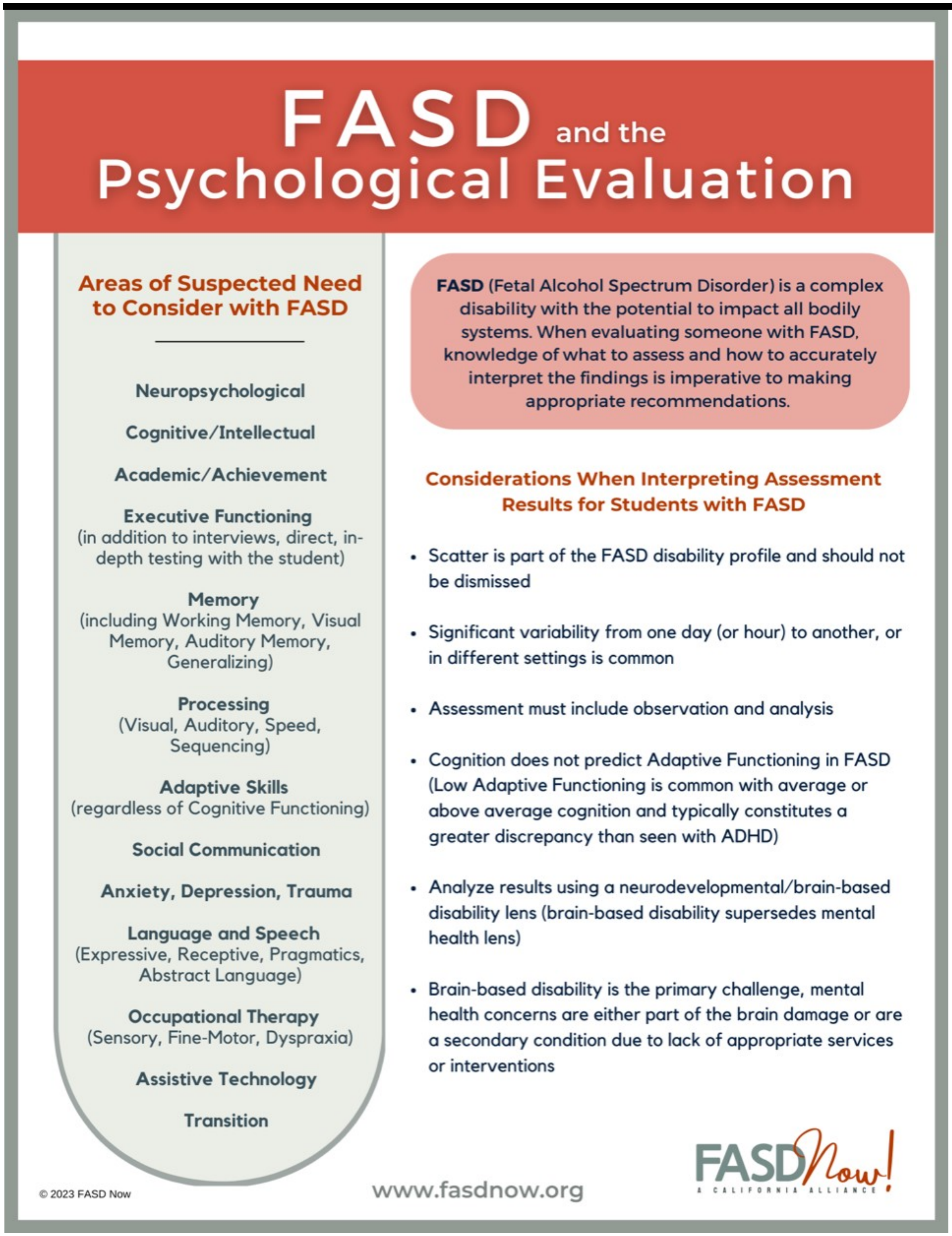
Capacity to Stand Trial issues and ensuring effective participation for defendants with FASD: an International Perspective

Valerie McGinn, Mansfield Mela, Maria Pecotić, Stephen Greenspan, David Junior Gilbert

E4

Using Community Outreach and Organizational Partnerships to Make Change for Those Living with FASD: FASDNow!, a California Alliance

Annette Kunzman, Shannon Iacobacci



FASD and the Psychological Evaluation

Areas of Suspected Need to Consider with FASD

Neuropsychological

Cognitive/Intellectual

Academic/Achievement

Executive Functioning
(in addition to interviews, direct, in-depth testing with the student)

Memory
(including Working Memory, Visual Memory, Auditory Memory, Generalizing)

Processing
(Visual, Auditory, Speed, Sequencing)

Adaptive Skills
(regardless of Cognitive Functioning)

Social Communication

Anxiety, Depression, Trauma

Language and Speech
(Expressive, Receptive, Pragmatics, Abstract Language)

Occupational Therapy
(Sensory, Fine-Motor, Dyspraxia)

Assistive Technology

Transition

FASD (Fetal Alcohol Spectrum Disorder) is a complex disability with the potential to impact all bodily systems. When evaluating someone with FASD, knowledge of what to assess and how to accurately interpret the findings is imperative to making appropriate recommendations.

Considerations When Interpreting Assessment Results for Students with FASD

- Scatter is part of the FASD disability profile and should not be dismissed
- Significant variability from one day (or hour) to another, or in different settings is common
- Assessment must include observation and analysis
- Cognition does not predict Adaptive Functioning in FASD (Low Adaptive Functioning is common with average or above average cognition and typically constitutes a greater discrepancy than seen with ADHD)
- Analyze results using a neurodevelopmental/brain-based disability lens (brain-based disability supersedes mental health lens)
- Brain-based disability is the primary challenge, mental health concerns are either part of the brain damage or are a secondary condition due to lack of appropriate services or interventions

www.fasdnow.org

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IDENTIFYING FASD IN THE CLASSROOM

Red Flags

Red Flags are helpful tools to bring attention to situations where Fetal Alcohol Spectrum Disorders (FASD) may warrant consideration. With the exception of a direct notification of alcohol exposure in utero, individual red flags are not necessarily representative of FASD; however, when multiple red flags occur in the same individual, it is essential to consider the possibility of FASD as a contributing factor.

Primary Red Flags

- History of substance use or alcohol use during pregnancy should trigger an immediate consideration of FASD
- Foster care, adopted or living with a relative
- Parent in recovery
- Multiple mental health diagnoses (especially ADHD, RAD, ODD and mood disorders)
- Discipline does not seem to work, or effects do not last
- Repeat failure despite increasing interventions
- Adaptive functioning much lower than expected based on cognitive ability
- Has autistic traits (but may or may not meet full criteria for autism)
- Acts younger than expected for their age
- Atypical social relationships
- Receptive language lower than expressive language (an atypical profile)

Additional Red Flags

ADHD diagnosis with poor response to ADHD medications

Significant scatter in cognitive testing profile

Difficulty learning from one's own mistakes

Test results and classroom academic performance may not be aligned (often testing demonstrates higher ability than demonstrated in class)

Significant variability in academic performance from day to day (or within a day) (e.g. knowing and able to demonstrate a skill one day and unable to do so the next)

School dropout, suspension, or expulsion

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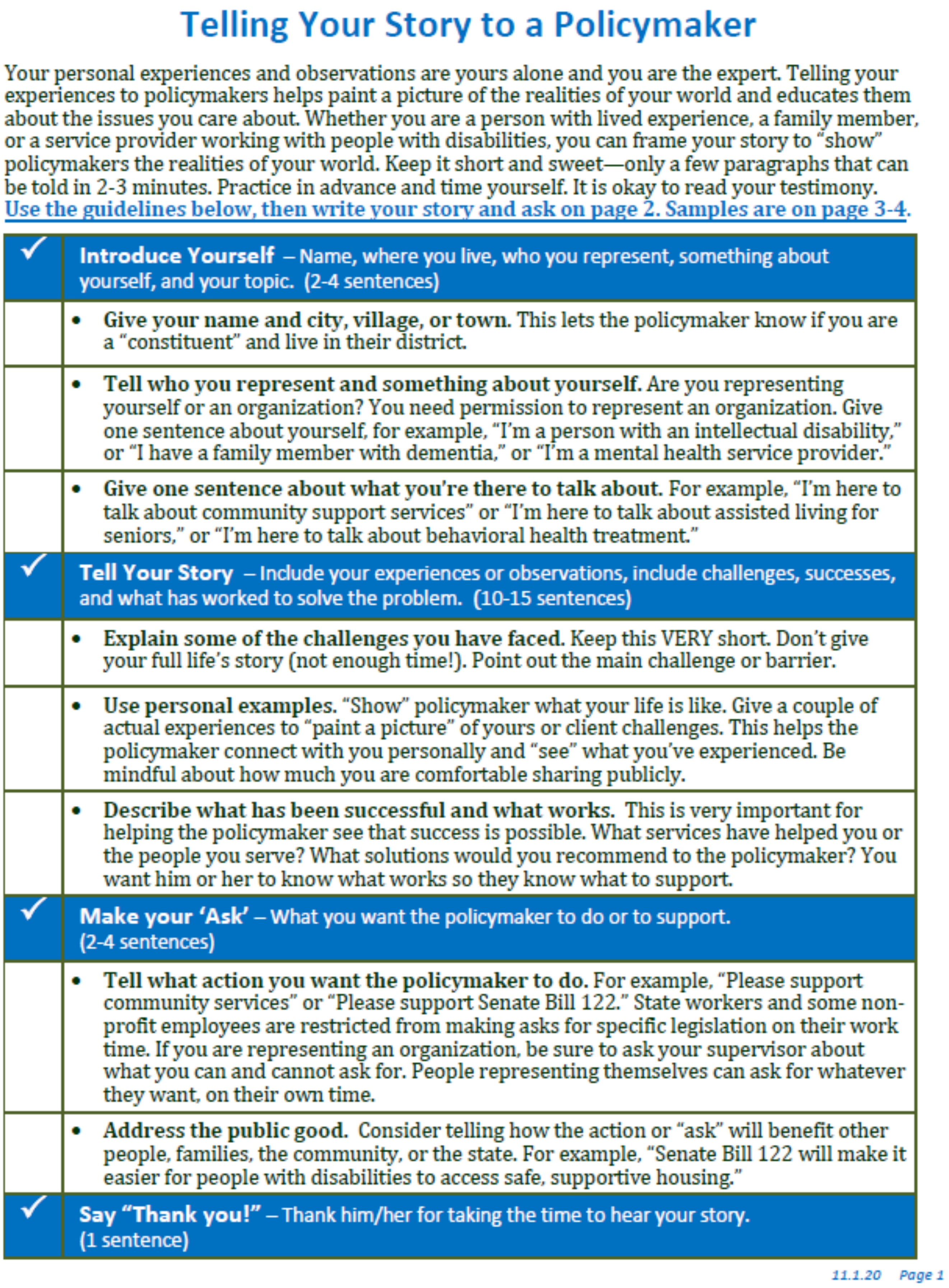
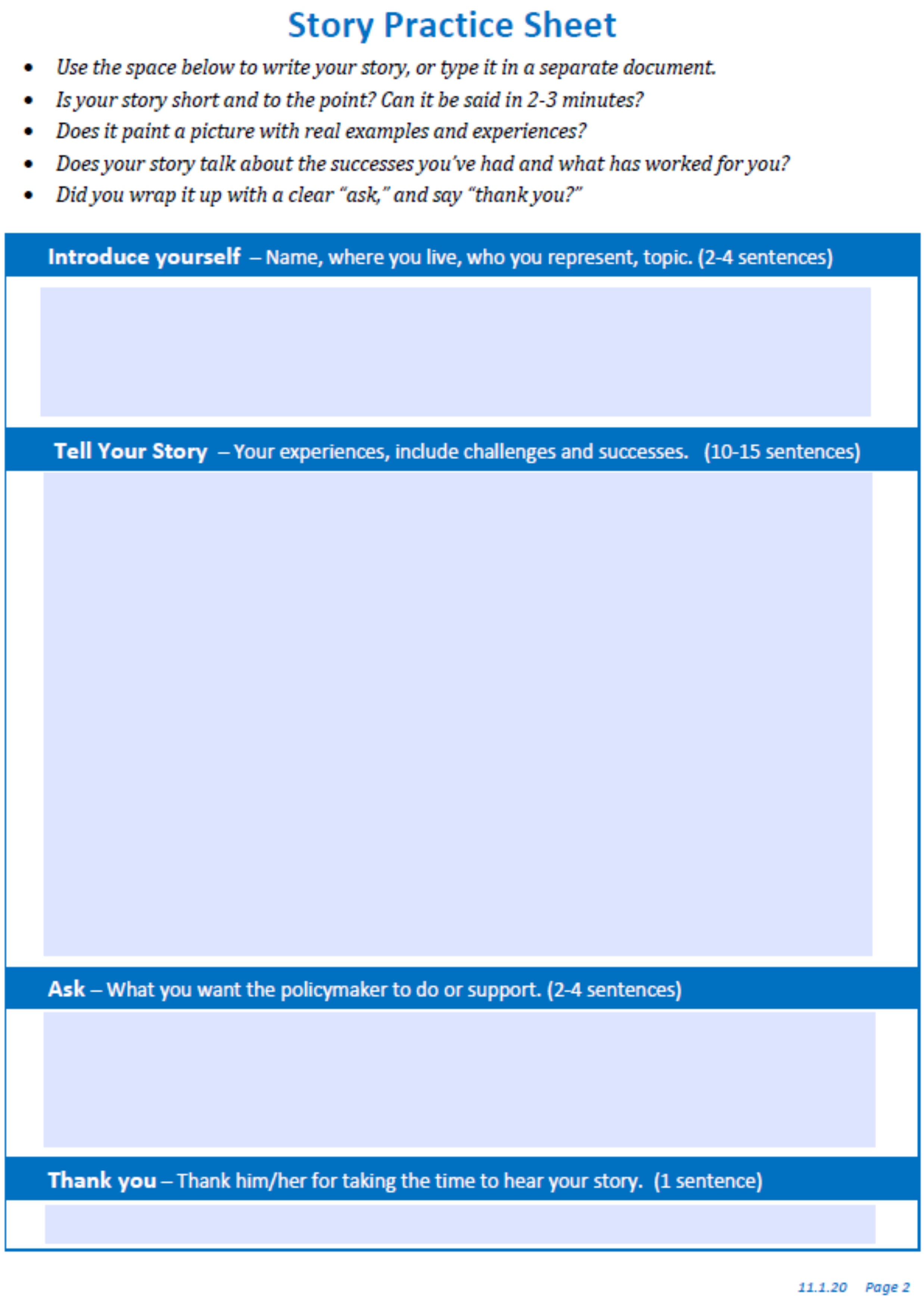


Telling Your Story to a Policymaker

Your personal experiences and observations are yours alone and you are the expert. Telling your experiences to policymakers helps paint a picture of the realities of your world and educates them about the issues you care about. Whether you are a person with lived experience, a family member, or a service provider working with people with disabilities, you can frame your story to "show" policymakers the realities of your world. Keep it short and sweet—only a few paragraphs that can be told in 2-3 minutes. Practice in advance and time yourself. It is okay to read your testimony. Use the guidelines below, then write your story and ask on page 2. Samples are on page 3-4.

✓	**Introduce Yourself** – Name, where you live, who you represent, something about yourself, and your topic. (2-4 sentences)
	• **Give your name and city, village, or town.** This lets the policymaker know if you are a "constituent" and live in their district.
	• **Tell who you represent and something about yourself.** Are you representing yourself or an organization? You need permission to represent an organization. Give one sentence about yourself, for example, "I'm a person with an intellectual disability," or "I have a family member with dementia," or "I'm a mental health service provider."
	• **Give one sentence about what you're there to talk about.** For example, "I'm here to talk about community support services" or "I'm here to talk about assisted living for seniors," or "I'm here to talk about behavioral health treatment."
✓	**Tell Your Story** – Include your experiences or observations, include challenges, successes, and what has worked to solve the problem. (10-15 sentences)
	• **Explain some of the challenges you have faced.** Keep this VERY short. Don't give your full life's story (not enough time!). Point out the main challenge or barrier.
	• **Use personal examples.** "Show" policymaker what your life is like. Give a couple of actual experiences to "paint a picture" of yours or client challenges. This helps the policymaker connect with you personally and "see" what you've experienced. Be mindful about how much you are comfortable sharing publicly.
	• **Describe what has been successful and what works.** This is very important for helping the policymaker see that success is possible. What services have helped you or the people you serve? What solutions would you recommend to the policymaker? You want him or her to know what works so they know what to support.
✓	**Make your 'Ask'** – What you want the policymaker to do or to support. (2-4 sentences)
	• **Tell what action you want the policymaker to do.** For example, "Please support community services" or "Please support Senate Bill 122." State workers and some non-profit employees are restricted from making asks for specific legislation on their work time. If you are representing an organization, be sure to ask your supervisor about what you can and cannot ask for. People representing themselves can ask for whatever they want, on their own time.
	• **Address the public good.** Consider telling how the action or "ask" will benefit other people, families, the community, or the state. For example, "Senate Bill 122 will make it easier for people with disabilities to access safe, supportive housing."
✓	**Say "Thank you!"** – Thank him/her for taking the time to hear your story. (1 sentence)

11.1.20 Page 1



Story Practice Sheet

- *Use the space below to write your story, or type it in a separate document.*
- *Is your story short and to the point? Can it be said in 2-3 minutes?*
- *Does it paint a picture with real examples and experiences?*
- *Does your story talk about the successes you've had and what has worked for you?*
- *Did you wrap it up with a clear "ask," and say "thank you?"*

Introduce yourself – Name, where you live, who you represent, topic. (2-4 sentences)

Tell Your Story – Your experiences, include challenges and successes. (10-15 sentences)

Ask – What you want the policymaker to do or support. (2-4 sentences)

Thank you – Thank him/her for taking the time to hear your story. (1 sentence)

11.1.20 Page 2

Sample Story #1

Introduce Yourself

My name is Allie Taylor and I live in Sitka, Alaska. I was born with cerebral palsy which affects my ability to move my body. I am also a senior citizen and am representing myself. I would like to talk about community support services for people with disabilities.

Tell your Story

I have used a wheelchair since I was a young child. Growing up, I depended on my parents to help me eat, change clothes, go to the bathroom, and basically get around. When my mother died and my father became too old to care for me, I was moved into a care facility with round the clock care out of state.

Unfortunately, the facility was understaffed and couldn't always provide a lot of support, so I sat around a lot, watched TV, and didn't do much else. My speech is slurred so people often think I'm stupid. The thing is, I have a physical impairment, but not a cognitive impairment, my IQ is above 120, and so I'm way more capable than people think.

When my sister came down to visit me and saw the conditions, she went back to Alaska and researched how to bring me home. She learned that through the state's Medicaid Home and Community-Based Waiver program it was cheaper for me to live in my own apartment with a personal care attendant, than it was to live in a round-the-clock care facility.

Today I receive community support services—like supportive housing, transportation, day habilitation, and personal care assistance—all which help me live a meaningful life in my community. I have a part-time job and I'm enrolled at the University finally getting my bachelor's degree!

Make Your 'Ask' and say 'Thank You'

I hope that you will support community-based services for people with disabilities, so we can live at home in our communities close to family and friends, and out of expensive institutional care. Thank you for taking time to hear my story.

Sample Story #2

Introduce Yourself

My name is Justin Bello. I live in Anchorage and am the director of services for the Anchorage Street Clinic. I am here representing the clinic and plan to talk about Behavioral Health Treatment and Recovery Grants.

Tell your Story

The Anchorage Street Clinic provides counseling and support for people with substance use disorders. The majority of our clients are homeless with a primary diagnosis of chronic alcoholism, and do not have the resources to pay for our services.

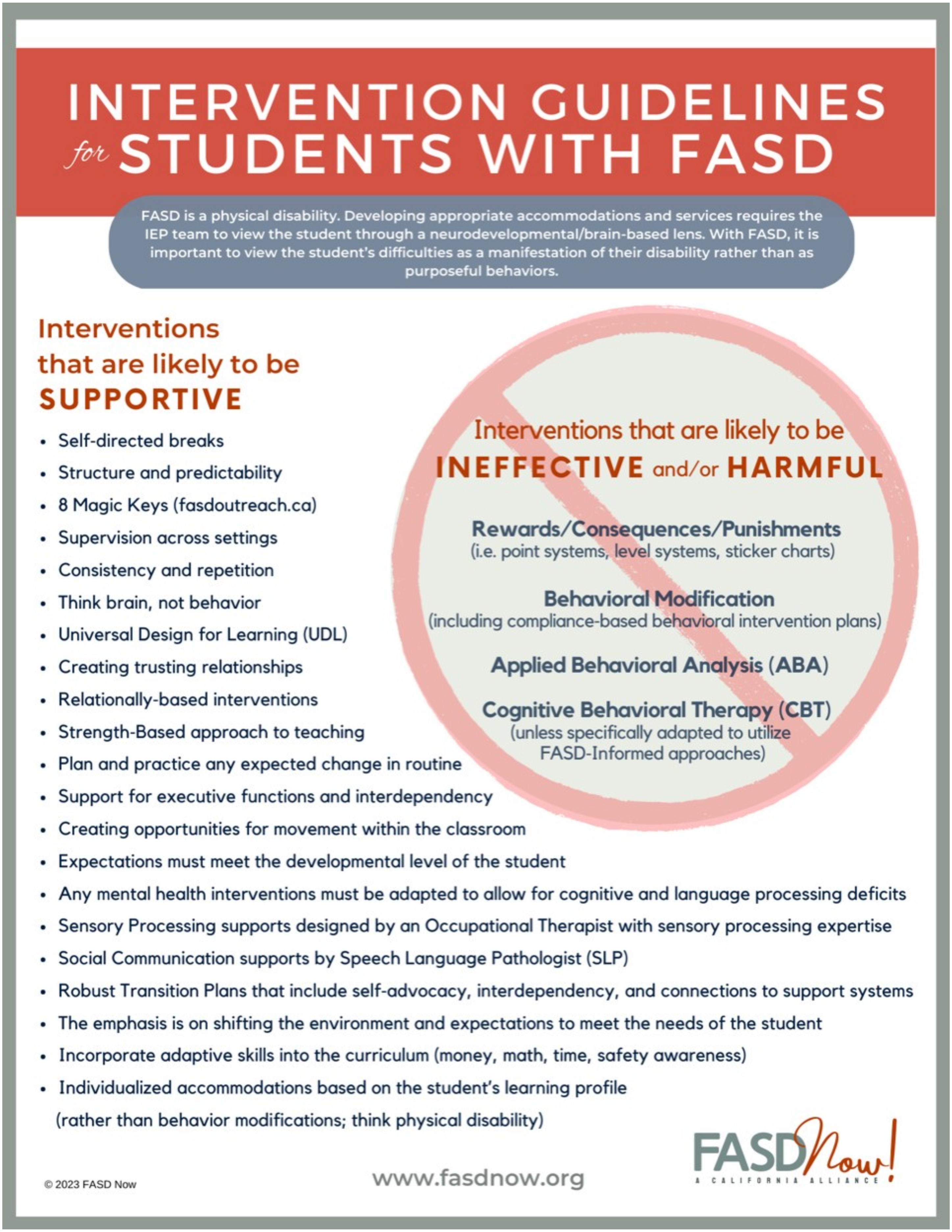
Our case manager is able to help clients access housing and employment services, residential treatment, and transitional services after incarceration, which are key for seeing people get back on their feet and off the streets. There are lots of successes once people get a place to live, get a job, and start on the road to their recovery. However, the need is still great and so she is very busy.

Our clinic is able to bill Medicaid for most of the services, but not all, so we depend on the state's Behavioral Health Treatment and Recovery Grants to supplement this gap. These grants help keep our doors open and our staff paid.

Without the behavioral health grants, we would not be able to help Anchorage's most vulnerable citizens and would see more people continue to cycle in and out of expensive hospital emergency rooms, residential treatment, and/or prison—most of which the state will pay for anyway.

Make Your 'Ask' and say 'Thank You'

Please support funding for Behavioral Health Treatment and Recovery Grants in the state's budget so that the Anchorage Clinic, and other clinics like us, can continue serve Alaska's most vulnerable citizens and keep Anchorage's streets healthier and safer. Thank you for your support.



INTERVENTION GUIDELINES *for* STUDENTS WITH FASD

FASD is a physical disability. Developing appropriate accommodations and services requires the IEP team to view the student through a neurodevelopmental/brain-based lens. With FASD, it is important to view the student's difficulties as a manifestation of their disability rather than as purposeful behaviors.

Interventions that are likely to be SUPPORTIVE

- Self-directed breaks
- Structure and predictability
- 8 Magic Keys (fasdoutreach.ca)
- Supervision across settings
- Consistency and repetition
- Think brain, not behavior
- Universal Design for Learning (UDL)
- Creating trusting relationships
- Relationally-based interventions
- Strength-Based approach to teaching
- Plan and practice any expected change in routine
- Support for executive functions and interdependency
- Creating opportunities for movement within the classroom
- Expectations must meet the developmental level of the student
- Any mental health interventions must be adapted to allow for cognitive and language processing deficits
- Sensory Processing supports designed by an Occupational Therapist with sensory processing expertise
- Social Communication supports by Speech Language Pathologist (SLP)
- Robust Transition Plans that include self-advocacy, interdependency, and connections to support systems
- The emphasis is on shifting the environment and expectations to meet the needs of the student
- Incorporate adaptive skills into the curriculum (money, math, time, safety awareness)
- Individualized accommodations based on the student's learning profile
  (rather than behavior modifications; think physical disability)

Interventions that are likely to be INEFFECTIVE and/or HARMFUL

Rewards/Consequences/Punishments
(i.e. point systems, level systems, sticker charts)

Behavioral Modification
(including compliance-based behavioral intervention plans)

Applied Behavioral Analysis (ABA)

Cognitive Behavioral Therapy (CBT)
(unless specifically adapted to utilize FASD-Informed approaches)

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Advocacy from Home

When an interested person commits to perform one act of advocacy, the momentum grows, the effect gets larger, and policymakers pay more attention.

Following is a list of things you can do to make a change. Choose one (or more), make a commitment, and follow-through!

- ☐ Write a letter/email to a public official about a situation that matters to you.
- ☐ Call in or appear in person and give your personal testimony at a public meeting.
- ☐ Coordinate a letter/email campaign. Invite five people to write a letter/email to a public official.
- ☐ Make a telephone call to a public official's office (city council, representative, senator).
- ☐ Coordinate a telephone-calling campaign. Invite five people to call a public official.
- ☐ Write a letter-to-the-editor about a situation that matters to you.
- ☐ Coordinate a letter-to-the-editor campaign. Invite five people to write letters to the editor.
- ☐ Use Facebook and other social media to post an opinion on matters related to vulnerable Alaskans.
- ☐ Go to the Alaska Mental Health Trust Authority's JOINT ADVOCACY webpage and learn about actio you can take, or organize five people to do it, at: www.alaskamentalhealthtrust.org/jointadvocacy.
- ☐ Host a reception for a public official in your home or place of work. Show them firsthand what your situation is. A fundraiser is even better.
- ☐ Ask five people to host a reception for a public official in their homes or places of work.
- ☐ Tag onto a public event, party or reception, set up a table that raises awareness about an issue.
- ☐ Visit your own legislator in your hometown and ask others to do it. Go to http://akleg.gov/lios.php to learn who your personal legislators are (scroll to the bottom and input address under WHO REPRESENTS ME).
- ☐ Make five personal contacts to friends to spread the word about an issue.
- ☐ Post on Facebook a link to a news story or letter to the editor on a topic you care about, or talk with your friends and co-workers about the issue.
- ☐ Write a longer opinion piece for your local newspaper, or find someone else to do it.
- ☐ Go on the radio talk show and discuss an issue, or find someone else to do it.
- ☐ Write a personal story and send it to a policymaker.
- ☐ Gather five written personal stories and send them to policymakers.
- ☐ Coordinate a local media campaign (with newspaper, radio, and/or TV).
- ☐ Attend a 'Super Advocate' advocacy training sponsored by the Trust and partner advisory boards.
- ☐ Testify at a public meeting (State Legislature, Assembly, City or Village Council, School Board).
- ☐ Gather letters of support (on letterhead) from organizations that support an issue. Give the stack (hard copies) to a public official.
- ☐ Coordinate a local advocacy effort in your community. Contact the media, host receptions, organize letter-writing and telephone, coordinate volunteers in your area, visit legislators, etc.).

10.21.20

E5

Closing the FASD Health Service Gap in the Eastern Doorway— Taking Action on Canada's Truth and Reconciliation Commission (TRC)'s Calls to Action— Participant Action Research in Wabanaki

Lori Vitale Cox

E6

The FASD United Family Navigator: Support and Resources for the FASD Community and Resources from CDC and Partners

Jennifer Wisdahl, Laura Bousquet, Elizabeth Dang

A Rights Perspective Versus Best Interest

Peter Choate, Terri Pelton

1

Research/Science

Prenatal alcohol and cannabinoid exposures impose distinct, sex-specific behavioral phenotypes for coordination and alcohol-seeking in adult mice.

Poster Session

Siara Rouzer

PhD, Postdoctoral Research Fellow, Texas A&M School of Medicine, Dept of Neuroscience & Experimental Therapeutics, Bryan, TX.

Rajesh Miranda

PhD, Shelton Professor of Neuroscience, Dept of Neuroscience and Experimental Therapeutics, Texas A&M University, School of Medicine, Bryan, TX.

Abstract:

Background/Purpose: Individuals prenatally exposed to alcohol or synthetic cannabinoids, like marijuana, are at greater risk of developing motor impairments and drug-seeking behaviors later in life. However, with increasing rates of polysubstance use in humans, little is known about the outcomes of simultaneous alcohol and cannabinoid (SAC) exposure. We therefore investigated whether SAC augments behavioral symptoms in mouse offspring compared to single-drug exposure alone.

Method: Pregnant C57Bl/6J mice were assigned to one of four groups: drug-free control, alcohol-exposed, cannabinoid-exposed or SAC-exposed. Drug exposure occurred daily between Gestational Days 12-15, equivalent to the beginning of the second trimester in humans. For cannabinoid exposure, dams received an intraperitoneal injection of cannabinoid agonist CP-55940 (750µg/kg) or volume-equivalent saline. For ethanol exposure, dams were placed in vapor chambers for 30min of inhalation of 95% ethanol or identical chambers without ethanol (controls). Adult male and female offspring (Postnatal Days 90+) were assessed for a) motor deficits in a Rotarod performance test, b) preference for 20% alcohol in a 3hr two-bottle-choice homecage assessment, and c) alcohol-seeking activity within operant chambers administering alcohol following lever presses.

Results: All drug exposures reduced offspring time balanced on the Rotarod in males, but females were resistant to cannabinoid-associated deficits. Compared to control males, cannabinoid and SAC-exposed males drank significantly more alcohol over three weeks in a social, homecage setting, while only SAC females drank more alcohol than control females. Operant administration experiments indicate that, compared to drug-free and single-drug exposed offspring, dual-exposed

male offspring lever-pressed for alcohol more under a progressive ratio paradigm, indicating greater willingness to work for alcohol, and demonstrated significantly greater preference for higher alcohol concentrations (40% ethanol). SAC males also persisted in lever-pressing for ethanol during a three-day abstinence period, while all other groups reduced their alcohol-seeking behaviors during extinction. This SAC effect was notably absent in female offspring of the same litters.

Conclusions/Implications: Simultaneous alcohol and cannabinoid exposure in utero imposes distinct offspring motor impairments and changes in alcohol-seeking behaviors from exposure to either drug individually. Furthermore, male and female offspring demonstrate distinct outcomes following exposure, indicating that sex is an important consideration for symptom expression. Ongoing follow-up investigations will determine whether these behavioral phenotypes correspond with distinct changes in brain morphology.

Learning Objectives:

Audience members will learn the following through this presentation:

1) Determine whether prenatal polysubstance exposure imposes distinct behavioral outcomes in adult mouse offspring compared to single-drug exposure.

2) Investigate whether exposure-specific behavioral phenotypes differ between biological males and females.

3) Emphasize co-occurring behavioral effects within-subject to inform symptom profiles that may translate to individuals with a history of prenatal drug exposure.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

As FASD is a lifelong disorder, my research emphasizes investigating different domains of this disorder across the lifespan, allowing for the possibility of identifying early-life symptoms that predict susceptibility to later-life symptoms. Furthermore, this particular project aims to identify co-occurring symptoms within-subject, to determine the likelihood that expression of one symptom increases the likelihood of expressing other symptoms.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

My research has determined that prenatal co-exposure to alcohol and a synthetic cannabinoid leads to distinctly different offspring outcomes than prenatal alcohol exposure alone, indicating the importance of understanding all forms of prenatal exposure to inform better treatment for exposed individuals.

FASD and Systems Change in Arkansas

Poster Session

Consider as another presentation type: Yes

Elizabeth Cleveland

PhD, Associate Director, University of Arkansas; Executive Director, Specialty Diagnostic Resource Center; Director of Training; Arkansas Leadership Education in Neurodevelopmental Disabilities; Chair, Association of University Centers on Disability FASD Special Interest Group

Abstract:

Purpose: There are currently very few diagnostic services in AR (Cleveland et al., 2020) and almost no dedicated interventions for individuals with FASD or similar conditions, despite the high prevalence of almost 1 in 15 (May et al., 2018). The purpose of this state-funded project is to build systems of care for Arkansans with FASD and other disabilities affecting both development and mental health that will support individuals with FASD and their families, expand diagnostic capacity, prevent crisis, develop interventions, and promote education on FASD and other prenatal exposure.

Method: The FASD Pilot consists of four major components 1) diagnostic expansion will consist of a three-level process, including a strengths-based screener, differential diagnostic training, and complex case evaluation. Diagnostic teams all over the state will be trained on the Hagan et al., 2016 diagnostic criteria for ND-PAE. 2) Additional FASD intervention will be developed. This intervention promotes the social model of disability (Tortorelli et al., 2023) and consists of a consultative approach to intervention to promote caregiver empowerment, respite, and acute de-escalation intervention. 3) A two-part (basic and advanced) interactive training program will be developed for practitioners and community members. Finally, 4) this project will be analyzed at regular intervals throughout the award period.

Results: This funding cycle begins February 1, 2024. Although no preliminary results are available now, they will be available in April for the convention.

Implications: The potential impact of this program is immense. It not only has the potential to increase the amount of FASD identified and decrease the age of initial diagnosis, but

also has the potential to provide much needed intervention services for individuals and their families.

References:

Cleveland, E., Deere, D., Kyzer, A., & Smith, S. (2020). Fetal alcohol spectrum disorders advocacy in Arkansas. Journal of Arkansas Medical Society. May 2020 Issue.

Hagan, J. F., Jr, Balachova, T., Bertrand, J… Zubler, J., Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure Workgroup, & American Academy of Pediatrics (2016). Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure. Pediatrics, 138(4), e20151553. https://doi.org/10.1542/peds.2015-1553

May, P. A., Chambers, C. D., Kalberg, W… 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

Tortorelli, C., Badry, D., Choate, P., & Bagley, K. (2023). Ethical and Social Issues in FASD. In Fetal Alcohol Spectrum Disorders: A Multidisciplinary Approach (pp. 363-384). Cham: Springer International Publishing.

Learning Objectives:

Participants will

a. Describe the three-level diagnostic expansion system

b. List the four major phases of FASD intervention services in Arkansas

c. Define the various state systems potentially impacted by this program.

d. Explain three ways that individuals and family members can be involved in systems- level work

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

I believe that the development of this program will greatly impact adolescents and young adults that receive Medicaid in Arkansas. This program was created with adults with FASD as steering-committee members and subject matter experts, allowing the lived experience to be infiltrated into the program design. By doing this, the importance of what is best for the individual with FASD will be highlighted through every phase.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Although the funding period has not started yet, I have confidence that many questions willarise during the program implementation. One question that has already arisen from this work is, what are the trends of individuals that will receive a referral for FASD diagnostic evaluation? Additionally, do billable respite hours decrease the likelihood of admittance to a psychiatric residential treatment facility?.

Strengthening Tribal Child Welfare and Preserving Indigenous Families Amidst PSE/PAE Challenges

Poster Session

Carly Dunn

MPH, Senior Research Associate, James Bell Associates, Arlington, VA

Priscilla Day

MSW, Ed.D., Professor Emeritus of Social Work at University of Minnesota Duluth

Erin Geary

Ph.D., M.S.W., Senior Research Associate, James Bell Associates, Arlington, VA

Erin Ingoldsby

PhD, Director of Child Welfare Practice Area, James Bell Associates, Arlington, VA

Abstract:

Purpose: This poster presents cumulative efforts aimed at preserving Indigenous families by enhancing tribal child welfare practices in addressing Prenatal Substance Exposure (PSE) and Prenatal Alcohol Exposure (PAE). It shares key lessons from a multi-method study including an environmental scan and a tribal child welfare case study, culminating in the development of a process mapping tool to address identified challenges.

Methods: This project employed a multi-methods approach to address PSE and PAE within tribal child welfare contexts:

1. Environmental Scan: Involved peer-reviewed literature searches, gray literature reviews, and expert conversations, followed by content analysis to synthesize key themes.

2. Tribal Child Welfare Case Study: Conducted in northern Minnesota, using service process mapping and key informant interviews to explore culturally-grounded service delivery.

3. Process Mapping Tool Development: Based on insights from the environmental scan and case study, this tool was created to guide tribal child welfare agencies in improving existing services to address PSE/PAE effectively.

Results:

- The Environmental Scan identified themes including historical trauma, challenges

in FASD identification, the role of cultural practices in recovery, and the need for community education, mental health, and economic support.

- The Case Study outlined key characteristics and the beneficial impact of a culturally-sensitive, prevention-oriented approach in a tribal child welfare agency, suggesting broader applicability in similar contexts.

Implications:

- Environmental scan findings point to the necessity of interventions focusing on community education, mental health support, economic aid, and cultural engagement, with policy recommendations for family preservation.

- The case study emphasizes the effectiveness of culturally tuned, prevention-oriented strategies in tribal child welfare.

- Together, these insights advocate for a holistic approach that considers physical, social, emotional, economic, and cultural factors in addressing PSE and PAE in tribal communities.

Use and Integration of the Process Mapping Tool:

- This tool emerged as a practical means to apply the lessons learned, providing a structured approach for tribal child welfare agencies to implement culturally relevant strategies for addressing PAE/PSE.

- It represents a fusion of traditional wisdom and modern methodologies, offering a tangible resource for enhancing practices and supporting Indigenous family preservation amidst PSE/PAE challenges.

Through this poster, we aim to highlight a framework for best practices in tribal child welfare, merging traditional insights with contemporary methods of delivery, to strengthen support systems for Indigenous families facing the impacts of PSE and PAE.

Learning Objectives:

Poster audiences will:

1. Understand the integration of approaches in tribal child welfare to address Prenatal Substance Exposure (PSE) and Prenatal Alcohol Exposure (PAE).

2. Learn about the methods and results of a multi-methods approach, including an environmental scan and case study, for enhancing tribal child welfare practices in the context of PSE/PAE.

3. Recognize the role and application of a process mapping tool in translating field insights into practical strategies for preserving Indigenous families affected by PSE/PAE.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

The work is highly relevant to the field of tribal child welfare and directly impacts adolescents and adults directly or indirectly affected by Fetal Alcohol Spectrum Disorders (FASD). By integrating cultural practices with modern and responsive child welfare methods, the project offers a model for supporting individuals, families, and communities affected by FASD, emphasizing the need for specialized care that encompasses medical, educational, vocational, and emotional support. This holistic approach, rooted in cultural understanding, is crucial for effectively addressing the complex needs of those with FASD in Indigenous communities.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

This work raises key questions for future research, such as the long-term effectiveness of culturally integrated child welfare strategies on individuals and families impacted by PSE/PAE and FASD, the development of customized interventions for diverse needs within this group, the impact of community and family involvement, and the role of cultural competency in service delivery. These questions point towards the need for in-depth studies on the efficacy of culturally informed and comprehensive support systems for children, adolescents and adults impacted by FASD in tribal settings.

Caregiver-Reported Evaluation and Diagnosis of Fetal Alcohol Spectrum Disorders: Findings from the 2022 National Survey of Children's Health

Poster Session

Nicholas Deputy

Health Scientist, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Jacquelyn Bertrand

Child Psychologist, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Amanda Dorsey

G2S Corporation, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Clark Denny

Health Scientist, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Ashleigh Kellerman

Epidemiologist, G2S Corporation, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Mary Kate Weber

Behavioral Scientist, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Shawn Thomas

Epidemic Intelligence Service Officer, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Jessica Jones

Team Lead and Assistant Survey Director, National Survey of Children's Health, Office of Epidemiology and Research, HRSA/Maternal and Child Health Bureau, Rockville, MD

Shin Kim

Team Lead, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Abstract:

Purpose: In-person, active case ascertainment studies found the prevalence of fetal alcohol spectrum disorders (FASDs) ranges from 1%-5% among first-grade children in

select communities in the United States (U.S.). Nationwide, population-based estimates ofFASDs in the U.S. are unavailable, as is information about FASD evaluation and diagnosis pathways. We estimated the proportion of U.S. children and adolescents who were recommended for an FASD evaluation, had an FASD evaluation, and received an FASD diagnosis, and we examined the overlap in these experiences to understand evaluation and diagnosis pathways.

Methods: Data are from the 2022 National Survey of Children's Health, a nationally representative cross-sectional survey of U.S. children and adolescents (n=54,103). Caregivers reported whether their child ever was recommended for an FASD evaluation by a healthcare provider or educator, had an FASD evaluation, and received an FASD diagnosis by a healthcare provider. Weighted prevalence estimates were calculated overall, for children (age 0-10 years) and adolescents (11-17 years), and by demographics; Chi- Square tests assessed differences by demographics. Among the subpopulation with either an FASD evaluation recommended, an FASD evaluation received, or an FASD diagnosis, we estimated the proportion with only one or with all three experiences reported.

Results: Overall, 2.8 per 1,000 children and adolescents were recommended for an FASD evaluation, 3.5 per 1,000 received an evaluation, and 2.4 per 1,000 had an FASD diagnosis;
2.7 per 1,000 children and 1.9 per 1,000 adolescents had an FASD diagnosis. Prevalence varied by selected demographics, including family composition. Overall, 4.8 per 1,000 children and adolescents (n=234) had one or more FASD experience reported; among them, 30.3% were recommended for an evaluation, received an evaluation, and were diagnosed with an FASD, 14.3% were recommended for an evaluation but did not receive an evaluation or diagnosis, 31.5% received an evaluation but did not have an evaluation recommended and did not have an FASD diagnosis, and 7.7% had an FASD diagnosis but did not have an evaluation recommended or received.

Implications: These caregiver-reported estimates represent the first nationally representative estimates of FASD evaluation and diagnosis among children and adolescents, provide insight about gaps in clinical pathways, and can inform service needs. Given not all those recommended for evaluations received them, and caregiver-reported estimates of FASDs were lower than those from in-person studies, efforts to increase screening and diagnostic capacity may be needed to ensure all suspected of, or diagnosed with, an FASD receive appropriate evaluation, diagnosis, and care.

Learning Objectives:

1. Describe how the National Survey of Children's Health assesses information about evaluation of and diagnosis for FASDs.
2. Describe how caregiver-reported estimates of FASD evaluation and diagnosis

can be used to inform public health and clinical care.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

These data represent the first nationally representative estimates of children and adolescents with FASDs. These data describe the population of youth with these conditions, which can be used to inform service needs. These data also describe recommendation for and receipt of FASD evaluations, which provides insight into clinical care pathways and associated gaps that might relate to underdiagnosis of FASDs among children, adolescents, and adults.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

In 2022, the National Survey of Children's Health (NSCH) for the first time included questions that assess FASD diagnosis and evaluation. The NSCH includes information on multiple other health conditions and experiences that can be examined in relation to FASD evaluation and diagnosis. For example, future analyses can examine co-occurring behavioral and developmental conditions and how social determinants might influence FASD evaluation and diagnosis. The NSCH is an annual survey, which will allow future studies to examine how caregiver-reported FASD evaluation and diagnosis changes over time. Furthermore, combining multiple years of survey data will allow analyses to be adequately powered to examine differences across subgroups. These analyses will complement clinical and active case ascertainment studies that provide more detailed information on smaller, more defined populations of children and adolescents.

Washington and Alaska statewide fetal alcohol spectrum disorder diagnostic clinical networks: Comparison of three decades of 4-Digit Code diagnostic outcomes and prenatal alcohol exposure histories.

Poster Session

Susan Hemingway

PhD, Professor of Epidemiology/Pediatrics, University of Washington; Director, Washington State FAS Diagnostic & Prevention Network, Seattle WA

Michael Baldwin

MS, Senior Evaluation & Planning Officer, Alaska Mental Health Trust Authority, Anchorage Alaska

Marilyn Pierce-Bulger

ARPN, MN, FNP-BC, CNM-ret, Pioneer Consulting, Anchorage, Alaska

Abstract:

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 1993. 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 30th 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 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 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/families impacted by FASD.

Conclusions

WA and AK have demonstrated the feasibility and value of establishing statewide interdisciplinary FASD diagnostic clinics that serve as the foundation for FASD screening, surveillance, intervention, prevention, education and research. State 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. Twenty years of patient surveys confirm a FASD 4-Digit-Code interdisciplinary diagnosis afforded substantial access to interventions that met patients' needs across the lifespan.

Learning Objectives:

Demonstrate the feasibility and value of establishing longstanding, statewide, interdisciplinary FASD diagnostic clinics.

Compare the 4-Digit-Code FASD diagnostic outcomes and prenatal alcohol exposure histories documented in WA and AK over 2-3 decades among patients (newborn to adult).

Illustrate how clinical data helped guide FASD public health policies and track successful prevention efforts.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

WA and AK have demonstrated the feasibility and value of establishing longstanding, statewide, interdisciplinary FASD diagnostic clinical networks using the FASD 4-Digit Diagnostic Code. FASD diagnostic clinics serve as the cornerstone of FASD identification, intervention and prevention. Ongoing legislative support, centralized data collection, and use of an evidence-based FASD diagnostic system with online training continue to be key to the ongoing success of these two networks.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Although AK and WA have maintained statewide FASD diagnostic clinics for 20-30 years respectively, establishing and maintaining interdisciplinary FASD diagnostic teams are not without challenges. Briefly, challenges include geographic reach, training and turnover of professionals on FASD diagnostic teams, stigma related to those who consume alcohol during pregnancy and their offspring, funding, and community education/readiness. Utilizing telemedicine platforms like zoom proved indispensable during the COVID

pandemic for remotely connecting clinicians and patients with the core interdisciplinary teams when in-person attendance was not possible. These platforms continue to be useful to address some of the challenges faced in rural communities. Having access to self-paced online diagnostic training programs like the FASD 4-Digit Code Online Course greatly facilitated training of new clinical team members. To enhance interest and education related to FASD the University of Alaska College of Health in Anchorage established a 3- credit elective asynchronous course in 2021 for allied health and related professional students entitled Interdisciplinary Approaches to Fetal Alcohol Spectrum Disorders
(FASD): Best Practices in Alaska. For comprehensive reviews of WA and AK FASD diagnostic and prevention efforts, challenges, accomplishments and programmatic recommendations, please see the 2014 comprehensive report to the WA State Legislature on achievements, current challenges and recommended solutions to screen, diagnose, treat and prevent FASD prepared by the WA FASD Interagency Work Group and the 2020 Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations prepared for the Alaska Mental Health Trust Authority (2020).

Navigating Alternative Therapy Approaches and Neurodevelopmental Disabilities

Poster Session

Shannon Foster

Registered Social Worker, MCSW
Kristene MacDonald
Registered Social Worker, MCSW

Abstract:

Psychological and therapeutic interventions for children and adolescents with FASD and the efficacy of their methods has widely been ignored. Conversations around best practice in working with those with FASD in a therapeutic capacity has been of growing interest and is needed as the demand for therapeutic services for this population is growing. Within the therapeutic field, there has been a recent push for innovative and accessible alternatives to traditional talk therapy, such that we have seen a rise in a variety of play-based approaches (Bratton & Ray, 2000), art therapies (Talwar, 2010), nature-based play therapy (Ramshini, Hassanzadeh, Afrooz, Hashemi Razini, 2018), and familial or multisystemic therapies (Cornett & Bratton, 2014; Henggeler, Schoenwald, Borduin, Rowland, & Cunningham, 1998) which focus upon a variety of ways to support children, youth, and their families in improving their wellbeing and managing difficult or challenging life events. The use of alternative therapeutic modalities, particularly those of a professional, multi-disciplinary nature and the concept of evidence-based policy and practice in the field of FASD, is increasing to meet the needs of this population. The purpose of this commentary is to illustrate that they are particularly suited to working with children and youth with various neuro-developmental disabilities, particularly FASD and it is also the intent to recognize the voice of individuals with disabilities as this review explores the therapeutic effectiveness and subjective experiences of children, youth and their families accessing alternative forms of therapy. Alternative forms of therapy were used to assess and treat children and youth with neurodevelopmental disability through multi-session implementation of play-based or action therapy. A wraparound approach inclusive of family and primary systems, such as school, was additionally implemented for each participant. The emerging narratives following therapeutic intervention included the (mis)

understanding of non-traditional therapeutic approaches; the value of play and being with an individual; an existing disregard for the emotional needs of individuals with neurodevelopmental disabilities; and the need to do better and dignity promotion for individuals with neurodevelopmental disabilities. These narratives helped us to co-generate knowledge and explore possibilities for future actions for individuals with FASD through better understanding how alternative therapeutic approaches can provide environments and opportunities for expression of self, advocate for their right to accessible and appropriate services, and respect their autonomy and self determination.

Learning Objectives:

1. Participant should be able to understand that individuals with FASD suffer no less distress than those without and are not immune to emotional problems, trauma, or the need for an outlet to express their emotions and that this is important to the promotion of rights, dignity, and respecting the self-determination of each individual with FASD.

2. Participants should be able to draw connections between the ideas that alternative forms of therapy such as play therapy, action therapy and/or multi-systemic wraparound approaches are particularly suited to working with children and youth with various neuro- developmental disabilities, particularly FASD and that future research should focus on the efficacy of these models.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD? What questions has your work identified or what else has arisen from your work that research may be able to answer?

Broadening our understanding of alternative therapeutic modalities encourages more nuanced and tailored options that will guide future research and available services for individuals and families with FASD. Highlighting the ways in which alternative forms of therapy can best serve children and youth with neurodevelopmental disabilities has implications for other underserved populations and for the practitioners, educators, and the general population who work with them. The use of psychotherapeutic methods with individuals with neurodevelopmental disabilities can no longer go overlooked. We need to provide appropriate services to this population as is within social work ethics and standards; focusing on how they best express themselves, their desire and right to accessible and appropriate services and respecting their autonomy and self determination. It has been discussed how alternative forms of therapy, specifically play-based, action and multisystemic forms of therapy, are suitable alternatives to working with this population and future research should focus on the efficacy of these models.

Machine-Based Learning Over Narrative Length and Grammatical Complexity Data Provides a Marker of Neurodevelopmental Differences in Children with Fetal Alcohol Spectrum Disorders

Poster Session

Alan Armen

M.Sc, Director of Data Science, Shipt, Seattle, WA.

John Thorne

PhD., CCC-SLP, University of Washington: Associate Teaching Professor for the Department of Speech and Hearing Sciences; Discipline Leader for Speech-Language Pathology - Institute On Human Development and Disability; Clinician and Researcher - Fetal Alcohol Syndrome Diagnostic and Prevention Network; Seattle, WA.

Angela Armen

MD, Clinical Assistant Professor of Pediatrics, University of Washington, Seattle Children's Hospital, Seattle, WA.

Susan Hemingway

PhD, Professor of Epidemiology/Pediatrics, Schools of Public Health and Medicine, University of Washington; Director, Washington State FAS Diagnostic & Prevention Network, Seattle, WA

Abstract:

Purpose:

The purpose of this study was to examine whether machine-learning algorithms analyzing the length and grammatical complexity of narratives told by children could be trained to identify neurodevelopmental differences in those with FASD as well as or better than analysis of grammatical and referencing errors in those same stories (see Thorne, 2017). In other words, how well could the machine-learning algorithm identify which stories were told by children with FASD only by examining the length and grammatical complexity of their narratives?

Methods:

A retrospective analysis of narrative and clinical data was conducted on 138 children 7-12 years of age. Sixty-nine had confirmed prenatal alcohol exposure and were diagnosed with

FASD at the University of Washington in Seattle using the FASD 4-Digit Code. Sixty-nine were typically developing with no reported history of prenatal alcohol exposure. After training, narrative analysis was conducted by the machine-learning algorithms blind to diagnosis. Markers of neurodevelopmental differences were represented as probability scores between 0 and 1, with closer to 1 being more consistent with FASD. Probability scores were estimated with machine-learning algorithms to predict whether a story was told by a child with an FASD diagnosis. Performance was compared to performance using grammatical and reference errors.

Results:

The marker identified by a machine-learning algorithm using length and grammatical complexity data demonstrated similar performance when identifying neurodevelopmental differences in the FASD group versus coding using a combination of age and grammatical and cohesive referencing errors (Thorne, 2017). Moreover, the marker identified from length and grammatical complexity data showed diagnostic value not only as a complement to the error-based coding, but also as a substitute for the child language disorder severity level assessed by an interdisciplinary clinical team.

Conclusions:

Narrative length and grammatical complexity data commonly available from narrative samples, as analyzed by a machine-learning algorithm, provides significant potential to contribute to the FASD diagnostic process.

References:

Thorne, J. C. (2017). Accentuate the negative: Grammatical errors during narrative production as a clinical marker of central nervous system abnormality in school-aged children with fetal alcohol spectrum disorders. Journal of Speech, Language, and Hearing Research, 60(12), 3523-3537. https://doi.org/10.1044/2017_JSLHR-L-17-0128

Learning Objectives:

1. Understand the potential role of machine learning in the diagnostic evaluation process for FASD
2. Know that speech-language differences, which reflect underlying neurocognitive differences, are a component of an FASD diagnosis

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Machine learning (AI) is increasingly being applied to clinical questions in health care. This work demonstrates the potential utility of machine learning as a complement to the FASD diagnostic evaluation process.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

The question still remains on how machine learning can be implemented and embedded into the clinical workflow for diagnosing FASD. There is also the need for further work in machine learning algorithms which can detect speech-language differences across a diverse population, based on language samples.

Development of an FASD-focused Resource Collection for Child Welfare Staff and Administrators

Poster Session

Erin Ingoldsby

Director of Child Welfare Practice Area, James Bell Associates

Leah Bouchard

Research Associate, James Bell Associates

Elizabeth Eaton

Senior Manager of Child Welfare and Education, ICF

Nancy Lefler-Panela

Consultant, ICF

Sharon Newburg-Rinn

Social Science Research Analyst, Children's Bureau

Jacquelyn Bertrand

Child Psychologist, Centers for Disease Control and Prevention

Abstract:

Purpose: This poster presents the Children’s Bureau’s and Centers for Disease Control and Prevention’s interagency efforts to develop and evaluate a resource collection aimed at enhancing child welfare case workers’ and administrators’ practices to identify children with prenatal alcohol exposure, refer to appropriate services and support families. The resource collection—a set of concise action-oriented practice guides, tip sheets, and other resources—is coupled with online self-guided training curriculum to provide essential information and guidance on how child welfare workers can approach serving families affected by fetal alcohol spectrum disorders (FASDs). With intention, this content also seeks to show how case workers and administrators can address this work with sensitivity and without stigma, honoring the family’s autonomy. The objectives, content, and application of the resource collection will be described.

Methods: The project employed an evidence-building development process, which included: 1) a 5-state, 22-agency descriptive study of current child welfare agency practices; 2) an environmental scan involving literature reviews and consultant interviews; 3) initial resource development with collaborative expert input; 4) usability testing with

child welfare and public health teams, and equity reviewers to assess reaction and feasibility; 5) extensive revisions; and 6) an ongoing formative evaluation in which four child welfare teams are applying the resource collection and reporting on reaction, gains in awareness and knowledge, and transfer potential.

Results: Across data sources results from the evidence-building methods identified the need for an FASD-informed, culturally responsive approach specifically designed for child welfare contexts. Usability results showed this approach should provide concise, action-oriented tools and resources that fit into workers' daily practice and aligns with goals towards family preservation and advancing equity. The three-part practice guides and trainings collection developed in this project provide knowledge to recognize indicators of FASDs and guidance to sensitively engage caregivers and collaborate closely with allied providers. This is to ensure clear diagnostic assessment and services to improve outcomes for children and families affected by FASDs.

Implications: The collection, which will be publicly disseminated upon completion of the formative evaluation, has potential to enhance child welfare practice in identifying prenatal alcohol exposure and providing the appropriate support and referral to services for affected children and families.

References:

Morehouse, E., Ingoldsby, E., Newburg-Rinn, S., Bertrand, J., & Usher, K. (2023). Knowledge, training, and support needs for identification and appropriate care of children with prenatal alcohol and other drug exposures in the child welfare system. In E. Ingoldsby & J. Collins (Eds.), Opportunities for child welfare to respond to prenatal alcohol and other substance exposures [Special issue]. Child Welfare, 101 (3).

Learning Objectives:

1. Professionals and caregivers/families will learn key insights from evidence-building efforts involving child welfare professionals, caregivers/parents, and allied service providers and experts about the needs and opportunities for enhanced awareness, training, and collaborative care planning regarding children with fetal alcohol spectrum disorders (FASDs) and their families served in a child welfare agency context.

2. Professionals and caregivers/families will be introduced to the set of resources, including child welfare practice guides, tip sheets, online trainings, and linked resources to community service providers and advocacy organizations that a) aim to increase awareness and knowledge of children FASDs and their families; b) present clear action steps to support children and families, that will be made available in the near future.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD? What questions has your work identified or what else has arisen from your work that research may be able to answer?

This project offers the opportunity to better support families affected by FASDs engaged in the child welfare system. It seeks to promote appropriate services and support families while honoring their autonomy. We believe this is essential to avoid or minimize punitive action and inappropriate services for families affected by FASDs and that they receive the care needed for their own unique family needs. Further, research may be able to answer questions of ensuring FASD services are accessible and culturally responsive for families.

“Breaking the Stigma: Innovative Approaches to Delivering Addiction Prevention Education for the Next Generation

Poster Session

Yisel Alaoui

LCADC, ICADC, FASD, Community Education Coordinator for the Partnership For Maternal and Child Health of the Northern NJ, Newark, New Jersey.

Yvelisse Gonzalez

MSW, LSW, PMH-C, Senior Manager, Public Health Programs at the Partnership for Maternal and Child Health of Northern New Jersey, Newark, New Jersey.

Abstract:

Title: “Breaking the Stigma: Innovative Approaches to Delivering Addiction Prevention Education for the Next Generation.”

Presenter: Yisel Alaoui, MA, LCADC, ICADC, FASD, Community Education Coordinator for the Perinatal Addictions Prevention Project (PAPP), Partnership for Maternal and Child Health of Northern NJ. Yvelisse Gonzalez, MSW, LSW, PMH-C, Senior Manager, Public Health Programs at the Partnership for Maternal and Child Health of Northern New Jersey, Newark, New Jersey.

Background: The Perinatal Addictions Prevention Program (PAPP) aims to deliver addiction prevention education innovatively. The PAPP team has incorporated four lessons learned from "Becoming Better Ancestors: 9 Lessons from Global Health to Change the World.” These lessons from public health leaders, introduced at the American Public Health (APHA)2022 conference, were considered when addressing society's problems. The goal was to advocate and amplify the voices of the unheard who are being stigmatized and marginalized by addiction.

Methods: To help educate high school and middle school audiences on preventing substance use, the PAPP team began using their pronouns when introducing themselves and incorporating both LGBTQ+ and Trans flags into their presentations. This created an invitation for more open dialogue about drug and alcohol use, the importance of delaying

use due to their underdeveloped brain, and again abstaining from using when planning for future families. As a result, community members felt confident and comfortable engaging with the PAPP team. Consequently, the PAPP team had an increased request for presentations to schools in their attachment area.

Results: The PAPP team has educated 817 students in 2021, 2,567 students in 2022, and 888 students in 2023, with an increasing number of requests for presentations. The team also developed an evaluation component to receive feedback from their audience, demonstrating increased awareness and knowledge.

Conclusion: The integration of these innovative approaches, along with the active participation of students and insightful feedback obtained, reaffirms commitment to evolving and improving our prevention education. It also reflects our dedication to staying at the forefront of education, embracing diversity, and bringing health equity to the students and communities.

Learning Objectives:

1. To Educate All Audiences, regardless of age, Sexuality, Gender, Religion, and Race, about the dangers of substance use during the teen years and pregnancy.
2. To become aware that we can all learn to become "Better Ancestors" and utilize the lessons learned from them to help us modify and adapt our programs in any setting.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

The broader relevance of our work in the field, particularly for adolescents and adults with Fetal Alcohol Spectrum Disorders (FASD), is significant. With 86% of adolescents experiencing unplanned pregnancies and engaging in illicit substance use, this population becomes highly susceptible to having children born with Fetal Alcohol Syndrome (FAS) and (FASD). Our involvement in the Perinatal Addictions Prevention Project (PAPP) is crucial as it aims to prevent such occurrences. Our goal extends beyond educating individuals solely before pregnancy; we are committed to providing awareness and education during the crucial adolescent years. By addressing substance use dangers during this developmental phase, marked by experimentation and self-discovery, we strive to mitigate the risk associated with FAS and FASD, contributing to healthier outcomes for both adolescents and their future children.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Our work has led us to some important questions for research. One big question is whether an ultrasound can show if a fetus has been affected by light drinking. We are curious because spotting the effects of even small alcohol intake early on is crucial. Another question is about the brain's ability to change (neuroplasticity). We are wondering if we can improve parts of the brain impacted by alcohol through medication, proper diet, exercise, and other activities. Answering these questions could help us find better ways to detect and address the effects of alcohol on a developing baby.

Challenges and Opportunities in FASD Diagnosis and Management: Insights from a Survey of Developmental Pediatric Clinicians

Poster Session

Yasmin Senturias

Yasmin Senturias, MD, Division Chief, Developmental Behavioral Pediatrics, Atrium Health. Clinical Professor, Wake Forest School of Medicine. Charlotte, North Carolina

Denise Bothe

Denise Bothe, MD, Developmental Behavioral Pediatrician, Associate Professor of Pediatrics, Rainbow Babies and Children's Hospital, Case Western Reserve University School of Medicine, Cleveland, OH.

Kimberly Burkhart

Kimberly Burkhart PhD, Clinical Psychologist, Rainbow Babies and Children's Hospital, Associate Professor, Case Western Reserve University School of Medicine, Cleveland, OH.

Catherine Lipman

Catherine Lipman, MD, Developmental-Behavioral Pediatrician, Cleveland Clinic Children's Hospital; Assistant Professor of Pediatrics

Cleveland Clinic College of Medicine of Case Western Reserve University, Cleveland Ohio

Tanaporn Jasmine Wilaisakditipakorn

Tanaporn Jasmine Wilaisakditipakorn, MD, Developmental Behavioral Pediatrician, University of California Davis MIND Institute; Assistant Clinical Professor, University of California Davis, Sacramento, CA

Abstract:

CHALLENGES AND OPPORTUNITIES IN FASD DIAGNOSIS AND MANAGEMENT: INSIGHTS FROM A SURVEY OF DEVELOPMENTAL PEDIATRIC CLINICIANS BACKGROUND

Fetal alcohol spectrum disorder (FASD) encompasses a range of conditions resulting from prenatal alcohol exposure, marked by facial abnormalities, growth issues, and central nervous system problems, with neurobehavioral challenges that include difficulties in self regulation, neurocognition and adaptive skills. Developmental and behavioral

pediatricians play a crucial role in FASD prevention, identification, diagnosis, and management, including support for affected families.

METHODS

In 2023, a survey was conducted among 199 members of the Society of Developmental and Behavioral Pediatrics (SDBP), of whom 97 were actively engaged in evaluating or managing FASD. Participants reported their diagnostic criteria, preparedness levels, and training needs. Data were analyzed descriptively, maintaining participant confidentiality.

RESULTS

There were 199 respondents to the SDBP Annual Survey. 97 (49%) of them were involved in evaluating or managing children with FASDs. Among these 97 individuals, 34% utilized the University of Washington criteria, another 34% relied on the DSM-5 criteria for Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure, 26% participants followed the NIAAA guidelines for FASD diagnosis, 12% adhered to the 2004 CDC criteria and 7% used the Canadian Guidelines. It was noted that 9% of respondents either did not use a specific diagnostic system or declined to specify. Furthermore, among these 97 professionals, 25% of them employed a combination of various diagnostic guidelines, while 68% of individuals utilized a single diagnostic system. Among the 97 professionals diagnosing FASD, 23% reported that their training made them very prepared while the rest ranged from somewhat unprepared to completely unprepared.Of those diagnosing or managing FASD, 58% expressed a desire for additional training in diagnosis and management, 7% sought training in diagnosis alone, and 14% desired training in management. Only 21% felt their current training was adequate.

CONCLUSIONS

Fetal Alcohol Spectrum Disorder (FASD) poses a complex challenge resulting from prenatal alcohol exposure, and developmental and behavioral pediatricians play a crucial role in its prevention and management. A survey in 2023 revealed a diversity in approaches to FASD diagnosis, with various diagnostic criteria and guidelines being employed. While some professionals felt adequately prepared, a significant portion expressed a need for additional training, emphasizing the importance of standardized education in this field. In summary, the survey underscores the need for additional training on the diagnosis and management of Fetal Alcohol Spectrum Disorders among developmental and behavioral pediatric clinicians.

Learning Objectives:

1: To inform the audience about the diverse approaches and diagnostic criteria used by developmental and behavioral pediatric clinicians in diagnosing Fetal Alcohol Spectrum Disorder (FASD) as well as their level of preparedness in diagnosing and managing this condition.

2. To emphasize the crucial role played by developmental and behavioral pediatricians in FASD prevention and management, and to underscore the importance of addressing the training needs of these professionals to enhance their preparedness in diagnosing and managing FASD cases effectively.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Developmental and behavioral pediatricians play a crucial role in FASD prevention, identification, diagnosis, and management, including support for affected individuals and families. Well-trained developmental and behavioral pediatric clinicians can lead to earlier and more accurate diagnoses of FASD in adolescents and adults. This can result in better access to appropriate interventions and support, ultimately improving the quality of life for those affected.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

From our study, we could branch out into research on effective training programs for developmental and behavioral pediatric clinicians. While the AAP FASD toolkit is freely accessible and diagnostic guidelines are widely accessible for developmental behavioral pediatricians, we could explore the factors that prevent developmental behavioral pediatricians from obtaining more training on FASD.

Building on a Basis of Understanding: Barriers and Opportunities for Housing Solutions for Young Adults with Fetal Alcohol Spectrum Disorder

Poster Session

Celisse Bibr

Research Assistant, Canada FASD Research Network (CanFASD); PhD Candidate, Laurentian University, Sudbury, ON, CA

Kelly Harding

Director of Research Administration, Canada FASD Research Network (CanFASD); Adjunct Professor, Department of Psychology, Laurentian University, Sudbury, ON, CA

Kathy Unsworth
Managing Director, Canada FASD Research Network (CanFASD)

Jacqueline Pei
Professor, School and Clinical Child Psychology Program, University of Alberta, Edmonton, AB, CAN; Intervention Research Lead, Canada FASD Research Network (CanFASD)

Abstract:

Purpose: A novel approach is urgently needed to address the housing challenges experienced by youth and young adults with Fetal Alcohol Spectrum Disorder (FASD). While the United Nations cites access to adequate housing as a basic human right, housing instability continues to be a challenge for individuals with FASD in Canada as the system often fails to consider the unique needs and experiences of individuals with FASD. Funded by the Canada Mortgage and Housing Corporation’s Solutions Labs program, this project seeks to leverage existing community-based knowledge and expertise in the FASD and housing space, including the Harmonizing Housing Framework for Housing Individuals with FASD, by blending this knowledge with current research to develop new, informed, and human-centered housing solutions. As a step towards improving housing for individuals with FASD, this research aims to explore the barriers and enablers that prevent or support people with FASD in obtaining and maintaining safe and secure housing.

Methods: To date, 47 semistructured interviews have been conducted across a pan-Canadian sample of four participant groups: individuals with FASD (n = 11), their caregivers (n = 17), housing service providers (n = 17), and policymakers (n = 7). Representation

includes participants from Western and Northern Canada (n = 28), Central Canada (n = 14), and Atlantic Canada (n = 5). Interview guides were customized to fit individual participant groups and involved topics such as describing the housing journey for individuals with FASD, supports that would be necessary for ideal living situations, defining safe housing, and solutions at the policy level. Thematic analysis has been utilized to generate key insights from the interviews.

Results: Housing stability could be strengthened through deeper understanding of FASD and willingness to adapt to the unique individual. Currently, housing systems act as a cycle of failures to keep housing unstable and inconsistent for individuals with complex needs. Our results indicate that centering discussion around the goals of access, collaboration, individualization, and understanding are the way forward in improving housing for individuals with FASD.

Implications: Individuals with FASD are stuck in a cycle of failure by a system not designed for them. Successful housing and support models include those that begin at deep understanding of the individual and work their way up. Embedding understanding into the intersectional process of housing would have far-reaching effects across all supports for individuals with FASD.

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Learning Objectives:

1. To convey the difficulties with housing within Canada, and the diverse housing experiences that individuals with FASD have had.

2. To discuss the barriers and enablers to attaining and maintaining safe and stable housing that individuals with FASD experience.

3. To explore how those barriers could be reduced, and how those enablers could be strengthened.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

The broader relevance of this work centers around the conversation of housing for individuals with FASD. While this work takes place in Canada, the findings and implications have relevance for individuals with FASD in many countries, including the United States, who are all facing a housing crisis. This work urges provincial, territorial, and federal governments, who have recognized housing as a fundamental human right for persons with disabilities, to ease the barriers to safe and stable housing for individuals with FASD. This work has policy implications, calling for policy to be: (1) developed with community organizations, individuals with FASD, and their supports; (2) person-centered, accounting for variability in diagnosis and geography; and, (3) an interdepartmental initiative, supported by cross-ministry communication. Housing is intersectional and reaches far into all aspects of life. To support housing, then, all other areas must also be considered.

Improving housing for individuals with FASD requires a universal improvement of all supports. The housing crisis is not localized to individuals with FASD: taking an intersectional approach to housing would be beneficial across Canada.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Questions that have arisen from this work include: (1) "best practice" models of housing for individuals with FASD, and how they would need to be adapted across diverse geography; (2) how to write FASD-informed policy, taking special consideration to make sure it is relational and adaptable to the individual; (3) how to bridge gaps between services, exploring best practices of cross-service communication throughout an individual's lifetime, and; (4) exploration of interdepartmental committees to address the intersectional nature of FASD and housing, taking precedent from committees that already exist within their specific jurisdictions.

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

Poster Session

Consider as another presentation type: Yes

Christina Tortorelli

PhD (c), RSW. Assistant Professor and Acting Academic Director - Social Work, Mount Royal University, Faculty of Health, Community and Education Calgary, Alberta, Canada

Peter Choate

PhD, Professor Social Work, Mount Royal University, Faculty of Health, community and Education, Calgary, Alberta, Canada

Dorothy Badry

PhD, RSW, Professor Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada

Abstract:

NOTE: this submission is for an oral presentation - not a poster.

The presenters published a chapter in Developments in Neuroethics and Bioethics: Neuroethics and Neurodevelopment titled "Disrupted life narratives of children in care with neurodevelopmental disabilities: Whose story is it?" The chapter was awarded special recognition by Elsevier for World Disabilities Day 2024. Following up on this chapter we will unpack further the experiences of children, adolescents and families when child welfare becomes involved using case examples related to FASD. Thinking about how a youth or adult might request access to their file information - professionals should be concerned that the documented information contains assumptions, highlights deficits in the knowledge base of professionals, creates gaps that consequently result in unfair, uninformed planning, decision making and service delivery access. Medical models and dependency frameworks as well as strict policy and practice guidelines inform life altering decisions (Tortorelli, et al., 2023).These failed approaches begin with identification and diagnosis and continue across the lifespan. File information no matter the accuracy follows across the life course informing future decisions. Through our work, we hope to elevate the ethical imperative that the individual and family stories be reflective of the individual and family realities rather than interpreted by various systems such as child welfare, education, health and justice.

Learning Objectives:

1. Increased understanding of the intersection between neurodevelopmental disorders - specifically FASD and child welfare

2. Understand the complex narrative that emerges when systems such as child welfare become involved

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Our work identifies the gaps and resulting misrepresentation that occur when the narrative of the child/adolescent and family are overtaken by professionals, government systems, policy and practice.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Taking a closer look at the experiences of persons living with FASD we hope to elevate the ethical imperative that the individual and family stories be reflective of the individual and family realities rather than interpreted by various systems such as child welfare, education, health and justice.

A National Fetal Alcohol Spectrum Disorders Learning Collaborative for Prenatal and Pediatric Healthcare Teams

Poster Session

Kendra Gludt

MPH, Director of National Programs, Proof Alliance, St. Paul MN

Dan Alford

MD, MPH, Medical Director, Boston Medical Center, Boston University Chobanian & Avedisian School of Medicine, Boston MA

Vincent Smith

MD, MPH, Division Chief of Newborn Medicine, Boston Medical Center; Professor of Pediatrics, Boston University Chobanian & Avedisian School of Medicine, Boston, MA

Additional Authors:

Nicole Kitten, MPH; Jacqueline S. German, MPH; Amy Harlowe, Sara Messelt, Jacey Greece, DSc, MPH; Candice Bangham, MPH; Ilana Hardesty, MA

Abstract:

Prenatal alcohol exposure (PAE) resulting in fetal alcohol spectrum disorders (FASD) is the most common preventable cause of intellectual and developmental disabilities in the United States. Primary healthcare teams can play a vital role in preventing alcohol use during pregnancy and identifying and caring for patients with suspected or diagnosed FASD. However, they are unprepared to do so. The HRSA-funded SAFEST Choice Learning Collaborative aims to reduce the incidence of prenatal alcohol exposure and improve outcomes in individuals with suspected or diagnosed FASD by engaging and educating healthcare teams on FASD prevention, identification, and management.

The SAFEST Choice Learning Collaborative uses Project ECHO® virtual education to engage interdisciplinary healthcare teams in education about FASD and PAE prevention. Enrolled clinics learn how to screen for and counsel patients about the risks of alcohol use during pregnancy, and how to identify and care for children and adolescents with suspected or diagnosed FASD. Participants receive an introductory webinar on FASD foundational science followed by ten virtual ECHO sessions. Each ECHO session includes a brief lecture, case-based learning, and collaborative problem solving. Lived experience of individuals impacted by FASD is also incorporated into ECHO sessions. Participants have ongoing access to a team of faculty experts and technical assistance to help them

integrate new tools into their practice. A comprehensive mixed methods evaluation assessed program effectiveness. Surveys administered before and after the program assessed participants' change in knowledge, self-efficacy, and clinical practices.

From 2021 to 2023, there have been 237 health care professionals from 57 clinic practices in 17 different states that have participated in the SAFEST Choice Learning Collaborative. From matched pre-/post-surveys, participants reported 100% increased knowledge about PAE screening in both the prenatal and pediatric groups. They reported increased self- efficacy to screen for PAE (100% prenatal group, 94% pediatric group), and to counsel families on PAE (100% prenatal group) and FASD (100% pediatric group). Participants also reported statistically significant increases in clinical practices including discussing alcohol screening in non-stigmatizing ways, assessing for FASD diagnosis, providing PAE/FASD resources and education, and coordinating care for patients with suspected/diagnosed FASD.

A virtual FASD learning collaborative provided a successful means for educating healthcare teams on FASD identification, care, and management. The program increased participants' FASD-related knowledge, confidence, and FASD-informed clinical practices. This is an important step toward creating health care teams that are better equipped to reduce PAE and support individuals and families impacted by FASD.

Learning Objectives:

1. Understand the importance of FASD education for healthcare professionals.
2. Discover how Project ECHO® virtual education can be used to deliver FASD education to interdisciplinary healthcare teams.
3. Describe participant learning outcomes following a virtual learning collaborative program on FASD.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

When healthcare professionals are not equipped to recognize FASD and care for individuals with FASD within their practices, those individuals receive insufficient health care, and their well-being can be profoundly impacted. By educating interdisciplinary healthcare teams about FASD, they can significantly change the trajectory of an individual's life. Healthcare professionals play a pivotal role in early identification, care, and support for individuals with FASD throughout the lifespan, as their patients grow through adolescence into adulthood. This learning collaborative provides the education, skills, and support for healthcare teams to deliver the care that individuals with FASD deserve.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

This work has identified an opportunity for further research to measure the long-term healthcare outcomes of individuals with FASD when they receive care from FASD-competent healthcare teams.

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Nevin AC, et al. A survey of physicians’ knowledge regarding awareness of maternal alcohol use and the diagnosis of FAS. BMC Fam Pract. 2002;3(1):2. doi:10.1186/1471-2296-3-2

O'Connor MJ, Portnoff LC, Lebsack-Coleman M, Dipple KM. Suicide risk in adolescents with fetal alcohol spectrum disorders. Birth Defects Res. 2019 Jul 15;111(12):822-828. doi: 10.1002/bdr2.1465. Epub 2019 Jan 24. PMID: 30677250; PMCID: PMC6650307.

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The Animation Curriculum

Poster Session

Consider as another presentation type: Yes.

Jessica Rutherford

Independent Researcher; Founder and CEO The Animation Curriculum

Abstract:

The Animation Curriculum, designed specifically for individuals with diagnosed or suspected FASD, centres around the use of the film making process for educational purpose. It promotes the narrative building and storytelling elements of film making and enables the student to explore their own understanding of topics of learning. The curriculum does not seek to teach film making or creative practice, but encourages exploration of a range of creative tools, materials, and actions to complete required tasks. Completion of the programme results in a short moving image (animated film) for the student to showcase and take pride in. However, the achievements lie in the experiential learning through completion of the curriculum.

This innovative new programme is made up of a series of 7 sessions, and incorporates theories of Active Learning Theory, Learning Through Play and Experiential, Inquiry-based or Problem-based learning. It encourages students to construct their own understanding as they explore the topic through different means, leaning to Hart's theory of participation (Hart, 1992) as the student is more heavily guided in the earlier stages, but then begins to take ownership and authorship as they programme continues, becoming the Director of their own animated film, as well as of their learning.

The programme evolved through more than 10 years of research and lived experience, both personal and professional. A mixed method approach was applied to utilise auto ethnographic writing, interviews, and evaluative feedback through co-design with leading experts in the fields of FASD, Education and applied animation practice. The curriculum is currently in Phase 2 testing in two Colorado based schools, and in each application is evolved in response to feedback and data gathered.

This presentation discusses the background and rationale of the curriculum, the methodological design and initial exploration through my Ph.D Animation based learning

for Individuals with Fetal Alcohol Spectrum Disorders (Rutherford, J 2023), facilitation and environmental considerations, to the present-day testing. It highlights opportunities for application and suggests opportunities for use in settings beyond education, concluding with the latest data generated by Phase 2 testing.

Learning Objectives:

1. Learners will be informed of how creative arts and film making practices can be utilised in all aspects of a school curriculum in all subject areas
2. Learners will understand how the film making process can be broken down to create a multi modal learning curriculum for students to engage with continually or periodically
3. Learners will consider wide applications and use of such curriculum for communication purposes (how the production of a film can act as a communication opportunity for the student)
4. Learners will understand the importance of narrative building and story telling practices for educational purposes for those with FASD

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

My work in this field seeks to explore, identify and disseminate alternative approaches to education that can not only accommodate the learning differences of those with FASD, but assist them in taking ownership, understanding their differences and developing their own individual approaches to taking on new knowledge. I am confident my work in this area can equip adolescents and adults with FASD with valuable tools and increase self confidence through engaging, creative, multimodal educational programmes.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Engaging with my programme is said to be therapeutic, and whilst therapeutic benefits are not the primary intention, it would be highly beneficial to explore this area in a research capacity to identify true therapeutic benefits.

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Domains of The Family Needs Met Questionnaire and Related Characteristics Prior to Fetal Alcohol Spectrum Disorders Treatment

Poster Session

Julianne Myers

PhD, Postdoctoral Clinical Psychology Fellow, University of Rochester Mt. Hope Family Center; Division of Developmental and Behavioral Pediatrics, University of Rochester Medical Center, Rochester, NY **Maddy Rockhold**

BA, Doctoral Student, University of Rochester, Rochester, NY

Carson Kautz-Turnbull

MA, Doctoral Student, University of Rochester, Rochester, NY

Emily Speybroeck

BA, Doctoral Student, University of Rochester, Rochester, NY

Lynn Cole

DNP, Associate Professor of Clinical SON Faculty, Division of Developmental and Behavioral Pediatrics, University of Rochester Medical Center, Rochester, NY

Christie Petrenko

PhD, Research Associate Professor, Mt. Hope Family Center University of Rochester; Associate Professor of Pediatrics, Division of Developmental and Behavioral Pediatrics, University of Rochester Medical Center, Rochester, NY

Heather Carmichael Olson

PhD, Clinical Professor, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, WA

Abstract:

Purpose. Individuals with fetal alcohol spectrum disorders (FASD) experience lifelong benefits from stable environments with good quality caregiving. However, caregivers of children with FASD face significant barriers at a systemic level that require caregivers to be parents, advocates, and system navigators. Additionally, caregivers experience high levels of stress that may impact their interpretation of their own skill level and their understanding of their child's behaviors and needs. The Families Moving Forward (FMF) Program focuses on expanding caregiver connections to increase their needs met, and confidence in their parenting and advocacy skills. To better inform care, it is crucial to understand the areas in

which caregivers require support and how those areas are related to their child's behavior and the caregiver's self-interpretation.

Methods. Families participated in one of two research trials focused on feasibility and outcomes for the FMF Connect mobile app (N=207). This study utilized demographic variables and baseline data for the Family Needs Met Questionnaire (FNQ), the Parenting Sense of Competence (PSOC) Efficacy and Satisfaction scales, and the Eyberg Child Behavior Inventory (ECBI) Intensity and Problem scales. Exploratory factor analysis (EFA) was utilized on the FNQ to determine domains of need and Pearson's r correlations were utilized to relate needs domains to the PSOC and ECBI.

Results. The FNQ EFA resulted in four domains of family needs: inclusive engagement in information exchange, access to professional opinion and resources, access to self-care, and personal support and hope. Correlation analyses indicated all domains of family needs met are positively correlated with parenting sense of efficacy (ps=.003-.02) and satisfaction (ps=.0004-.007). Further, higher levels of child behavior intensity were associated with lower levels of needs met in information exchange (p=.018), resources (p=.03), and self-care (p=.016) domains. Similarly, lower levels of inclusion in information exchange (p=.01) and access to resources (p=.003) were associated with higher frequency of child problem behaviors.

Implications. Caregivers of children with FASD report unmet needs in multiple domains. This is especially true among caregivers who feel ineffective and unsatisfied, and those raising children with more frequent and higher intensity behaviors. This suggests that caregiver self-interpretation is an important treatment focus, especially within systems that lack built-in supports for caregivers and individuals with FASD. Focusing on creating systems of inclusivity and support to empower caregivers' sense of ability to support themselves and their family is crucial in interventions for improving family and child outcomes.

Learning Objectives:

1. Learners will understand the importance of understanding the needs of caregivers with children with FASD.
2. Learners will understand main areas of unmet caregiver needs for families with FASD.
3. Learners will understand the relation between caregiver needs, child behavior, and parent self-efficacy.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Youth outcomes have been linked to the quality of home environments and caregiving. Caregivers of youth with FASD have high levels of barriers and stress while raising their children. The work presented in this poster considers the main areas of caregiver unmet needs and how that relates to youth behavior and self-efficacy. As many caregivers maintain a large role in their child's life, these outcomes may elucidate the role of caregiver needs on developmental stability as the youth grows into an adolescent and adult.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

This work brought about additional questions about how the current systems are missing caregiver needs throughout the lifespan. Additionally, there is the possibility to utilize this work to understand how different interventions impact the domains identified in caregiver unmet needs.

Examination of Epigenetic Profiles Associated with Prenatal Exposure to Alcohol

Poster Session

Aileen Baldwin

Ph.D., MPH, Assistant Laboratory Director for Research, United States Drug Testing Laboratories, Des Plaines, IL

Abstract:

Purpose:

Strong evidence supports that environmental exposures, in utero or in early postnatal life can cause epigenetic changes that can impact the developmental health and wellbeing outcomes for an individual from infancy to adulthood. The purpose of this project is to examine epigenetic profiles in newborns with or without in utero alcohol exposure using DNA extracted from neonatal blood spot filter cards. Our hypothesis is that since prenatal alcohol exposure has been shown to induce epigenetic modifications within the genome, that alcohol-associated alterations in DNA methylation profiles, identified from neonatal blood spot samples, could be used as biological markers of prenatal alcohol exposure in neonates.

Methods:

For this study, a total of 299 mother/newborn dyads were enrolled from our site at the Charleston Area Medical Center Women and Children's hospital. Data collected included the infants' gender, maternal risk factors, infant payer group, growth parameters, estimated gestational age at time of delivery, Apgar scores, need for NICU care, NAS diagnosis and severity, and results of prenatal alcohol and other substance exposure testing. Newborn heel stick dried blood spots were collected for both Phosphatidylethanol (PEth) screening (using liquid chromatography-tandem mass spectrometry following extraction into methanol) and DNA methylation analysis (following extraction of genomic DNA). PEth is a direct biomarker of alcohol metabolism that has been shown to be a highly sensitive and

specific indicator of alcohol use and an objective measurement of prenatal alcohol exposure.

Results: From the 299 women that were enrolled in this study, 48 women/newborn dyads were selected (25 drug negative/PEth negative and 23 drug negative/PEth positive) for examination of their whole epigenome methylation patterns. The selected newborn DNA samples were sent to the University of Chicago Genomics facility where they were analyzed using the Infinium MethylationEPIC v2.0 Kit (Illumina), which screens DNA methylation at over 950,000 sites across the genome at single nucleotide resolution. Differential methylation analysis between these two groups is currently underway to identify sites within the epigenome that are statistically different between PEth positive and PEth negative newborns.

Implications: The focus of our research is to identify epigenetic signatures at birth that may be associated with not only prenatal alcohol exposure but also provide insight into associated developmental outcomes. Further research will be focusing on how the epigenetic profiles we have identified at birth are associated with these children's adolescent development as well as their epigenetic profiles later in childhood.

Learning Objectives:

1. Explain the current use of and purpose of biological markers of prenatal alcohol exposure.
2. Explain the rationale of using epigenetic signatures as a method of detecting prenatal alcohol exposure.
3. Provide insight into why identifying epigenetic signatures associated with prenatal alcohol exposure at birth would be beneficial.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Identifying infants with FASD requires confirmation of maternal drinking during pregnancy or detection of prenatal alcohol exposure (PAE) in the newborn. Multiple studies have found under-reporting of PAE using maternal self-report methods and our research has found biological markers of alcohol exposure can sometimes be more sensitive. Our work aims to identify biological markers that not only confirm prenatal alcohol exposure but also provide information at an early age (at birth) on possible associated developmental outcomes due to the prenatal alcohol exposure.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

One additional question that we hope our ongoing research can examine is whether these epigenetic profiles identified at birth are similar in early adolescence and if the patterns are specific to which type of samples are analyzed (buccal versus blood).

Effects of a Self-Management Intervention on the Academic Engagement of an Adolescent with FASD

Poster Session

Megan Griffin

Professor, School of Education, Whitworth University

Abstract:

Individuals with FASD are notably absent from the extensive self-monitoring literature in the field of Applied Behavior Analysis. Only two studies have addressed this topic (Copeland et al., 2021; Griffin & Copeland, 2018), both of which included elementary-age participants. This is surprising, since FASD is a common cause of developmental disability and those with FASD could benefit greatly from learning self-management skills. To extend this research to older populations, we conducted a study with an adolescent with FASD, posing the research question: Does a function-based self-monitoring intervention result in increased academic engagement for a middle-school student with FASD?

Methods

Participant: Sofia, a 12-year-old Hispanic girl diagnosed with FASD, participated in the study. Her parents reported significant, longstanding problems with academic work completion.

Procedures: To assess Sofia's behavior, we interviewed her and her parents using standard measures (e.g., Durand & Crimmins, 1988; O'Neill et al., 2015). We also observed her behavior at home over two days (14 instances of noncompliance).

After collecting baseline data, we taught Sofia a homework routine, how to self-monitor her behavior, and how to use a point-system for earning rewards. We used an ABAB experimental design to assess the effects of this intervention.

Results

We found that Sofia's academic engagement (measured with momentary time sampling in 1-min intervals) increased when the intervention was in place and decreased when it wasbnot. A graph from our paper (Griffin et al., 2023) will be included. We will also share answers to interview questions regarding the acceptability of the intervention to Sofia and her mother.

Conclusion

The broader relevance of this work is that behavioral interventions that teach self-management strategies can be of benefit to adolescents with FASD, though much additional research is needed in this area. Learning and adopting self-management strategies can help individuals with FASD to live more independently and thrive in their school, work, and home lives.

References

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O'Neill, R. E., Albin, R. W., Storey, K., Horner, R. H., & Sprague, J. R. (2015). Functional assessment and program development for problem behavior: A practical handbook (3rd ed.). Cengage Learning.

Learning Objectives:

1. Learners will be able to identify effective behavioral strategies utilized to support academic engagement for our adolescent participant with FASD.
2. Learners will be able to identify research and policy implications of this study as pertains to adolescents and adults with FASD more broadly.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

The broader relevance of this work is that behavioral interventions that teach self-management strategies can be of benefit to adolescents with FASD, though much additional research is needed in this area in order to establish the generalizability of this approach.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Our work prompts questions about whether such interventions can be helpful to older adolescents and adults. It also suggests the need for policy changes to support behavioral intervention with those with FASD and a need to scale up interventions such that they are more readily available to those who might benefit.

Juvenile Detention Clinic Staff Training Pilot Study: Screening for Fetal Alcohol Spectrum Disorders

Poster Session

Cassidy Boyd

MPH, Manager of Population Health at Rady Children's Hospital-San Diego, San Diego, California

Kenneth Lyons Jones

MD, Medical Director of the MotherToBaby California Pregnancy Health Information Line; Co-Director of the Center for Better Beginnings, San Diego, California

Miguel del Campo

MD, PhD, Professor of Clinical Pediatrics at the University of California, San Diego School of Medicine; Researcher at the Center for Better Beginnings, San Diego, California

Jael Niebla

RN, Health Services Administrator at San Diego County Youth Transition Campus and East Mesa Juvenile Detention Facility, San Diego, California

Abstract:

This study looks to address the urgent issue of adolescents with Fetal Alcohol Spectrum Disorder (FASD) going undiagnosed within the justice system. Adolescents with FASD often exhibit behaviors such as impulsiveness, aggressiveness, and poor judgment, contributing to an increased risk of incarceration. However, they may also become involved in criminal activities due to their tendency to be overly trusting and easily coerced. A formal diagnosis is crucial as it opens avenues for specialized resources and educational accommodations that can improve their trajectory within and outside the justice system.

This study focuses on operationalizing FASD screening practices in a juvenile justice setting. The goal is to equip the workforce supporting these adolescents with practical tools to reduce recidivism. The study introduces a new self-paced training program, the Fetal Alcohol Screen Training (FAST), designed for the San Diego Probation Department clinic staff. The training prepares staff to use the Life History Screen (LHS) tool during the intake process for newly incarcerated teenagers.

The LHS tool, an evidence-based screening tool, requires training to ensure proper use. The research design employed a quantitative pilot approach, utilizing a cross-sectional pre- and post-intervention FAST knowledge survey. Participants included all clinic staff from the East Mesa Juvenile Detention Facility (15 staff, 9 RN and 6 LVN). The measurement tools included a pre- and post-educational intervention knowledge survey

hosted on the REDCap platform and the LHS tool, which employs a manual scoring system.

The results indicate an improvement in knowledge scores, by an average of 17.8% in all areas after the educational intervention, particularly in identifying physical indications of FASD (33.17% improvement). 47% of participants passed the pre-test and 69% passed the post-test. Statistical analysis suggests the need for further investigation with a larger study group (p value 0.1115, CI –0.264 - 2.397), as the observed changes were not statistically significant. There is a need for further exploration and emphasis on the importance of ongoing research to enhance screening practices and support for adolescents with FASD within the juvenile justice system.

This pilot project builds upon the research that supports using the LHS tool to screen for FASD in adolescents by validating an accompanying self-paced training module to measurably increase understanding of the disorder and how to screen for it. This pilot project adds to the limited scholarly publications and understanding surrounding practical tools for FASD screening.

Learning Objectives:

1. Understand the need for practical FASD screening and training tools in probation.
2. Appraise the Fetal Alcohol Screen Training (FAST) method of training for juvenile justice clinic staff to learn how to screen for FASD using the Life History Screen (LHS) at in-take.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Creating a basis for a nationwide comprehensive screening for FASD among incarcerated adolescents has the potential to significantly impact both their sentencing and subsequent access to supportive therapeutics. By identifying individuals with FASD, the justice system can recognize the cognitive and behavioral challenges they may face, leading to more informed sentencing decisions that prioritize rehabilitation over punishment. Furthermore, connecting these adolescents with appropriate therapeutic interventions can address their specific needs, enhancing their chances of successful reintegration into society and reducing the likelihood of recidivism.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

This pilot project is just the start of meeting this need. Despite finding anecdotal score improvement between the pre-and post-intervention, further study with a larger sample size is required to determine statistically significant improvement. With that, we could potentially see the outcome of implementing nationwide comprehensive screening for FASD among incarcerated teenagers.

Findings from Healthy Native Nation Family Support Project: integrated support for reservation-based Indigenous families of children (0-17) with FASD and other developmental disabilities

Poster Session

Annika Montag

PhD, Department of Pediatrics, University of California San Diego, San Diego, CA.

Rhonda Romero

Southern California Tribal Health Clinic, CA

Melina Munoz
MEd, Southern California Tribal Health Clinic, CA

Shandiin Armao
BS, Southern California Tribal Health Clinic, CA

Ami Admire
BA, Southern California Tribal Health Clinic, CA

Christina Chambers
PhD MPH, Department of Pediatrics, University of California San Diego, San Diego,

Abstract:

Purpose: Developmental disabilities (DD), including fetal alcohol spectrum disorders (FASDs), present challenges for individuals affected, their families, and communities. Reservation-based Indigenous communities often experience different challenges and strengths compared to the general population. Context matters and culture is protective. Among Southern California American Indian communities, we created and feasibility tested a model of culturally congruent support.

Methods: Under the guidance of our Community Advisory Board, using structured interviews (n=101 caregivers, n=>10 key informants), focus groups (n=11), and a community survey (n=305), we determined overall needs, resources, and priorities. An electronic medical record search among children (0-17yrs) served at the local clinic was conducted. Detailed health assessments for a subset of 25 families included child medical and neurobehavioral assessments, caregiver surveys including CBCL, child Adverse

Childhood Experiences, child prenatal exposures, current substance use, and perceived stress, social support, and wellness.

Results: Using EMR we determined the prevalence of developmental disabilities and delays (DDDs) to be 29.8%. Caregivers indicated they are not accessing optimal services for their children and that they themselves have unmet needs. The PSS and MSPSS screens reflected moderate to severe stress in caregivers and moderate/high perceived social support. Barriers to care included limited local care options, distrust of services outside the reservations, fears that child will be harmed, transportation and childcare, and lack of culturally appropriate services and support. Caregivers' desired services include education for families and professionals, local access to diagnostic services, treatment, and support, support groups, increased access to mental health services, Native advocates, culturally congruent childcare and respite, safe after-school and weekend space, learning interventions, and adolescent life skills courses and groups.

Among 25 families of children 4-17 years of age (11.6±0.7 years; 46% female) with DDDs, caregivers were primarily biological parents (84%) but also grandparents (12%) and biologically linked foster parents (4%). Common initial child diagnoses or concerns, prior to realized referrals, included autism, ADHD, anxiety, learning disorders, and behavioral issues. At least 68% of children were at high risk for chronic health issues as indicated by high ACEs scores and 42% screened positive for anxiety using the SCARED instrument.
Culture, tradition, and Indigenous knowledge were strong protective factors and opportunities for treatment and support.

Implications: It is feasible to provide comprehensive, culturally congruent care to increase access and uptake of services, increase the wellbeing of child, caregiver, and family, and decrease stress. The HNNFSP model was acceptable and appreciated.

References: Montag, A.C., Romero, R., Jensen, T., Goodblanket, A., Admire, A., Whitten, C., Calac, D., Akshoomoff, N., Sanchez, M., Zacarias, M. and Zellner, J.A., 2019. The prevalence of fetal alcohol spectrum disorders in an American Indian community. International journal of environmental research and public health, 16(12), p.2179.

Learning Objectives:

1. Describe how the reservation-based context may differ from a general population context

2. Discuss challenges and strengths unique to Indigenous communities and the need for cultural congruence

3. List at least three priorities of Indigenous caregivers participating in this study
4. Review support techniques found to be helpful for adolescents

5. Identify research findings that can be translated into health policy for Indigenous as well as non-Indigenous populations

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

This work further supports that context matters and culture is protective among reservation-based Indigenous populations. Our findings may prove helpful in structuring healthcare delivery to families impacted by FASD and to individuals and caregivers looking for support.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

How might context and culture improve and strengthen the impact of existing evidence-based interventions? How might the dominant culture learn from Indigenous frameworks and approaches? How might diagnosis look different in different contexts? How are caregivers best connected to support each other (where transportation and distance are a problem, where childcare may not be available, in low resource environments, ...)? How are health care professionals and providers best connected to each other and to families, individuals, and community services/support? Does the efficacy of community-based services improve with cultural congruence (e.g., culturally informed parenting, childcare and respite)?

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Program/Policy

Recovering Mothers Anonymous: An International Resource for Recovery

Poster Session

Consider as another presentation type: Yes

Julene Zizza

MA, Special Education and rehabilitation, Co-facilitator Recovering Mothers Anonymous, Staffing Coordinator, English Teacher, Special Education Teacher, Colorado Springs School District 11, Colorado Springs, CO.

Abstract:

Recovering Mothers Anonymous (RMA) is a fellowship of women, who are mothers, who share their experience, strength and hope with each other that they may find self-forgiveness and help other mothers to recover from having the lived experience of using alcohol or other harmful substance while pregnant.

The only requirement for membership is a desire for healing through connections with other mothers. RMA is not allied with any sect, denomination, politics, organization or institution; does not wish to engage in any controversy, neither endorses nor opposes any causes.

RMA recognizes that there is no exclusive path to recovery for all women; We share our experience, strength, hope, strategies, challenges, laughter, and tears with one another. We can be our true selves with a community of women who understand, know, and love us.

RMA has but one purpose: To support women who have used during pregnancy on their recovery journey to live a life filled with hope, meaning, and purpose.

We meet on Zoom every Wednesday at 7pm ET, USA.

Learning Objectives:

1) To improve and strengthen the lives of birth families
2) To provide peer support for birth families
3) To decrease the stigma, blame and shame that birth families may experience

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

To become a strong international network that will work to mentor birthing individuals who are struggling with addiction or have used alcohol or other drugs while pregnant. Most members have a child or children with Fetal Alcohol Spectrum Disorders (FASD). Our mission is to increase understanding and support for birthing individuals and to strengthen recovery for individuals who drank during their pregnancies as well as to support their families. - Kathy Mitchell, Senior Vice President of Circle of hope and Recovering Mothers Anonymous.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

How can we grow the community resources for birthing individuals? Most community based support groups are composed by adoptive parents who demonstrate shame, blame, and anger toward the birthing individual. Recovering Mother Anonymous includes a) individuals in active treatment centers, b) individuals freshly re-introduced into the community, c) individuals with short term recovery and d) individuals with long term sobriety. We build healthy birth family systems for the individuals with an FASD.

The In Reach Program: Innovative FASD Services for Corrections Staff and Residents

Poster Session

Consider as another presentation type: Yes

Angela Kemble

Executive Director, Willow Winds Support Network, Alberta

Julie Nanson

Executive Director, Central Alberta FASD Network, Red Deer, Alberta

Melissa Tremblay
University of Alberta

Abstract:

Purpose: Given the general lack of Fetal Alcohol Spectrum Disorder (FASD) awareness and limited FASD supports in correctional settings, there is a critical need for improved access to FASD diagnostic assessments and FASD education in corrections facilities. Two Alberta FASD Networks (Willow Winds Support Network and Central FASD Network) have developed and implemented the In Reach project in Alberta, Canada, with aims to: 1. Provide training for corrections staff to increase their FASD knowledge and awareness; 2. Facilitate educational sessions for justice facility residents to increase their FASD knowledge and awareness; 3. Administer in-facility FASD assessments for residents; and 4. Offer transitional mentorship for residents upon release.

Methods: For the past four years, we have used a collaborative and participatory approach to research and evaluate the emerging outcomes of In Reach. Enacting multiple methods, we have collected qualitative data in the form of interviews with staff (n=8) and stakeholders (n=32), and feedback surveys from stakeholders (n=60). We engaged in data analysis using a qualitative descriptive approach. In addition, we collected quantitative data in the form of project statistics (e.g., numbers of educational sessions, staff trainings, FASD assessments, FASD informed release plans).

Results: Across both FASD Networks, dozens of annual trainings were delivered to hundreds of staff; FASD assessments were initiated and completed in corrections facilities; and over 100 educational sessions were completed with approximately 1600 residents. In addition, strong stakeholder relationships were fostered. The project is influencing transformative changes in residents and facilities through elevated FASD

awareness, knowledge, and connections, thus setting the stage for prevention of FASD and recidivism.

Implications: There is a clear need for In Reach services based on the perspectives of stakeholders and research literature. Moreover, the potential long-term cost savings are substantial. Through this presentation, we will discuss key learnings related to delivering collaborative FASD assessment, education, and support in correction facilities, reflect on areas for project refinement, and share learnings for project replication and/or expansion.

Learning Objectives:

By the end of this session, attendees will (1) Be familiar with the In Reach project and the main facilitators of the project's success; (2) Understand the main considerations important to delivering FASD assessments and education in corrections facilities; and (3) Reflect on areas of learning for project replication and/or expansion.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

This work has strong relevance to multiple disciplines across the field of FASD. Clinical, educational, and front-line support staff will benefit from our learnings in terms of service delivery approaches and methods. Adolescents and adults with FASD are benefiting from our client-centered educational, assessment and diagnosis, and transitional mentorship services. Our hope is that, by sharing our learnings, the provision of FASD-informed services in the criminal legal system can continue to grow and evolve in line with emerging evidence.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

What our research and evaluation has made clear, based on the perspectives of project stakeholders as well as the research literature, is that there exists an urgent need for FASD- informed services in the criminal legal system. Moreover, the potential long-term cost savings of supporting justice-involved people with FASD are substantial. Thus, the importance of this work has been established, and our research and evaluation demonstrates that In Reach work is being carried out in a way that is highly regarded and evidence-informed. We continue to explore how investment in the In Reach project can be immediate and continued over the long-term, and to engage in ongoing learning about ways that In Reach services can evolve based on stakeholder needs.

Playful healing: Using a trauma informed play therapy in the mental health treatment of individuals with FASD

Poster Session

(Fatima) Natascha Lawrence

MA, RCC, BCRPT, CO-Founder FASD Institute

Abstract:

Little practice nor evidence-based research explores mental health interventions for FASD, though research has indicated that between 60 to 97% of those who come to a clinic for an FASD diagnosis will have one or more mental health disorders (Fryer et al. 2007; O'Connor et al., 2000; Walthall et al., 2008; Ware et al., 2013). Pei et al. (2011) even argue that 90% of individuals with FASD are estimated to experience mental health conditions including but not limited to depression, mood and anxiety disorders, addictions and suicidal ideation. It is unclear if there is a direct correlation between prenatal alcohol exposure and mental health conditions or if the high rate of diagnoses is a result of secondary disabilities. In 2018, Mela et al. developed the Psychotropic Medication Algorithm for FASD/Prenatal Alcohol Exposure. Before using the algorithm, it recommends "addressing the non-medication factors including social support, sleep, exercise and nutrition". However, the algorithm does not identify which evidence-based psychosocial interventions are recommended because we do not have that information. That is why we must highlight practice-based interventions being used successfully with this population.

Considering secondary disabilities, research has also indicated that individuals with FASD are more likely to experience ACEs, and the combination of PAE and a history of trauma is more damaging than trauma alone (Price et al., 2017). Despite this reality, there are limited studies that explore mental health interventions for the treatment of trauma for individuals with FASD.

The Board of the Association for Play Therapy (APT) has written a statement that details the theory, rationale, and research supporting the facilitation of play therapy as an effective treatment for children with trauma, and numerous studies explore the benefit of play therapy for special populations, including Autism, ADHD, learning disabilities, and across the lifespan.

This presentation will show research findings on the effectiveness of play therapy for trauma treatment. Clinical experience will highlight the successful use of play therapy

across the lifespan of individuals with FASD.

This presentation is for mental health professionals, educators, frontline workers, caregivers, and individuals with FASD. Interventions presented can be used across multiple settings.

When introducing play therapy interventions, accessibility and inclusivity are prerequisites. Clinical practice examples will be given about creating welcoming and safe environments for all populations.

Learning Objectives:

1. Discuss the relationship between prenatal alcohol exposure, trauma, and ACEs
2. Summarize the research literature on the treatment of trauma, ACEs using play therapy methodology and interventions
3. Identify the benefits of using play therapy as a treatment modality for individuals with FASD
4. Discuss how to utilize play therapy techniques across various settings: in treatment, at school, at home, in the community and across the lifespan

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Play therapy is a treatment modality that is often only discussed for young clients, but is beneficial across the life span

What questions has your work identified or what else has arisen from your work that research may be able to answer?

My presentation will identify that there are currently no studies that explore using play therapy for individuals with FASD

Overcoming Stigma: Navigating Systems as a caregiver and advocate

Poster Session

Consider as another presentation type: Yes

(Fatima) Natascha Lawrence

MA, RCC, BCRPT, Co-Founder FASD Institute

Abstract:

Stigma is a complex social process where society has a set of negative or unfair beliefs about a person or a group of people. Stigma plays a significant role in the experiences of people who have FASD and their families. Stigma is pervasive in all levels of society, particularly concerning alcohol and other drugs, and even more so in terms of FASD.

These sentiments have significant implications on how communities view individuals with FASD and their caregivers, and these misconceptions can adversely affect their quality of life and their ability to access health-related services and resources (Green et al., 2016) and restrict the management of FASD across the lifespan (Bell et al., 2016). Stigma is often reported as the most significant barrier for individuals and their families in accessing services, leading to increased discrimination, isolation, and worsening of symptoms and disability (Sickle et al., 2014).

This presentation will discuss the everyday experiences caregivers experience in navigating systems based on clinical experience, focus groups, and personal caregiver experience. This presentation will explore strategies to effectively battle prejudice and discrimination, advocate for your child's rights across the lifespan, and find allies for effective collaboration.

Learning Objectives:

1. Identify how individuals with FASD and their caregivers can face stigma when navigating systems.
2. Summarize the current literature on FASD and stigma.
3. Discuss how to challenge stigma, shift perspectives, and advocate effectively.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

Stigma is a significant obstacle to inclusive services for individuals with FASD and their families. This stigma often increases in adolescence and adulthood

What questions has your work identified or what else has arisen from your work that research may be able to answer?

There is a significant need for more education for professionals and advocacy broadly across systems, particularly in adolescence and adulthood. Research has limited guidance to how to eliminate stigma for individuals with FASD or their caregivers.

Risk and Resilience Variants in the Retinoic Acid Network and Developmental Pathways Influence FASD Outcomes

Poster Session

Leo McKay

The Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.

Songyan Liu

The Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.

Berardino Petrelli

The Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.

Molly Pind

The Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.

Bresham Omar Malik

The Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.

Geoffrey Hicks

The Department of Biochemistry & Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba, and The Children's Hospital Research Institute of Manitoba.

Abstract:

Purpose: Fetal Alcohol Spectrum Disorder (FASD) is the most common neurodevelopmental disorder in the world, affecting 1-5% of North Americans. A genetic component contributing to the risk of FASD outcomes is well established1; however, our understanding of specific genetic variants underlying FASD remains limited. We, and others, have established acute prenatal alcohol exposure (PAE) induces retinoic acid (RA) deficiency during early development and results in FASD-like phenotypes2–4. If PAE-induced RA deficiency is a major etiology of FASD, we hypothesize genetic variants in RA metabolism exist that could either enhance or reduce FASD outcomes following PAE. Thus, we predict that genetic variants in RA metabolism that increase the risk or resilience of FASD outcomes will be significantly enriched or reduced, respectively, in children diagnosed with FASD. Accordingly, this prediction could extend to

include genetic variants in RA-regulated developmental genes and in many rare neurodevelopmental disorders that involve RA signaling and share FASD comorbidities1.

Methods: To test this hypothesis, variant analysis using a gene candidate approach of RA-metabolic and neurodevelopmental genes was completed on whole exome sequencing data of 23 FASD diagnosed individuals. Differences in statistically significant genetic variant allelic frequencies were determined for children diagnosed with FASD against the expected population frequencies represented in the Thousand Genomes database. Allelic frequencies of variants of interest were validated using Taqman qPCR.

Results: We found that FASD individuals in our study are significantly enriched in 104 candidate genetic variant allele frequencies (risk) and are significantly reduced in 39 genetic variant allele frequencies (resilience), compared to control frequencies. Risk alleles discovered in alcohol metabolism genes included 11 variants that are already associated with alcohol consumption, dependence and clearance rate. 24 variants altering enzymatic activity of RA metabolism genes, and 109 variants within RA-controlled developmental pathways also have significant differences in allele frequencies. Interestingly, 38 variants in the causative genes of neurodevelopmental disorders with shared phenotypes to FASD were also enriched in the FASD cohort, when compared to controls.

Implications: This research is the first to associate genetic risk and resilience variants with the risk of FASD outcomes. Overall, this research is the first to identify these variants as associated with FASD and may help identify molecular mechanisms of PAE and new diagnostic tools. The findings demonstrate the importance of these genes in the mechanism of ethanol teratogenesis; and, moreover, may identify new biomarkers of the risk of FASD outcomes following acute PAE.

References:

1. McKay, L., Petrelli, B., Chudley, A. & Hicks, G. Genetics of FASD: Confounding Craniofacial and Neurodevelopmental Disorders. in Fetal Alcohol Spectrum Disorder. Advances in Research and Practice (2022).

2. Yelin, R. et al. Ethanol exposure affects gene expression in the embryonic organizer and reduces retinoic acid levels. Dev. Biol. 279, 193–204 (2005).

3. Marrs, J. A. et al. Zebrafish fetal alcohol syndrome model: Effects of ethanol are rescued by retinoic acid supplement. Alcohol 44, 707–715 (2010).

4. Petrelli, B. et al. Genetically programmed retinoic acid deficiency during gastrulation phenocopies most known developmental defects due to acute prenatal alcohol exposure in FASD. Front. Cell Dev. Biol. 11, 1–17 (2023).

Learning Objectives:

1. Outline how prenatal alcohol exposure (PAE) reduces retinoic acid levels and signaling which results in PAE phenotypes
2. Discuss how risk and resilience genetic variants in alcohol and retinol

metabolic and other retinoic acid-mediated developmental pathways influence FASD outcomes

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

The goal of our research is to further our understanding of the genetics of FASD and discover genetic biomarkers that influence PAE outcomes, specifically by identifying PAE resilience and risk alleles found within the RA signalling network. Once the identified alleles have been validated, mechanistic studies, using in vivo PAE-animal models will be conducted to clarify how they contribute to alcohol teratogenic effects. Our final aim is to use this information in conjunction with existing diagnostic criteria to enable an earlier, assured diagnosis of children with FASD. This will allow for early intervention that would significantly mitigate many secondary disabilities associated with FASD and thus have a profound impact on the life course trajectory of adolescents and adults with this disorder.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Our research has provided additional evidence that PAE-induced RA deficiency is a major contributor to the etiology of FASD, as the new identified genetic variants are all regulated by RA-signaling. However, experiments are needed to validate the biological effect of these alleles during PAE with in vivo animal experiments. Future research therefore is planned to validate the effect of these alleles upon prenatally exposed alcohol animal models (Xenopus laevis and mice) which have been genetically modified to carry the identified genetic variants when compared to wild-type controls.

Can Dysmorphology Examinations at Midlife Detect Physical Differences Between Adults With and Without Prenatal Alcohol Exposure?

Poster Session

Susan Stoner

PhD, Research Associate Professor of Psychiatry & Behavioral Sciences, Ann Streissguth PhD Professor of Fetal Alcohol Spectrum Disorders, University of Washington School of Medicine, Seattle, WA.

Emmy Smith-Stewart

B.F.A., Research Coordinator, Department of Psychiatry and Behavioral Sciences, UW Medicine, Seattle, WA.

Margaret L. P. Adam

M.D., Professor, Department of Pediatrics, UW Medicine; Center for Clinical and Translational Research, Seattle Children's Hospital.

Tamara S. Bodnar

Ph.D., Assistant Professor, Department of Biological Sciences, University of Calgary, Calgary, AB.

Charlis Raineki

Ph.D., Assistant Professor, Department of Psychology, Brock University, St. Catharines, ON.

Parker J. Holman

Ph.D., Adjunct Professor, Department of Psychology, Brock University, St. Catharines, ON.

Julie A. Kable

Ph.D., Associate Professor, Department of Psychiatry and Behavioral Sciences, Associate Director, Emory Neurodevelopmental Exposure Clinic, Emory University School of Medicine, Atlanta, GA.

Alexandra Perez

Psy.D., Assistant Professor, Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, GA.

Tim F. Oberlander

M.D., FRCPC, Professor, Division of Developmental Pediatrics, Department of Pediatrics, Faculty of Medicine, University of British Columbia; BC Children's Hospital Research Institute, Vancouver, BC.

Christine Loock

M.D., FRCPC, Associate Professor, Department of Pediatrics, Children's & Women's Health Center of British Columbia, Faculty of Medicine, University of British Columbia, Vancouver, BC.

Kenneth L. Jones

M.D., Professor Emeritus, Department of Pediatrics, Division of Pediatric Dysmorphology-Teratology; Co-Director, Center for Better Beginnings, UC San Diego School of Medicine, San Diego, CA.

Miguel Del Campo

M.D., Ph.D., Professor of Clinical Pediatrics, Medical Genetics and Genomics Residency Program Director, Department of Pediatrics, University of California, San Diego; Genetics Section Chief, Rady Children's Hospital San Diego; San Diego, CA.

Joanne Weinberg

PhD, Professor Emerita, Department of Cellular & Physiolgocial Sciences, Faculty of Medicine, University of British Columbia, Vancouver, BC.

Claire D. Coles

PhD, Director, Center for Maternal Substance Abuse and Child Development and Emory Neurobehavior and Exposure Clinic, Professor, Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, GA.

Abstract:

Background & Rationale: Dysmorphology examinations have established that fetal alcohol spectrum disorders (FASD) are associated with several characteristic physical features early in life. Cardinal features include relatively shorter palpebral fissures, smoother philtrum, and thinner vermilion border of the upper lip. As the aging process gradually changes many physical features, it is possible that differences in these features are attenuated over time. Thus, the purpose of this study was to determine whether the features that are characteristic of FASD in childhood continue to be so at midlife.

Methods: Subjects (N=192) were recruited from two longitudinal cohorts in Seattle and Atlanta and from Vancouver, British Columbia. About two-thirds (n=132) had an FASD or previously documented prenatal alcohol exposure (PAE). A standard dysmorphology examination was conducted in person by expert dysmorphologists who were blinded to the subjects' documented FASD or PAE status. One-sided t-tests were used to compare physical characteristics between those with and without PAE.

Results: Subjects' mean (SD) age was 35.6 (11.3). 56% were female. 18.2% were American Indian/Alaska Native/Indigenous/Aboriginal, 22.4% were Black/African American, 47.4% were White/Caucasian, and 10.4% were more than one race. 4.2% were Hispanic.
Collapsing across gender, race, and ethnicity, we found significant differences according to PAE status in the following measures: occipito-frontal circumference, t(190)=2.212, p=.014; palpebral fissure lengths, ts(190)>3.10, ps=.001; hypoplastic midface, t(134.8)=-3.258, p=.001; anteverted nares, t(180.5)=-2.244, p=.013; philtrum lipometer, t(188)= 3.702, p=.001; vermilion border lipometer, t(188)=-3.213, p=.001; camptodactyly, t(131.0)=-4.548, p=.001; and difficulty with pronation/supination of elbows, t(169.6)=-2.109, p=.018.

Conclusions & Implications: Individual differences in physical characteristics according to PAE status continue to be observable at midlife in the three cardinal features of FASD, among other features. Dysmorphology examination could thus continue to be useful in the identification of FASD later in life.

Learning Objectives:

1. Identify the three cardinal physical features of fetal alcohol spectrum disorders
2. Describe physical features associated with prenatal alcohol exposure at midlife

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

It has been demonstrated that getting a diagnosis of FASD is beneficial to persons who are affected by prenatal alcohol exposure, yet an untold number of persons with FASD never receive a formal diagnosis. Current methods of identifying and diagnosing FASD have primarily established their reliability in childhood and adolescence. There is a significant need to establish reliable methods to identify and diagnose adults with FASD.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Our work explores physical, physiological, and psychological differences at midlife between those with and without histories of prenatal alcohol exposure. Our research can help to recognize the ongoing impact of prenatal alcohol exposure across the life course with the goal of maximizing the health and wellbeing of persons with FASD.

Adapting Proven Models: Supporting Youth with FASD Through Innovative Program Design

Poster Session

Luke Dumaran

Luke Dumaran, LBA, Psychological Developmental Counselor, Autism Treatment Assistance Program, Nevada Department of Health and Human Services

Abstract:

In this presentation, we showcase two of Nevada's innovative programs aimed at supporting youth diagnosed with autism spectrum disorder (ASD). We explore how Nevada's Autism Treatment Assistance Program (ATAP), and Detention Alternative for Autistic Youth (DAAY) Court can be adapted to support youth with Fetal Alcohol Spectrum Disorder (FASD) and their families. We share practical insights and recommendations for professionals, caregivers, and policymakers on how to improve funding of support services for youth with FASD and reduce justice involvement and recidivism rates. The presentations highlight evidence-based approaches that have been successful in addressing the high cost of therapy for youth with neurodevelopmental disorders and how professional collaboration can reduce their involvement in the justice system.

The Autism Treatment Assistance Program (ATAP) started in 2007 as a pilot program and was signed into law in 2011. The cost for autism services can be extremely high, even with insurance. ATAP provides temporary funding assistance for evidence-based treatments for children with ASD under the age of 20. Families also receive case management, special education advocacy, and service coordination. This helps to reduce the number of days waiting for services and promotes a better match with the service provider.

Nevada's Clark County 8th Judicial District Court launched the Detention Alternative for Autistic Youth (DAAY) Court in 2018 and in 2023, Nevada became the first state to recognize a diversionary court for autistic youth (SB 411). Many youth served in DAAY Court received little to no support services and are often undiagnosed or misdiagnosed. DAAY Court is focused on addressing gaps in access to appropriate services by youth with ASD to reduce recidivism in the juvenile justice system. The program helps families obtain an appropriate diagnosis, connects youth with appropriate intervention services and supports the whole family through education, respite, and other counseling services. DAAY Court is comprised of involves the cooperation of representatives from the prosecution, defense counsel, probation department, and community partners.

We hope to inspire and encourage other State's and jurisdictions to develop and improve on similar programs for youth with FASD and their families.

Learning Objectives:

1) Demonstrate how Nevada's programs in disability services and juvenile justice can be adapted to effectively support youth with FASD, providing practical frameworks for implementation."

2) Use research findings to inform ethical policy and decision-making and the development of integrated and collaborative approaches across systems.

3) Why we must advocate for more universal screening to identify youth with or at-risk of a FASD in existing medical visits and within children services, like early intervention and child welfare systems.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

The broader relevance of this work is to demonstrate the successful impact of Nevada's innovative autism programs and how they can be adapted to provide essential support to youth with FASD and their families. Given its effectiveness in reducing juvenile justice involvement for youth with ASD, the DAAY court model could be adapted to benefit youth with FASD who face similar challenges. These individuals are 30 times more likely to contact the criminal justice system, so diversion programs will play a key role in reducing recidivism and promoting healthy communities. After diagnosis, specialized service coordination can promote quicker access to appropriate supports for the individual and their care givers.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

Our work identified gaps in knowledge and support services for individuals with FASD.

How to increase knowledge of FASD outside of the medical profession and within local provider networks, schools, child welfare and government programs to reduce barriers to diagnosis and services?
How to implement universal screenings that lead to increase early identification rates for those with FASD and reduce rates of misdiagnosis?

How to design public programs and supports that address the whole person rather than their diagnosis?

How to design public-private partnerships to fund Respite programs for care givers?

How to develop education and/or vocational programs to address missing skills needed for independent living and to reduce substance abuse?

Considering the lack of diagnosing specialist, can the field develop a diagnostic screener to be implemented by non-medical personnel that results in high-confidence provisional diagnosis so an individual may begin accessing support services while they waits for a neuropsychological evaluation and diagnosis?

Would having FASD as a separate disability category on an IEP promote better awareness, improve specialized program design, and reduce youth involvement in the justice system?

When reviewing applications for regional center eligibility, is there evidence that suggests an individual's adaptive scores taken as a youth vs as an adults can differ significantly? Should an applicant be ineligible for borderline scores if other evidence supports a FASD diagnosis?

What are the financial costs to local governments for missed diagnosis at different stages of life (ie. early childhood, elementary, high school, etc.)?

The Integral Role of Social Workers… The urgent need to do things differently. Training for Social Workers and other practitioners who engage in front line assessment services.

Poster Session

Angela Geddes

Angela Geddes Integrative Support and Wellness

Abstract:

Purpose:

Can we be helpful to individuals and families even without an official diagnosis. Can we still guide people to a path of helpful and relevant supports in the absence of a diagnosis? Can we really build inclusive social service delivery systems? The Social Work training consists of 6 modules which cover the following:

Introduction – why should we be concerned? What can Social Workers and other front line assessment clinicians do within our scope of practice to contribute to understanding and comprehensive multi-disciplinary assessments? Understanding the role of Stigma, intergenerational trauma, mental health, addictions and intergenerational FASD and how can we support families in helpful and relevant ways focusing on family preservation?

Overview of the Canadian Guidelines of Dx.

Samples of a comprehensive Social Work/Assessment report and examples of how they can be so impactful.

How can we augment what we already do to be better positioned to address the complexities in a good way?

Case studies and examples to bring the learning home and to discuss and brainstorm together. Methods:

We have completed many Social Work assessments and have helped people to understand the implications of the symptoms that are often associated with prenatal exposure to alcohol and other complex neurodevelopmental conditions. These assessments and the recommendations provided have been quite helpful even prior to the formal diagnosis. Additionally, although we have a small Social Work private practice, the feedback and evaluations we have received indicate that all our assessments have been able to provide individuals and families access to more of the support they needed, and most times for the first time ever. Also, we have not been wrong yet with our conclusion that further assessment services are required, and that prenatal alcohol exposure is quite likely linked to the symptoms that we are observing and hearing about.

The literature confirms an urgent need for Social Workers to play a more integral role in screening and assessment, and in the prevention of family disruption, and specifically by providing accurate information and relevant, customized, strength-based supports and services, we can help to prevent both the incidents and the impact of prenatal alcohol (and other substances) exposure.

The pilot training session was offered live and on-line and was well received. We had 12 participants and they the program was evaluated following completion.

Results:

We have seen that Social Work assessments can be instrumental in assisting individuals, and families access the supports that they require that will help them to realize the outcomes that we all are hoping for. Social Workers and front-line practitioners indicate that training to improve screening and assessment services for complex mental health and learning difficulties often related to prenatal exposures have been 'game-changing'. So far, 100% of participants have said they:

- Have a better understanding of how stigma can be a barrier to accurate diagnosis and helpful supports. Feel more competent and confident in their ability to screen and identify people with complex neurodevelopmental conditions; who may be affected by PAE.
- They would recommend this training to their other clinicians.

Implications:

Recent research confirms that very few of people who have been impacted by prenatal alcohol exposure have been adequately diagnosed. In fact, globally 2% of individuals who would qualify for an FASD know it. Training specific for social workers and front line practitioners who engage in assessment services can be game-changing and given the limited full multi-disciplinary assessment services that are available, we need to act now. 'When we know better.. we can do better."

References:

- http://www.canfasd.ca/wp-content/uploads/2013/02/Linking_diagnosis_and_prevention_building_the_next_generation_of_policy_responses_March_2011.pdf
- http://www.fasdcenter.samhsa.gov/documents/eightmagickeys.pdf
- https://www.saskfasdnetwork.ca/resources/networkresources
- https://www.iriss.org.uk/resources/insights/social-work-and-fetal-alcohol-spectrum-disorders-fasd
- Exploring the experiences of social workers in working with children suspected to have fetal alcohol spectrum disorders. https://journals.sagepub.com/doi/pdf/10.1177/03085759211011735

Learning Objectives:

1. Participants will understand the urgent need to do things differently to provide the kind of screening, assessment and direct support services that will lead to improved clarity and outcomes.
2. Participants will be inspired to learn more and to be able to demonstrate the current landscape; the prevalence rates compared to other more readily acknowledged complex neurodevelopmental disorders, and why we need to build skills and system capacity to be able to reduce both the impact and the incidents of prenatal alcohol (substance) exposures
3. Participants will understand that we need to build system capacity in terms of screening, assessment and prevention at the front-line level and Social Workers in particular have an integral role in terms of better addressing the overrepresented yet underdiagnosed population within child welfare, special education, mental health, justice and social welfare.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

This session will help to demonstrate the need and the opportunities available to increase skills and capacity for Social Workers and assessment practitioners. Training and mentorship opportunities will allow practitioners to be better positioned to identify when the emotional, and behavioural difficulties that we are seeing in the people we support may be more to do with developmental trauma and prenatal exposures and not always solely related to parenting challenges, and adverse childhood experiences. We learn that FASD is an indiscriminate disorder and query the likelihood that FASD is found in all of our circles; both professional and personal. Participants will see the need to be better able to offer more comprehensive screening, identification, and support services while simultaneously targeting prevention.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

We will highlight research and in particular the integral role of Social Workers including this article: Social Work and FASD Insight 68 – Iriss, UK

Key messages from this article:

- Given the prevalence, severity, and impact of FASD, there should be more Social Worker's competent and confident.
- Social Workers can play a more positive role in prevention and identification.
- Training allows for Social Workers to fulfill their potential in this role.

Social Workers can be helpful even in the absence of a diagnosis which will increase the likelihood of fewer families being disrupted and a reduced need for foster and residential placements. The presentation will challenge the audience to look at how stigma and negative biases contributes to the invisibility of CND and in particular, FASD. We know that this lack of awareness interferes with accurate diagnosis and helpful supports. Dr. Carl Bell found that approximately 50% of his patients in the mental health clinic actually qualified for an FASD dx when investigated further. He called it a hidden epidemic and in spite of our prevention efforts, more people are drinking alcohol during pregnancy than 10 years ago. We can do better. Alcohol use in our society will be explored, and we will highlight that FASD is an indiscriminate disorder and not reserved for people with serious mental health or addiction issues.

- The stigma creates barriers to services and results in an even lower quality of life while increasing the likelihood of traumatic experiences, compounding issues including overrepresentation in child protection, justice, mental health agencies, special education, poverty supports and home and food insecurity and a variety of other poor outcomes.

Holistic approaches to family support with considerations for intergenerational trauma and FASD will be examined.

All people have the right to appropriate medical, mental health, education, occupation, and social supports. People who have been exposed to alcohol prenatally do fall within our job descriptions and the Ministry mandates across all sectors.

There will be a 15-minute section for Q and A within this workshop.

Genetically programmed retinoic acid deficiency during gastrulation phenocopies most known developmental defects due to acute prenatal alcohol exposure in FASD

Poster Session

Berardino Petrelli
Department of Biochemistry & Medical Genetics; Regenerative Medicine Program, Faculty of Medicine, University of Manitoba, Winnipeg, Canada.
Molly Pind
Department of Biochemistry & Medical Genetics; Regenerative Medicine Program, Faculty of Medicine, University of Manitoba, Winnipeg, Canada.
Geoff Hicks
Department of Biochemistry & Medical Genetics; Regenerative Medicine Program, Faculty of Medicine, University of Manitoba, Winnipeg, Canada.

Abstract:
Purpose: Fetal Alcohol Spectrum Disorder (FASD) arises from maternal consumption of alcohol during pregnancy affecting 2%–5% of the Western population. Our Xenopus laevis studies showed that alcohol exposure during early gastrulation reduces retinoic acid (RA) levels at this critical embryonic stage causing craniofacial malformations associated with FASD sentinel facial features. It is now understood that acute ethanol exposure overwhelms the aldehyde metabolic enzymes that would normally convert retinol (Vitamin A) to retinoic acid (RA). We hypothesize that PAE reduces RA levels during critical developmental stages in early gastrulation that drives the later craniofacial malformations associated with FASD sentinel facial features. A genetic mouse model that induces transient RA deficiency in the node during gastrulation is described.
Method: To biochemically mimic the alcohol-induced RA deficiency at gastrulation, we genetically engineered a mouse expressing Cyp26A1 from the endogenous Goosecoid (Gsc) promoter. The Gsc promoter dictates spatial-temporal expression to the node during gastrulation. Cyp26A1 degrades endogenous RA in these cells, mimicking the reduced RA levels induced by acute alcohol exposure and dysregulating neural crest cells induction.
Result: These mice recapitulate the phenotypes characteristic of prenatal alcohol exposure (PAE) suggesting a molecular etiology for the craniofacial malformations seen in children with FASD with sentinel facial features. Gsc+/Cyp26A1 mouse embryos have a reduced RA domain and expression in the developing frontonasal prominence region and delayed HoxA1 and HoxB1 expression at E8.5. These embryos also show aberrant neurofilament expression during cranial nerve formation at E10.5 and have significant FASD sentinel facial feature-like craniofacial phenotypes at E18.5. In adulthood, Gsc+/Cyp26A1 mice develop severe maxillary malocclusions. Furthermore, we show that Vitamin A supplementation during gestation rescues the craniofacial malformation phenotypes caused by PAE and associated with FASD sentinel facial features.
Implications: Taken together, our data provides mammalian evidence that strongly supports PAE-induced retinoic acid deficiency during gastrulation as a major molecular etiology of craniofacial malformations associated with FASD sentinel facial features in children. Moreover, our model provides evidence that Vitamin A supplementation may significantly reduce or prevent FASD outcomes in children with PAE.

Learning Objectives:

1. Participants will understand the molecular basis of how Prenatal Alcohol Exposure reduces retinoic acid levels during early gestation and how it results in craniofacial malformations later in development.
2. Participants will recognize the craniofacial malformations found in our mouse model, and their significance to other PAE mouse models and clinical cases of FASD.
3. Participants will recognize how Vitamin A supplementation during pregnancy prevents craniofacial malformations in mice and may prevent or reduced FASD outcomes in children.

What do you believe to be the broader relevance to your work in the field and to adolescents and adults with FASD?

I believe that my work in the field of FASD, specifically in the Vitamin A deficiency hypothesis has broad implications in the potential for Vitamin A as a micronutrient supplement may prevent or reduce FASD outcomes and significantly improve the life trajectories of adolescents and adults with FASD. Vitamin A supplementation (titrated appropriately, through clinical trialing) can be used prophylactically to rescue or prevent FASD, similarly to how folic acid supplementation is used to prevent spina bifida during pregnancy.

What questions has your work identified or what else has arisen from your work that research may be able to answer?

To that point, I believe my work has also shown the retinoic acid developmental pathway in a new light, specifically looking to determine which other gene pathways RA cross-talks with during development such as SHH and WNT. These gene pathways are also implicated in FASD as they regulate craniofacial and neurodevelopment in FASD and other craniofacial disorders and must be further studied.