



Spring 2021 Public Meeting Summary

Friday, April 23, 2021

Table of Contents

ICCFASD Spring 2021 Public Meeting Videocast link	1
ICCFASD Meeting Participants	1
ICCFASD Agenda	5
Welcome, Introduction, and Comments	6
Overview of ICCFASD.....	6
Special Panel: FASD Prevention and Services During the COVID-19 Pandemic: Focus on Women and Individuals Living with FASD.....	6
Part 1	6
Alcohol Use in Women in the 20th Century and the Impact of COVID-19 Pandemic	6
FASD Prevention and Services for Women During COVID-19 Pandemic – Title V Measurement of FASD	9
Part 2	13
FASD Diagnostic Services for Children During the COVID-19 Pandemic	14
Safe Return to In-person School for Children with Disabilities	15
Reports of Activities from FY2020: ICCFASD Federal Agencies.....	18
The Administration for Children and Families (ACF).....	18
Administration for Community Living (ACL)	19
Office of the Assistant Secretary for Planning and Evaluation (ASPE)	20
Centers for Medicare & Medicaid Services (CMS).....	20
Discussion.....	22
The National Institute on Alcohol Abuse and Alcoholism (NIAAA).....	22
The National Institute on Drug Abuse (NIDA).....	23
The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) .	24
The National Institute of Mental Health (NIMH).....	24
Discussion.....	26
Centers for Disease Control and Prevention (CDC)	26
The Indian Health Service (IHS)	27
The Substance Abuse and Mental Health Services Administration (SAMHSA)	28
The Health Resources and Services Administration (HRSA).....	29
Discussion ICCFASD Agency Representatives, Speakers, and Guests	31
Adjournment	33
Appendix: Abbreviations	34

ICCFASD Spring 2021 Public Meeting

A videocast of the ICCFASD Spring 2021 Public Meeting held on April 23, 2021 is available on the NIH videocast [website](#).

ICCFASD Meeting Participants

ICCFASD Chairperson

Patricia A. Powell, PhD
Deputy Director
National Institute on Alcohol Abuse and Alcoholism (NIAAA)

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

Minki Chatterji, PhD
Program Officer (Health Science Administrator)
Prevention Research Branch (PRB)
Division of Epidemiology, Services and Prevention Research
National Institute on Drug Abuse (NIDA), NIH, HHS

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
Division of Metabolism and Health Effects
National Institute on Alcohol Abuse and Alcoholism, 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

JB Kinlacheeny, MPH
Public Health Advisor
National Lead - Alcohol and Substance Abuse Program
Office of Clinical and Preventive Services
Division of Behavioral Health
Indian Health Services Headquarters (IHS), HHS

Dawn Levinson, MSW
Behavioral Health Lead
Division of Healthy Start and Perinatal Services
Maternal and Child Health Bureau
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

Sarah Ruiz, PhD
Associate Director
Office of Research Sciences
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

Deidra Roach, MD
Health Scientist Administrator
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

Special Advisor to ICCFASD Leadership

Sally M. Anderson, PhD

Invited Guest Speakers

Christina A. Gurnett, MD, PhD
A. Ernest and Jane G. Stein Professor of Developmental Neurology
Professor of Neurology
Head, Division of Pediatric and Developmental Neurology
Associate Director, Institute of Clinical and Translational Sciences
Washington University School of Medicine
Neurologist-in-Chief, St. Louis Children's Hospital
St Louis, Missouri

Erin Johnson, PhD
Clinical Psychologist
Southcentral Foundation
Child and Family Developmental Services
Anchorage, Alaska

Katherine M. Keyes, PhD
Associate Professor of Epidemiology
Columbia University
Mailman School of Public Health
New York, New York

Tara Trego, M.Ed.
Director
Bureau of Family Health
Pennsylvania Title V Maternal and Child Health Services Block Grant
Harrisburg, Pennsylvania

Keriann Uesugi, PhD, MPH
Health Scientist
Division of State and Community Health
Maternal and Child Health Bureau
Health Resources Services Administration (HRSA), HHS
Rockville, Maryland

ICCFASD Agenda

AGENDA	
10:30 am	Zoom room opens
11:00 am	Welcome, Introductions, and Comments <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i> <i>ICCFASD Members</i>
11:15 am	Overview of ICCFASD <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and</i> <i>Executive Secretary</i>
11:20 am	Special Panel FASD Prevention and Services During the COVID-19 Pandemic: Focus on Women and Individuals Living with FASD
	Moderator: <i>Dawn Levinson, MSW, Health Resources and Services Administration (HRSA)</i>
	Trends in U.S. Women’s Binge Drinking in Middle Adulthood by Socioeconomic Status, 2006 - 2018 <i>Katherine Keyes, PhD, Columbia University, NY</i>
	FASD Prevention and Services for Women During COVID-19 Pandemic <i>Keriann Uesugi, PhD, MPH, Maternal and Child Health Bureau, HRSA</i> <i>Tara Trego, M.Ed., Pennsylvania Department of Health, Harrisburg, PA</i>
	Break
	Moderator: <i>Tracy M. King, MD, MPH, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)</i>
	FASD Diagnostic Services for Children During the COVID-19 Pandemic <i>Erin Johnson, PhD, Southcentral Foundation, Anchorage, AK</i>
	Safe Return to In-person School for Children with Disabilities <i>Christina A. Gurnett, MD, PhD, Washington University School of Medicine, St. Louis, MO</i>
1:30 pm	LUNCH BREAK
2:00 pm	Reports of Activities from FY2020: ICCFASD Federal Agencies <i>ACF, ACL, ASPE, CMS</i>
	Q&A, Discussion
	Reports of Activities from FY2020: ICCFASD Federal Agencies <i>NIAAA, NIDA, NICHD, NIMH</i>
	Q&A, Discussion
	Break
	Reports of Activities from FY2020: ICCFASD Federal Agencies <i>CDC, IHS, SAMHSA, HRSA</i>
	Q&A, Discussion
4:00 pm	General Discussion, ICCFASD Agency Representatives, Speakers, and Guests
4:30 pm	Adjournment <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i> <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and</i> <i>Executive Secretary</i>

Welcome, Introduction, and Comments

Patricia Powell, PhD, 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), welcomed participants to the annual ICCFASD meeting. She explained that this is a hybrid meeting with ICCFASD members and speakers on Zoom, as well as a live NIH Videocast, which allows more people to attend. She then gave a brief overview of the meeting's agenda, followed by introductions of speakers and agency representatives.

Overview of ICCFASD

Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary

Dr. Balachova spoke about the mission of the ICCFASD, which is to enhance and increase communication, collaboration, and partnership among disciplines and federal agencies to address health, education, and other areas relevant to prenatal exposure to alcohol. She then stated ICCFASD's vision, which is that collaborative partnership, including governmental and other organizational resources, will reduce the prevalence of FASD and will provide appropriate interventions and support to families affected by FASD.

Dr. Balachova noted that ICCFASD was created in 1996 by NIAAA following an Institute of Medicine study of fetal alcohol syndrome and related birth defects. Recommendations of the IOM study, which was undertaken in response to a Congressional inquiry in 1994, included establishing an interagency group of representatives from relevant federal agencies to coordinate national efforts. ICCFASD is supported and administered by NIAAA. The diverse missions of ICCFASD member agencies include basic and clinical research, treatment and health care delivery, disease prevention, education, and community living support, and reflect the complex issues faced by individuals affected by FASD.

Dr. Balachova showed a chart of current and past ICCFASD partners, noting that many are within the Department of Health and Human Services. She stated that the Administration for Community Living (ACL) joined the ICCFASD in 2020 and introduced ACL's representative, Dr. Ruiz. Dr. Balachova stated that the ICCFASD started a strategic planning process in 2020 and that a Strategic Planning Working Group (Working Group) had been formed. They are currently drafting an outline to request input from the public to inform the strategic planning process. She ended her overview with mention of the ICCFASD website (<https://www.niaaa.nih.gov/interagency-coordinating-committee-fetal-alcohol-spectrum-disorders>), where more information can be found.

References:

Institute of Medicine. Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment. Washington, DC: The National Academies Press. 1996. <https://doi.org/10.17226/4991>.

Special Panel: FASD Prevention and Services During the COVID-19 Pandemic: Focus on Women and Individuals Living with FASD

Part 1

Moderator, Dawn Levinson, MSW, Health Resources and Services Administration (HRSA)

Alcohol Use in Women in the 20th Century and the Impact of COVID-19 Pandemic

Katherine Keyes, PhD, Columbia University, NY

Dr. Keyes thanked the ICCFASD for being invited to speak and said that she is fortunate to be able to present epidemiological data on drinking trends in women and the implications of those trends. She began her presentation

with an orientation to some important context – namely, that although alcohol consumption is common in the U.S., it confers adverse health risks, even at low levels of consumption. Over the last 20 years, the public health understanding of alcohol’s toxicity has changed dramatically. At early as the 1980s, it was believed that low levels of drinking were beneficial, especially to heart health. However, the studies that showed such benefits have now been disputed and called into question since many were funded by the alcohol industry. Currently, evidence suggests that there is no level of alcohol consumption that improves health and that even low levels can lead to adverse health outcomes. However, alcohol consumption, including binge drinking is increasing in the U.S. Dr. Keyes then listed some of the adverse effects of binge drinking, including injury, poisoning, cardiovascular disease, cancer, and liver damage.

Rates of binge drinking have been increasing in the U.S. since about 2005, and this increase is almost entirely attributable to an increase in binge drinking among women. Although many people view binge drinking as a youth phenomenon, recently, women in mid-life (in their 30s and 40s) have had increases in binge drinking rates, with the prevalence almost doubling from 20 to 36% from 2016 to 2018. The cohorts of women that have demonstrated the strongest increases in drinking are the ones born in the 1970s, 1980s, and 1990s. Although one hypothesis for these increases is that women are delaying having children, Dr. Keyes has shown that binge drinking is increasing among both women with children and women without children, so family composition does not seem to explain the increased rates of binge drinking. The rate of binge drinking among younger men (ages 18-29) has decreased from 2006 to 2018, but it has increased in women of the same age and in both older men and women (ages 45-55).

Dr. Keyes then went into more detail about the characteristics of women whose binge drinking rates have increased over the last few decades. She focused on two studies that her group has done, led by a doctoral student, Sarah McKetta. Women in midlife who are increasing their alcohol consumption are generally thought of as Gen X or millennial. They are the also completing higher levels of education at higher rates than men, entering the workforce at unprecedented levels, and holding high income jobs. Women are now strong market participators, and the alcohol sector has taken note by creating products centered around women and by creating messaging around alcohol consumption as self-care or as a reward. This is known as the “pinkening” of the alcohol market and has been going on for over two decades.

In terms of women in mid-life, who are the ones who show the largest increases in binge drinking, Dr. Keyes thinks that socioeconomic gains, especially in income and education, may be important determinants of binge drinking trends. She pointed out that both college attendance and income levels influence alcohol consumption. She described a dose-response relationship, based on data from Gallup, between overall alcohol consumption and education and between overall alcohol consumption and income. The highest levels of drinking correspond to the highest levels of income and education. She stated that the national shift in women’s socioeconomic attainment may be a key component of women’s binge drinking patterns.

To further explore this hypothesis of a relationship between binge drinking rates and education and income levels, her group examined binge drinking trends in mid-life women across gradients of income and education. They used self-reported data from the National Health Interview Surveys from women aged 30 to 49 and measured the past-month’s binge drinking (defined as four or more drinks in a single sitting). They examined trends stratified by education categories (from less than high school to master’s level or higher) and income (from less than 100% of the federal poverty line [FPL] to over 400% FPL).

When looking at data stratified by education, they saw an increase in binge drinking among all women across the study years (2006-2018). However, the increase was not significant in women with less than high school education. The highest increases in binge drinking among women in mid-life were among women with the highest education (college degree or master’s degree or higher). Among women with a college degree, the prevalence of binge drinking increased from 14% in 2006 to 34% in 2018, compared to an increase from 15% to 22% in women with a high school education. According to their analyses, there is a threshold for binge drinking at the level of a college degree, beyond which binge drinking rates did not increase further with more education. They also looked at the data stratified by income, which showed a trend similar to the education data – that is, with higher levels of income, the prevalence of binge drinking increased, from 17% in 2006 to 36% in 2018 for women with incomes at or above

400% FPL, while it went from 11% to 16% over the same time period for women with incomes less than 100% FPL. Although they saw similar patterns between binge drinking and income and between binge drinking and education in men, the trends were much less pronounced in men than they were in women.

Dr. Keyes then summed up the data she had spoken about: that all groups of women increased their binge drinking throughout the study period and that these increases were most concentrated among women with the highest levels of income and education. They also saw a threshold effect at the level of college completion.

Dr. Keyes then started discussing her group's interest in determining the role of labor in the observed increases in binge drinking among women. She explained that various dimensions of labor force engagement are related to alcohol consumption patterns. One such dimension is a person's occupation, which confers varying environmental exposures, physical risks, and workplace norms and stressors, which may influence alcohol use. To understand how these dimensions of labor pertain to gendered binge drinking trends among midlife adults in recent years, Dr. Keyes examined trends in past-year binge drinking according to occupation, work prestige, and work structure. Her study sample was National Health Interview Survey data from U.S. men and women in the civilian labor force, from 2006 to 2018. Binge drinking was defined as four or more drinks in a sitting for women, and five or more for men. Dr. Keyes described how occupation, prestige, and work structure data were gathered and coded.

She first describes the trends observed in gendered trends in binge drinking by individual occupation. Men and women in higher (relative to low) prestige, authority, autonomy, expertise occupations increased binge drinking. Although binge drinking increased for both men and women in all high-prestige individual occupations over the time period studied, the increases for women were more pronounced than those in men for nearly every individual occupation. Additionally, the highest increases were in legal professions for both men and women. Among low-prestige occupations, men did not have increases in binge drinking over the time period studied. Women in three out of ten low-prestige occupations (production, administrative, and sales) demonstrated increases in binge drinking, but to a lesser extent than their high-prestige counterparts. The trends for binge drinking with respect to general occupation prestige and work structure followed similar patterns, namely that increases in binge drinking were most pronounced among women with high prestige occupations and with high-authority and high-autonomy occupations.

Dr. Keyes then summarized their two main findings from the labor data analysis: both men and women in higher prestige and higher authority occupations increased binge drinking over the time period studied, and that women's increases were steeper than men's.

This implies that labor force participation and changes in women's labor roles may contribute to the national trends in binge drinking. However, since these were all descriptive studies, causal inferences cannot be made, but Dr. Keyes elaborates on some explanatory hypotheses. She stated that socioeconomic determinants are highly relevant to understanding why women are drinking more, and for example, women may be increasing their leisure spending on alcohol and may be more vulnerable to messaging around heart health and alcohol, even though that benefit has been debunked. Dr. Keyes stated that both stress and drinking as a coping mechanism may play a role in the binge drinking trends among women, and that this stress may be caused by different things, such as high-status careers, the responsibility for performing most household and childcare duties, and exposure to gender-specific work-related stress such as sexism and being overlooked for promotions, which may be more of an issue in higher-status positions compared to lower-status positions. However, since binge drinking increased for all women, Dr. Keyes emphasized the importance of identifying population-level causes that go beyond the labor variables they studied.

Dr. Keyes then turned her attention to the impact of COVID-19 and concerns around potential increases in alcohol consumption during the COVID-19 pandemic. Utilizing data from the Understanding America Study, her group looked at trends in daily drinking during the pandemic and in years prior to the pandemic. Although there was a slight increase in the predicted count of past week drinking days for both men and women, there was a difference by COVID-19 burden. The biggest increases in daily drinking during the pandemic were in states with the lowest COVID-19 burden which may be related to broad categories of policy changes and reduced consumption in bars and restaurants in states with the high burden of COVID-19 disease. Dr. Keyes emphasized that this data shows how important it is to screen not just for COVID-19 symptoms, but for all health risk behaviors.

She closed her talk by pointing out that care providers and policymakers should remain mindful of the fact that focusing resources on the pandemic should not come at the expense of screening and managing other health risks.

References:

McKetta S, Keyes KM. Trends in U.S. women’s binge drinking in middle adulthood by socioeconomic status, 2006–2018. *Drug and Alcohol Dependence*, Volume 212, 2020. doi:10.1016/j.drugalcdep.2020.108026.

McKetta S, Morrison CN, Keyes KM. Trends in US Alcohol Consumption Frequency During the First Wave of the SARS-CoV-2 Pandemic. *Alcohol Clin Exp Res*. 2021 Apr;45(4):773-783. doi: 10.1111/acer.14575. Epub 2021 Mar 3. PMID: 33587290; PMCID: PMC8014717.

McKetta S, Prins SJ, Bates LM, Platt JM, Keyes KM. US trends in binge drinking by gender, occupation, prestige, and work structure among adults in the midlife, 2006–2018. *Ann Epidemiol*. 2021 Oct;62:22-29. doi: 10.1016/j.annepidem.2021.06.004. Epub 2021 Jun 20. PMID: 34161795; PMCID: PMC8463484.

Research was funded by the National Institute on Alcohol Abuse and Alcoholism, R01 AA026861 (PI: Keyes and Jager)

FASD Prevention and Services for Women During COVID-19 Pandemic – Title V Measurement of FASD

Keriann Uesugi, PhD, MPH, Maternal and Child Health Bureau, HRSA
Tara Trego, M.Ed., Pennsylvania Department of Health, Harrisburg, PA

Dr. Uesugi introduced herself and said that her division within the Health Resources & Services Administration (HRSA) administers the Title V Maternal and Child Health Services Block Grant Program. She said that she would be talking about how Title V is involved with FASD prevention and monitoring.

She began with an explanation of Title V block grants, so called because they are authorized by Title V of the Social Security Act. The grants go to 59 jurisdictions, including all 50 states, and the mission of the grants is to improve the health and well-being of America’s mothers, infants, children, and youth. The grants give jurisdictions flexibility in spending the funds, although at least 30% needs to be spent on children with special health care needs, and at least another 30% needs to be spent on primary and preventive care services. Administrative costs are capped at 10%.

The grants are also designed to hold recipients accountable. Grant recipients need to conduct an assessment every five years to determine the priorities of the maternal and child populations within their jurisdiction. Based on this analysis, they then develop a five year action plan. They also submit both annual reports that reflect prior year activities and an application for the upcoming year’s plans.

Accountability is partly achieved by tracking state and national progress against a performance measurement system which includes 36 outcome measures at the national level. There are also national performance measures which are upstream of outcomes, indicate whether program efforts are on the right track, and influence the outcome measures. For example, in terms of FASD-related performance measures, they don’t want to wait until children are diagnosed with FASD to find out whether they are making progress. Therefore, they look at the percent of women who attend a well woman visit each year where preventive services, such as alcohol screening, brief intervention, and referral to treatment should occur.

State action plans are tied to national performance and outcome measures. Moreover, states are required, by Title V legislation, to report on specific measures, including the proportion of infants born with fetal alcohol syndrome, a measure which has been operationalized as “percent of women who drink alcohol in the last three months of pregnancy.” This operationalized measure and HRSA’s data come from the CDC Pregnancy Risk Assessment and Monitoring System (PRAMS), an annual state-level survey of women who recently gave birth. However, states can choose whether or not to include the specific survey question in their version of the PRAMS, as the question’s inclusion became optional in 2016. The national outcome measure is also related to a Healthy People 2030 objective: Increase abstinence from alcohol among pregnant women, but the data for the Healthy People objective

comes from a different source (the National Survey on Drug Use and Health [NSDUH]).

Dr. Uesugi then spoke about 2019 state-level data for this national outcome measure. Colorado had the highest percent of women who drank alcohol in the last three months of pregnancy, at 15.6%, while Georgia had the lowest at 4.1%. The national estimate, which is based only on states that included the relevant survey question in their PRAMS survey, is 7.5%. However, there are limitations to this data – specifically, that not every jurisdiction collects this data (since the survey question is optional) and that states have to meet a minimum response rate before releasing the data. The strengths of the PRAMS data are that it provides state-level data, meets the legislative reporting requirement, and only samples women with a recent, live birth.

States recently conducted their 2020 Needs Assessment and set new priorities. Dr. Uesugi stated that four states had set a priority focused on reducing substance use, including alcohol, during pregnancy, and that one of them, Alaska, is developing a state performance measure to monitor progress. She then spoke about strategies that states are using to address their priorities, such as increasing screening of alcohol use for all women of childbearing age and collaborating with state FASD taskforces.

Ms. Trego then introduced herself and explained that she would present about home visiting programs, including conducting screening for alcohol use and other behavioral health issues during pregnancy and providing interventions and referrals to other resources for women. First she spoke about how Pennsylvania developed some of their strategies around using their Title V block grant. During their required five-year Pennsylvania Maternal and Child Health Needs and Capacity Assessment in 2015, they determined that there was a need to focus on preconception and interconception health care and support to help address behaviors and risk factors before pregnancy and before such behaviors would have a negative effect on parenting and the infant health. Based on the assessment, they created a new priority, which was that adolescents and women of childbearing age should have access to and participate in preconception and interconception health care and support. They also included a priority to ensure that people needing services were identified and referred for behavioral health services. For that, women receiving prenatal care or home visiting are screened for behavioral health and referred for assessment and services as needed. She then spoke about data that went into informing those two priorities. Although the numbers vary over time from 2007 to 2018, the percent of Pennsylvania women who reported using alcohol during the last three months of pregnancy was between six and eight. Pennsylvania also looked at outcome measures related to infants born with neonatal abstinence syndrome and found that its numbers are significantly higher than the national numbers. This data indicated a need for strategies to address behavioral health needs in the state.

Ms. Trego then showed data that reflected how many alcoholic drinks PRAMS respondents had in an average week in the three months before pregnancy, noting that the highest percentage of women, about 40% to 50%, were reporting having less than one drink per week. She then showed data about alcohol consumption by PRAMS respondents in the last three months of their pregnancies, noting that most women (around 90%) reported no drinking, while some women (about 7-9%) reported less than one drink per week, and some (1-2%) reported having between one and three drinks per week. Ms. Trego noted that even though the numbers are small, there is still concern around women who are drinking during the last three months of their pregnancies and that the percent of women drinking during this time increased from 2012 to 2015. When the data is broken down by demographic characteristics, it is apparent that certain groups have higher alcohol usage in the last three months of pregnancy, including age groups over 35 years, people who are married, people who have a higher education level, people who have relatively high income levels, people who are white, and people who are not Hispanic. These patterns are the opposite of the patterns observed for many other concerning behaviors for which younger, single, lower income families are most at risk.

The data about risk factors influenced Pennsylvania's strategies to address the two aforementioned priorities. The strategies were to 1) implement evidence-based or informed home visiting services, 2) use motivational interviewing techniques, and 3) use the integrated screening tool, the 5Ps, which was developed by the Institute for Health and Recovery. Ms. Trego then went into more detail on each of these strategies, starting with home visiting services. County and municipal health departments chose the evidence-based home visiting programs or curriculums that the state Department of Health ended up using. Pennsylvania has a number of evidence-based or

informed home visiting models and curriculums, including Healthy Families America, Early Head Start Home Based Options, Nurse Family Partnership, Partners for a Healthy Baby, and Bright Futures. The majority of home visiting services are available through the Maternal, Infant and Early childhood home visiting program (MIECHV). Title V serves is a small percent of the people receiving home visiting services in the state.

To implement the other two strategies – motivational interviewing and the 5Ps – Pennsylvania’s Bureau of Family Health trained 10 of Pennsylvania’s county and municipal health departments. Ms. Trego then described motivational interviewing as a style of communication that is a combination of good listening and giving information and advice, and is designed to empower people to change by drawing out their own capacity for change while maintaining client autonomy. Since motivational interviewing requires the clinician to engage with the client as an equal partner and takes self-awareness from the clinician, training and practice are essential. The county and municipal health departments were also trained on the 5Ps screening tool. The 5Ps refer to the parents, peers, partner, past, and present. The tool is quick, easy, and non-threatening and is meant to facilitate conversation about a patient’s current or past alcohol or drug use or use among people close to the patient.

The state department of health first initiated these strategies in 2017, and of the 122 health professionals who were trained on the 5Ps and motivational interviewing techniques in that year, 63 of them worked in Title V programs. Altogether, the tool assesses substance use, domestic violence, and emotional health issues in an attempt to motivate women to make healthy changes in their lives. In 2017, nine County Municipal Health Departments (CMHD) home visiting programs were using 5Ps, along with Motivational Interviewing and 1,304 women enrolled in home visiting programs were screened. In 2018, there were an additional 121 people trained on the 5Ps and motivational interviewing, and 1,005 people were screened using those tools, and in 2019, 1,322 people were screened. Since that, two of nine programs have stopped using the 5Ps screening tool.

Ms. Trego then spoke about the tool’s challenges. Because the Pennsylvania Department of Health does not require the county health officials to track individual responses to the screening tool, the state has not been able to link the use of the tool to FASD rates or to how many women get referred to alcohol treatment. Additional challenges, some of which are common to their home visiting programs on the whole, include untrue answers, refusal to screen, fear of stigma, concerns about child welfare depending on how a woman answers some of the tool’s questions, and inconsistent messaging around alcohol during pregnancy, from both doctors and the media.

Ms. Trego then spoke about a major success of using the screening tool, which is that home visitors in the Title V programs feel comfortable administering it and feel that it is a good way to start a conversation regarding alcohol or drug use. Because of this comfort level, home visitors have continued using it and honed their screening skills, which allows for better conversations. The screening tool has also spread to other programs, including one that does universal screening of mothers to determine whether an infant has been exposed to substances. Ms. Trego ended by expressing her thanks for being able to present.

Discussion:

Ms. Levinson thanked the panel for their talks and summarized what the three speakers had spoken about, including state-level PRAMS data, trends in binge drinking among women, and Pennsylvania’s strategies for addressing drinking during pregnancy. She then talked specifically about the pandemic, stating that that alcohol use among adults increased by 14% from 2019 to 2020, and that binge drinking among women rose by 41% in the same timeframe. Alcohol sales also went up during the pandemic, and social isolation made it harder for people to maintain their recoveries. Stress and uncertainty during the pandemic have impacted people’s abilities to meet their basic needs, and this has increased anxiety, depression, substance use, trauma, and suicidal ideation, especially among people of color who have been disproportionately burdened by the pandemic, parents and caregivers who have had increased stress related to childcare and homeschooling.

Ms. Levinson then brought up the first question which centered around what the data show about alcohol use among women relative to race and ethnicity, and how the data might impact prevention and intervention efforts.

Dr. Uesugi answered first, saying that they do stratify their national outcome measure about drinking during the last

three months of pregnancy by several variables, including race and ethnicity. The highest rates at the national level are among Hispanic women, and the next highest level is among non-Hispanic white women, followed by American Indian and Alaska Native women. Non-Hispanic Black and non-Hispanic Asian have the lowest rates of drinking during the last three months of pregnancy.

Dr. Keyes then said that in her data, the increases in drinking that they see over the last 10 years and the magnitude of that increase by socioeconomic status do not depend on race or ethnicity. She pointed out that the concentration of exposure (to income and occupational prestige) do differ by race and ethnicity, so that the ultimate burden of drinking does vary with race and ethnicity. She also pointed out that although there was an increase in binge drinking in 2020 compared to 2019, this trend was no different than the increase from 2018 to 2019, so the problem of increased binge drinking should not be expected to go away when the pandemic is over.

Ms. Trego said that Pennsylvania is seeing trends that are similar to what Dr. Uesugi has observed in terms of race and ethnicity. She also stated that it is important to look at other questions in the PRAMS survey, such as the ones related to home visitors asking about alcohol use or other substances, as there may be differences in race and ethnicity.

Ms. Levinson then stated that these data support recommendations for universal screening.

Dr. King from NICHD asked the next question about whether there is concern that the rates at which people respond accurately to screening survey questions differ by race or ethnicity. She wondered whether that sort of thing could be the field astray in terms of where it concentrates its prevention efforts.

Ms. Trego agreed that they do have concerns with survey questions and said that they sometimes compare survey answers to independent birth record data that was collected at the hospital at the time of birth. However, she stated that they believe people fill out the PRAMS survey accurately because people fill it in anonymously at home, but there are still a lot of unknowns with respect to who is answering accurately. While they do not have a great solution to address this issue, they always keep this concern in mind when they do data analysis. She also pointed out that their sample sizes are sometimes small, so that also limits how much they can generalize data on accuracy of screening in different subpopulations.

Ms. Levinson then reminded the public watching the NIH videocast to use the box on the videocast to submit questions or send live feedback.

Dr. Uesugi, citing another set of data, said that alcohol use among pregnant women in their third trimester is about 3.5%, so much less than the 7.5% seen in PRAMS. To try to explain this difference, Dr. Uesugi pointed out that PRAMS is conducted in the home a few months after delivery, whereas the other data is gathered during pregnancy, and that this timing difference could influence how comfortable someone is with reporting alcohol use during pregnancy.

Dr. Newburg-Rinn said that the Children's Bureau collects a lot of data about children who are maltreated and children in foster care and that there is concern within the Children's Bureau that poorer people or minorities may be surveilled more. She stated that it is important to keep track of this issue and asked whether anyone had anything to say about it.

Ms. Trego said that Pennsylvania focuses on population groups at higher risk for negative outcomes, such as maternal mortality, but they are concerned that even in areas that do not have the greatest risk, there tends to be more surveillance for women and children of color.

Dr. King stated that NICHD has also been thinking about how to address, in a thoughtful way, the issue of over-surveillance, not necessarily related to alcohol use, but in terms of maltreatment more broadly.

Dr. Dunty then introduced a question from a Videocast participant about the rationale for the PRAMS's exclusive focus on preconception drinking and drinking during the third trimester, rather than the early stages of pregnancy.

Dr. Uesugi pointed out that since CDC develops and administers the PRAMS survey in partnership with states, it would be helpful to hear from CDC colleagues about this question. In terms of focusing on the last three months of

pregnancy, Dr. Uesugi said that they are sticking with measures developed in 2015 (whereas the PRAMS survey was developed in 2016) which, at the time, represented drinking during pregnancy. She said they are evaluating outcome performance measures currently to identify whether they need to be modified.

Ms. Kim, from the CDC, works closely with PRAMS, and her division has brought the question about the last three months of pregnancy and preconception to the attention of the Division of Reproductive Health. She stated that there is space and cost consideration, but also the PRAMS questions about preconception and the last three months of pregnancy were chosen when results were tested against other population-based surveys. It was found that PRAMS questions related to the earlier months of pregnancy may not have been eliciting accurate data compared to other instruments. Ms. Shin said PRAMS questions are standardized. Potentially, a question about earlier months of pregnancy could be added as a state-specific question, rather than part of the core PRAMS questions.

Ms. Levinson said that she has heard from experts in the field that if a woman is still drinking in late pregnancy, it is more likely that she is struggling with a substance use disorder compared to women who stop drinking in the first several months of pregnancy.

Dr. Anderson asked the next question about a HRSA report on the use of the 5Ps/4Ps Plus in California. She also stated that Grace Chang, a researcher who is supported by NIAAA and CDC, has written several recent review articles about important parameters around why pregnant women drink. Some of those parameters are found in the 5Ps plus.

Dr. Balachova answered by saying that there are several measures to provide screening for use of alcohol during pregnancy and that research has shown that screening women for alcohol use is very effective. Most measures do not include all parameters that the 5Ps includes. But screening is usually integrated with asking women about other aspects of their lives. In general, these are screening measures, and research supports that alcohol screening, brief intervention, and referral to treatment are effective

Dr. Anderson clarified that she was referring to a recent study by Grace Chang that showed how partner and family drinking patterns influence women's drinking during pregnancy.

Dr. Dunty then asked introduced another question from a Videocast participant about why families of lower income continue to be targeted if women of higher education and socioeconomic status have higher rates of alcohol use.

Dr. Keyes stated that this question touches on the disconnect between the communities that are surveilled and the communities that might be at highest risk. Dr. Keyes said that a takeaway from their studies is that access to alcohol services doesn't fit a certain model anymore, where there were certain groups that were perceived to have the highest alcohol burden. That burden is shifting, gender differences are converging. Currently work that is being done in the alcohol intervention area is to ensure that people of all different levels of the socioeconomic status have access to outpatient treatment. Everyone needs to know that alcohol services are effective and available, and that there's a low burden to receive services.

Dr. Anderson discussed the high-risk demographic groups of high-income women in wine country in California and women in upscale bedroom communities in Connecticut. She stated that children who were prenatally exposed to alcohol in these families had tremendous resources postnatally, while women living in poverty would not have such resources to help their children postnatally.

Ms. Levinson then announced a break, after which Dr. Balachova welcomed participants back, announced the panel's two remaining presentations, and introduced the two speakers Drs. Erin Johnson and Christina Gurnett. She then introduced the session moderator, Dr. King.

Part 2

Moderator, Tracy M. King, MD, MPH, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

FASD Diagnostic Services for Children During the COVID-19 Pandemic

Erin Johnson, PhD, Southcentral Foundation, Anchorage, AK

Dr. Johnson introduced herself. She was born and raised in Alaska and received her PhD in clinical psychology at the University of Alaska. She talked how she began her professional career as a clinical psychologist at a hospital serving population of Nome, a remote, small town in Alaska and 13 surrounding villages. She created the first FASD diagnostic team and served as the Director of Child and Family Services for several years. For the last four years, she has been working at the Indian Health Services facility, the Alaska Native Medical Center, in Anchorage, where she is part of the FASD diagnostic team. She described how the teams are set up throughout the state and what her team did to adapt to the pandemic.

Although Alaska is a large state with hundreds of small communities, many of which are not connected by roads to larger communities, and it is difficult to connect to people across the state and provide diagnoses, it is important to diagnose FASD earlier to prevent secondary issues, such as drug and alcohol abuse, disrupted education, legal involvement, and mental health problems that can be mitigated if FASD are diagnosed at younger age. FASD are very prevalent and underdiagnosed. A 2018 study that collected data on a representative group of first graders in a U.S. midwestern city found that about 5% of children had FASD. Experts estimate that the rate may double in Alaska.

Dr. Johnson then spoke about how diagnostic teams are set up. Alaska set aside funding for organizations that provide multidisciplinary teams for diagnostic purposes, and the state will reimburse a small amount per evaluation. Alaska has five diagnostic teams throughout the state. Nome's is the only one not on the road system. Only two of the teams will evaluate people over 18 years old, but some people can get evaluated through means other than the teams. All teams use the University of Washington's four-digit diagnostic code, and each team has a medical provider, psychologist, speech language pathologist, and occupational or physical therapist. Teams evaluate four primary areas: current and past growth, facial characteristics associated with FASDs, central nervous system damage, and prenatal alcohol exposure. Any damage incurred by the central nervous system is assessed, which can include anything from fine motor skills, delays, attention deficit, emotional dysregulation, language delays, and etc. It's important that a child is evaluated by a multidisciplinary team to identify areas where the child might need additional assistance.

Dr. Johnson started sharing data collected by the diagnostic teams over nearly a decade. The data showed the percent of diagnoses within each FASD diagnosis (neurobehavioral disorder, static encephalopathy, partial FAS, FAS, and other). Consistent with other areas in the U.S., in Alaska, the majority of individuals are diagnosed with a neuro behavioral disorder and static encephalopathy, with fewer being diagnosed with partial or full FAS. About 48% of people who go through Alaska diagnostic teams' evaluation are American Indian or Alaska Native (AI/AN). Dr. Johnson explained that the majority of referrals for diagnostic evaluation come from Alaska's Office of Children Services workers who are well-informed about FASD and diagnostic teams and tend to seek evaluation for children who are in custody. While Alaska Natives account for only about 20% of Alaska's population, they account for about 55% of individuals in foster care. This may be part of the reason why such a high proportion of people who go through diagnostic teams are Alaska Native or American Indian. In addition, the majority of the FASD diagnostic clinics, including the team in Anchorage, provide services to Indian Health Services beneficiaries. Therefore AI/AN children are more likely to be evaluated for FASD, compared to other ethnic groups.

Dr. Johnson then talked about what the diagnostic process looks like. Prior to the pandemic, there were three primary appointments: 1) a hearing and vision screening and a well child check with the child's primary care provider; 2) testing with Dr. Johnson to evaluate for cognitive function, academic skills, executive functioning, social functioning; and 3) clinical interviews for parents and clinical evaluations for the child, such as evaluation by a speech language pathologist and occupational therapist. At the end of that third appointment, the family leaves with a diagnosis, and a week later, they get a report with a summary of findings, recommendations, and lists of resources. Since the pandemic, the diagnostic process has gone from three appointments to more, with most providers doing the evaluations by telemedicine. Dr. Johnson's team at Alaska Native Medical Center had been set up for telemedicine appointments, they had to adapt the evaluations to be done remotely. She found that many tests,

including language and memory, could be done by video- or tele-conferencing, but some tests, like the facial analysis and nonverbal IQ and processing speed tests, among others, had to be done in person. The evaluations for speech language pathology, and physical and occupational therapy, could all be done remotely.

After diagnosis, individuals may seek services, but there are few providers (psychologists, occupational therapists, and speech-language pathologists) in the state, and the scarcity problem is more pronounced in rural areas. Moreover, providers may not live in Alaska full time, and they may not have training or knowledge about working with people with FASDs. For these reasons, it takes about nine months to get in with a provider, but Alaska has individuals and nonprofit organizations to help connect families to services. Additionally, every diagnostic team has a coordinator who assists families during and after the diagnostic process.

Dr. Johnson expressed her thanks at being invited to speak and welcomed questions.

References:

May PA, Chambers CD, Kalberg WO, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *Journal of the American Medical Association*, 319(5), 474–482, 2018.
<https://doi:10.1001/jama.2017.21896>

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O’Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Developmental and Behavioral Pediatrics*, 5(4), 228-238, 2004.

State of Alaska (2021). About Fetal Alcohol Spectrum Disorders (FASD).
<http://dhss.alaska.gov/osmap/Pages/fasd.aspx>

Safe Return to In-person School for Children with Disabilities

Christina A. Gurnett, MD, PhD, Washington University School of Medicine, St. Louis, MO

Dr. Gurnett introduced herself and gave thanks for the opportunity to talk about the safe return to in-person school for children with disabilities. She mentioned that she is a pediatric neurologist and physician scientist who runs a basic science lab at Washington University in St. Louis. Like many others, she has taken on additional new roles during the COVID 19 pandemic. Over the last year, she has gained new perspective on her patients’ lives because of seeing them both at home through telemedicine and at school where her current study took place.

She stated that she is going to talk about her ongoing community partnership to make schools safe, especially in light of the realization they had early in the pandemic that COVID-19 is having a disproportionate effect on the most vulnerable people in society, including children with disabilities. Her patients, including those with FAS, have had their lives disrupted, which has resulted in a mental health crisis that is apparent nationwide. Additionally, children with developmental and intellectual disabilities fare worse when infected with the novel coronavirus – for example, the case fatality rate for children with disabilities is about 1.6% compared to less than 0.1% in children without disabilities. The lack of in-person learning has also meant the loss of a variety of school-based services, such as speech therapy, occupational and physical therapy, socialization opportunities, and opportunities for early detection and prevention of neglect and abuse. Overall, the burden on all families has been tremendous.

There are several challenges to in-person learning, some of which are particularly relevant to children with disabilities, including problems adhering to COVID-19 mitigation strategies (i.e., mask wearing, social distancing, and hand hygiene); the fact that in school, many people interact with a child on any given day; and that for some children with impaired communication skills, it may be hard to know when a child is ill. These challenges resulted in prolonged school closures and parents choosing to homeschool or continue virtual learning until the risk subsides.

In light of all this, Dr. Gurnett was excited to see that NIH devoted resources to help underserved populations through the Rapid Acceleration and Diagnostics for Underserved Populations (RADX-UP) program, which has supported the study of school safety for children with disabilities. Dr. Gurnett’s experience in helping develop a saliva-based SARS-CoV-2 diagnostic test, led her to think of it as an opportunity to bring testing to schools since

saliva tests are better tolerated than nasal swab tests. To realize this vision, Dr. Gurnett's team at Washington University partnered with the Special School District of St. Louis County to bring free and voluntary staff and student surveillance testing to six schools that serve students with moderate to severe intellectual and developmental disabilities. These schools are considerably under-resourced. They had a phased re-opening starting in October 2020, which was a few weeks before Dr. Gurnett's study started.

Dr. Gurnett's study, COVID-19 Measuring for Special School District Testing (COMPASS-T), has a few goals, one of which is to identify effective messaging strategies to encourage testing uptake. Another goal is to understand the barriers and facilitators of testing in the communities served by the schools.

Dr. Gurnett then spoke about results from the first 14 weeks of school staff testing. Testing started in mid-November 2020, which coincided with the peak of the pandemic in the St. Louis region. The team enrolled about half of the schools' staff and has now run more than 5000 tests on staff members. Student enrollment is slower than staff enrollment, partly because of challenges with reaching parents for consent and partly due to the difficulty of collecting saliva samples. However, student enrollment is gradually growing. Dr. Gurnett then discussed a graph that shows the number of positive cases across the Special School District, reflecting positive cases both within her study and from outside studies. She mentioned that at the height of the pandemic, they had a 1.2% test positivity rate among staff who participated in the study. They found that many staff who tested positive had mild symptoms that had previously been falsely attributed to other causes such as sinus infections. Overall, school staff positivity rates in the surveillance program were not higher than community rates, despite schools being perceived as high-risk environments, and staff positivity rates for all 14 weeks of the study were also lower than pre-surgical screening of asymptomatic people in a hospital system. Compared to students on campus, the Special School District staff had comparable test positivity rates. The study's results also showed that after contact tracing, in-school transmission was rare. The study team also identified effective school mitigation strategies: children with disabilities wore masks and remained in single classrooms to minimize movement around the school. Additionally, Dr. Gurnett's team, in partnership with the Special School District, created a website, to which they are still adding content, to provide guidance to other schools based on the experience of school staff and administrators on how to keep vulnerable students safe. Dr. Gurnett mentioned another website – the ABC Science Collaborative – that has general advice for the safe return to schools.

The COMPASS-T study also has ongoing components. The team, in partnership with Dr. George Gotto who studies decision making, has created group sessions with school staff and parents that focus on how people make decisions. The team will use these sessions to understand why some parents are reluctant for their children to return to school, which will allow researchers to address the different in-person learning rates across schools, which vary from 45% to 87%. The team will also expand their surveillance testing to schools in Baltimore which will elucidate regional differences in school openings and parental attitudes toward school safety and vaccinations. Lastly, Dr. Gurnett's team, working with many community partners, will deploy a national survey, that will allow them to understand the impact of the pandemic and the barriers to testing, vaccine use, and a full return to school. She closed by thanking the audience and their community and academic partners.

References:

Research reported was funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development under Award number 3P50HD103525-01S1 to the Intellectual and Developmental Disabilities Research Center at Washington University, and the Washington University Institute of Clinical and Translational Sciences Award number UL1TR002345 from the National Center for Advancing Translational Sciences (NCATS).

Discussion:

Dr. Powell clarified a point from the first half of the panel discussion, which is that NIAAA and all federal agencies are dedicated to reducing prenatal alcohol exposure and preventing fetal alcohol spectrum disorders across all of the population. She said that prevention may look different across different populations, but that no segment of the population is being left out. The panel then proceeded to address questions submitted from NIH videocast participants or raised by ICCFASD representatives.

The first question was whether mothers are screened for FASD and how has the program adapted to needs of mothers who are diagnosed with FASD.

Dr. Johnson said that gathering such health information is part of their clinic assessment, but they might not have complete information on birth mothers since many people who bring children in for diagnostics or treatment are legal guardians or other family members. Her clinic adapts recommendations and makes sure that parents are connected to resources and individuals in the community who can provide additional support.

Another question asked whether the diagnostic protocol used by Dr. Johnson and her team was developed by them, and if so, what kind of research would help to improve their diagnostic capacity and speed of diagnosis.

Dr. Johnson said that the four-digit diagnostic code protocol from the University of Washington was selected by the state many years ago. The teams have found the protocol to be helpful and are comfortable with that aspect of their diagnostic work. Dr. Johnson said that one hindrance that slows down diagnostics is that she is the only psychologist on the FASD diagnostic team who can do testing, and she also conducts psychological testing for autism spectrum disorders, and other neurodevelopmental evaluations. She said that access to providers is a huge hindrance.

A discussant noted that the Alaska Mental Health Trust Authority released a report in 2020 that said there was a decline in the number of FASD diagnostic teams working in the state from twelve to six, and asked Dr. Johnson how concerned Alaska health officials are about this trend and how telemedicine could be used to address this shortfall in diagnostic capacity. She answered by saying that everyone is concerned and that keeping and attracting providers to rural areas has always been a struggle. Educational programs, such as a graduate psychology education program, have been developed to train professionals in the state, and Dr. Johnson has heard anecdotally of an increase in people willing to stay in the state and live or travel to rural areas. In terms of telemedicine, she said that it is a state mandate that all sorts of providers and boards look into the possibility, but broadband access is still an issue.

Dr. Gurnett was asked to speak more about the other school mitigation practices besides the testing. Dr. Gurnett agreed that surveillance is not practical to implement across the country and said that other practices were effective. These strategies included maintaining a strong commitment to a safe environment, making sure there was enough personal protective equipment for students and staff, and maintaining separation of students within classrooms. She also said that many people were surprised at how readily children with disabilities wear masks.

Dr. Gurnett was also asked about whether there is an increased need of services once children go back to school since so many children have been away from services for so long. Dr. Gurnett said that the schools she worked with were closed for about five months and that there is concern about the children who have still not yet been back to school. Dr. Gurnett said that gradual processes are helpful so not all the children are coming back at the same time, but there are still challenges. She also said that there may be a shift toward more personalized schooling, such as homeschooling for students who were not homeschooled before the pandemic.

Dr. Balachova said that some parents of children with FASD reported that studying at home had been less stressful for the child and family, compared to when they were going to school. She asked Dr. Gurnett how children with FASD are represented in Dr. Gurnett's developmental disabilities programs and whether the needs of children with FASD are similar to those of children with other disabilities. This question is important for opportunities to improve integration of children with FASD into disability services.

Dr. Gurnett said that it has been helpful to participate in this ICCFASD meeting. FASD is probably underdiagnosed in community settings. She thinks that especially since there is such an emphasis on genetic testing, colleagues and medical trainees are probably missing the diagnosis considerably. She also said that there are special needs among people with FASD that hospital settings need to think about more.

A Videocast participant asked whether Alaska has considered diagnostic assessments with single providers or smaller diagnostic teams for more straightforward cases. Dr. Johnson said that in many cases, they do simplify or shorten testing, in some cases by not repeating testing that has already been done, for example, in

school/educational settings. However, most children in the state do not have such testing done at schools.

Dr. Johnson was asked to describe the laws in Alaska around merchants selling alcohol to women while pregnant and about how laws might affect Dr. Johnson's ability to freely ask questions to women about drinking while pregnant. Dr. Johnson responded to say that there are no specific laws preventing the sale of alcohol to pregnant women. To assess a child for prenatal alcohol exposure, they ask mothers or try to get information about a birth mother's drinking from people who may have witnessed them drinking or check public records to determine if a mother became incarcerated due to alcohol consumption during their pregnancy. Most people are forthcoming with the information.

Dr. Anderson commented on increasing diagnostic capacity, an issue of which the American Academy of Pediatrics (AAP) has taken ownership and has designated children exposed to prenatal alcohol at high risk for future problems. They say these children have special needs and should be followed throughout life. The AAP has also developed tools to train pediatric health care workers to do diagnosis, but there is a problem with diagnostic codes in that the only ICD billing code is for FAS. This was true up until recently with DSM codes as well. However, there is a list of codes that a health care worker can bill under based on the symptoms that the child has, which helps address the variability of problems different children have across the FASD spectrum. Moreover, providers can get children services based on symptoms without having a diagnosis of FAS or FASD. Dr. Anderson believes it is important that Alaska and other states get on board with this training from the AAP. She emphasized that FASD are highly prevalent, and the diagnostic capacity of specialty diagnostic teams is not sufficient to evaluate these significant numbers of cases. Diagnosing children with FASD needs to be moved into pediatric care.

Reports of Activities from FY2020: ICCFASD Federal Agencies: ACF, ACL, ASPE, CMS

The Administration for Children and Families (ACF)

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

Dr. Newburg-Rinn introduced herself and stated that the Children's Bureau is interested in the topic of prenatal alcohol exposure and has been collecting and analyzing data on children who come to the attention of the welfare system, especially those in foster care. The Children Bureau's project on prenatal exposures has multiple parts, and the first focuses on what the data show in a sample of five state child welfare agencies and one tribe. They specifically look at the agencies' approaches when a child first comes to attention of child protection services, including the policies and staff training, knowledge, and attitudes. To collect data on these topics, the Children's Bureau conducts interviews and reviews case files. Dr. Newburg-Rinn stressed the importance of looking at case files because there can be discrepancies between what the case worker knows and what is in the case file notes. These discrepancies can be a problem for analyses that is based on what the state agency is reporting.

Dr. Newburg-Rinn discussed their findings from the analysis, saying that agencies' staff need more knowledge about the effects of prenatal alcohol exposure (PAE) and importance of early identification of PAE and that alcohol exposure is under-investigated compared to other drugs. Additionally, agencies often rely on toxicology tests, although such tests are not very reliable in determining PAE because traditional tests may not detect alcohol few hours after alcohol consumption. Therefore, many children who have prenatal alcohol exposure are missed and not referred for clinical evaluation for FASD.

In the second part of the study, the Children's Bureau is looking at what help can be offered to state agencies to improve the identification of prenatal alcohol exposure and improve treatment and care for affected children and youth. Part of this study is to field test new tools that can help agencies identify children with PAE and treat them. Dr. Newburg-Rinn emphasized the need in creating tools that can help social workers determine whether a child should be referred to more detailed testing for PAE, rather than trying to determine whether the child has FASD. Such tools would help social workers to determine what they should be looking, to whom they should speak, and

what are the best ways to begin and conduct conversations about alcohol use. Dr. Newburg-Rinn said that she thinks one example of a helpful policy would be that any child with neonatal abstinence syndrome (NAS) is automatically referred for the possibility of PAE since misuse of alcohol is prevalent among people who use opioids.

Dr. Newburg-Rinn concluded by saying that the new head of the Children's Bureau, Aysha Schomburg, is interested in this project and wants to ensure that during this work, families of color are not over-surveilled.

Administration for Community Living (ACL)

Sarah Ruiz, PhD, Associate Director, Office of Research Sciences, National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living

Dr. Ruiz pointed out that the Administration for Community Living (ACL) is new to the ICCFASD. Therefore, she started with an introduction about ACL, explaining that its focus is on improving the lives of older adults and people with disabilities, especially in terms of having choices about where to live, earning a living, participating in society, and making decisions about their lives. There are four sub-components to ACL: the National Institute on Disability, Independent Living, and Rehabilitation Research, the primary disability research agency for the federal government; the Administration on Disability; the Center for Innovation and Partnership; and the Administration on Aging. Dr. Ruiz said that ACL joined the ICCFASD partly because of ACL's work on the opioid crisis and its impact on older adults and people with disabilities.

Dr. Ruiz then spoke about some of ACL's FASD-related work. First, she stated that there is evidence of developmental delays as a result of in utero opioid exposure. The Administration on Disability developed and implemented the Neonatal Abstinence Syndrome initiative, a training program that shows promise based on pilot test results. These results showed that the initial states involved responded positively to the training, showing increases in self-reported knowledge and confidence in implementing strategies. The initiative will expand to over 30 states over the next three years. More information is available on [ACL's Neonatal Abstinence Syndrome National Training Initiative](#) page.

ACL also supports the [National Research Center for Parents with Disabilities](#), which supports parents with disabilities, specifically in terms of protecting them against wrongfully losing custody of their children.

Dr. Ruiz emphasized that ACL frames its programming and research work in terms of the social and built environment and on how we can improve outcomes, rather than individual barriers. For their work with children with developmental disabilities, ACL focuses on improving outcomes and looking at systemic issues that may prevent these children from achieving life goals.

References:

Center for Behavioral Health Statistics and Quality. A Day In The Life Of Older Adults: Substance Use Facts. Rockville, MD: Substance Abuse and Mental Health Services Administration. May 11, 2017. Retrieved from: https://www.samhsa.gov/data/sites/default/files/report_2792/ShortReport-2792.html.

Center for Behavioral Health Statistics and Quality. Opioid Misuse Increases Among Older Adults. Rockville, MD: Substance Abuse and Mental Health Services Administration. July 25, 2017. Retrieved from: https://www.samhsa.gov/data/sites/default/files/report_3186/Spotlight-3186.html.

Frenk SM, Porter KS, Paulozzi L. 2015. Prescription opioid analgesic use among adults: United States, 1999-2012 (No. 2015). US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics.

Olfson et al. National trends in the office-based prescription of schedule II opioids. *Journal of Clinical Psychiatry*, 74(9): 932-9, 2013. doi: 10.4088/JCP.13m08349

Jones HE, Kaltenbach K, Benjamin T, Wachman EM, O'Grady KE. Prenatal opioid exposure, neonatal abstinence syndrome/neonatal opioid withdrawal syndrome, and later child development research: shortcomings and

solutions. *Journal of Addiction Medicine*, 13(2), 90-92, 2019.

Bakhireva LN, Holbrook BD, Shrestha S, Leyva Y, Ashley M, Cano S, ... Leeman L. Association between prenatal opioid exposure, neonatal opioid withdrawal syndrome, and neurodevelopmental and behavioral outcomes at 5–8 months of age. *Early Human Development*, 128, 69-76, 2019.

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

Ms. West spoke about the FASD-related activities of the Office of the Assistant Secretary for Planning and Evaluation (ASPE). She started by listing ASPE's roles and functions within HHS: advising the Secretary of HHS on policy development and evidence-based policymaking; coordinating HHS's evaluation, research, and demonstration activities; managing HHS's strategic planning; conducting policy and research evaluations; and estimating costs and benefits of policy alternatives and regulatory actions. ASPE has also led the coordination of HHS's response to the opioid epidemic, and it is interested in opioid-co-occurring disorders and issues with other substances, including alcohol. Ms. West noted that for pregnant women with opioid use disorder, alcohol is one of the most frequent co-occurring substances. ASPE is interested in alcohol use in the prenatal period, FASD and disability, integration of affected individuals into society and adapted services.

ASPE has two briefs on FASD currently in development. One brief is on states' responses to FASD, including states' strategies for FASD prevention, identification, and intervention. In the brief, ASPE also includes ideas from technical experts, as well as challenges and opportunities for states to expand these services.

The second brief is about the role of health and human service providers in preventing FASD and the need for multidisciplinary approach to prevention, treatment, and recovery. It looks at health care providers, health care payers, and social service providers (including the child welfare and criminal justice systems), their efforts, and opportunities for health and human services professionals to expand their participation in FASD prevention and treatment.

Ms. West then spoke about other FASD topics that ASPE is interested in as a part of the COVID-19 pandemic-related concerns. Some issues, such as the health equity concern, preexisted and have been exacerbated by the COVID-19 pandemic. ASPE is interested in improving access to services and prevention, advancing racial equity, and supporting underserved communities. For example, in the context of alcohol use disorder, research shows that Native American women have high risks but are less likely to have access to needed services, therefore ASPE is interested in improving access to treatment and prevention in this population. A second concern is increases in alcohol and other substance use, including an increase in alcohol use among women. Additionally, alcohol use and alcohol-related fatalities have also increased during the pandemic. Another pandemic-related concern is that school closures have prevented many children with disabilities from receiving services, in part because not everyone has been able to adapt to telehealth. Ms. West emphasized that as schools re-open, it will be important to determine what kind of integration children with disabilities need and whether there is an increased need for services. Ms. West outlined ASPE's next steps, including moving the two briefs along the development process and bringing more visibility to FASD within the Office of the Secretary.

Centers for Medicare & Medicaid Services (CMS)

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

Dr. Cross-Barnet spoke about the Maternal Opioid Misuse (MOM) Model, which addresses the fragmentation in the care of pregnant and postpartum Medicaid beneficiaries through state-driven transformation of the delivery system surrounding this population. Eight state Medicaid agencies received awards to implement the MOM Model, under which they will coordinate with care delivery partners to engage pregnant beneficiaries, provide referrals, and coordinate care. Dr. Cross-Barnet spoke about when each state would begin using the MOM Model and in what

portion of each of the states the model will be used.

Dr. Cross-Barnet spoke about how alcohol use or abuse and opioid use disorder are often comorbid conditions. Additionally, alcohol use is common among pregnant people, and, based on Medicaid claims from three states, among pregnant and postpartum Medicaid beneficiaries who have any documented substance use disorder, the most common is alcohol use disorder (AUD).

The MOM Model addresses AUD and related needs. It provides early screening for alcohol use and misuse, health-related needs, and social needs. The MOM Model also provides counseling and integrated treatment and support that involves various professionals and fields including psychiatry, social work, counselors, care coordinators, peer recovery coaches, and any other care that the woman is receiving as part of her pregnancy and substance use disorder. The programs provide care continuity which helps build trust and focus on family preservation. There is also an attempt through the MOM Model to provide care through the entire first postpartum year.

The Center for Medicare & Medicaid Innovation (CMMI) also has another model – the Integrated Care for Kids Model – that is a child-centered local service delivery and state payment model. Its goal is to reduce expenditures and improve quality of care for children under age 21 who are covered by Medicaid and, if the state chooses, the Children’s Health Insurance Program (CHIP), through prevention, early detection, and treatment for behavioral and physical health needs. The model will be implemented in January 2022 and its programs are still being developed. Dr. Cross-Barnet referred to websites with more information about the two initiatives: the [MOM Model](#) page and the [Integrated Care for Kids Model](#) page.

References:

Lynch V, Clemans-Cope L, Howell E, Hill I. Diagnosis and treatment of substance use disorder among pregnant women in three state Medicaid programs from 2013 to 2016. *J Subst Abuse Treat.* 2021 May;124:108265. doi: 10.1016/j.jsat.2020.108265. Epub 2020 Dec 26. PMID: 33771273.

Discussion:

Dr. Balachova thanked presenters and reminded the audience how to submit questions over the live videocast. She invited questions and comments directed at the four agency speakers.

Ms. Levinson welcomed Dr. Ruiz and said that she enjoyed Dr. Ruiz’s presentation and learning about her work at the ACL and the National Research Center for Parents with Disabilities. She then noted fear that mothers may experience when they mention drinking or substance use during pregnancy and asked Dr. Newburg-Rinn to clarify whether she meant foster or birth mothers when Dr. Newburg-Rinn was talking about mothers being in fear when social workers talk about alcohol use during pregnancy.

Dr. Newburg Rinn said she was talking about both foster and birth mothers. She also said that the Children’s Bureau has a major movement toward prevention of children from going into foster care. In some states, any alcohol use that is perceived as damaging to the child means that the child is taken out of the home and put into foster care. However, the Children’s Bureau is trying to not take the child into foster care but rather, to provide services to the family so that the parents can be the best possible parents to that child. There are concerns about whether children of color and their families are being disproportionately targeted which could lead to children of color be removed from the home. Dr. Newburg-Rinn emphasized that it is important to think about what families need. It may be that families of color or low-income families may need more help.

Dr. Balachova addressed Dr. Ruiz as a new ICCFASD member. Dr. Balachova pointed out that when FASD was first identified, it was in young children, but those children are grown. There are a lot of young adults who are active in the FASD community, speak about their needs, and help researchers understand the needs of people living with FASD. Dr. Balachova asked Dr. Ruiz how she believes that may fit in the ACL programs and priority areas.

Dr. Ruiz said that a lot of ACL’s programming is focused on transitions – transitions from education to first employment, for example. ACL has funded interventions that help with this transition, and they are scaling them and funding other programming to promote vocational rehabilitation and employment. ACL has also heavily

invested in aging with long-term disability, and ACL has a dedicated page that describes its research and activities dedicated to this population. She said that there is still more to learn and know about aging with long-term disabilities. She also said that ACL recently published a brief on pregnancy and disability. ACL's National Center for Parents with Disabilities has focused a lot on helping families, including protecting their rights, but ACL found that there is still a need for more information for the time period from conception to birth.

At Dr. Dunty's request, Ms. West provided more detail about ASPE's Brief about the role of health and human service providers in preventing FASD. She said that ASPE issued the Brief because they wanted to show that various systems and providers, including pediatrics, obstetrics-gynecology, primary care, and behavioral health, need to be involved in FASD prevention. She also said that payers should be involved since there are opportunities for payers to fund prevention efforts. ASPE has some examples of payers funding prevention models, but not specifically in the context of alcohol use. Ms. West said that criminal justice and child welfare should also be involved in FASD-related activities so that staff within those systems can recognize the signs of FASD. This is important because similarly the situation in the child welfare system, FASD may be underdiagnosed and underdiagnosed among incarcerated people.

Dr. Balachova concluded this discussion and encouraged participants to submit questions and comments online and then introduced Dr. Dunty as the speaker for the first NIH ICCFASD member agency to give an update, NIAAA.

Reports of Activities from FY2020: ICCFASD Federal Agencies: NIAAA, NIDA, NICHD, NIMH

The National Institute on Alcohol Abuse and Alcoholism (NIAAA)

Bill Dunty, PhD, Program Director, Division of Metabolism and Health Effects, National Institute on Alcohol Abuse and Alcoholism, NIH

Dr. Dunty said that NIAAA support four areas of FASD-related research through grants and other activities: etiology, interventions, prevention, and diagnosis. In FY2020, NIAAA funded \$419 million for research and training grants. Such funding has been on the rise for the last five years (2016-2020). Over the same five years, awards to FASD researchers have remained steady and makes up 7-8% of the NIAAA's total research and training budget. In 2020, \$30 million supported 107 FASD grants, 14 of which were new. Dr. Dunty suggested that anyone interested in learning more about the research projects could use NIH RePorter, and he then listed three publications from NIAAA-funded research that NIAAA had recently publicized. The first was about a clinical trial on the beneficial and lasting effects of choline supplementation in children with FASD. The second publication was about prenatal alcohol exposure as a risk factor for metabolic diseases in adults, and the third was about how combined prenatal smoking and drinking greatly increases the risk of sudden infant death syndrome. He said that more details about these three studies are on [NIAAA's news and events](#) page.

Dr. Dunty then spoke about the COVID-19 pandemic. Alcohol misuse was already a public health concern before the pandemic, but alcohol may complicate the pandemic in many ways. NIAAA has shared resources on its [Alcohol and COVID-19](#) website for the public, clinicians, and researchers, including the Alcohol Treatment Navigator at <https://alcoholtreatment.niaaa.nih.gov/>. He then spoke specifically about FASD and COVID-19 pandemic research. NIAAA awarded two administrative supplements. The first is to Dr. Ludmila Bakhireva at the University of New Mexico, who is studying the comorbid effects of the COVID-19 pandemic and alcohol use on adverse maternal and infant outcomes, with a particular focus on the psychosocial and psychological measures. Dr. Bakhireva's project is also receiving funding from the National Institute on Environmental Health Sciences. The second project is to Dr. Claire Coles at Emory University, who is studying the impact of COVID-19 on health, social outcomes, mental health status, and substance use in adults with FASD in the Atlanta and Seattle areas.

Because there is still a need to build the evidence base for interventions that improve outcomes in people with FASD and for prevention efforts to decrease alcohol use during pregnancy and the incidence of FASD, NIAAA released two new funding opportunity announcements (FOAs), which focus on intervention and prevention research, PAR-21-097

and PAR-21-098 - Prevention and Intervention Approaches for Fetal Alcohol Spectrum Disorders. The two FOAs employ different grant mechanisms, which allows NIAAA to reach all stakeholders, and more information on the FOAs is available at [on grants.nih.gov](https://grants.nih.gov).

NIAAA also conducted FASD outreach efforts throughout 2020. In the fall, NIAAA released an issue of NIAAA Spectrum webzine which focuses on advances in FASD research and NIAAA FASD-related activities. A copy of the webzine can be found at https://www.spectrum.niaaa.nih.gov/Content/archives/Fall_2020.pdf. Additionally, NIAAA's 50th anniversary was in 2020, and to mark the occasion, NIAAA hosted an online scientific symposium that featured eight presentations, one of which was by Dr. Michael Charness who spoke about NIAAA's funded research on FASD over the last 50 years (<https://www.niaaa.nih.gov/agenda-niaaa-50th-anniversary-science-symposium>). NIAAA also partnered with the American College of Obstetricians and Gynecologists (ACOG), CDC, and the National Organization on Fetal Alcohol Syndrome to conduct two Twitter chats on the topics of FASD prevention and risky alcohol use.

The National Institute on Drug Abuse (NIDA)

Minki Chatterji, PhD, Program Officer (Health Scientist Administrator), Prevention Research Branch, Division of Epidemiology, Services and Prevention Research, National Institute on Drug Abuse, NIH

Dr. Chatterji presented highlights of NIDA-funded research related to prenatal exposure to a broad array of substances, including alcohol. Data from the National Survey on Drug Use and Health (NSDUH) shows that polysubstance use is common among pregnant women. Without addressing polysubstance use, it would not be possible to disentangle the effect of alcohol from the effects of other substances.

NIDA has a multidisciplinary portfolio that includes studies in neuroscience, epidemiology, and interventions. Studies are funded by one of three divisions (Neuroscience and Behavior; Therapeutics and Medical Consequences; and Epidemiology, Services and Prevention Research). Within the three divisions there are about 10 ongoing studies related to prenatal exposure on a broad range of topics, such as developing a screening and brief intervention package to address substance use risk in pregnant and postpartum women.

NIDA also has two initiatives that support studies on prenatal exposure to substances. These two initiatives are the Adolescent Brain and Cognitive Development study (ABCD) and the Healthy Brain and Child Development study (HBCD).

ABCD is a longitudinal study of 12,000 children who are followed from age 9-10 until early adulthood. The study period is from 2015 to 2025. Researchers collect imaging data, behavioral assessments, and biospecimen data, all of which is publicly available. Both ABCD and non-ABCD researchers analyze the data and conduct research. The ABCD study has recently led to a few studies related to prenatal exposure to alcohol and other outcomes. Recently published research report that prenatal exposure to alcohol is associated with greater psychopathology, attention deficits, and impulsiveness in offspring.

The HBCD study will establish a large cohort of 7,500 pregnant women and their infants who will be studied for 10 years. The study will include both children who are not exposed to substances and children who are exposed to substances. HBCD will assess the effects of pre- and postnatal exposure to opioids and other substances, including alcohol, on developmental trajectories. The study will collect imaging data, social and emotional assessments, environmental exposures, and biospecimens, and it will have two phases. NIDA started Phase I in September 2019 with the award of 29 R34 planning grants, designed to allow researchers to work out the legal, ethical, and other challenges in recruiting and retaining pregnant women. NIDA will launch Phase II in September 2021. HBCD's data will be publicly available.

References:

Paul SE, Hatoum AS, Fine JD, Johnson EC, Hansen I, Karcher NR, Moreau AL, Bondy E, Qu Y, Carter EB, Rogers CE, Agrawal A, Barch DM, Bogdan R. Associations Between Prenatal Cannabis Exposure and Childhood Outcomes: Results from the ABCD Study. *JAMA Psychiatry*, 78(1): 64-76, 2021. DOI: 10.1001/jamapsychiatry.2020.2902

Lees B, Mewton L, Jacobus J, Valadez EA, Stapinski LA, Teesson M, Tapert SF, Squeglia LM. Association of

Prenatal Alcohol Exposure With Psychological, Behavioral, and Neurodevelopmental Outcomes in Children From the Adolescent Brain Cognitive Development Study. *American Journal of Psychiatry*, 177(11): 1060-1072, 2020. DOI: 10.1176/appi.ajp.2020.20010086

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

Tracy M. King, MD, MPH, Medical Officer, Intellectual and Developmental Disabilities Branch, Eunice Kennedy Shriver National Institute of Child Health and Human Development, NIH

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

Dr. King noted that as it was reported previously NIAAA is the lead NIH institute supporting research on FASD while NICHD funds few awards that are focused specifically on children with FASD or alcohol use during pregnancy. But it does fund research on combinations of high-risk behaviors during pregnancy, including drug and alcohol use. NICHD also provides support for basic science research on the effects of prenatal exposures using cellular or animal models and for research involving children with intellectual and developmental disabilities which is relevant to children with FASD. NICHD also participates in trans-NIH collaborations that inform the field of FASD research.

Dr. King then provided examples of NICHD activities related to FASD, including combinations of high-risk behaviors during pregnancy, basic science research, and collaborations. In the first example, researchers at the University of Michigan are studying alcohol in the context of multiple co-occurring high-risk behaviors during pregnancy. The study's premise is that sexually transmitted infections often occur in combination with alcohol or drug use among pregnant women, and the researchers are conducting a clinical trial of an intervention that simultaneously targets behaviors that increase the risk of sexually transmitted infections and behaviors associated with drug and alcohol use.

The next example was about basic research. Researchers at the University of Houston have developed an innovative application of a type of imaging technology called Optical Coherence Tomography to study how different patterns of exposure to alcohol and nicotine in pregnant mice affect the brain development of their unborn pups.

Dr. King's last example was about a trans-NIH collaboration, the Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE), the focus of which is reducing maternal morbidity and mortality. IMPROVE focuses on cardiovascular disease, infection, and immunity, which are the leading causes of maternal mortality. However, it considers other contributing health conditions and social factors such as substance use disorders and alcohol use during pregnancy. The initiative is led by the NIH Immediate Office of the Director, NICHD, and the NIH Office of Research on Women's Health, with additional support from other NIH Institutes, Centers, and Offices. More information is available on the [Improve Initiative](#) website.

References:

Technology-Based Intervention For Reducing Sexually Transmitted Infections and Substance Use During Pregnancy. PI: G. Tzilos Wernette. <https://reporter.nih.gov/project-details/9932799>

Optical Coherence Tomography to Study Effect of Poly-Drug Exposure on Fetal Brain Development. PI: K. Larin. <https://reporter.nih.gov/project-details/9842558>

The National Institute of Mental Health (NIMH)

Christopher Sarampote, PhD, Chief, Biomarker and Intervention Development for Childhood-Onset Disorders

Branch, Division of Translational Research, National Institute of Mental Health, NIH

Dr. Sarampote stated the mission of NIMH, the leading federal agency for research on mental health disorders: to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery, and cure. NIMH's research portfolio spans a range of scientific inquiry, including basic studies of the mechanisms of mental illness, mental illness development and risk, novel intervention and prevention development, and approaches to reducing the burden of mental illness.

While there are no current NIMH-funded studies that focus specifically on FASD, there are many potential areas of relevance to NIMH's mission. Prenatal alcohol exposure, even at lower levels than those associated with FASD, increases the risk of adverse mental health outcomes and psychiatric symptoms, including emotional dysregulation, impulsivity, and impaired executive function. Additionally, NIAAA-funded research showed that teenagers with FASD are at a high risk of suicide attempts, and prenatal exposure to alcohol may be undiagnosed and therefore unknowingly present in NIMH-studies. Finally, studying how fetal alcohol exposure impacts development may lead to a better understanding of the underlying mechanisms of mental illness.

NIMH is collaborating on HBCD, which will establish a large cohort of pregnant women from different regions of the U.S. affected by the opioid crisis. The women and their children will be followed for at least ten years. HBCD's findings will improve understanding of normal child brain development and of the long-term impact of prenatal and postnatal opioid and other drug and environmental exposures. This is of interest to the FASD community because opioid use is comorbid with alcohol abuse. The HBCD cohort is expected to capture infants with the full range of exposures, including nicotine, alcohol, and multiple exposures over time. NIMH has a strong interest in this study and is contributing funds and scientific expertise to HBCD to understand normative brain development and the factors that disrupt it, in order to better understand the mechanisms of brain development, which NIMH is interested in.

Discussion:

Dr. Balachova welcomed everyone back and reminded the videocast audience how to submit questions. Addressing Dr. Sarampote, she emphasized that it is important to have NIMH represented in the ICCFASD. She reminded about a survey done by young adults with FASD "FASD Change Makers" in collaboration with FASD researchers recently. The survey identified ten priorities for addressing the needs of individuals with FASD, and the top two priorities are mental health clinicians who specialize in FASD and a doctor or nurse who understands FASD. Dr. Balachova said that these priorities underscore the need to improve training to ensure there are well-prepared mental health practitioners. She then opened the discussion up to questions.

Ms. West addressed Dr. Chatterji, asking her about the HBCD study. Ms. West asked how pregnant mothers are being recruited to the study. Ms. West explained that her question is being asked in the larger context of engaging these women in services, which has always been difficult.

Dr. Chatterji reiterated that the HBCD is still in the planning/Phase I. Phase II will be initiated at the end of September to recruit 7,500 women. Although the pandemic blocked some of the study's efforts, researchers have taken innovative approaches to collecting data remotely, including biospecimens and survey data. However, neuroimaging has not been able to proceed due to the pandemic. Dr. Chatterji said that social media are being used to inform potential participants about the study. She also said that while NIDA is leading HBCD, NIMH, NICHD, and NIAAA also participate and contribute to the study.

Dr. Balachova said that her hope is that participation on the ICCFASD can help in increasing collaboration among NIH institutes on FASD.

Dr. Powell brought up the ABCD study and its findings that even very low levels of alcohol use during pregnancy has effects on the developing brain. She also mentioned Dr. Sarampote's remarks about the mental health outcomes of prenatal alcohol exposure that fall below the level of FASD. She asked how to amplify the message that low levels of prenatal alcohol exposure can have subtle effects on mental health outcomes, and she also asked about how carefully HBCD will capture these low levels of alcohol use during pregnancy and its potential consequences.

Dr. Chatterji said that that information will be collected from pregnant women who participate in the HBCD study on substances that women use, and that the children will be followed up to age 10. Therefore, researchers should be able to learn about exposures and their impacts on child development. However, a lot of women who are using alcohol are also using other substances, so it will be hard to isolate the effect of alcohol versus other substances.

Dr. Powell said that the people who use alcohol more heavily are probably co-using, but there are other women who use alcohol at lower levels and think they are using alcohol at a safe level.

Dr. Chatterji said that the HBCD study will be able to capture this low-level alcohol use during pregnancy.

Dr. Sarampote said that alcohol use or misuse has been among exclusion criteria for a lot of mental health studies in the past, so HBCD is an opportunity for NIMH researchers to study prenatal alcohol exposure and how these risk factors play out in long-term neurodevelopment and risk for mental illness.

Dr. King asked whether big cohort studies, such as ABCD or HBCD, may have exclusion criteria that prevent some of the populations of interest to the FASD research community from participating in the study. Could populations with cognitive limitations be disproportionately excluded from these studies or parts of the study, if, for example, they can't tolerate an MRI? She thinks that it would be important to be transparent about those things to understand and interpret the results.

Reports of Activities from FY2020: ICCFASD Federal Agencies: CDC, IHS, SAMHSA, HRSA

Centers for Disease Control and Prevention (CDC)

Mary Kate Weber, MPH, Acting Team Lead, 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

Ms. Weber gave an update on projects related to FASD from the Prenatal Substance Exposure Surveillance and Research Team at CDC. CDC collaborates with the National Organization on Fetal Alcohol Syndrome (NOFAS) to promote FASD awareness and prevention. NOFAS's five focus areas are its National Resource Directory, dissemination, capacity building, media, and their Speaker's Bureau. Highlights of activities over the last year include a large increase in visitors to NOFAS' National Resource Directory, an increase in the number of people who receive the NOFAS newsletter, a growth in the NOFAS Affiliate Network, the annual affiliate summit, and the awarding of microgrants to affiliates.

CDC also has four projects aimed at implementing alcohol screening and brief intervention (SBI). At the end of the year, the projects had implemented alcohol SBI in 31 clinics. Ms. Weber then spoke about some site-specific highlights that went beyond implementing SBI. Boston Medical Center launched a podcast, Alcohol and Pregnancy: The More You Know. Additionally, the Henry Ford Health System piloted an electronic SBI program and expanded it to two additional clinics. The University of Alaska shifted trainings to a virtual platform to address challenges due to the pandemic. Lastly, the University of Connecticut created a newsletter to regularly share data with health centers and system leadership to highlight implementation successes and barriers.

CDC also has a cooperative agreement with healthcare professional organizations and universities to promote FASD prevention through medical societies and professional organizations. Through this agreement, for example, the American Academy of Family Physicians recruited Office Champions to implement alcohol SBI at 15 sites and is providing ongoing training and support. Other activities related to reaching healthcare professionals through national professional organizations for FASD prevention were performed by the American College of Obstetricians and Gynecologists (ACOG), nurses at the University of Alaska, the University of Nevada in partnership with the American Association of Medical Assistants, and social workers at the University of Texas.

Ms. Weber then described activities related to this year's Alcohol Awareness Month. ACOG hosted a Twitter Chat with CDC, NOFAS, and NIAAA and will create weekly posts about risky alcohol use and SBI on various social

media platforms. She also described three universities' activities related to Alcohol Awareness Month, which were aimed at raising awareness of alcohol screening and the role of various professionals, including medical assistants and social workers, in alcohol screening and treatment.

CDC has also been working with the MITRE Corporation since fall 2019 to create standards-based clinical decision support (CDS) for alcohol SBI in primary care. CDS tools are available to the public through CDS Connect and other platforms. Select CDS tools are currently being pilot tested, including a project to integrate the CDS tools within Alliance Chicago's electronic health record system. More information is available on the [CDC's Clinical Decision Support for Alcohol Screening and Brief Intervention](#) page.

In terms of training, resources, and communications research, CDC is developing messages about providing alcohol SBI to women of reproductive age and enhancing patient-provider communication about the risk of alcohol use during pregnancy. Work under a two-year contract with Oak Ridge Associated Universities will test patient-provider communications concepts and products. To date, the development of the research plan, which included subject matter interviews, and submission of an OMB package have been completed, and research is scheduled to begin in summer 2021.

Lastly, CDC is working on promoting FASD identification and care in pediatric settings by collaborating with the American Academy of Pediatrics (AAP) to provide training and education. These efforts fall into four areas: an FASD Champions Network, the Extension for Community Healthcare Outcomes (ECHO) project, pediatric resident trainings, and resources related to FASD awareness and education. The ECHO program offers tele-mentoring sessions that consist of a presentation by expert faculty, a case presented by a practice, and a discussion on diagnosis and referral. The sessions focus on children with neurodevelopmental impairment with an emphasis on children with prenatal alcohol exposure. In 2020, AAP offered two rounds of ECHO programs, continued to increase pediatric provider awareness of FASD, and coordinated social media campaigns around alcohol and FASD.

The Indian Health Service (IHS)

JB Kinlacheeny, MPH, Public Health Advisor, Alcohol and Substance Abuse Lead, Indian Health Services Headquarters

Mr. Kinlacheeny described IHS. It is an agency within HHS that is responsible for providing federal health services to American Indians and Alaska Natives and is the principal federal healthcare provider and health advocate for Indian people. As of April 2021, IHS served 2.6 million people within 574 federally recognized American Indian Tribes and Alaska Native Villages. IHS's mission is to raise the physical, mental, social, and spiritual health status of American Indians and Alaska Natives to the highest possible level. Its vision is healthy communities and quality healthcare systems through strong partnerships and culturally relevant practices.

IHS has external partners, such as ACOG, AAP, HRSA, and SAMHSA, that support maternal and child health. IHS's priorities in this area include addressing social determinants of health, improving American Indian and Alaskan Native births and reducing maternal mortality and morbidity, and improving emergency medical readiness for children in emergency departments and prehospital settings. Mr. Kinlacheeny then said that over 90% of American Indian and Alaska Native births occur outside federal facilities and over 75% of births occur outside of federal or tribal facilities, but that IHS works to improve the health of all American Indian and Alaska Native children regardless of where they are born.

He then spoke about IHS's FASD-related activities. The Indian Children's Program, through the IHS's Telebehavioral Health Center of Excellence, provides education, training, and clinical consultation on FASD, as well as other issues that affect American Indian and Alaska Native children and youth, and services are available to all IHS, tribal, and urban providers. Mr. Kinlacheeny said that training is available through an IHS website and listed some training topics, including FASD screening and diagnosis, and intervention.

Mr. Kinlacheeny next described IHS's efforts around screening for alcohol and drug use in pregnant women. More information can be found on the [IHS Maternal and Child Health and Wellness](#) page and the [IHS FASD](#) page. He

said that IHS also provides education to patients and families about treatment and recovery and the importance of family and peer support.

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

Mr. Dunbar-Cooper spoke about SAMHSA resources related to FASD and an FASD prevention program in Indiana.

The first resource he spoke about was screening, brief intervention, and referral to treatment (SBIRT). SBIRT is designed to enhance state and tribal continuum of care for substance use disorder and reduce consumption of and negative health impacts from alcohol and drug use. He then gave the contact information for SAMHSA's SBIRT program. More information about the program can be found on [SAMHSA's SBIRT](#) page.

Mr. Dunbar-Cooper then introduced SAMHSA's Living Well with Serious Mental Illness resources, which include information about how treatment and support make it possible for people living with serious mental illness to manage their disorder and live healthy lives. More information can be found on [SAMHSA's Serious Mental Illness](#) page. SAMHSA also has an [early serious mental illness treatment locator](#). Mr. Dunbar-Cooper explained that the earlier a person receives treatment, the better the outcomes are. SAMHSA also has a new treatment locator at [findtreatment.gov](#), which can help people who have a substance use disorder find quality treatment and learn about different treatment types and what to expect when starting treatment.

Mr. Dunbar-Cooper then spoke about [Indiana's affiliate of the National Organization on Fetal Alcohol Syndrome \(INOFAS\)](#), which is run through block grant funds and is a subsidiary of Mental Health America of Indiana. INOFAS seeks to prevent FASD and promote awareness of behavioral health and wellness issues of people affected by FASD through public messaging, resources, and training. INOFAS uses a three Ps approach to their FASD prevention program: presentation, presence, and partnership.

With respect to "presentation," INOFAS offers a variety of trainings. INOFAS uses evidence-based research and facts to provide training that address building a relationship with a person who is at risk for prenatal alcohol exposure and tools to assist participants with developing a safety plan. This training offers continuing education credits through Mental Health America of Indiana. Another training is FASD 101, which defines FASD, offers information on the effects of prenatal alcohol exposure on the brain, describes symptoms of FASD, and describes person-centered interventions. FASD 101 also offers continuing education credits. INOFAS's Outside the Box Thinkers, another training, covers many of the same topics as FASD 101. The FASD in a Nutshell, is a one-hour training that defines FASD, identifies the impact and needs in other services (e.g., mental health, justice, and education), and describes the increased risks of suicide and addiction.

Mr. Dunbar-Cooper then spoke about INOFAS's efforts that fall into the "presence" category of the three Ps. INOFAS maintains a website with many resources, participates in social media platforms, and runs at least one large social media campaign each year. INOFAS has also developed infographics to communicate the message that no amount of alcohol is safe during pregnancy. Its infographics also have other prevention messages.

In terms of "partnerships," INOFAS stays informed of national best practices and emerging trends. It also serves on state-level committees such as the Indiana Quality Improvement Collaborative, the Commission to Improve the Status of Children, and the Indiana System of Care. INOFAS also oversees the Indiana FASD Coalition which is a cross-sector group that has various opportunities to further FASD prevention efforts.

Mr. Dunbar-Cooper closed his presentation with a brief statement of SAMHSA's mission, which is to reduce the impact of substance abuse and mental illness in America's communities.

The Health Resources and Services Administration (HRSA)

Dawn Levinson, MSW, Behavioral Health Lead, Division of Healthy Start and Perinatal Services, Maternal and Child Health Bureau, Health Resources and Services Administration

Ms. Levinson first spoke about the HRSA and its Maternal and Child Health Bureau (MCHB) mission. HRSA works across diverse populations to ensure access to a broad range of primary care and public health services for everyone from infants to the elderly, especially for people who are geographically isolated, or economically or medically vulnerable. HRSA's mission is to improve the health outcomes and address health disparities through access to quality services, a skilled health workforce, and innovative high-value programs.

MCHB's programs focus on improving mental health, behavioral health, and wellbeing for mothers, children, and families. MCHB's programs target multiple levels, including systems, providers, and policy. Their systems-level programs, such as the Title V Maternal and Child Health (MCH) Block Grant Program, reach national, state, and local stakeholders. At the provider level, MCHB offers training; clinical guidelines and quality improvement efforts such as Bright Futures; and direct programming such as Healthy Start and the federal home visiting program. MCHB also supports policy and innovation efforts, including requesting increased access to pediatric well child visits and increasing immunization services. Ms. Levinson summed up MCHB's programming by saying that as a whole, it is aimed at promoting, preventing, screening, intervening, referring, treating, training, and supporting.

Ms. Levinson then provided an update on MCHB's FASD-related activities, specifically screening and intervention. MCHB's has a new activity related to workforce training – the Supporting FASD Screening and Intervention program (SFASDSI). Boston Medical Center, in partnership with the Minnesota-based Proof Alliance, is the single SFASDSI award recipient. The award is for a three-year primary care provider education and technical assistance program that aims to reduce the incidence of prenatal alcohol exposure and improve outcomes in children with diagnosed or suspected FASD. The program is meant to educate providers in areas that have high rates of binge drinking among pregnant women, especially in rural areas. The program's two goals are to help primary care providers (PCP) provide SBIRT to pregnant women and to help PCPs screen and provide referral for children and adolescents with prenatal alcohol exposure. SFASDSI has three measurable program objectives which center around giving PCPs increased knowledge about the risks of alcohol use during pregnancy and options for screening for alcohol use during pregnancy; increased self-efficacy in terms of using recommended approaches for screening, intervention, and referral; and increased use of appropriate methods of screening for both alcohol use during pregnancy and prenatal alcohol exposure.

Boston Medical Center calls their SFASDSI program the Safest Choice Learning Collaborative, and through this collaborative, offers community health centers and tribal clinics the opportunity to participate in cohorts that aim to reduce prenatal alcohol exposure and improve FASD-related outcomes. These cohorts are known as Extension for Community Healthcare Outcomes (ECHO) cohorts and focus on either reducing prenatal alcohol exposure or improve pediatric issues and outcomes related to alcohol exposure. Project ECHO is a knowledge-sharing approach in which expert teams lead virtual clinics, amplifying the capacity for providers to deliver care informed by best practices to underserved populations. The Safest Choice Learning Collaborative has been recruiting health centers and clinics that serve communities in New England and the upper Midwest. The first cohort has been filled and will run from June 2021 until May 2022. Practices wishing to join the second cohort, which will start in March 2022, should contact Kendra Gludt at kendra.gludt@proofalliance.org. More information can be found on [Boston Medical Center's Safest Choice](#) website.

Discussion:

Dr. Dunty asked Ms. Weber to discuss how the barrier of stigma was addressed in the project about message testing to improve patient-provider communications. Ms. Weber said that they are still working on the research plan so have not started on the research yet, but that stigma is a key issue they will address.

Ms. West said that she was surprised to learn about how many Native American women use facilities outside their area to deliver. Ms. West asked about collaborations between providers outside IHS and those within IHS facilities.

Dr. Ruiz commented that through ACL's Title VI of the Older Americans Act, ACL has experience working with Indian Country. She said that because of remote modalities, some evidence-based interventions, such as applied behavioral analysis, are more widely available. Although this modality is not specific to FASD, it can be helpful for children with developmental disabilities, and that modalities are beneficial for remote settings because it expands the availability of evidence-based care.

Dr. King echoed Dr. Ruiz's comment about the expansion of services to include remote administration. She said that people are thinking more about how to deliver remote assessments and how to show they're valid and reproducible, and that this thinking has had positive consequences. NICHD is involved in a lot of rare disease research, and so NICHD has experience with people who are located far away from specialty medical centers. However, when people communicate remotely, as they have done during the pandemic, it helps build community and resources. Moreover, this remote communication may help in building the evidence base to support the idea that certain types of care can work remotely, even if they had previously been done only in person.

Dr. Balachova gave an example of a pandemic effect that is not always recognized. She heard from NIAAA grantees about young American Indian and Alaska Native women who reside in urban areas and that the pandemic has been particularly difficult for them. Typically, these women would go between their residence and their native communities, but with the COVID-19 pandemic, they have not been able to do this which has made connecting to their social and cultural networks difficult.

Dr. Powell asked Ms. Levinson about HRSA's education of providers program and congratulated Ms. Levinson on filling the first cohort. Dr. Powell asked specifically for more information about the groups that had filled the first cohort – whether it is groups who are already fairly well educated in this area and just want more help providing services or if it is groups who may be little more resistant to the idea that alcohol use during pregnancy is a real risk.

Ms. Levinson said that it is the grantee who is coordinating and training the cohort, so she does not have a lot of detail on what the cohort looks like. Ms. Levinson also said that many of the practices within the cohort provide both maternity and pediatric services. Therefore, HRSA hopes to see the maternity and pediatric providers in these practices integrate and share information with each other, which may facilitate early prevention and other services.

A Videocast participant asked about how important collaboration and shared goals among the different member agencies is when they are developing programs.

Mr. Dunbar-Cooper said that in terms of the INOFAS program, there have been many collaborations at the community levels, which include parent-teacher associations and YMCA, and with the national NOFAS organization. He said that because of these connections, each organization is aware of what is going on in a larger context. INOFAS is the first program Mr. Dunbar-Cooper knows about that is supported by block grant funding that targets a younger population who have warnings about school truancy, date rape, and interpersonal violence. Although the program does not specifically target FASD, it has messaging about alcohol use related to FASD and underage drinking. Therefore, the program is comprehensive, and Mr. Dunbar-Cooper is interested in seeing whether it can be promoted in the prevention field with block grant funding. He also said that the education system is involved in INOFAS, which is significant because it can prevent bullying and marginalization of children with FASD and facilitate recognition of their special education needs.

Ms. Kim said that collaboration and not being redundant is important to all ICCFASD agencies and that agencies do communicate with each other. She said that although the agencies may all be addressing the same topic, FASD, each agency targets different populations and brings a unique perspective, allowing them as a whole to fill gaps that cannot be addressed by any single agency. Ms. Kim cited an example when CDC was discussing surveillance, and they invited other agency representatives. She said there are a lot of efforts to collaborate and that these efforts are important.

Dr. Balachova thanked the ICCFASD members for their work and speakers and audience for great discussion of agencies' existing programs and plans. She noted that the meeting would soon move to general discussion. She said she hopes the meeting had helped the viewers understand what ICCFASD does and learn more about the ICCFASD federal agencies' work during the current pandemic situation. Dr. Balachova turned the meeting over to Dr. Powell

and opened the meeting to general discussion.

Discussion ICCFASD Agency Representatives, Speakers, and Guests

Dr. Powell thanked everyone for participating and the Videocast audience for listening through the day-long meeting. She said that the general discussion would provide a chance for people to ask any questions, whether they reflected a single presentation or multiple presentations. Circling back to the panel discussion, Dr. Powell said that she was impressed with what Dr. Gurnett had accomplished during the pandemic and asked for comments about that or anything else that people wanted to bring up.

Dr. King, following up on previous comments, said that she appreciates the ICCFASD group as a forum for sharing information and providing groundwork for collaborations. There is a lot of room for collaboration between researchers and service delivery people, as well as people in healthcare and education. Dr. King said she hopes that education specialists continue getting involved since education-related outcomes are important and the NICHD has prioritized return to school.

Ms. Kim commented about CDC's work with Research Triangle Institute (RTI) on interviewing clinicians and pregnant and postpartum people to understand the impact of COVID-19 and substance use disorder treatment and follow up in terms of care for pregnant persons and postpartum persons. The environmental scan was just completed, and they are currently developing data collection tools. She thinks this research will provide valuable information about the effects of certain aspects of the pandemic, including treatment facility closures, telehealth, and other implications.

Dr. Dunty asked a question from a Videocast participant about whether there are any immediate actions being taken to prevent spikes in FASD, given the pandemic-related spike in drinking.

Dr. Powell said that NIAAA-funded researchers had found that some subpopulation groups were drinking less during the pandemic, while others were drinking more. She said it would be helpful to understand the motivators behind those trends.

Dr. Gurnett pointed out that the pandemic had waves that affected different parts of the country at different times and emphasized that knowing what the local environment is at a given time is important in thinking about how to intervene in each community.

Dr. Ruiz, as a new ICCFASD member, said that she was struck by the interrelated nature of the work across the member agencies. Since ACL does a lot of service delivery, they collect a lot of output data, including data about the transition from in-person to remote services. ACL has noticed that across their programs, and across different demographic groups, people are staying in interventions longer with remote versions. For example, for a six-week intervention, people are staying in the intervention for the full six weeks, rather than dropping out after 2-3 weeks, which might be typical for the in-person versions. Therefore, thinking about service delivery may provide ways to reach more people.

Dr. Powell said anecdotally, psychologists and psychiatrists have been saying that people are showing up for their online appointments.

Mr. Dunbar-Cooper said that he has asked some of SAMHSA's Native American and opioid grantees about universal messaging, such as "don't drink and drive," in light of the fact that certain trends are being observed in specific populations. He thinks it may be helpful for grantees to do local surveys and gather qualitative data about what is going on locally in communities. Some of the tribes Mr. Dunbar-Cooper works with did conduct such surveys with youth online to gather information about parental drinking and job loss. Based on this research, grantees changed their strategies and messaging to focus more on intervention rather than on general prevention. For example, some of the tribes did not have the resources or technical expertise to do virtual strategies, but they came together and, in many cases, were successful in efforts to decrease drinking, and therefore, FASD. Mr. Dunbar-Cooper thinks future efforts will be more about intervention and screening than about general prevention messaging.

Ms. Levinson added to Mr. Dunbar-Cooper's comments, encouraging federal agencies to push more for universal screening for substance use and mental health issues among women of childbearing age. She also stated that there should be efforts to train the workforce and provide technical assistance to help the workforce integrate screening into electronic health records. She pointed out that the pandemic has brought attention to the country's behavioral health crisis, which includes mental health issues, substance use, trauma, and suicide, and emphasized the need for universal screening in a variety of settings from primary care to hospitals and schools.

Mr. Dunbar-Cooper added to what Ms. Levinson had said, stating that there are more co-occurring disorders than before. There are more people with mental health issues and substance misuse issues, so it is important to look at what staff have been trained on and whether they can address these co-occurring issues.

Ms. Levinson said she is a mental health first aid instructor. She advocated for applying some of the same ideas as HHS's vaccine community core, including educating your friends and family, to address mental health and substance use. This would help people find access to treatment and reduce stigma around behavioral health issues.

Dr. Balachova announced that Mr. Kinlacheeny had rejoined the meeting by phone. She thanked Dr. Gurnett for staying during the entire meeting and asked Dr. Gurnett about how to increase the identification of children with FASD and how to increase the integration of children (and families) into existing networks and services for people with developmental disabilities.

Dr. Gurnett said that she thinks that the public needs to be reminded about FASD regularly, and that these messages could be sent through the public press, including social media. Messaging about FASD should also be kept up among providers.

Dr. Powell said that NIAAA has spoken about how, if providers thought about FASD, among other things, when a child presents with symptoms, it could reduce the stigma around FASD.

Dr. Newburg-Rinn spoke about how social workers who work with children do not see alcohol as important. She said that many social workers may dismiss alcohol, not considering it a "substance" since "everyone uses alcohol." She is concerned that because of these attitudes among social workers, it may be difficult for appropriate referrals to occur. Dr. Newburg-Rinn wants to get social workers to pay more attention to alcohol and to make sure people understand that someone can be a good parent even if they have exposed their children to alcohol. She asked Dr. Gurnett for input on what social workers should do and what they should ask when they first encounter a family.

Dr. Gurnett emphasized the importance of getting out the general public message about exposures. Because genetics does not account for everything in terms of health outcomes, Dr. Gurnett wants providers and the public to be more aware of all the preventable exposures.

Dr. Newburg-Rinn lamented the fact that many children or families will never see the wonderful diagnostic tools that exist since so many investigative workers do not see the importance of alcohol, don't ask, and don't refer children for a diagnostic evaluation.

Dr. Powell pointed out that while the long-term effects of opioids may not be known, the long-term effects of alcohol are known.

Mr. Dunbar-Cooper said that social workers may not know what to do with a child with FASD, in terms of referral, so the social worker may not want to deal with thinking about alcohol exposure.

Dr. Newburg-Rinn agreed with Mr. Dunbar-Cooper's point.

Ms. West said that there is a lack of services for children with mental health issues and developmental disabilities. She said the shortage of providers is huge. Anything to alleviate these issues, from training to payment and reimbursement, would help families access specialty providers and be helpful in general. Ms. West welcomed Mr. Kinlacheeny and said she is excited for IHS to be part of the ICCFASD because of the need among American Indian women. She asked that given the large percentage of women who deliver outside IHS facilities, where connections occur among providers.

Mr. Kinlacheeny said there are a lot of factors that go into Ms. West's question, so he would like to discuss her question with her after the meeting in more detail. He said that IHS has a lot of activities that support providers in identifying children who have FASD and their parents.

Adjournment

Dr. Powell thanked Dr. Gurnett for staying through the meeting's entirety and thanked the speakers for recording their presentations in advance. She also thanked the NIAAA IT and NIH Videocast staff. She expressed her indebtedness to the group, praising its collaboration and brainstorming and emphasizing that there is still a lot more they can do together. She then adjourned the meeting.

Appendix: Abbreviations

AAP	American Academy of Pediatrics
ABCD	Adolescent Brain and Cognitive Development study
ACF	Administration for Children and Families
ACL	Administration for Community Living
ACOG	American College of Obstetricians and Gynecologists
ASPE	Office of the Assistant Secretary for Planning and Evaluation
CDC	Centers for Disease Control and Prevention
CDS	Clinical decision support
CHIP	Children’s Health Insurance Program
CMMI	Center for Medicare & Medicaid Innovation
CMS	Centers for Medicare & Medicaid Services
COMPASS-T	COVID-19 Measuring for Special School District Testing
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECHO	Extension for Community Healthcare Outcomes
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
FOA	Funding Opportunity Announcement
FPL	Federal poverty level
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
ICD	International Classification of Diseases
IMPROVE	Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone
INOFAS	Indiana’s affiliate of the National Organization on Fetal Alcohol Syndrome
IHS	Indian Health Services
MCHB	Maternal and Child Health Bureau
MOM	Maternal Opioid Misuse (Model)
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
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NOFAS	National Organization on Fetal Alcohol Syndrome
NSDUH	National Survey on Drug Use and Health
PCP	Primary care provider
PRAMS	Pregnancy Risk Assessment and Monitoring System
RADX-UP	Rapid Acceleration and Diagnostics for Underserved Populations
SAMHSA	Substance Abuse and Mental Health Services Administration
SBI	Screening and brief intervention
SBIRT	Screening, brief intervention, and referral to treatment
SFASDSI	Supporting Fetal Alcohol Spectrum Disorder Screening and Intervention program