



Spring 2023 Public Meeting Summary
Monday, April 17, 2023

Report Prepared by Ripple Effect Communications

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ICCFASD Spring 2023 Public Meeting

A videocast of the ICCFASD Spring 2023 Public Meeting held on April 17, 2023, is available on the NIH videocast website at <https://videocast.nih.gov/watch=45706>.

Meeting Participants on Zoom

A list of ICCFASD Executive Committee members and their contact information can be found on the ICCFASD website at <https://www.niaaa.nih.gov/iccfasd/iccfasd-members>. The list is included in Appendices.

ICCFASD Chairperson

Patricia A. Powell, PhD
Deputy Director
National Institute on Alcohol Abuse and Alcoholism (NIAAA)
National Institutes of Health (NIH)
The United States Department of Health and Human Services (HHS)

ICCFASD Scientific Coordinator and Executive Secretary

Tatiana Balachova, PhD
Health Science Administrator
Division of Epidemiology and Prevention Research
National Institute on Alcohol Abuse and Alcoholism, NIH, HHS

ICCFASD Primary Representatives

Caitlin Cross-Barnet, PhD
Social Science Research Analyst
Research and Rapid-cycle Evaluation Group
Center for Medicare and Medicaid Innovation
Centers for Medicare and Medicaid Services (CMS), HHS

Jon Dunbar-Cooper, MA, CPP
Public Health Analyst
Division of Systems Development
Center for Substance Abuse Prevention
Substance Abuse and Mental Health Services Administration (SAMHSA), HHS

William Dunty, PhD
Program Director, NIAAA FASD Research Coordinator
Division of Metabolism and Health Effects
National Institute on Alcohol Abuse and Alcoholism (NIAAA), NIH, HHS

Shin Y. Kim, MPH
Team Lead, Lead Health Scientist
Prenatal Substance Exposure Surveillance and Research Team
Infant Outcomes Monitoring, Research and Prevention Branch
Division of Birth Defects and Infant Disorders
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention (CDC), HHS

Tracy M. King, MD, MPH
Medical Officer

Intellectual and Developmental Disabilities Branch
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), NIH, HHS

Dawn Levinson, MSW
Deputy Director
Division of Healthy Start and Perinatal Services
Maternal and Child Health Bureau (MCHB)
Health Resources and Services Administration (HRSA), HHS

Sharon Newburg-Rinn, PhD
Social Science Research Analyst
Office of Data, Analysis, Research and Evaluation
Children's Bureau
Administration for Children and Families (ACF), HHS

Tina Pattara-Lau, MD, FACOG
Maternal and Child Health Consultant
Office of Clinical and Preventive Services
Indian Health Service (IHS), HHS

Janani Prabhakar, PhD
Program Officer
HEALTHy Brain and Child Development (HBCD) Study
Division of Neuroscience and Behavior
National Institute on Drug Abuse (NIDA), NIH, HHS

Amanda Reichard, PhD
Project Officer
National Institute on Disability, Independent Living, and Rehabilitation Research
Administration for Community Living (ACL), HHS

Chris Sarampote, PhD
Chief, Biomarker and Intervention Development for Childhood-Onset Disorders Branch
Division of Translational Research
National Institute of Mental Health (NIMH), NIH, HHS

Kristina West, MS, LLM
Social Science Analyst
Division of Behavioral Health Policy
Office of Behavioral Health, Disability, and Aging Policy
Office of the Assistant Secretary for Planning and Evaluation (ASPE), HHS

Participating Alternate ICCFASD Representatives

Elizabeth Parra Dang, MPH
Behavioral Scientist
Health Communication and Research Translation Team
Infant Outcomes Monitoring, Research, and Prevention Branch
Division of Birth Defects and Infant Disorders
Centers for Disease Control and Prevention (CDC), HHS

Keisher S. Highsmith, DrPH
Commander, United States Public Health Service
Health Scientist Administrator
Services Research Branch
Division of Epidemiology, Services and Prevention Research

National Institute on Drug Abuse (NIDA), NIH, HHS

JB Kinlacheeny, MPH

Public Health Advisor

Alcohol and Substance Abuse Program Lead

Indian Health Services Headquarters (IHS), HHS

Deidra Roach, MD

Medical Project Officer

Treatment, Health Services, and Recovery Branch

Division of Treatment and Recovery Research

National Institute on Alcohol Abuse and Alcoholism (NIAAA), NIH, HHS

Mary Kate Weber, MPH

Behavioral Scientist

Prenatal Substance Exposure Surveillance and Research Team

Infant Outcomes Monitoring, Research, and Prevention Branch

Division of Birth Defects and Infant Disorders

Centers for Disease Control and Prevention (CDC), HHS

Julia Zehr, PhD

Branch Chief

Developmental Mechanisms and Trajectories of Psychopathology Branch

Division of Translational Research

National Institute of Mental Health (NIMH), NIH, HHS

Other Participating Staff from ICCFASD Agencies on Zoom

Amy Board, DrPH

Prenatal Substance Exposure Surveillance and Research Team

Infant Outcomes Monitoring, Research, and Prevention Branch

Division for Birth Defects and Infant Disorders

National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention (CDC), HHS

George Koob, PhD

Director

National Institute on Alcohol Abuse and Alcoholism (NIAAA), NIH, HHS

Invited Guests and Speakers

Special Panel on Lived Experiences

- Nicholas Davis-Maglioizzi
- Katrina Griffin
- Kathy Hotelling, PhD
- Jan Lutke
- Kathy Mitchell, MHS, LCADC
- Justin Shepherd, BFA
- Rebecca Tillou

Special Panel on the FASD United Family Navigator Program

- Tom Donaldson

- Heather French
- Jenn Wisdahl

Meeting Participants on NIH Videocast

The meeting was NIH Videocast with 156 participants attending the live videocast. Attendees were able to submit questions and comments live online.

The archived meeting videocast is available on the [NIH Videocast page](https://videocast.nih.gov/watch=45706) at <https://videocast.nih.gov/watch=45706>.

ICCFASD Agenda

TIME	AGENDA
10:00 am	<p>Welcome and Introductions <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i> <i>ICCFASD Members</i></p> <p>ICCFASD: Overview and Updates <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary</i></p>
10:20 am	<p>Reports of Activities from FY2022: ICCFASD Federal Agencies ACF, ACL, CMS, HRSA</p>
	Q&A, Discussion
	Break
11:20 am	<p>Reports of Activities from FY2022: ICCFASD Federal Agencies (Continued) CDC, IHS, SAMHSA, ASPE</p>
	Q&A, Discussion
12:10 pm	LUNCH BREAK
12:40 pm	<p>Special Panel Part I: <i>Moderator: Jan Lutke</i> What is Working in Your Community—Lessons Learned from Lived Experiences <i>Christie Petrenko, PhD Community Engaged Research: What Works from Lived Experience Perspectives</i> <i>Nicholas Davis-Maglioizzi</i> <i>Katrina Griffin</i> <i>Kathy Hotelling, PhD</i> <i>Kathy Mitchell, MHS, LCADC</i> <i>Justin Shepherd, BFA</i> <i>Rebecca Tillou</i></p>
	Discussion
	Break
2:30 pm	<p>Special Panel Part II: <i>Moderator: Elizabeth Parra Dang, MPH</i> The FASD United Family Navigator Program – Here to Help <i>Tom Donaldson, CEO FASD United</i> <i>Heather French, Family Navigation Lead</i> <i>Jenn Wisdahl, COO FASD United</i></p>
	Discussion
	Break

TIME	AGENDA
3:20 pm	Reports of Activities from FY2022: ICCFASD Federal Agencies (Continued) <i>NIAAA, NICHD, NIMH, NIDA</i>
	Q&A, Discussion
	General Discussion <i>Moderators:</i> <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i> <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary</i>
4:30 pm	Adjournment

Welcome, Introduction, and Comments

Patricia Powell, Ph.D., Deputy Director, NIAAA, NIH; ICCFASD Chair

Dr. Patricia Powell, Deputy Director at NIAAA and Chair of the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD), introduced herself and welcomed participants to the 2023 public ICCFASD meeting. The special panels will focus on services and supports available for people living with FASD and their families and will feature people speaking about their own lived experiences with FASD. Dr. Powell briefly introduced Jan Lutke, a panel moderator and parent of people with FASD, and Christie Petrenko, Ph.D., whose research is influenced by her interactions with people with FASD and their families. Dr. Powell then introduced the panel members and mentioned the second panel presentation, which would be from FASD United. She announced that the meeting would be archived on the NIH Videocast website. She then gave an overview of the meeting's agenda and asked that each agency representative introduce themselves.

Sharon Newburg-Rinn, Ph.D., Children's Bureau, Administration for Children & Families (ACF), Department of Health and Human Services (HHS). She highlighted the large number of children in the foster care system affected by FASD and that many cases of FASD are not recognized.

Amanda Reichard, Ph.D., National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living (ACL), HHS. Dr. Reichard emphasized that her agency encourages applications for research related to FASD.

Shin Y. Kim, MPH, Prenatal Substance Exposure Surveillance and Research Team, Center for Disease Control and Prevention's (CDC), HHS. She stated that her team has many activities related to pregnancy and alcohol and other substance use, both on the prevention side and for affected individuals.

Caitlin Cross-Barnet, Ph.D., Center for Medicare and Medicaid Innovation (CMMI), Centers for Medicare & Medicaid Services (CMS), HHS. Dr. Cross-Barnett explained that CMMI tests models of care and that CMS covers many Americans, including more than 40% of pregnancies and many children in the U.S.

JB Kinlacheeny, MPH, Alcohol and Substance Abuse Branch, Indian Health Services (IHS). He stated that IHS has several activities related to maternal and child health and alcohol and substance abuse, including provision of direct care for American Indian and Alaska Natives throughout the country.

Dawn Levinson, MSW, Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA). Ms. Levinson highlighted MCHB's mission—to improve the health and well-being of the nation's mothers, children, and families and said that she would talk about her group's activities related to training providers on FASD.

Jon Dunbar-Cooper, MA, CPP, Substance Abuse and Mental Health Services Administration (SAMHSA). He stated SAMHSA's role in providing substance abuse prevention and treatment services for adolescents and adults.

William Dunty, Ph.D., Division of Metabolism and Health Effects, National Institute on Alcohol Abuse and Alcoholism (NIAAA), NIH. He is NIAAA's FASD Research Coordinator.

Julia Zehr, Ph.D., Developmental Mechanisms and Trajectories of Psychopathology Branch, National Institute of Mental Health (NIMH), NIH. Her branch works with developmental risk and resilience across children and adolescents.

Kristina West, MS, LLM, Office of the Assistant Secretary for Planning and Evaluation (ASPE), HHS. Ms. West's office leads policy development and advises on policy in several areas, including substance abuse. She highlighted that her team has done a lot of research on prenatal substance exposures, including alcohol exposure.

Dr. King, Intellectual and Developmental Disabilities Branch, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), HHS.

Dr. Powell then introduced Tatiana Balachova, Ph.D., the Executive Secretary for ICCFASD, and thanked everyone for joining the meeting.

Overview of ICCFASD and 2022 Updates

Tatiana Balachova, Ph.D., NIAAA, ICCFASD Scientific Coordinator and Executive Secretary and Program Official with the Division of Epidemiology and Prevention Research, NIAAA.

She thanked participants for joining the meeting and provided an introduction to the ICCFASD.

The committee's purpose is to improve communication, cooperation, and collaboration among disciplines and federal agencies that address issues related to FASD and its prevention. Alcohol use during pregnancy increases the risk of complications, such as miscarriage and FASD in children. FASD is estimated to affect 1-5% of school-age children in the U.S., and FASD is a lifelong condition.

The ICCFASD was created in response to a request by the U.S. Congress and recommendations from the Institute of Medicine (IOM) based on a 1996 report about fetal alcohol syndrome. The committee is supported and administered by NIAAA, and led by the NIAAA Deputy Director, who is currently Dr. Powell. Dr. Balachova showed a slide with the various federal agencies that are current or past members of ICCFASD and explained that representatives from each current agency will give updates on agency activities from 2022. She spoke about the wide variety of areas that the agencies work on, such as prevention, basic and clinical research, community living and support, and others. ICCFASD members work together by sharing ideas, collaborating in tasks and program development, and reporting results to each other and to the public.

Dr. Balachova spoke about how ICCFASD forms special focus working groups to implement specific goals. She described the current working group, which focuses on screening, brief intervention, and referral to treatment (SBIRT) for pregnant and postpartum people, that was formed in 2021. Its objectives are to exchange information and resources, identify gaps for improved implementation and research, and expand partnerships among federal agencies related to SBIRT for pregnant and postpartum people. The effort aligns with one of ICCFASD's goals, which is to reduce the prevalence of FASD in the U.S. Dr. Balachova encouraged meeting participants to visit the ICCFASD website for more information, described how to find ICCFASD contact information, and encouraged participants to contact ICCFASD and its representatives. She then transitioned the meeting into the 2022 agency presentations.

Reports of Activities from FY2022: ICCFASD Federal Agencies: ACF, ACL, CMS, HRSA

The Administration for Children and Families (ACF)

Sharon Newburg-Rinn, Ph.D., Social Science Research Analyst, Office of Data, Analysis, Research and Evaluation, Children's Bureau, Administration for Children & Families ([email: sharon.newburg-rinn@acf.hhs.gov](mailto:sharon.newburg-rinn@acf.hhs.gov))

Dr. Newburg-Rinn introduced the Children's Bureau and spoke about the Children's Bureau work and projects carried out in collaboration with the CDC.

She showed a list of the Children's Bureau's recent work and described in greater detail that she represents ACF to the White House Office on National Drug Control Policy, led Stephen Patrick, M.D. Dr. Patrick requested recommendations that would have a positive impact on prenatal exposures and that would not require additional funds or new laws. Dr. Newburg-Rinn described her group's suggestion to the committee, which was to develop an informational memorandum to the ACF regional offices and to the states. The memorandum would cover the following points: FASD are important and preventable disorders, the identification of which is important; identification strategies must avoid making parents fearful that children would be removed from the home; and any funds "saved" by keeping children out of foster care will be needed to provide the services that children and

families need for the children to remain safely at home. The Children’s Bureau is currently working on creating this memorandum.

Dr. Newburg-Rinn described another Children’s Bureau effort, an ongoing collaboration with the Child Welfare League of America. The two groups are planning a special journal issue on children prenatally exposed to alcohol and other drugs. They are including other drugs in addition to alcohol, to have a broader reach. Many papers have been received and reviewed, and publication is expected in 2024.

The Children’s Bureau is also engaged with the CDC on a five-year collaborative research project on FASD in the context of child welfare. The team, together with their contractor, James Bell Associates, is recruiting child welfare agencies nationwide to participate in developing and evaluating a toolkit for usability and efficacy. She spoke about various aspects of this project, including that the team is working with FASD national experts, a Tribal community to ensure the group takes into account tribal needs and traditions, and research experts on race and ethnicity.

Dr. Newburg-Rinn described how the team has been meeting with the National Center on Substance Abuse and Child Welfare (NCSACW) to determine how the information in the toolkit can be used and disseminated. Since NCSACW already provides technical assistance to state child welfare agencies, it is well positioned to help with dissemination.

Dr. Newburg-Rinn then spoke about Head Start, which is part of ACF. Through this program, in 2022, ACF described FASD to a large group of Head Start grantees.

Administration for Community Living (ACL)

Amanda Reichard, Ph.D., Project Officer, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living ([email: amanda.reichard@acl.hhs.gov](mailto:amanda.reichard@acl.hhs.gov))

Dr. Reichard introduced herself and said that she would talk about ACL-funded projects related to addressing the needs of people with intellectual and developmental disabilities (IDD), including FASD. ACL’s mission is to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers. She listed ACL’s four major components, emphasizing that NIDILRR is ACL’s science component. She then described the mission of NIDILRR: to generate new knowledge and to promote its effective use to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. She emphasized that NIDILRR focuses on long-term outcomes, such as independence, community participation, and employment, and on the whole person since a person’s ability to function and quality of life are dependent on complex interactions among several factors.

She began describing NIDILRR’s 2022 activities by talking about research grants intended to improve employment outcomes for people with IDD. For the first of two examples of projects funded by these grants, Dr. Reichard described a Cornell University project called [Improving Vocational Rehabilitation \(VR\) Outcomes for Out-of-School Youth Involved in the Justice and/or Foster Care Systems](https://www.yti.cornell.edu/work/improving-vr-outcomes-for-out-of-school-youth-involved-in-the-justice-and-or-foster-care-systems) (<https://www.yti.cornell.edu/work/improving-vr-outcomes-for-out-of-school-youth-involved-in-the-justice-and-or-foster-care-systems>). The research objectives are to increase understanding of the experiences of these youth and to identify effective approaches for connecting them and their families with vocational rehabilitation services to improve employment outcomes. The project also examines the unique considerations pertaining to the COVID-19 pandemic.

The second employment-related grant example was a project led by a group from the University of Kansas called [Promoting Career Design and Development via Telehealth for Rural Adults with Intellectual and Developmental Disabilities](https://lifespan.ku.edu/promoting-career-design-and-development-telehealth-rural-adults-intellectual-and-developmental) (<https://lifespan.ku.edu/promoting-career-design-and-development-telehealth-rural-adults-intellectual-and-developmental>). The team is studying the feasibility, efficacy, and cost-effectiveness of implementing a telehealth-based career design intervention for rural-dwelling adults with IDD. The intervention uses an evidence-based intervention (the Self-Determined Career Design Model) designed for people with IDD that is effective in promoting self-determination and employment. The Kansas team will translate the model into a virtual setting.

Dr. Reichard then spoke about two recipients of research grants intended to improve health and function outcomes for people with IDD. The first team is studying the impact of the COVID-19 pandemic and related policies on people with IDD and the services they rely on to live independently. The project involves looking at people's Medicaid utilization, their support needs, and personal- and systems-level outcomes. The goal of this research is to inform state IDD systems administrators and advocates in Virginia, where the research is taking place, and to provide guidance for other states to follow. The second example is from Brandeis University where the grant recipients are adapting and testing the reliability of a postnatal depression scale for use with people with IDD.

Dr. Reichard transitioned to speaking about two research grant projects intended to improve community participation among people with IDD. The first project is evaluating an assistive smartwatch app designed to help neurodiverse people in independent living acquire or improve self-regulation skills. The second project aims to increase participation in future planning, such as legal, financial, and residential plans, and in self-determination and daily choice-making in people with IDD, with a goal of decreasing feelings of caregiver burden. The intervention involves both self-paced modules and live sessions with peer trainers, and the grant is called [Virtual Future Planning for Adults with Intellectual and/or Developmental Disabilities and Aging Families](https://ahs.uic.edu/disability-human-development/lifespan-health-community-living-and-intellectual-developmental-disabilities-research-and-training-programs/virtual-future-is-now/) (<https://ahs.uic.edu/disability-human-development/lifespan-health-community-living-and-intellectual-developmental-disabilities-research-and-training-programs/virtual-future-is-now/>).

Dr. Reichard spoke about other relevant resources funded by ACL. The first, the [National Center on Advancing Person-Centered Practices and Systems](https://ncapps.acl.gov/) (NCAPPS; <https://ncapps.acl.gov/>), is supported jointly by ACL and CMS. It helps states, Tribes, and territories implement person-centered thinking, planning, and practice by providing technical assistance, learning collaboratives, public webinars, and a national clearinghouse of actionable resources. NCAPPS works to integrate the voices of people with lived experience of disability and older adults who use long-term services and supports. The second resource she spoke about was the [University Centers for Excellence in Developmental Disabilities](https://acl.gov/programs/aging-and-disability-networks/national-network-university) (<https://acl.gov/programs/aging-and-disability-networks/national-network-university>) which are university centers in every state and territory that work to improve the health and well-being of people with IDD by training health professionals, conducting research, offering model diagnostic and clinical services, and providing resources for individuals and professionals. Last, Dr. Reichard spoke about the [Centers for Independent Living](https://acl.gov/programs/aging-and-disability-networks/centers-independent-living) (<https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>), which are designed and operated by people with disabilities and provide independent living services for people with disabilities, such as assistance with job searches, teaching local transit skills, and helping with school-to-career transition.

Centers for Medicare & Medicaid Services (CMS)

Caitlin Cross-Barnet, Ph.D., Social Science Research Analyst, Research and Rapid-cycle Evaluation Group, Center for Medicare & Medicaid Innovation (CMMI), Centers for Medicare & Medicaid Services ([email: caitlin.cross-barnet@cms.hhs.gov](mailto:caitlin.cross-barnet@cms.hhs.gov))

Dr. Cross-Barnet showed a slide with a list of several resources that she then briefly described. She stated that CMS has done a lot of recent work around postpartum care, emphasizing the importance of extended postpartum care, for example, for receiving ongoing treatment for alcohol use disorder. She spoke briefly about the [Improving Postpartum Care Learning Series](https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement-initiatives/maternal-infant-health-care-quality/postpartum-care/index.html) (<https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement-initiatives/maternal-infant-health-care-quality/postpartum-care/index.html>) that has webinars and other resources on the website. CMS also has a [Maternity Care Action Plan](https://www.cms.gov/files/document/cms-maternity-care-action-plan.pdf) (<https://www.cms.gov/files/document/cms-maternity-care-action-plan.pdf>) that suggests expanding postpartum care to a year for Medicaid beneficiaries, and Dr. Cross-Barnet noted that the American Rescue Plan allowed for this expansion from the previous 60-day timeline. She mentioned a presentation on CMS' [Pathways to Prevention \(P2P\) Postpartum Care Program](https://prevention.nih.gov/research-priorities/research-needs-and-gaps/pathways-prevention/identifying-risks-and-interventions-optimize-postpartum-health) (<https://prevention.nih.gov/research-priorities/research-needs-and-gaps/pathways-prevention/identifying-risks-and-interventions-optimize-postpartum-health>) that covers CMS' past work on postpartum care, learnings from CMMI models, and an explanation of CMS' postpartum care plan. In addition, CMMI has two programs that directly address issues related to diagnosis, treatment, and prevention of FASD: the [Maternal Opioid Misuse \(MOM\) Model](https://innovation.cms.gov/innovation-models/maternal-opioid-misuse-model) (<https://innovation.cms.gov/innovation-models/maternal-opioid-misuse-model>), which provides integrated care for pregnant and postpartum people with an opioid use disorder, many of whom have other substance use disorders

(SUD), and the [Integrated Care for Kids](https://innovation.cms.gov/innovation-models/integrated-care-for-kids-model) (<https://innovation.cms.gov/innovation-models/integrated-care-for-kids-model>), which provides support for integrating health-related social services such as food and housing, early childhood resources, and behavioral health care. From both of these models, CMS has noted specific barriers to data sharing, such as legal restrictions and siloed business processes, that can make integration of care difficult. Dr. Cross-Barnet spoke in more detail about other barriers to data sharing, such as incompatible electronic health record platforms, a lack of staff bandwidth, challenges to creating data use agreements, and a general lack of practice in using data to integrate care. She concluded her presentation by reiterating that CMS is working on these issues to help families access the care they need, either for Alcohol Use Disorder (AUD) or for children displaying signs of FASD.

The Health Resources and Services Administration (HRSA)

Dawn Levinson, MSW, Deputy Director, Division of Healthy Start and Perinatal Services, Maternal and Child Health Bureau, Health Resources and Services Administration ([email: dlevinson@hrsa.gov](mailto:dlevinson@hrsa.gov))

Ms. Levinson spoke about the HRSA and its Maternal and Child Health Bureau (MCHB) mission, strategic plan, and FY2023 funding in the maternal and infant health portfolio. MCHB's programs address mental health and well-being for maternal and child health populations at multiple levels across the lifespan, and their work is guided by the idea that there is no health without mental health.

MCHB recently launched a new strategic plan that will guide their work for the next 10-15 years. The plan's four goals relate to access to health services, health equity, improved capacity for maternal and child health, and improved impact. For FY2023, MCHB received a large increase in funding relative to their FY2022 budget, and the Division of Healthy Start and Perinatal Services, in which HRSA's FASD-related programs reside, received part of this increase. The Division is putting this funding toward a variety of programs, some of which are new and some of which previously existed. Because of the increased funding, MCHB has five open funding opportunities with deadlines in May and June. Ms. Levinson directed interested parties to check their [funding page](https://mchb.hrsa.gov/funding) (<https://mchb.hrsa.gov/funding>) for details.

She then spoke about MCHB's FASD investment, the Supporting FASD Screening and Intervention Program. The grant recipient, Boston Medical Center in partnership with a Minnesota-based organization dedicated to raising awareness and delivering education around FASD, named the program they developed with the grant funding the Safest Choice Learning Collaborative. The program's purpose is to reduce alcohol use among pregnant women and improve developmental outcomes for children and adolescents with a suspected or diagnosed FASD in areas in the U.S. that have high rates of binge drinking among pregnant women. The program provides education to primary care providers and was extended beyond its original three-year timeline because of providers' interest in the program's training and technical assistance. This extension will allow a fourth cohort to participate in the learning collaborative. The Learning Collaborative's training has two goals: to improve the ability of primary care providers who serve pregnant women to screen patients for alcohol use, provide brief intervention, and refer high risk pregnant women to specialty care; and to improve the ability of primary care providers who serve children and adolescents to screen patients for prenatal alcohol exposure and to provide referrals for services when needed. The providers who have participated in the Learning Collaborative include physicians, nurse practitioners, behavioral health specialists, nurses, and others.

The Learning Collaborative recruits and educates health care professionals at community and tribal health centers, and the first year-long cohort ran from June 2021 to April 2022. The second cohort will run from May 2022 to April 2023. Through the program, participating health centers receive a stipend and technical assistance. The program's curriculum includes information about the foundational science of FASD, the stigma and bias associated with FASD, screening for FASD, community resources, and legal issues. Sessions also include interactive and multimedia material, such as demonstration videos of patient conversations, interviews with people with lived experience, skills practice sessions, case presentations, and clinic-specific community resource expeditions. Ms. Levinson then described the professional expertise and diversity of the faculty and advisory board involved in the program. She next spoke about themes that emerged during case presentations from the health centers, noting that

fear, guilt, shame, and mixed messages about alcohol use during pregnancy, as well as cultural issues when navigating a prenatal alcohol exposure history, were common issues raised by cohort participants. Ms. Levinson spoke about the areas of technical assistance offered by the Learning Collaborative, such as treating AUD, diagnosing an FASD, and identifying and accessing community resources.

Ms. Levinson then spoke about program evaluation, which will assess the program's implementation and outcomes in its three cohorts. She discussed preliminary results from the first cohort, emphasizing that 100% of participants agreed that the program increased their knowledge about the risks of prenatal alcohol exposure and options for screening for alcohol use during pregnancy. Many participants also felt that the program increased their knowledge about screening for exposure among children and adolescents with a suspected FASD, and 100% said they planned to use what they learned in the training. MCHB is looking forward to evaluating the second and third cohorts in the future.

Discussion and Q&A

Dr. Balachova introduced Amy Board, DrPH, with the CDC's Center on Birth Defects and Developmental Disabilities, who is a co-leader of ICCFASD's Working Group on Screening and Brief Interventions. She also introduced Kathy Hotelling, Ph.D., the co-founder of North Carolina FASD Informed, a non-profit which is dedicated to helping individuals with FASD. Dr. Hotelling's 29-year-old daughter was diagnosed with FASD at age 10. She then opened the discussion period for questions.

A Videocast participant asked whether anyone is working with the Canada FASD Research Network (CAN FASD) on FASD-related issues.

Dr. Balachova explained that the network includes researchers, practitioners, government representatives, and other partners across Canada. She said ICCFASD has been collaborating with CAN FASD and some of the panel participants in this meeting are from Canada. She mentioned that there are joint research projects between U.S. and Canadian scientists.

Dr. Dunty agreed that there are information exchanges between NIAAA-funded researchers and CAN FASD. He described one such effort in which researchers are trying to build a single research definition for FASD.

Dr. Hotelling asked for clarification on the toolbox mentioned in one of the presentations.

Dr. Newburg-Rinn said her group was working on the toolbox and that they are working with states to develop approaches that can be used by social workers on first contact with families where there may have been prenatal alcohol exposure. The toolbox will include helpful hints on what social workers can do in those situations.

Dr. Hotelling then mentioned that the American Academy of Pediatrics has extensive information on FASD that starts with screening and reasons to screen. She hopes that ACF's efforts are not duplicative. She also mentioned Tip 58 from the Center for FASD Excellence, although it is out of print. Dr. Hotelling transitioned to talking about the special journal issue that Dr. Newburg-Rinn had spoken about. Dr. Hotelling voiced her concerns about including substances other than alcohol in the issue because the magnitude of alcohol's effects on lifelong disability is larger than that of other substances. Dr. Hotelling mentioned her daughter as an example of someone who suffers with FASD and suggested that emphasis placed on other substances detracts from the fact that FASD is a public health crisis, especially since alcohol is socially acceptable.

Dr. Balachova directed a question to Dr. Cross-Barnet, of Centers for Medicare and Medicaid Services (CMS) about whether individuals with FASD have been represented in CMS's programs and services and what can be done to improve quality of life for people with FASD.

Dr. Cross-Barnet explained the FASD is underdiagnosed and often misdiagnosed. She said that children who have symptoms of autism spectrum disorder or attention-deficit/hyperactivity disorder (ADHD) are not being screened for FASD most of the time, perhaps because of stigma, unfamiliarity, or difficulty with the diagnosis. She said that FASD is not getting the attention that it should get, but this problem is widespread and not just limited to CMS,

which does not currently track FASD. She asked whether Dr. Reichard from ACL had any additional information about supporting adults with disabilities.

Dr. Reichard said that ACL also does not have anything specific to FASD and she believes that ACL needs to pay more attention to FASD.

Dr. Newburg-Rinn reiterated that the Children's Bureau is working with the CDC toward developing the ability to collect data on FASD. She said that when children come to the attention of the child welfare system, it is hard to ask the right questions, but she hopes that eventually they will be able to collect data on whether a child has been prenatally exposed to alcohol.

A videocast participant asked about how to overcome ignorance or lack of interest about FASD in a particular state, specifically because an FASD organization tried, without success, to get prenatal or pediatric clinics in the state to join the Safest Choice Learning Collaborative described in the HRSA presentation.

Ms. Levinson suggested that she would be happy to put the person who asked the question in contact with the Learning Collaborative to address this issue, as the Collaborative might be able to provide tailored messaging appropriate for providers in that state. She also reiterated some of the program's features that might be appealing to health providers, such as continuing education credits and technical assistance that practices would not otherwise be able to obtain.

Another videocast participant asked whether ICCFASD had other federal partners, specifically the Department of Education or the Department of Justice, that are not at the meeting.

Dr. Balachova said that those departments are not represented on ICCFASD now, but that there had been representatives from both departments previously who were significantly involved. She voiced the desire that the Department of Education or the Department of Justice would re-join ICCFASD.

Dr. Balachova announced that the meeting would continue with more agency presentations, and reminded participants that there would be time for questions later and that the agenda for the meeting was online.

Reports of Activities from FY2022: ICCFASD Federal Agencies: CDC, IHS, SAMHSA, ASPE

Centers for Disease Control and Prevention (CDC)

Shin Y. Kim, MPH, Team Lead, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention ([email: skim1@cdc.gov](mailto:skim1@cdc.gov))

Ms. Kim started by describing CDC's surveillance efforts. Polysubstance abuse is common during pregnancy. More than half of pregnant women who used opioids for non-medical reasons reported drinking alcohol, and about three quarters of women who continued marijuana use during pregnancy also smoked cigarettes. CDC researchers recently published a systematic review that found variations in studies on polysubstance use during pregnancy. These variations may contribute to the wide prevalence estimates of polysubstance use during pregnancy. She emphasized the importance of consistently defining exposures and better understanding the factors that influence polysubstance use.

The CDC continues to analyze data on alcohol use and SBIRT during pregnancy from several data sources: the Behavioral Risk Factor Surveillance System, the National Survey on Drug Use and Health, the Pregnancy Risk Assessment Monitoring System, and DocStyles. In a January 2023 CDC Morbidity and Mortality Weekly Report (MMWR), the CDC found that while 80% of people who were pregnant were asked about alcohol use during health care visits in the last two years, only 16% of those who reported current drinking were advised to quit or reduce their use. These findings highlight the importance of improving efforts around education in alcohol screening during pregnancy.

As Dr. Balachova mentioned in her introduction, ICCFASD created a working group to look at screening and brief intervention activities. The group's objectives are to exchange information and resources, identify gaps and opportunities for improved implementation and research, and expand partnerships among federal agencies related to SBIRT services for pregnant and postpartum people. The working group's effort aligns with the ICCFASD priority area of reducing prenatal alcohol exposure and prevalence of FASD.

The CDC also has cooperative agreements with four health systems and universities, which focus on alcohol screening and brief intervention (SBI) implementation in a variety of health care settings. The effort also includes training clinical staff on SBI delivery and has screened over 120,000 patients for alcohol use.

Ms. Kim then spoke about the CDC's Enhancing Screening and Brief Intervention to Reduce Disparities in Prenatal Alcohol and Other Substance Exposure project, which started in September 2022 and will end in September 2024. The project's objective is to identify disparities in access to SBI for prenatal and postpartum alcohol and other substance use and develop appropriate communications materials for future SBI planning efforts. The CDC is consulting with FASD United to work with grassroots organizations and health care provider organizations to conduct surveys and interviews with health care providers, people with lived experience of substance use during pregnancy, and others. This collaboration is also working on research to guide communications materials and future work in SBI.

The CDC recently funded a cooperative agreement with national partners to address prenatal alcohol and other substance use and FASD. The overall purpose of the work is to build a collaborative framework of national partner organizations that contributes to reducing prenatal alcohol and other substance use, improves support services and access to care, and improves identification of FASD and the health of children and families living with FASD.

The CDC is also continuing their work on message testing and product development to improve patient-provider communication about the risks of alcohol use during pregnancy. The ultimate goal of this work is to develop a guide for FASD-related messaging.

Ms. Kim stated the CDC has other FASD-related resources on their [website](https://www.cdc.gov/ncbddd/fasd/training.html) (<https://www.cdc.gov/ncbddd/fasd/training.html>).

The CDC has also been exploring opportunities to surveil children with FASD. Related activities include exploring different approaches to understand the population, such as caregiver-reported estimates, health care claims databases, and clinical health care data. Ms. Kim then spoke about the National Survey of Children's Health, an annual, cross-sectional survey designed to provide information on children up to age 17 that is administered in collaboration with HRSA. They added three new questions to the 2022 questionnaire that relate to FASD, and data collection began in summer of 2022. Data will be available later in 2023.

Ms. Kim spoke about another recent cooperative agreement that will inform future surveillance activities related to documentation of FASD diagnosis-related information, including information about prenatal alcohol exposure.

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- Luong J, Board A, Gosdin L, et al. Alcohol Use, Screening, and Brief Intervention Among Pregnant Persons—24 U.S. Jurisdictions, 2017 and 2019. *MMWR Morbidity and Mortality Weekly Report* 2023; 72:55-62.

The Indian Health Service (IHS)

Tina Pattara-Lau, M.D., FACOG, Maternal and Child Health Consultant, Office of Clinical and Preventive Services, Indian Health Services ([email: tina.pattara-lau@ihs.gov](mailto:tina.pattara-lau@ihs.gov))

Dr. Pattara-Lau stated that she is an ob-gyn who provides care in the Phoenix area. She described IHS as a federal agency that provides direct health care services to approximately 2.7 million American Indian and Alaska Native

members of 574 federally recognized tribes. Many IHS facilities provide services primarily through a collaborative care model with physicians and certified nurse midwives, but more rural settings use a holistic family medicine model. In both settings, however, nursing is supported as a central partner in maternity care teams. She then spoke about health inequities among Native communities and mentioned that according to a 2022 CDC report, 80% of pregnancy-related deaths are preventable, with mental health conditions among the leading causes of pregnancy-related deaths and over 50% occurring postpartum. Dr. Pattara-Lau talked about other statistics related to Native American and Alaska Native women, prenatal care, and mortality rates among pregnant or postpartum women, as well as statistics on what settings Native births occur in. She mentioned areas of limited or no access to maternity care, which are known as maternity care deserts. She explained that with so many birth sites being in maternity care deserts, it is difficult for people to obtain services for mental health conditions or SUD. Additionally, historical trauma and social determinants of health contribute to health disparities in maternal health outcomes. The IHS is trying to close the gaps with a multidisciplinary approach.

Since maternal SUD has serious negative consequences for pregnant and postpartum people and their children, IHS is working to strengthen supports and improve access to prenatal addiction services for people with SUDs for pregnant people and women of reproductive age among Tribal Nations and Tribal communities. She spoke about The Plans of Safe Care, a collaborative effort between an Indian Health Board in Oregon, Indian care provider subject matter experts, and individuals with lived experience. The Plan contains a provider guide and patient fact sheets for pregnant and parenting people who have SUD. The provider guide has evidence-based recommendations for different points of intervention and customizable patient education resources. IHS has another collaboration to provide education on heroin, opioid, and pain efforts through webinars on SUD. Lastly, Dr. Pattara-Lau described an IHS pilot program that will provide telehealth and home visit support to parent-child dyads from preconception, through pregnancy, and through the postpartum period. The model increases patient access to care in screening, education, intervention, and treatment.

The Substance Abuse and Mental Health Services Administration (SAMHSA)

Jon Dunbar-Cooper, MA, CPP, Public Health Analyst, Division of Systems Development, Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration ([email: jon.dunbar@samhsa.hhs.gov](mailto:jon.dunbar@samhsa.hhs.gov))

Mr. Dunbar-Cooper introduced himself and stated that SAMHSA has early childhood mental health programs, which support SAMHSA's aim to reduce the impact of substance use and mental illness on communities. Additionally, through early childhood grant funding, SAMHSA is supporting a future in which all young children can thrive in all developmental domains and in which caregivers have access to the supports and services needed for the young children they care for. With strong caregiver relationships and nurturing environments, young children can thrive, and healthy children and families build a healthier future for communities in general.

Mr. Dunbar-Cooper spoke about SAMHSA's mental health program for children from birth to 8 years of age, which is called [Project LAUNCH](https://www.samhsa.gov/early-childhood-mental-health-programs/project-launch) (<https://www.samhsa.gov/early-childhood-mental-health-programs/project-launch>) and stands for "Project Linking Actions Unmet Needs in Children Health." There is also a parallel [Project LAUNCH for American Indian and Alaska Natives](https://www.samhsa.gov/early-childhood-mental-health-programs/project-i-launch) (<https://www.samhsa.gov/early-childhood-mental-health-programs/project-i-launch>). These initiatives address the social, emotional, cognitive, physical, and behavioral aspects of child development and prepare children to thrive in school and beyond. Mr. Dunbar-Cooper briefly mentioned other SAMHSA programs related to early mental health:

- The [Infant Early Childhood Mental Health Grant Program](https://www.samhsa.gov/early-childhood-mental-health-programs/iecmh-grant-program) (<https://www.samhsa.gov/early-childhood-mental-health-programs/iecmh-grant-program>) improves outcomes for children up to 12 years of age by supporting mental health promotion, intervention, and treatment.
- The [Center for Excellence for Infant and Early Childhood Mental Health Consultation](https://www.samhsa.gov/early-childhood-mental-health-programs/center-of-excellence-iecmh) (<https://www.samhsa.gov/early-childhood-mental-health-programs/center-of-excellence-iecmh>).
- The [National Child Traumatic Stress Initiative](https://www.samhsa.gov/child-trauma) (<https://www.samhsa.gov/child-trauma>) raises awareness on the impact of trauma on children and adolescents as a behavioral health concern. More information on signs

of child traumatic stress, the impact on children, treatment options, and how families can help are on the website.

Mr. Dunbar-Cooper next spoke about SAMHSA's SBIRT efforts, first describing that SBI is a comprehensive public health approach to the delivery of early intervention and treatment services for people with SUDs and people who are at risk for developing such disorders. He listed various settings that provide opportunities for such early interventions and the various types of entities to which SAMHSA has awarded SBI grants. A list of SAMHSA grantees working on SBIRT is available on the [SBIRT Grantee](https://www.samhsa.gov/sbirt/grantees) (<https://www.samhsa.gov/sbirt/grantees>) website, and SAMHSA also has a website on [Resources for SBIRT](https://www.samhsa.gov/sbirt/resources) (<https://www.samhsa.gov/sbirt/resources>).

Mr. Dunbar-Cooper then spoke about medications for SUDs and how medications can be used to treat SUDs, sustain recovery, and prevent overdose. He stated that SAMHSA promotes the use of medications in combination with counseling and behavioral therapies, and that the ultimate goal of treatment is full recovery, which includes the ability to live a self-directed life. Such a treatment approach improves patient survival, increases retention in treatment, decreases illicit opiate use, and increases ability to maintain employment. Additionally, medications for SUDs improve birth outcomes among pregnant women with SUD and can reduce risk of contracting HIV or hepatitis C by lowering the potential for relapse. Mr. Dunbar-Cooper spoke about FDA-approved medications for AUD and opioid use disorders, which can relieve withdrawal symptoms and cravings that cause chemical imbalances in the body. He listed the common medications for AUD (acamprosate, disulfiram, and naltrexone) and stated that they are most effective when patients also participate in a treatment program. He listed additional resources on AUD medications, including a [2015 Medication Guide](https://store.samhsa.gov/product/Medication-for-the-Treatment-of-Alcohol-Use-Disorder-A-Brief-Guide/SMA15-4907) (<https://store.samhsa.gov/product/Medication-for-the-Treatment-of-Alcohol-Use-Disorder-A-Brief-Guide/SMA15-4907>) and [TIP 49 on Incorporating Alcohol Pharmacotherapies Into Medical Practice](https://store.samhsa.gov/product/TIP-49-Incorporating-Alcohol-Pharmacotherapies-Medical-Practice/SMA13-4380) (<https://store.samhsa.gov/product/TIP-49-Incorporating-Alcohol-Pharmacotherapies-Medical-Practice/SMA13-4380>). He then spoke about medications for opioid use disorder.

Harm reduction was Mr. Dunbar-Cooper's next topic. At SAMHSA, it is a proactive and evidence-based approach to reducing negative impacts of behavior associated with alcohol and substance use. He spoke in detail about how harm reduction is part of the continuum of care and how it is relevant in prevention, treatment, and recovery. SAMHSA has funded 25 harm reduction grant programs with funding authorized by the American Rescue Plan. The programs will help increase access to community harm reduction services and will support harm reduction providers who work to prevent overdose deaths.

Regarding trauma and violence, SAMHSA has the [Disaster Distress Helpline](https://www.samhsa.gov/find-help/disaster-distress-helpline) (<https://www.samhsa.gov/find-help/disaster-distress-helpline>), which provides crisis counseling 24/7, 365 days a year, including in Spanish and for hearing impaired.

Mr. Dunbar-Cooper spoke about SAMHSA's stances on criminal and juvenile justice, stating that SAMHSA promotes early intervention and treatment as preferable alternatives to detaining people with behavioral health conditions. He said that people with mental health and SUDs are over-represented in the justice system and suggested that interested parties could learn more on SAMHSA's [Criminal and Juvenile Justice](https://www.samhsa.gov/criminal-juvenile-justice) page (<https://www.samhsa.gov/criminal-juvenile-justice>). He listed SAMHSA [grant programs](https://www.samhsa.gov/criminal-juvenile-justice/grants-grantees) (<https://www.samhsa.gov/criminal-juvenile-justice/grants-grantees>) related to behavioral health and criminal justice issues. SAMHSA's [Sequential Intercept Model](https://www.samhsa.gov/criminal-juvenile-justice/sim-overview) (<https://www.samhsa.gov/criminal-juvenile-justice/sim-overview>) is a tool that can help communities better serve individuals with mental and substance use problems who come into contact with the criminal justice system.

SAMHSA also has tools for suicide prevention, including a Trans Lifeline, which is a trans-led organization that helps improve the quality of the lives of transsexual people by providing direct service, support, advocacy, and education. The Zero Suicide initiative is built on the belief that suicide deaths among people under the care of health and behavioral health systems are preventable. Lastly, the #BeThe1To messaging of the National Suicide Prevention Lifeline raises awareness of actions everyone can take to prevent suicide.

Office of the Assistant Secretary for Planning and Evaluation (ASPE)

Kristina West, MS, LLM, Social Science Analyst, Division of Behavioral Health Policy, Office of Behavioral Health, Disability, and Aging Policy, Office of the Assistant Secretary for Planning and Evaluation ([email: kristina.west@hhs.gov](mailto:kristina.west@hhs.gov))

Ms. West described ASPE's function, which is to advise the Secretary of Health and Human Services on policy related to health, disability, human services, and science, and to provide advice on economic policy. She works within the Office of Behavioral Health, Disability, and Aging Policy, which works on substance use and prenatal substance exposures. The Office has a large portfolio of substance use work and they have cross-agency activities related to children's mental health and substance use. FASD is included in ASPE's broad substance use portfolio. ASPE also leads the federal Prenatal Substance Exposure Work Group with representatives across HHS. Ms. West described the function of the group. She also acknowledged that it was Black Maternal Health Week and that Black women with SUD have more barriers to accessing treatment than the rest of the population. She emphasized that it is important to think about how to improve access to treatment for Black women with AUD.

Ms. West then presented research findings on [postpartum use of services depending on Medicaid coverage \(https://pubmed.ncbi.nlm.nih.gov/36958993/\)](https://pubmed.ncbi.nlm.nih.gov/36958993/). Using a large Medicaid claims dataset, and studying women who had lost coverage within 90 days postpartum and those who had not lost coverage, Ms. West and her colleagues found that behavioral health use was lower among women who lost coverage, including less use for outpatient visits for SUD (including AUD) and other mental health concerns and less use of routine postpartum care. Previously, it had been shown that postpartum care was a gateway to accessing treatment, but the research findings suggest that when there is no postpartum coverage beyond 60 days, treatment for SUD is limited. Ms. West mentioned the policy implication of the research, which is to extend postpartum coverage in Medicaid, and that the American Rescue Plan created a permanent option for states to extend postpartum coverage to 12 months. Extended postpartum care can improve access to behavioral health treatment for women with SUD.

Ms. West then spoke about another study in which her team examined the prescribing of psychotropic medications for individuals with FASD compared with individuals without FASD using Medicaid and commercial claims databases. The impetus behind the work was the limited data on psychotropic medication use in the FASD population, even though psychotropic medication use has been a concern among people with FASD for years. The team separated the sample between people who were on Medicaid and people who were on private insurance. They found that a higher percentage of people with FASD on Medicaid used psychotropic medications compared to people with FASD on private insurance, but the difference was not large. Moreover, a significant proportion of people with FASD without a co-occurring mental health condition are prescribed psychotropic medications, whether they are on Medicaid or private insurance. The study also identified the co-occurring medical conditions among children with FASD who use psychotropic medications, with encephalopathy and ADHD being the most common. She emphasized the high rate of ADHD in children with FASD and suggested that children with ADHD should be screened for FASD. The next most common co-occurring medical conditions were epilepsy, which is concerning because some psychotropic medications can exacerbate seizures, and autism spectrum disorder. Ms. West suggested that these results indicate that psychotropic medication use among children with FASD should be monitored. While some children with FASD may require psychotropic medication use, for others with FASD, these medications should be administered with prudence, given the risk of side effects. She also emphasized that psychotropic medications should not be used as a substitute for non-pharmacological interventions for the neurobehavioral challenges of FASD, such as parental education, child and family behavioral therapy, self-regulatory supports, and school interventions. She concluded by emphasizing the importance of provider education regarding the judicious use of psychotropic medications.

Ms. West lastly spoke about topics that ASPE is following in relation to FASD. Rates of behavioral health service use has increased among children in general, but there are still unmet needs and less is known about behavioral health service use among children with FASD. ASPE is also monitoring health equity in terms of access to care, and Ms. West reiterated her earlier statements about Black Maternal Health Week. ASPE is also interested in the

pediatric mental health workforce's capacity to diagnose and treat FASD. Finally, ASPE is interested in the role of school-based behavioral health services in identifying and delivering services to children with FASD.

Discussion and Q&A

Dr. Balachova thanked the presenters and opened the meeting to discussion and questions and answers.

Dr. Powell started the discussion with the first comment, which was about health equity. She mentioned that a recent study showed that Black women may be screened for SUD more than others. She pointed out that screening for everybody is desirable so that all children are protected, and emphasized the importance of ensuring intervention and treatment options are available to everyone. She said that making screening a normal procedure for all pregnant people is a good goal.

A videocast participant asked whether the speakers and their staffs have received detailed training on FASD to help identify differences in approaches for that population relative to programs and initiatives that are not specifically geared toward the FASD population. The question also noted that many programs spoken about seem to be geared toward people with IDD in general, but that FASD is specific and needs its own focus.

Ms. Levinson reminded participants that most federal programs fund efforts that are legislatively required of the agencies. With respect to FASD-specific activity, HRSA has a legislative callout for FASD, so that is why HRSA is able to fund FASD-specific trainings.

Ms. Kim stated that the CDC funds the American Academy of Pediatrics, which has several FASD-specific trainings. She listed several FASD-specific trainings, including one that is specific to clinicians.

Elizabeth Parra Dang, of the CDC, said that they offer free trainings and referenced the CDC [FASD Training page](https://www.cdc.gov/ncbddd/fasd/guidelines-training.html) (<https://www.cdc.gov/ncbddd/fasd/guidelines-training.html>). Some of the trainings offer continuing education credits. The CDC also has a database with resources that are organized according to provider type.

Mr. Kinlacheeny stated that the IHS also has a series of webinars on FASD that are geared toward provider education, including screening. Because FASD is a significant challenge in Tribal communities, IHS is considering different ways to address it. One such way is by having a biweekly pediatrician consultation clinic for providers who treat American Indian and Alaska Native children within the IHS. With this clinic, IHS hopes to help children and families with issues such as FASD. More information can be found on the [Indian Children's Program](https://www.ihs.gov/icp/) (<https://www.ihs.gov/icp/>) page.

Mary Kate Weber, of the CDC, repeated that the CDC has been working with American Academy of Pediatrics to provide training and education to pediatric providers, and that the American Academy of Pediatrics has a toolkit with FASD resources and does an annual webinar series as part of alcohol awareness month.

Dr. Balachova stated that people interested in more information could contact ICCFASD members directly.

Mr. Dunbar-Cooper stated that SAMHSA developed FASD-specific resources through its FASD Center for Excellence in 2013, which are downloadable from the SAMHSA website. The audience for the publications is prevention professionals, program providers, administrators, and project managers. The guide reviews screening tools for alcohol use, including women of childbearing age, and has methods for identifying people living with FASD and modifying treatment accordingly.

Another videocast participant asked if SAMHSA is funding anything specific to identifying and treating people with FASD.

Mr. Dunbar-Cooper said that they are not currently funding any initiatives specific to FASD.

Dr. Balachova asked whether Ms. West had heard feedback from practitioners about [FASD Research Briefs](https://aspe.hhs.gov/fasd-research-briefs) (<https://aspe.hhs.gov/fasd-research-briefs>) that Ms. West had been involved in developing a year and a half ago. She also asked what Ms. West thinks could be done to improve services.

Ms. West clarified that the briefs, which were published on ASPE’s website, looked at state initiatives and what states can do to improve access to prevention and treatment. She stated that she has not heard from the community but that she thinks many states were focused on addressing COVID-19 when the briefs were published. She spoke about a new technical assistance center being set up by the Department of Education and CMS that will focus on school mental health, and this could be one venue in which to disseminate ASPE’s resources.

Dr. Balachova said that the briefs were excellent and expressed her wish that the briefs would get more attention.

Dr. Newburg-Rinn pointed out differences between the medical field and the child welfare field. She said that in 13 states, if a child is found to have been prenatally exposed to a substance, that is reason enough for the child to be placed in foster care. She explained that this means that even asking questions about alcohol can be a fear-inducing question for parents, so social workers need special education in how to handle this problem.

Special Panel, Part I: What Is Working In Your Community – Lessons Learned From Lived Experiences

Dr. Balachova introduced the panel, pointing out that various services have been developed by different agencies, and ICCFASD is aware that some work and some do not and that there is a need for more services. Therefore, it is important to hear from people with lived experiences to better understand and inform the field. Dr. Balachova then introduced the panel’s moderator, Jan Lutke, an international expert who is well known for her work with people with FASD and their families. In addition to writing papers and being on many committees, Ms. Lutke also adopted 22 children from foster care, including 16 with FASD. She has also helped many professionals to know and understand FASD better.

Dr. Balachova also introduced Dr. Petrenko, the first speaker of the panel. She is a clinical psychologist and scientist and does research that involves individuals with FASD and communities.

What is Working in Your Community—Lessons Learned from Lived Experiences

Christie Petrenko, Ph.D.

Dr. Petrenko started her presentation by thanking the ICCFASD, noting that she was looking forward to the rest of the panel discussion, and giving a brief overview of the organization of her talk. She then led meeting participants through an interactive activity in which participants collectively created a word cloud in answer to the question “who is in the FASD Community?” Answers spanned a wide variety of groups of people.

Dr. Petrenko next described community engaged research. She first went over definitions of researcher (someone who has a question and works to systematically answer it) and a person with lived experience (someone who has personal knowledge of an issue gained through direct experience). She said that engaging people with FASD and the broader FASD community is advantageous to research. Next, she explained several variations of community-engaged research, including community based participatory research (CBPR), in which people with FASD or other community members are actively involved in the research project at all major stages; community advisory boards (CAB), in which people with FASD and other community members provide input on a project; data collection with community member feedback, which includes community members participating in interviews, surveys, or focus groups so that the researchers can gather information to inform their research; outreach and relationship building; directly talking with the FASD community to learn what research questions are important and how effective programs can be developed; and communicating findings to the public. Since people with lived experience can offer important input, Dr. Petrenko encourages researchers to think about CBPR and CAB approaches when designing their research.

Dr. Petrenko then spoke about what works based on findings from FASD-community-engaged research. Although modalities that have been known to work are not always easily available, knowing what they are is a good starting point to build programming and strategies. Some of the things that work, according to published qualitative research studies based on the perspectives of children and adults with FASD, are support from parents and family, providers

who understand and advocate for services and supports, peer mentorship, proactive supports, feeling connected with peers and community, being aware of one's own strengths and needs, balancing independence and accepting support, putting challenges into perspective, and having coping skills. From the perspective of families, one of the most important things is getting an FASD diagnosis because it helps them get the right services and supports for their children. Other things that work for families include support from understanding professionals, proactive and coordinated care, respite care, working together as a family, support from other families with lived experience, and FASD conferences, trainings, and support groups.

Dr. Petrenko spoke about reframing, as it has been shown to be helpful. She explained that in society, willful or purposeful behavior impacts parenting strategies, such as punishments and sticker charts. However, in families with someone with FASD, these strategies are usually ineffective, and families end up frustrated. Reframing is an understanding of behavior in the context of neurodevelopmental or brain-based disabilities, rather than viewing behavior as willful. She suggests that with reframing, adults can use proactive and preventive strategies (i.e., accommodations) to avoid further problems, which can lead to increased success and less frustration. She stated that consequence-based strategies generally do not work well for people with FASD because they require executive functioning skills that people with FASD struggle with, such as being able to generalize to new situations and solving problems. Instead, proactive accommodations such as monitoring, using prompts and reminders, setting up structure and routine, and supporting strengths and interests are helpful, according to families.

Community-engaged research strategies can also be used to develop and test new programs, which may increase the likelihood that a developed program will meet the needs of the intended users. Dr. Petrenko used community-engaged research to create a self-directed app for caregivers that incorporates ideas of reframing. They got feedback from caregivers and providers at each step of app development, including initial design, beta testing, feasibility trials, and a randomized control trial to test whether the app produced change for families. The app was effective at helping families improve reframing skills and increasing their parenting satisfaction.

Dr. Petrenko has also been working on developing an app, My Health Coach, for adults with FASD. Her team has partnered with members of the Adult Leadership Committee (ALC) of the FASD Changemakers to co-design and test the app, and having these people on the team has ensured that the app will meet the needs of the community it intends to serve. She spoke about survey and focus group results, saying that the ALC participants found the app addressed some of their needs and that it appeared to be useful with managing symptoms and with advocacy. Participants offered recommendations to help improve the app, which was to be released in its completed form to the first group of study participants in April 2023. The team also found the ALC participants perceived that they had experienced most of the best practices for CABs, including collaborative partnerships, co-learning, and empowerment, enabling the ALC members to feel like full members of the team.

Dr. Petrenko then discussed future directions of her team's work. She said it will be important to shift their view from one that focuses on surviving (a deficit-focused view) to one that focuses on thriving (a strength-based view), which is better for people's quality of life. However, shifting to this viewpoint requires attending to barriers, such as limited awareness and understanding, access to care, and stigma. She closed her presentation by speaking about what her team has learned from dissemination and implementation science, which she stated could help overcome some of those barriers and leverage what they have found to work while getting programs out into communities. She then showed the final version of the word cloud from the initial activity.

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Discussion: Lessons Learned from Lived Experiences

Moderator: Jan Lutke; Nicholas Davis-Magliozi; Katrina Griffin; Kathy Hotelling, Ph.D.; Kathy Mitchell, MHS, LCADC; Justin Shepherd, BFA; Rebecca Tillou

Ms. Lutke started the discussion section of the panel and noted that each panelist's bio was online at the ICCFASD website at <https://www.niaaa.nih.gov/iccfasd/iccfasd-meetings/iccfasd-2023-invited-speakers>.

Dr. Hotelling, a parent of a 29-year-old daughter, spoke about what is working. She said that what is working for her daughter is that she comes from a White, highly educated, and privileged family. Dr. Hotelling has been able to stay at home with her daughter for the last 16 years to help her navigate her life, which has been very important, although Dr. Hotelling admits to being embarrassed about this. She spoke about the services which benefited her daughter. She had services related to being born three months premature, including speech/language therapy and physical education. Additionally, Dr. Hotelling gave her daughter horseback riding lessons which improved her hand to eye coordination. Her daughter also had an individualized education program, which was initially based on a diagnosis of ADHD. When her daughter was 10, she received an FASD diagnosis due to Dr. Hotelling pursuing that diagnosis since she did not believe her daughter had ADHD. Although Dr. Hotelling is a psychologist, she knew nothing about developmental disabilities or FASD. Once her daughter received the FASD diagnosis, she got training by Diane Malbin in the neural behavioral approach, and this training has been very helpful, in part because the other therapy and parenting strategies Dr. Hotelling had been using were not working. Dr. Hotelling also spoke about the importance of getting respite, which she got when her daughter was placed on the Medicaid Innovations Waiver. Dr. Hotelling stated that despite her daughter's diagnosis and her experience living in two different states, she was not told about the waiver that exist in every state by any health care or allied health care professional and instead, found out about it from someone at a meeting from a meeting attendee. Dr. Hotelling also described how she has served as her daughter's "external brain," helping her make decisions and think about things, and how helpful it was for her and her daughter to go to an [FASD conference](https://interprofessional.ubc.ca/fasd-conferences/) they attended in Vancouver, Canada (<https://interprofessional.ubc.ca/fasd-conferences/>). Having a psychiatrist who knew about FASD was also

beneficial. They have been able to access coaching, a crisis line, and respite through [Easterseals](https://www.easterseals.com/) (<https://www.easterseals.com/>). Dr. Hotelling mentioned that her daughter's personality, as well as her own perseverance and a focus on building on her daughter's strengths, have been helpful in contributing to her daughter's success thus far. However, most of the supports and services her daughter received were not FASD-informed, but rather general services for people who have developmental disabilities. Dr. Hotelling also voiced her concern about what will happen with her daughter when she dies.

Nicholas Davis-Magliozi, a 19-year-old recent high school graduate, spoke next. He was diagnosed early in life and lived with his grandmother because his mother had died. Despite him having a diagnosis, his grandmother did not know what FASD was, but a doctor told her to learn as much as possible, so she participated in various groups, such as the National Organization on FASD, and attended FASD conferences. With the information she learned, she started educating Mr. Davis-Magliozi's teachers about his disability and how they could help him. He expressed hope that today's meeting participants would be able to address some of the issues around what is needed by people with FASD.

Rebecca Tillou was the next speaker. At the time of the meeting, she was 43, and was diagnosed with FASD at age 34 by a pediatric geneticist. The things that work for her are routine, structure, and repetition. She works full-time as an insurance adjuster and has been at the same job for 16 years. The job works for her because there is a lot of repetition and similar work every day. She stated that she did not have supports when she was younger and although her FASD was suspected by her pediatrician, nobody knew she had it. Additionally, no information was known about her birth mom. In terms of what is working for her now, she relies on her husband to be her "external brain." She has learned her triggers and how to not overbook herself. As a child, her only formal service was speech therapy, but that was not related to her FASD. She reflects that she still has issues with cause and effect and says that had she been diagnosed earlier, working on cause and effect may have been an objective. She stated her belief that a supportive core family and a repetitive job with an understanding supervisor have been helpful to her.

Katrina Griffin, a member of the ALC Changemakers, spoke next. Ms. Griffin introduced herself. She described how she makes her strengths work for her and that she understands what she needs for support, including people doing things for her at the moment the help is needed. She spoke about services and benefits she has received in Canada where she lives, including rent subsidies, a one-on-one support worker who understands FASD, and disability income support, which is based on her FASD diagnosis and not her IQ. Ms. Griffin has enjoyed her job as an FASD mentor at a clinic, and she spoke about the positive impact of mentoring for people with FASD, both for people receiving mentoring and for people being mentors. For example, teens and adults with FASD often learn best from others who share the experience of living with FASD. She spoke in greater detail about the logistics of receiving disability income while working part-time. Ms. Griffin spoke about the importance of having people, such as nurses or mental health therapists, with whom she can talk for advice or direction because navigating the system on her own would be impossible. She discussed how much of an understanding there is among people with FASD and mentioned the three-day conference for teens and adults with FASD hosted by the University of British Columbia (<https://interprofessional.ubc.ca/adults-conferences/>). She ended with the message that the community should change how it thinks about FASD prevention, as she believes that any kind of intervention is prevention.

Justin Shepherd, an ALC Changemaker, then introduced himself. He received his FASD diagnosis at age 40. He described how he came to be diagnosed while making a film called [The FASD Project](https://thefasdproject.org/) (<https://thefasdproject.org/>) after having already been part of the FASD community. He said that the needs of people with FASD are highly individualized, as FASD is a spectrum disorder. He spoke about his experience as someone who also has ADHD, how privileged he feels to have a formal FASD diagnosis, and the difficulties people have in receiving an FASD diagnosis. He said that his FASD is a collection of different health problems, such as congenital heart disease and diverticulitis, but it is often hard to get medical providers to take his complaints seriously. Mr. Shepherd has been helped by support systems like his wife who advocates for him. Raising awareness about FASD is important so that people with FASD do not have to continually educate every medical provider with whom they come into contact. Mr. Shepherd believes that with enough supports, from family and friends to government and community support, people with FASD can thrive, not just survive. Other important types of support for people with FASD are

financial, such as medical debt relief, and access to mental health services. He closed his talk by saying that action and results, rather than merely talking about the needs of the community, are what is needed to move forward.

Kathy Mitchell spoke next. She has been involved in the FASD community since the 1980s when her then-15-year-old daughter was diagnosed with FASD after many years of misdiagnosis. Her daughter is now 50 years old and has been living in a group home, where she receives services, for several years. Ms. Mitchell mentioned that she is in long-term recovery from alcoholism and drug addiction, but at the time of her daughter's diagnosis, she did not know that drinking could cause permanent damage to her unborn baby. When her daughter was diagnosed with FASD, Ms. Mitchell wanted to tell everyone she knew because others also did not know about the potential harms of alcohol exposure to unborn babies. She talked to Congress and got involved with the organization that became FASD United. Ms. Mitchell works with birth families—young mothers and fathers who are struggling with understanding FASD and getting the diagnosis. She also mentioned that she had two children who died in infancy, and she believes that their deaths were caused by substance exposure because she did not receive treatment. For birth families with children with FASD, there is a lot of guilt, remorse, shame, and stigma. Stigma comes from both health care providers and the families themselves. There is a lot of blame that goes toward birth families, as the perception is that if a child is born with FASD, the family did it to themselves so they should not be asking for anything. She spoke about her own experience working with parents who are dealing with SUD or AUD and the shame they feel when they learn their child's diagnosis is FASD. There is also a problem that families are not getting diagnoses. She spoke about the Zoom group, Recovery Mothers Anonymous, that she started and how many young mothers are not receiving FASD diagnoses for their children, in part because health care providers tend to focus on the mothers' other (non-alcohol) substance use. Ms. Mitchell stated that many such mothers find out about FASD from older mothers like herself. She listed several things that could help these families, such as having a safe place to live, food, transportation, and school help. She spoke about her own experience with forgiveness with her daughter and grandchildren and how she continues to raise awareness of FASD so that she is part of the solution.

Ms. Lutke opened the panel to discussion and questions and asked everyone to turn on their cameras. She started by asking the panel how they view the statement, made by several speakers, that intervention is prevention.

Mr. Shepherd started by explaining that during his making of his film on FASD, he interviewed people and asked them what they wanted the world to know about FASD. The majority of the answers was that FASD is preventable. Therefore, at the end of the film, there is a section that emphasizes that FASD is preventable. After speaking to many people in the FASD community, he believes that if attention is turned toward people living with FASD, that will turn other people's attention toward it until a critical mass of understanding is reached. This will mean that the FASD community is no longer struggling to get society to understand FASD and where it comes from, and with a greater understanding of where it comes from, there will be more natural prevention.

Ms. Lutke asked Ms. Griffin what she thought, but Ms. Griffin asked for a moment to process the question and what Mr. Shepherd had already said.

Dr. Hotelling said she believes that based on her conversations with people about FASD, the emphasis is not on prevention per se, but on intervention and getting diagnoses. She said that while intervention is always prevention, for the people already living with FASD, prevention is not intervention. In North Carolina alone, there are 7,000 people born with FASD each year, which is an overwhelming number.

Ms. Lutke next mentioned eligibility for services, which, based on her experience, is a significant problem, especially when services are based on an intellectual disability model, because 75% of people with FASD do not qualify for services based on that model. People with FASD may have a higher IQ but still struggle with everyday life because of executive function and other deficits. She asked to what extent negative outcomes could be mitigated if eligibility were not based on this model, pointing out that in British Columbia, some disability programs are based on diagnosis and not IQ, which is a significant change that improves quality of life and ability to survive for people with FASD. She asked Ms. Griffin to opine, as Ms. Griffin is a citizen of British Columbia who receives services based on her FASD diagnosis.

Ms. Griffin spoke about her work experience before she qualified for disability pay and contrasted it with her improved situation since starting to receive disability pay. She said the disability pay has covered her rent and that she would not be able to live without it since she does not have the stamina to work full-time. She spoke more about her part-time mentoring job.

Ms. Lutke asked Ms. Tillou, who has a repetitive job that gives her the structure she needs, what would happen if she could not have that type of job.

Ms. Tillou spoke about her experience in trying to become a speech therapist before landing at her current job. Work as a speech therapist is abstract and not repetitive, and she could not figure out how to work as a speech therapist. Without her current job, she thinks she might have been okay since there are many jobs in the insurance industry. She considers herself lucky but struggles with her job when new systems come out since it takes her longer to understand them.

Dr. Petrenko commented about eligibility for services. She said that from research, getting developmental disability services is one of the most protective factors against adverse outcomes. She said that in New York, FASD is not recognized as a developmental disability, but her team has tried increasing awareness of FASD. They are now engaged in a legislative policy approach to increase recognition of FASD as a disability. However, New York's disability agency has pushed back because it sees the addition of FASD as a fiscal problem, which could create more demand for limited services. She spoke about the need to add FASD as an equity issue since there are other people with fewer support needs who are receiving services.

Ms. Lutke then focused the discussion on stigma and how it impacts everything. She asked a question based on commentary from an audience member that suggested prevention messaging may convey the idea that people would prefer that people with FASD not be who they are. Ms. Lutke asked the panel what they would change in terms of prevention messaging.

Ms. Mitchell said she did not think she could address what the audience member was asking but made a point about "intervention is prevention." She pointed out the two-fold nature of intervention since intervention can be either with the person with FASD and/or with the mother. She emphasized the importance of getting mothers into addiction treatment and support services, since this is the best prevention. She spoke about the difficulty of receiving a diagnosis because there is no go-to person for diagnosing FASD. Additionally, health care providers may not focus on mothers' alcohol use, as they tend to focus on mothers' other substances.

Mr. Davis-Magliozi, in trying to answer the audience member's question, emphasized that people with FASD struggle but that society is not generally aware of that fact. He spoke about the importance of raising the awareness among people who drink that there are consequences to their actions, but that it is ultimately a person's own decision to drink alcohol. He suggested that the message that if parents want to make their child's life better, they can consider their decision to drink.

Ms. Lutke clarified the audience member's question which was more about what helps people thrive (both life-giving parents and people with FASD), rather than about the stereotypes of what pre-natal alcohol exposure looks like. Moreover, FASD does not look like any one thing, as it is very variable. The stereotype around FASD characterizes the child and the parent as bad, whereas for other disabilities, such as Down Syndrome, people adjust their expectations and accommodate the person with Down Syndrome. Ms. Lutke spoke about how this connects with stigma. Then she asked the panelists whether they have people in their lives who are a major support and what would happen if the most important person who supports them was not there.

Mr. Davis-Magliozi answered first by saying he did not know where he would be without his grandmother, and believed that he might be in jail or on the streets.

Ms. Tillou pointed out that she has the maturity of someone half of her age, and whereas she sometimes thinks she would be ok without the support of her husband and parents, in reality, she would be in a lot of debt, partly because of impulsivity. She realizes that debt would be her new normal and that she would think it would be okay, but it would not be. She acknowledged that she had been lucky.

Ms. Griffin acknowledged the importance of her family support but stated that she also has a support worker who is paid to be in her life. If the support worker suddenly disappeared, she would still have people in her life who are there for her unconditionally. However, if the people who are not paid to be her support system disappeared, Ms. Griffin said that she would be okay for a short time, although she would not last long.

Mr. Shepherd said he would probably not be alive had his wife not been there to support him and advocate for him. He spoke how helpful his wife had been in getting him diagnosis and treatment for his congenital heart issue. He said that if she disappeared today, he would probably have substance abuse and mental health issues, which would mean he would not be able to hold a job or run his company successfully. He said that his wife helps him in little ways and without that help he would be more disorganized and would not be as functional as he is with her help.

Ms. Lutke summarized that what she had heard was a lesson regarding services supports and systems. She said that people with FASD do not need massive services that are very expensive, but rather the system needs to figure out how to provide the kind of support that individuals with FASD need, although it is hard to quantify and qualify in a panel discussion. When people with FASD need support, it is for a particular item at a particular moment of time. She pointed out that adults with FASD are often found in high-cost systems, such as jails or addiction, that they need not be in if they receive appropriate support. She suggested that all meeting participants think about this. She spoke about two Canadian pilot programs that were so successful they became government-sponsored programs to help schools understand what to do with respect to their students who have FASD. They are the [Provincial Outreach Program for FASD](https://www.fasdoutreach.ca/) (<https://www.fasdoutreach.ca/>) in British Columbia and [WRaP 2.0](https://wrap2fasd.org/) (<https://wrap2fasd.org/>) in Alberta. The goal of the programs is to make school a better experience for students with FASD. The programs have been supported on a level that allows things to be done differently. She spoke about how the government made grants to families to help get their children needed supports, which was a change in how government programs usually work since it allowed families to make their own decisions about how to use the grant money rather than having to choose services from existing programs.

Ms. Lutke next spoke about mentoring programs, including Ontario's [Adopt4Life](https://www.adopt4life.com/) (<https://www.adopt4life.com/>) program which operates on the idea that people working as mentors should work under clinical supervision. She spoke about the importance of mentoring for people with FASD and how mentoring programs are not costly. She said that mentoring helps people with FASD view themselves as functioning, competent individuals, rather than as people who are problems, as many people with FASD often internalize societal messages that they are bad people.

Ms. Lutke responded to a question from Ms. West about how supports in British Columbia for people with FASD differ from supports in other provinces. Ms. Lutke explained that Canadian provinces set up their own systems, but the federal government allocates funds to each province that provinces can use as they see fit within their own systems. Additionally, the Canadian federal government also has its own programs. The federal government has disability tax credits and disability savings plans, and since FASD is recognized as a disability in Canada, people with FASD are qualified for these federal disability programs. She described how many small programs can coalesce to make a large impact.

Dr. Tracy King commented that she appreciated that people on the panel may be from high-resourced environments, and that she wondered about the type of people who are not on the panel. She said that the panel is not a particularly diverse one and that she hopes issues of diversity can be kept in mind as groups increase outreach to the FASD community.

Dr. Hotelling emphasized that one of her greatest resources was time, in the sense that she retired before she expected to and that she had the financial means to do so. This extra time allowed her to look for FASD-related programs, and she recognizes that many people do not have the privilege she had. This is what led her to start her [NC FASD Informed](https://ncfasdinformed.org/) organization (<https://ncfasdinformed.org/>).

Dr. Dunty thanked the panelists and acknowledged that there were several comments made in the chat that would be shared with agency members and panelists offline.

Ms. Lutke spoke to Dr. King's comment about diversity and agreed that children in foster care or in isolated communities or in disadvantaged families may not be heard to the same extent as other children with FASD. There

is a program in British Columbia that is trying to bring in these generally excluded children with FASD to better serve them.

Dr. Balachova thanked the presenters and expressed her wish that this discussion could continue after the meeting. She also pointed out that there would be more time later in the meeting for more questions. After a short break, Dr. Balachova emphasized that many people with FASD and their families have not been represented, and that is one reason why it is so important to continue the work and efforts to hear from them.

Dr. Balachova introduced the second panel, which was about a program developed by FASD United to help families with needed supports and services. She also introduced Elizabeth Dang, the moderator and an ICCFASD representative from CDC.

Special Panel, Part II: The FASD United Family Navigator Program—Here to Help

Moderator: Elizabeth Parra Dang, MPH; Tom Donaldson, CEO FASD United; Heather French, Family Navigation Lead; Jenn Wisdahl, COO FASD United

Ms. Dang introduced FASD United, previously known as the National Organization on Fetal Alcohol Syndrome (NOFAS) and said that when people think of one main voice in the U.S. on the topic of FASD, they think about FASD United. The organization has expanded beyond its original state-by-state FASD resource directory to provide people with FASD and family members with experts, one-on-one support, and referrals. These services are collectively known as the [Family Navigator Program](https://fasdunited.org/family-navigator/) (<https://fasdunited.org/family-navigator/>). She introduced the three speakers from FASD United.

Jenn Wisdahl introduced her FASD United colleagues and spoke about the challenges around navigating an FASD diagnosis. She said that in the past, the focus on FASD had been on research and prevention, which left a gap for people with FASD who were seeking services and support. Effective programs and practices exist but are not consistently available or widespread. Access to diagnosis and FASD-informed mental health support, for example, has greater demand than supply. She spoke about the lack of updated or complete information from pilot programs or research studies. Due to a lack of centralized, updated information, families may spend a lot of time searching for supports that may not exist in their area. To respond to this need, FASD United's Family Navigation Program began in January 2022 as an active resource directory and mechanism for providing peer support. However, they realized that resource guides quickly become outdated, so they wanted to create a system that provided dynamic support and two-way feedback for ensuring resources were updated and aligned with current research. They also wanted to provide a resource through which families could find help and support. The Family Navigator Program was the result of a public-private partnership with funding from CDC and the National Alcohol Beverage Control Association, and the program provides nationwide, one-to-one individualized referrals, information on FASD and prenatal alcohol exposure, and peer support and connections between clinical and non-clinical resources. Ms. Wisdahl spoke about the logistics of how this support is provided and about the increase in the volume of inquiries since the program's launch. All program navigators have lived experience with FASD and with navigating systems of care. The navigators' goal in providing information is to give the user helpful resources and up-to-date information and resources. Peer support is a key component of the program. Ms. Wisdahl also described how the program functions behind the scenes and how it works to streamline services. She said that the program has been collecting meta data related to the inquiries, and that they are beginning to see trends in the data. She said that as the program has grown, they have seen the need for additional data collection and differentiation. She turned over the talk to Heather French, the first family navigator in the program, to talk about data capture.

Ms. French said that in 2022, the team of four navigators received 474 inquiries, and in the first quarter of 2023, they have received 233. She spoke about the various ways people ask for assistance, including the project's website form, email, and phone. The majority of requests are from caregivers. Professionals such as mental health providers and teachers also make inquiries. She spoke about how the team often looks for national resources or resources from states that have up-to-date information, as many states have outdated information. State resources are the most

requested type of information users ask for, and such resources include Medicaid waiver programs, vocational rehabilitation, wraparound services, and local programs on FASD. Other categories of requested information include diagnosis, mental health, benefits, support groups, and education. Ms. French closed her presentation by noting that people reach out to them for connections to resources but feeling understood is what means the most to users.

Ms. Wisdahl mentioned how their plans include an increased focus on data collection and a focus on the information they send to clinical and non-clinical organizations. They are continually assessing how the program is doing. For example, in January 2023, they started examining which resources are being requested versus which are available (by state and nationally). With this information, they plan to develop state data sheets by the end of 2023. She also spoke about how the data they are collecting could support policymaking and address filling gaps in programming availability. Ms. Wisdahl said that overall, the navigators provide hope, insight, and community to people. She spoke about their plans for the second half of 2023, including enhanced feedback mechanisms so that they can assess the utility to the end user of the resources found by the navigators. She closed her presentation by showing a word cloud based on 2022 feedback received by navigators from end users and by giving information about how people can access the program.

Discussion

Ms. Dang reiterated some high-level points about the FASD United Family Navigator program. She then asked a question from the public about whether the navigators knew how many requests from grandparents they received and whether there's a need for grandparents to connect with other grandparents.

Ms. Wisdahl said they do not track calls from grandparents but she knows that they do get requests from grandparents; however, she is unaware of any grandparent-specific resources. She suggested that the more people who ask for any given type of resource, the more FASD United can track data and unmet needs.

Ms. Dang asked whether there is anything else that might be helpful to inform the field or be helpful to families.

Dr. Powell asked FASD United whether they are tracking data about where and with what providers people are receiving diagnoses, given the difficulty in getting an FASD diagnosis.

Ms. Wisdahl said that the navigators connect families to available diagnostic resources and that they are currently tracking whether the diagnostic resource is over an hour away, out of state, or simply not available. She reiterated the fact that some diagnostic resources may not be available in all regions. She said that if practitioners contact FASD United, they provide them with resources such as FASD-related trainings and information.

Dr. Newburg-Rinn asked whether the Navigator program is collecting race and ethnicity data on the people seeking services, as that data would be of interest to the Children's Bureau. Ms. French answered that they do not collect such data currently. Ms. Newburg-Rinn stated that the Bureau is concerned that children of color are overrepresented in foster care, possibly because families of color are over-surveilled. She stated that she is also concerned that services are not being provided to those families. She spoke about the difficulties in maintaining fairness in providing services to both minority and majority families.

Ms. Wisdahl stated that the Navigator program does track whether the child is in the child welfare system.

Mr. Donaldson spoke about the knowledge that FASD United can gain from those they refer. They are considering how to capture data, and not just anecdotes, about outcomes for individuals who get a diagnosis. He pointed out that an FASD diagnosis is often just a starting point for many people.

Ms. Dang asked a question from an FASD United affiliate, who inquired about when the state-based "report cards" showing resource categories within each state would be available.

Ms. Wisdahl said they hope to have the report cards out later in 2023. She described the type of information that will be contained in the state report cards. They plan to include general categories, such as diagnostic resources available in the state, information on the capacity of the diagnostic resources and how that relates to the number of

births in the state, whether FASD is recognized by the special education in the state, and whether people with FASD qualify for disability services in the state.

Ms. Dang posed another question from the public asking whether the navigators ever receive requests for training (rather than for direct services).

Ms. French affirmed that they do get such requests, especially from professionals, such as social workers and teachers, or organizations seeking services or supports for someone they are working with.

Ms. Dang asked how the navigators' conversations with people requesting information has informed updating the directory and whether the goal is for people to still be able to use the static resource directory or to interact with the navigators.

Ms. French said the goal was for users to call the navigators, but that FASD United is also working on making the static directory more searchable. Ms. Wisdahl said it makes sense to have both resources (the navigators and the static database) and there is no intention to phase out either resource.

Dr. Dunty asked whether there is any way for the navigators to follow up with individuals a few months after providing them with resources to determine what did and did not work.

Ms. Wisdahl confirmed that such an effort will be part of their evaluation plan.

Dr. Balachova asked about the navigators' experiences with providers.

Ms. French reiterated that most of the professionals who call them are the ones who have specific families they are trying to help. Ms. Wisdahl said that through the FASD Collaborative, they provide information on discipline-specific special interest groups.

Ms. Lutke asked whether the navigators, in collecting data on people looking for diagnosis, are separating people out by age.

Ms. Wisdahl confirmed that they track pediatric versus adult requests for diagnosis, and that they think this distinction is important because while diagnostic capacity for youth is lacking, it is even more limited for adults.

Ms. Griffin asked whether there are people with FASD alongside the other people giving trainings from FASD United.

Ms. Wisdahl clarified that the Family Navigator Program does not focus on trainings, but that when people with FASD are present at trainings, they are able to speak to their lived experience, which is powerful and important and improves trainings.

Ms. Dang spoke to the importance of having people with lived experience involved in CDC's projects with national professional organizations, such as projects that try to educate health care providers on FASD.

Ms. Griffin reiterated the importance of having an individual with FASD be present for FASD presentations since such people can speak about what works for them, which is a different type of information than can be given by people who have only clinical or research experience working with FASD. She emphasized that having an individual with FASD at such events should be the standard at FASD-related trainings or presentations.

Ms. Lutke gave an example of an educational training on FASD in Ontario. One of the FASD Changemakers was at the event. While others were discussing issues around messy children's bedrooms, the Changemaker described why she kept a lot of things that her parents considered garbage, such as three-year old Christmas gift wrapping. The Changemaker said that having the wrapping paper was a memory support, as it helped her remember the good memories from that Christmas. Ms. Lutke emphasized that this type of insight can come only from a person with lived experience.

Dr. Balachova asked whether the navigators can make referrals to support groups or online groups.

Ms. French said that they get that type of inquiry a lot and they send those people to Facebook groups and other support groups, including ones listed by the FASD Collaborative.

Dr. Hotelling said that the FASD community does not have many adults who would feel comfortable speaking at trainings and other events, and she said that the adults with FASD on the call needed to realize they are special for being able to speak in such a setting.

Ms. Dang thanked everyone for speaking and said that everyone can help get the word out about the FASD United Navigator Program.

Dr. Balachova announced the continuation of federal agency reports of activities from 2022, starting with Dr. Dunty.

Reports of Activities from FY2022: ICCFASD Federal Agencies: NIAAA, NICHD, NIMH, NIDA

The National Institute on Alcohol Abuse and Alcoholism (NIAAA)

Bill Dunty, Ph.D., Program Director, Division of Metabolism and Health Effects, National Institute on Alcohol Abuse and Alcoholism, NIH ([email: duntyw@mail.nih.gov](mailto:duntyw@mail.nih.gov))

Dr. Dunty introduced himself as the FASD research coordinator for NIAAA and explained that NIAAA was established in 1970 and is the world's largest funder of alcohol research. He stated the [institute's mission](https://www.niaaa.nih.gov/our-work/mission-statement) (<https://www.niaaa.nih.gov/our-work/mission-statement>) and that NIAAA supports four areas of FASD-related research through grants and other activities: etiology, interventions, prevention, and diagnosis. NIAAA funding for research and training grants has been on the rise for the last five years (2018-2022), with about \$442 million allotted to those activities in FY2022. Over the same timeframe, awards to FASD researchers have remained steady, comprising about 8% of NIAAA's total research and training budget. In FY2022, about \$35 million supported 101 extramural FASD-related grants, 24 of which were new in 2022. Dr. Dunty suggested that anyone interested in learning more about the research projects could use NIH RePORTER. In the category of etiology, grants cover topics such as the impact of prenatal alcohol exposure on cellular aging and cognitive impairment, cardiovascular disease in FASD, and the mechanisms for predispositions to AUD after in utero exposure to alcohol and marijuana. Dr. Dunty listed grants in the areas of interventions (cognitive training and brain stimulation as a neurodevelopmental intervention in FASD) and prevention (interventions to prevent FASD and to reduce alcohol-exposed pregnancies). He also described some grants that cross multiple areas, and he described some that look at both etiology and intervention.

Dr. Dunty then spoke about the work of four NIAAA-funded consortia and centers:

- The [Collaborative Initiative on FASD](https://cifasd.org/) (<https://cifasd.org/>), which focuses on improving FASD diagnoses and health outcomes across the lifespan, and was renewed for another five years.
- The [New Mexico Alcohol Research Center](https://hsc.unm.edu/nmarc/) (<https://hsc.unm.edu/nmarc/>), which has both pre-clinical and clinical studies that address the neurobiological mechanisms underlying behavioral problems associated with FASD.
- The [Developmental Exposure Alcohol Research Center](https://www.binghamton.edu/centers/dearc/) (<https://www.binghamton.edu/centers/dearc/>), which focuses on prenatal alcohol exposure in animal models.
- The [Native Center for Alcohol Research and Education](https://ireach.wsu.edu/ncare/) (<https://ireach.wsu.edu/ncare/>), which works on preventing alcohol-exposed pregnancies among Native American women in South Dakota.

Dr. Dunty next spoke about NIAAA's current funding opportunity announcements (FOAs) that support research on prevention of FASD. FOAs cover topics such as prevention and intervention approaches for FASD across the lifespan; the pediatric-to-adult health care transition; emerging and existing issues related to COVID-19 in the context of women, children, and individuals with physical or intellectual disabilities; addressing gaps in evidence-based screening of alcohol use during pregnancy and screening for FASD; and secondary analysis of alcohol-related datasets. He directed interested persons to visit grants.nih.gov for more information.

Dr. Dunty then described other NIAAA activities from FY2022. In October 2022, NIAAA and the Interagency Working Group on Drinking and Drug Use in Women and Girls hosted a [scientific conference](#)

(<https://www.niaaa.nih.gov/news-events/meetings-events-exhibits/2022-national-conference-alcohol-and-other-substance-use-women-and-girls>), at which participants discussed causes, consequences, prevention, and treatment of alcohol and other substance use in women and girls. Participants were general health care providers; addiction, prevention, and treatment professionals; policymakers; addiction researchers; educators; and faith and community leaders. The overall goal of the conference was to identify important areas for future research and to highlight strategies that are already working. Dr. Dunty spoke more about parts of the conference that were specific to FASD, such as a panel discussion on model programs for mothers with AUD, other SUD, and children with prenatal substance exposure, and presentations on advocacy for the FASD community and FASD prevention. A summary and recording of the conference will be posted on the NIAAA website.

In FY2022, NIAAA also launched an online educational resource, the [Healthcare Professional's Core Resource on Alcohol](https://www.niaaa.nih.gov/health-professionals-communities/core-resource-on-alcohol) (<https://www.niaaa.nih.gov/health-professionals-communities/core-resource-on-alcohol>) which covers the basics of what every healthcare professional needs to know about alcohol, including how it can impact a patient's health. It also offers free continuing education credits, and several of the articles in the Core address prenatal alcohol exposure and FASD.

Lastly, NIAAA participates in and provides support for several NIH-wide pediatric initiatives, including the Adolescent Brain and Cognitive Development Study, the Gabriella Miller Kids First Pediatric Research Program, and the [Healthy Brain and Child Development Study](https://heal.nih.gov/research/infants-and-children/healthy-brain) (HBCD; <https://heal.nih.gov/research/infants-and-children/healthy-brain>).

Dr. Dunty closed his presentation by mentioning that interested parties can go to NIAAA's [FASD website](https://www.niaaa.nih.gov/research/fetal-alcohol-spectrum-disorders) (<https://www.niaaa.nih.gov/research/fetal-alcohol-spectrum-disorders>).

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Tracy M. King, M.D., MPH, Medical Officer, Intellectual and Developmental Disabilities Branch, Eunice Kennedy Shriver National Institute of Child Health and Human Development, NIH ([email: tracy.king@nih.gov](mailto:tracy.king@nih.gov))

Dr. King introduced herself and described the broad mission and scope of NICHD, which funds a spectrum of basic, translational, and clinical research that encompasses child health, including development and behavior, intellectual and developmental disabilities, growth and nutrition, and trauma and critical care. NICHD also funds studies on prenatal, perinatal, and neonatal health, which have relevance to FASD. NICHD is also a major funder of research on pregnancy, maternal health, and reproductive health, including gynecological health, contraception, and fertility/infertility. NICHD also houses the National Center for Medical Rehabilitation Research, which supports research on rehabilitation across the lifespan.

Dr. King noted that NICHD funds few awards that are focused specifically on children with FASD or alcohol use during pregnancy, but that it is involved in multiple ongoing initiatives and priority areas that have potential relevance to FASD. These include the Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE) Initiative, which focuses on reducing maternal morbidity and mortality; and activities related to ableism (i.e., discrimination against individuals with disabilities) in medicine and clinical research.

Dr. King detailed the [IMPROVE Initiative](https://www.nichd.nih.gov/research/supported/IMPROVE) (<https://www.nichd.nih.gov/research/supported/IMPROVE>), an NIH-wide initiative which focuses on addressing high rates of pregnancy-related complications and deaths in the U.S. and encompasses both foundational biology and social and biobehavioral research. Community partners are key to this project in assessing needs and implementing interventions. The initiative is led by NICHD, the NIH Office of Research on Women's Health, and the National Institute of Nursing Research, with additional participation from other NIH Institutes, Centers, and Offices, including NIAAA. Overall, IMPROVE focuses on addressing the leading causes of maternal morbidity and mortality by building an evidence base for better care and outcomes. IMPROVE focuses on cardiovascular disease, infection and immunity, and mental health and has an overarching theme of addressing racial, ethnic, age, and geographic regional disparities.

She next spoke about NICHD's efforts around disability inclusion and explained that ableism is the assumption that people with disabilities are inadequate or inferior, leading to discrimination. Ableism can result in people with disabilities being denied access to medical care, receiving lower quality care, and being denied the opportunity to participate in research. She discussed some of the arguments that have been used to justify denying disabled people access to research or clinical care, such as safety concerns, even though the concerns may not be based on evidence, and an underlying assumption that it is too expensive to make health care facilities accessible. To address some of these issues, the National Institute of Medical Rehabilitation Research, which is part of NICHD, hosted a workshop in April on ableism in medicine and clinical research. The goal was to highlight opportunities to mitigate the impact of ableism in clinical care research.

The National Institute of Mental Health (NIMH)

Christopher Sarampote, Ph.D., Chief, Biomarker and Intervention Development for Childhood-Onset Disorders Branch, Division of Translational Research, National Institute of Mental Health, NIH ([email: csarampo@mail.nih.gov](mailto:csarampo@mail.nih.gov))

Dr. Sarampote introduced himself and Dr. Julia Zehr. He described NIMH, the leading federal agency for research on mental health disorders, saying that it supports research that spans the entire pipeline of mental health research from basic studies of mechanisms of emotion and behavior to studies of trajectories of mental illness and studies that aim to develop and improve interventions. NIMH is committed to developing service delivery models to improve the outcomes of mental health services received by diverse communities and populations. The prevention and treatment of mental illness is part of NIMH's core mission. He spoke about challenges in mental health treatment, such as the pandemic and disparities. He mentioned that people with FASD have a higher risk for psychological disorders and that they are prescribed psychotropic medications at higher rates than other populations. Moreover, prenatal alcohol exposure is associated with negative mental health outcomes in children, and he listed more details about psychological and psychiatric conditions associated with prenatal alcohol exposure, including ADHD, mood disorder, and anxiety. Teens with FASD have been reported to be at extraordinarily high risk of suicide attempts, and Dr. Sarampote emphasized the importance of understanding the relationship between alcohol exposure, behavior, psychiatric symptoms, and other factors, as a better understanding will improve intervention efforts. He spoke about how more work is needed, especially in the context of FASD. Dr. Sarampote stated that NIMH does not fund grants specifically focused on FASD but that it partners with other institutes to provide expertise and identify new opportunities for collaboration. NIMH is involved in the NIH HEALTHY Brain and Child Development Study (HBCD), which is establishing a large cohort (~7500) of pregnant women from regions of the country significantly affected by the opioid crisis. The project will examine developmental trajectories (e.g., brain, cognitive, behavioral, social, emotional, academic) beginning prenatally through childhood (9-10 years). The cohort includes children exposed to opioids or other substances as well as non-exposed children to establish normative brain and developmental trajectories.

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The National Institute on Drug Abuse (NIDA)

Keisher S. Highsmith, DrPH, Commander, United States Public Health Service, Division of Epidemiology, Services and Prevention Research, National Institute on Drug Abuse (NIDA), NIH, HHS ([email: highsmithks@nih.gov](mailto:highsmithks@nih.gov))

Dr. Highsmith introduced herself and her NIDA colleague, Janani Prabhakar, NIDA representative to ICCFASD.

She spoke about the NIDA research portfolio on SUD and infant outcomes. NIDA awarded approximately \$119 million in 217 grants between FY2019 and FY2023 for research focused on SUD and perinatal outcomes. She gave details about what types of grants were awarded, including funding details about the HBCD Study. She also presented a word cloud that reflected that neonatal abstinence syndrome and opioid exposure were important research topics.

Dr. Highsmith next spoke about NIDA's [Women and Sex/Gender Research Group](https://nida.nih.gov/about-nida/organization/cross-cutting-research-teams-workgroups-interest-groups-consortia/women-sexgender-differences-research-group-0) (<https://nida.nih.gov/about-nida/organization/cross-cutting-research-teams-workgroups-interest-groups-consortia/women-sexgender-differences-research-group-0>) for which she is a co-chair. The group's mission is to promote careers of women scientists and to promote the conduct, translation, and dissemination of research on a variety of topics, such as sex and gender differences in the pharmacology of SUD, and the interactions of SUD risk factors with changes in female physiology and behavior across the lifespan. She spoke about how the group also focuses on treatment and the group's primary research focus areas: women's and maternal health, sex/gender differences, and career development for women scientists.

NIDA also held two Brain Development Research Consortium workshops in 2022. One focused on the impact of comorbid COVID-19 and SUD during pregnancy on fetal and infant development, while the other focused on placental function and addictive substances. The focus of the first was to review the state of the science on COVID-19 and SUD, with attention to research gaps and opportunities. Speakers discussed COVID-19 infection with attention to effects on the developing fetus, pandemic stress on maternal health, and the effects of COVID-19 infection or pandemic stress and SUD on neural development. Other topics covered at the workshop were remote data collection and telehealth. The second workshop covered clinical research, basic research, animal models, genetics and epigenetics, and emerging technologies. The workshop inspired the development of several funding opportunity announcements that support studies on opioids, alone or in combination with other substances of misuse, and its impact on placental function and neural development during pregnancy and the first year of life. These funding opportunity announcements were developed in collaboration with NICHD.

Dr. Highsmith then spoke about a workshop that was to take place in May 2023, the Engaging Child Welfare Systems in Research on Young Children Workshop. The workshop's goal was to promote collaboration between child and family development researchers and the child welfare service delivery system. She described the speakers and the topics they would present in greater detail. Overall, the presentations were meant to provide an overview of the child welfare system; explain the overlap between child welfare, substance use, and criminal justice systems; summarize the impacts of maltreatment and foster care on brain and behavioral development of children; and describe the impact of the child welfare system on children and families. The workshop was also meant to cover racial and ethnic disparities and other disparities in the child welfare system.

Dr. Highsmith then spoke about the HBCD Study. HBCD is a prospective longitudinal study that begins just before birth. Researchers assess prenatal exposures and environmental factors, as well as brain, cognitive, and emotional development from birth through childhood. The ultimate goal of the study is to determine how substance and environmental exposures affect developmental trajectories. She spoke about HBCD's participating sites and the other NIH institutes that support and fund HBCD. She then described HBCD's sampling characteristics and went into more detail about the timeline associated with the study, including the timing of participant visits, emphasizing that assessments are done in both English and Spanish and reviewed for bias. So far, 261 adults and 179 infants have been recruited for pilot studies, and all the sites that are doing pilot studies will test all the elements before moving onto cohort recruitment, which was expected to happen in May and June 2023. She spoke about how the HBCD Data Coordinating Center coordinates and establishes technology used for data collection.

Discussion

Dr. Balachova thanked everyone for the agency updates. She then asked the first question, reiterating that Dr. Petrenko engages the FASD community when she develops new programs and asking representatives from NIH institutes what experience they have with this type of research.

Dr. Zehr, a representative from NIMH, responded that community-engaged research is being seen more and more; however, for her branch, it is easy to bring in parents as partners, but it is difficult to bring in children because of consent issues. She also mentioned that NIMH had recently released an RFA on social media that encouraged the use of youth advisory boards and that she believes more of this type of research will be supported in the future.

Dr. King said that NICHD is moving toward encouraging or requiring input and perspectives from people with lived experience in research, especially in the context of rare conditions, IDD, or physical disabilities, but also across most of NICHD's supported research. She emphasized that they are trying to ensure that the perspectives of people for whom the research is relevant have input on the questions being asked.

Dr. Balachova mentioned that Ms. Lutke had commented that it is important to have perspectives from people with lived experience not only for research, but also in the context of service programs to make sure that the programs target outcomes that people want and need.

Dr. Dunty suggested that the desire to include individuals with FASD comes not only from the funding agencies but also from the researchers themselves. He spoke about his experience at a consortium meeting at which FASD researchers asked individuals with FASD what they wanted the researchers to study.

Ms. Lutke emphasized that the individuals with FASD who had been asked for input at the meeting Dr. Dunty had spoken about would be engaged in similar conversations in the future. She said the group has been working hard to prioritize the areas that are important for research.

Dr. Powell asked the group what, from a research perspective, would most help people with FASD.

Ms. Lutke said that she could not speak for the group of people with FASD who are talking to researchers, but suggested that a longitudinal study that follows people with FASD beyond the age of majority is needed. She emphasized the importance of gathering data on what happens to people with FASD in the long term, especially with respect to health issues such as iron deficiency. She suggested that certain underlying health conditions may be written off as mental health problems and that a more thorough understanding of the health issues associated with FASD could greatly improve people's lives.

Ms. Griffin emphasized the importance of having a better understanding of the health concerns of people with FASD as they get older. She gave examples of medical conditions which may come up later in life and asked what would happen when she or others with FASD get older.

Dr. Dunty, in addressing Ms. Lutke's comment about a need for a longitudinal study, pointed out that NIAAA has funded a study on health outcomes in adults, led by Claire Coles and Joanne Weinberg. The study's publications are beginning to come out, and continuing work is looking at how the immune and endocrine systems relate to health and mental health outcomes.

Ms. Lutke said that she was aware of that study and emphasized that there is still a need for a truly longitudinal study that follows children from a very young age through the lifespan. Such a study would address questions such as whether people with FASD are functioning well or whether they die early. She said that it is the only way to get a complete picture.

Dr. Dunty mentioned a study that looked at the impact of prenatal alcohol in sudden infant death syndrome and stillbirth. The researchers have received additional funding to follow research subjects into their early teens. He acknowledged that this study may not be of the scale that Ms. Lutke envisions.

Dr. Balachova said that she believes the message about treatment and support needs of people with FASD has been received well.

General Discussion: ICCFASD Agency Representatives, Speakers, and Guests

Dr. Dunty said that several comments from the public sharing similar stories to what had been discussed on the panel had been received. He said those comments would be shared with the panelists and agency representatives.

Dr. Balachova added that several comments from the public expressed thanks to the meeting participants.

Dr. Reichard echoed the sentiments of the public comments and thanked the panel members, as their contributions were meaningful and informative. She spoke about her own son who has a serious mental illness and said that she sees parallels to things people with FASD spoke about. She explained that both FASD and her son's mental illness are invisible disabilities and thus share similarities. She suggested that addressing invisible disabilities as a whole is important. She also spoke about an upcoming NIDILRR grant opportunity about improving methods for conducting research with people with cognitive disabilities in virtual environments. She said that this opportunity highlights NIDILRR's desire to encourage the development of methods to work with people with cognitive disabilities so that everyone is included in research. She encouraged FASD researchers to apply.

Dr. Powell spoke about invisible disabilities and pointed out that FASD can look different on any given day, which may cause the health care system and society at large to dismiss it.

Ms. Griffin agreed that FASD looks different every day but suggested that FASD is not invisible since people who are around it every day see it.

Ms. Lutke spoke about the stigma surrounding FASD, citing a quote from the autism community that people with autism did not cause their disability. She explained that when there is a known cause or a preventable condition, there is a problem with how people interact with people with such conditions. She suggested that this stigma makes FASD even more problematic than other invisible disabilities. She emphasized that it is important to "do it better" in terms of helping people with FASD so that eventually "we get to right."

Dr. King said that she had heard several people comment that there is a need for FASD-specific education, resources, and training, and that programs that broadly target people with cognitive disabilities or mental health issues were not meeting the needs of people with FASD. She said that she does not think it is an either/or choice and that there is value to both broad programs and FASD-specific resources. She said that her comment reflected her view as a former primary care provider, and not as someone associated with NIH. She went on to explain that she thinks the field should not lose sight of the opportunity to incorporate FASD into existing broader programs. She stated that primary care providers are overextended and under-resourced, so incorporating FASD information into bigger programs can benefit everyone.

Dr. Balachova agreed that it is important to integrate FASD with other disabilities into the developmental disability networks and health care systems, as it may improve access to services.

Dr. Dunty read two public comments:

- From a research perspective, it is imperative to translate findings into lay language.
- FASD is a social justice issue because it is not considered, under U.S. law, as a disability.

Mr. Dunbar-Cooper spoke next, explaining that he had been in the field since 2008. He said that messages warning people against drinking while pregnant are out there. He spoke about the difficulties in having FASD recognized as a risk factor in SAMHSA's programs that target underage or youth populations. He further emphasized that it is important to have more efforts around primary prevention (e.g., to stop alcohol-exposed pregnancies) and expanded on different types of prevention efforts.

Dr. Balachova explained that while members understand the importance of primary prevention, this meeting was focused more on services and supports for people with FASD than it did on primary prevention. She also emphasized how much work had been put into putting on this meeting and thanked Ms. Lutke for her efforts.

Dr. Reichard addressed the earlier comment that FASD is not considered a disability by law in the U.S. She pointed out that the ADA covers any person who has a physical or mental impairment that substantially limits one or more major life activity. She thinks that FASD fits that definition. She also said that the definition includes language about having a record of such an impairment, so that even if a person with FASD does not define themselves as having a disability, they still qualify under the ADA if someone else considers them to have the limitation(s). She emphasized that it is important for people with FASD to know they are covered under ADA law.

Dr. Balachova suggested that following up on Dr. Reichard's idea may help more people get services. She also said that the ICCFASD members follow up after the meeting to discuss points made and determine what they can do moving forward based on the meeting.

Adjournment

Dr. Powell thanked the audience for listening and for their input. She reminded listeners that anyone can contact ICCFASD, as the committee looks forward to their input. Dr. Powell also thanked the speakers, including the federal members and panel members. She acknowledged that the panel members are asked to speak about their lived experience on many occasions and that it can be taxing, but she appreciates their willingness to share and said that ICCFASD is truly listening. She also acknowledged the recommendations to broaden ICCFASD membership. She thanked Dr. Balachova for putting the meeting together.

Appendix A: Abbreviations

Abbreviation	Term
ACF	Administration for Children and Families
ACL	Administration for Community Living
ADHD	Attention-deficit/hyperactivity disorder
ALC	Adult Leadership Committee (of the FASD Changemakers)
ASPE	Office of the Assistant Secretary for Planning and Evaluation
AUD	Alcohol Use Disorder
CAB	Community Advisory Board
CAN FASD	Canada FASD Research Network
CBPR	Community-based Participatory Research
CDC	Centers for Disease Control and Prevention
CMMI	Center for Medicare & Medicaid Innovation
CMS	Centers for Medicare & Medicaid Services
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
FOA	Funding Opportunity Announcement
HBCD	HEALTHy Brain and Child Development study
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
ICCFASD	Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders
IDD	Intellectual and Developmental Disabilities
IHS	Indian Health Services
IMPROVE	Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone
MCHB	Maternal and Child Health Bureau
MMWR	Morbidity and Mortality Weekly Report
MOM	Maternal Opioid Misuse (Model)
NCAPPS	National Center on Advancing Person-Centered Practices and Systems
NCSACW	National Center on Substance Abuse and Child Welfare
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NICHD	The <i>Eunice Kennedy Shriver</i> National Institute of Child Health and Human Development
NIDA	National Institute on Drug Abuse
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NOFAS	National Organization on Fetal Alcohol Syndrome
ODD	Opioid Use Disorder
PAE	Prenatal Alcohol Exposure
SAMHSA	Substance Abuse and Mental Health Services Administration
SBI	Screening and brief intervention
SBIRT	Screening, brief intervention, and referral to treatment
SUD	Substance Use Disorder

Appendix B: ICCFASD Membership List

Primary Representatives

ICCFASD

Chairperson

Patricia A. Powell, Ph.D.

Deputy Director
National Institute on Alcohol Abuse and
Alcoholism (NIAAA)
National Institutes of Health
6700B Rockledge Drive,
Room 1207, MSC 6902
Bethesda, MD 20892- 6902
Phone: (301) 443-5106
Fax: (301) 443-7043
Email: ppowell@mail.nih.gov
For deliveries: Bethesda, MD 20817

ICCFASD

Scientific Coordinator and Executive Secretary

Tatiana Balachova, Ph.D.

Health Scientist Administrator
Division of Epidemiology and
Prevention Research
National Institute on Alcohol Abuse and
Alcoholism (NIAAA)
National Institutes of Health
6700B Rockledge Drive,
Room 1244, MSC 6902
Bethesda, MD 20892- 6902
Phone: (301) 443-5726
Email: tatiana.balachova@nih.gov
For deliveries: Bethesda, MD 20817

Caitlin Cross-Barnet, Ph.D.

Social Science Research Analyst
Research and Rapid-cycle Evaluation
Group
Center for Medicare and Medicaid
Innovation (CMMI)
Centers for Medicare and Medicaid
Services (CMS)
7500 Security Blvd., Mail Stop: WB-19-72
Baltimore, MD 21244
Phone: (410) 786-4912
Email: caitlin.cross-barnet@cms.hhs.gov

Jon Dunbar-Cooper, M.A., C.P.P.

Public Health Analyst
Division of Systems Development
Center for Substance Abuse Prevention
Substance Abuse and Mental Health
Services Administration (SAMSA)
5600 Fishers Lane
Sixteenth Floor - Room – 16E07B
Rockville, MD 20852
Phone: (240) 276-2573
Fax: (240) 276-2410
Email: jon.dunbar@samhsa.hhs.gov

William Dunty, Ph.D.

Program Director
Division of Metabolism and Health Effects
National Institute on Alcohol Abuse and
Alcoholism (NIAAA)
National Institutes of Health
6700B Rockledge Drive,
Room 1233, MSC 6902
Bethesda, MD 20892- 6902
Phone: (301) 443-7351
Email: duntyw@mail.nih.gov
For deliveries: Bethesda, MD 20817

Shin Y. Kim, M.P.H.

Team Lead, Lead Health Scientist
Prenatal Substance Exposure Surveillance
and Research Team
Infant Outcomes Monitoring, Research, and
Prevention Branch
Division of Birth Defects and Infant
Disorders
National Center on Birth Defects and
Developmental Disabilities (NCBDDD)
Centers for Disease Control and Prevention
4770 Buford Hwy NE, MS S106-3
Atlanta, GA 30341
Phone: (770) 488-6281
Email: skim1@cdc.gov

Tracy M. King, M.D., M.P.H.

Medical Officer
Intellectual and Developmental
Disabilities Branch
Eunice Kennedy Shriver National
Institute of Child Health and Human
Development (NICHD)
National Institutes of Health
6710B Rockledge Dr.
Room 2227D, MSC 7002
Bethesda, MD 20892-7002
Phone: (301) 402-1822
Email: tracy.king@nih.gov
For FedEx/UPS/courier deliveries:
6710B Rockledge Dr., Room 2227D
Bethesda, MD 20817

Dawn Levinson, M.S.W.

Deputy Director
Division of Healthy Start and Perinatal
Services
Maternal and Child Health Bureau
Health Resources and Services
Administration (HRSA)
5600 Fishers Lane, Room 18N76
Rockville, MD 20857
Office: (301) 945-0879
Email: dlevinson@hrsa.gov

Sharon Newburg-Rinn, Ph.D.

Social Science Research Analyst
Office of Data, Analysis, Research and
Evaluation
Administration for Children and
Families (ACF)
Portals Building, Room 8116
1250 Maryland Avenue, SW
Washington, DC 20024
Phone: (202) 205-0749
Email: [sharon.newburg-
rinn@acf.hhs.gov](mailto:sharon.newburg-rinn@acf.hhs.gov)

Tina Pattara-Lau, M.D., FACOG

Maternal and Child Health Consultant
Office of Clinical and Preventive
Services
Indian Health Service (IHS)
5600 Fishers Lane
Rockville, MD 20857
Email: tina.pattara-lau@ihs.gov

Janani Prabhakar, Ph.D.

Program Officer
HEALTHy Brain and Child
Development (HBCD) Study
Division of Neuroscience and
Behavior
National Institute on Drug Abuse
(NIDA)
National Institutes of Health
6001 Executive Boulevard, Room
5163
Bethesda, MD 20892-9589
Phone: (301) 827-4729
Email: janani.prabhakar@nih.gov

Amanda Reichard, Ph.D.

Project Officer
National Institute on Disability,
Independent Living, and
Rehabilitation Research
Administration for Community Living
(ACL)
330 C St SW
Washington, D.C. 20201
Phone: (202) 795-7786
Email: amanda.reichard@acl.hhs.gov

Chris Sarampote, Ph.D.

Chief, Biomarker and Intervention
Development for Childhood-Onset
Disorders Branch
Division of Translational Research
National Institute of Mental Health
(NIMH)
National Institutes of Health
6001 Executive Boulevard, Room
7164, MSC 9617
Bethesda, MD 20892-9617
Telephone: (301) 443-1959
Email:
<mailto:mcsarampo@mail.nih.gov>

Kristina West, M.S., LL.M.

Social Science Analyst
Division of Behavioral Health Policy
Office of Behavioral Health,
Disability, and Aging Policy
Office of the Assistant Secretary for
Planning and Evaluation (ASPE)
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201
Phone: 202-205-6479
Email: kristina.west@hhs.gov

Alternate Representatives

Elizabeth Parra Dang, M.P.H.

Behavioral Scientist
Health Communication and Research Translation
Team
Infant Outcomes Monitoring, Research, and
Prevention Branch
Division of Birth Defects and Infant Disorders
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy NE, MS S106-3
Atlanta, GA 30341
Phone: (404) 498-3947
Email: edang@cdc.gov

Andrea M. Harris, M.S.

Lead Public Health Advisor
Center for Substance Abuse Prevention
Substance Abuse and Mental Health
Services Administration (SAMSA)
5600 Fishers Lane, 13E77-D
Rockville, MD 20857
Phone: (240) 276-2441
Fax: (240)276-2560
Email: andrea.harris@samhsa.hhs.gov

Keisher S. Highsmith, Dr.P.H.

Commander, United States Public Health Service
Health Scientist Administrator
Division of Epidemiology, Services and Prevention
Research
National Institute on Drug Abuse (NIDA)
Email: highsmithks@nih.gov

Deidra Roach, M.D.

Health Scientist Administrator
Division of Treatment and Recovery
Research
National Institute on Alcohol Abuse and
Alcoholism
National Institutes of Health
6700B Rockledge Drive,
Room 1330, MSC 6902
Bethesda, MD 20892- 6902
Phone: (301) 443-5820
Fax: (301) 443-8774
Email: droach@mail.nih.gov
For deliveries:
Bethesda, MD 20817

Mary Kate Weber, M.P.H.

Behavioral Scientist
Prenatal Substance Exposure Surveillance and
Research Team
Infant Outcomes Monitoring, Research, and
Prevention Branch
Division of Birth Defects and Infant Disorders
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy, Mailstop S106-3
Atlanta, GA 30341
Phone: (404) 498-3926
Email: mweber@cdc.gov

JB Kinlacheeny, M.P.H.

Public Health Advisor
Alcohol and Substance Abuse
Program National Lead
Office of Clinical and Preventive
Services
Division of Behavioral Health
Indian Health Service (IHS)
5600 Fishers Lane
Mail stop 08N34B
Rockville, MD 20857
Office: (301) 443-0104
Email: jb.kinlacheeny@ihs.gov

Julia L. Zehr, Ph.D.

Branch Chief
Developmental Mechanisms and Trajectories of
Psychopathology Branch
Division of Translational Research
National Institute of Mental Health
National Institutes of Health
6001 Executive Blvd., MSC 9617
Bethesda, MD 20892
Phone: 301-443-1617
Fax: 301-480-4415
Email: zehrj@mail.nih.gov
For deliveries: Rockville, MD 20852