

ICCFASD

**Interagency Coordinating Committee
on Fetal Alcohol Spectrum Disorders**

Spring 2019 Public Meeting Summary

Friday, June 7, 2019

National Institute on Alcohol Abuse and Alcoholism
6700B Rockledge Drive, First Floor Conference Center, Rockville, Maryland 20817

Table of Contents

ICCFASD Spring 2019 Public Meeting Videocast link 1

ICCFASD Meeting Participants 1

ICCFASD Agenda 4

Welcome, Introductions, and Comments..... 5

Overview of ICCFASD Mission and Goals 5

Reports of Activities from FY2018: ICCFASD Agencies: ACF, IHS, NICHD, NIAAA, and NIDA..... 7

The Administration for Children and Families (ACF)7

Reference:8

The Indian Health Service (IHS)8

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).....9

The National Institute on Alcohol Abuse and Alcoholism (NIAAA).....10

The National Institute on Drug Abuse (NIDA)12

Overview of 8th International FASD Conference.....12

Reports of Activities from FY2018: ICCFASD Agencies: CDC, SAMHSA, CMS, and HRSA (Continued) 13

Centers for Disease Control and Prevention (CDC).....13

The Substance Abuse and Mental Health Services Administration (SAMHSA)15

The Centers for Medicare and Medicaid Services (CMS).....16

The Health Resources and Services Administration (HRSA)18

Special Panel Discussion: Considering, Recognizing, and Screening for Fetal Alcohol Spectrum Disorders (FASD) in Children in Primary Health Care, Education, Justice, and Social Service Settings 20

Engaging Parents/Caregivers in Early Childhood Development Monitoring: Resources From CDC.....20

Recognizing Children with FASD in Primary Health Care21

Recognizing Children with FASD and Engaging School Systems23

Discussion.....26

Recognizing and Screening for FASD in Juvenile Justice Settings.....26

Discussion:.....27

Promoting Recognition of FASD in Social Services Systems28

Discussion:.....28

Open Discussion All ICCFASD Agency Representatives and Guests 29

Closing Comments 31

Adjournment 31

ICCFASD Spring 2019 Public Meeting Videocast link

A videocast of the ICCFASD Spring 2019 Public Meeting held on June 7, 2019 is available at the NIH videocast [website](#).

ICCFASD Meeting Participants

A list of ICCFASD Executive Committee members and their contact information can be found on the ICCFASD [website](#).

ICCFASD Chairperson:

Patricia A. Powell, PhD

Deputy Director

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

National Institutes of Health (NIH)

The United States Department of Health and Human Services (HHS)

ICCFASD Scientific Coordinator and Executive Secretary:

Tatiana Balachova, PhD

Health Scientist Administrator

Division of Epidemiology and Prevention Research

National Institute on Alcohol Abuse and Alcoholism, NIH, HHS

Sally M. Anderson, PhD

Special Advisor to ICCFASD Leadership

Office of the Director

National Institute on Alcohol Abuse and Alcoholism, NIH, HHS

ICCFASD Primary Representatives:

Caitlin Cross-Barnet, PhD

Social Science Research Analyst

Research and Rapid-cycle Evaluation Group

Center for Medicare and Medicaid Innovation

Centers for Medicare and Medicaid Services (CMS), HHS

Jon Dunbar-Cooper, MA, CPP

Public Health Analyst

Center for Substance Abuse Prevention

Substance Abuse and Mental Health Services Administration (SAMSA), HHS

William Dunty, PhD

Program Director

Division of Metabolism and Health Effects

National Institute on Alcohol Abuse and Alcoholism, NIH, HHS

Chris Fore, PhD, *participating via Webex*

Director

Telebehavioral Health Center of Excellence

Division of Behavioral Health

Indian Health Service (IHS), HHS

Shin Y. Kim, MPH

Team Lead, Lead Health Scientist

Prenatal Alcohol, Opioid, and Substance Exposure Team

Prevention Research and Translation Branch

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, NIH, 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

Administration for Children and Families (ACF), HHS

Karen Sirocco, PhD

Health Scientist Administrator

Prevention Research Branch

Division of Epidemiology, Services and Prevention Research

National Institute on Drug Abuse, NIH, HHS

Invited Guest Speakers

Christopher Boys, PhD, LP

Associate Professor of Pediatrics

Department of Pediatrics

University of Minnesota Medical School

Kenneth Lyons Jones, MD

Professor of Pediatrics

Division of Dysmorphology/Teratology
School of Medicine
University of California, San Diego

Molly N. Millians, DEd
Senior Associate
Department of Psychiatry and Behavioral Sciences
Emory Neurodevelopmental Exposure Clinic
Emory University Brain Health Center

Yasmin Senturias, MD, FAAP
Professor of Pediatrics
Developmental and Behavioral Pediatrics
Medical Director
Developmental and Behavioral Pediatrics of the Carolinas – Charlotte Clinic, Atrium Health
Adjunct Professor of Pediatrics
University of North Carolina at Chapel Hill

Karnesha Slaughter, MPH, *participating via Webex*
Health Communication Specialist
"Learn the Signs. Act Early." Program
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention (CDC), HHS

ICCFASD Agenda

8:30 am	ICCFASD Executive Committee Meeting, closed session
	<u>ICCFASD PUBLIC MEETING</u>
9:30 am	Welcome, Introductions, and Comments <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i>
9:40 am	Overview of ICCFASD Mission and Goals <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary</i>
9:50 am	Reports of Activities from FY2018: ICCFASD Federal Agencies <i>ACF, IHS, NICHD, NIAAA, and NIDA</i>
10:40 am	Overview of 8 th International FASD Conference <i>Bill Dunty PhD, NIAAA, NIH</i>
10:50 am	BREAK
11:00 am	Reports of Activities from FY2018: ICCFASD Federal Agencies <i>CDC, SAMHSA, CMS, and HRSA</i>
11:40 am	Special Panel Discussion: Considering, Recognizing, and Screening for Fetal Alcohol Spectrum Disorders (FASD) in Children in Primary Health Care, Education, Justice, and Social Services Settings
	Moderator: <i>Tracy King, MD, MPH, NICHD</i> Introduction: <i>Sally Anderson, PhD, NIAAA</i>
	Engaging Parents/Caregivers in Early Childhood Development Monitoring: Resources from CDC <i>Karnesha Slaughter, MPH, Center on Birth Defects and Developmental Disabilities, CDC</i>
	Recognizing Children with FASD in Primary Health Care <i>Yasmin Senturias, MD, FAAP, Developmental and Behavioral Pediatrics of the Carolinas – Charlotte Clinic, Atrium Health and Pediatrics at UNC Chapel Hill, NC</i>
12:30 pm	LUNCH BREAK
1:30 pm	Special Panel Discussion: Considering, Recognizing, and Screening for Fetal Alcohol Spectrum Disorders (FASD) in Children in Primary Health Care, Education, Justice, and Social Services Settings, Continued
	Recognizing Children with FASD and Engaging School Systems <i>Molly Millians, DEd, Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, GA</i>
	Recognizing and Screening for FASD in Juvenile Justice Settings <i>Kenneth Lyons Jones, MD, Institute for FASD Discovery (IFASDD), Center for Better Beginnings University of California, San Diego, CA</i>
	Promoting Recognition of FASD in Social Services Systems <i>Christopher Boys, PhD, LP, Department of Pediatrics, University of Minnesota Medical School</i>
	Discussion: <i>Speakers and all ICCFASD Agency Representatives</i>
3:00 pm	BREAK

3:20 pm	Open Discussion <i>All ICCFASD Agency Representatives and Guests</i>
4:00 pm	Comments and Adjournment <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary</i> <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i>

Welcome, Introductions, and Comments

Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair

Dr. Powell introduced herself as the current Chair of the ICCFASD and acknowledged the importance of the Committee in bringing together the different perspectives of federal agencies that, collectively, enable more progress than any agency could achieve individually. Dr. Powell welcomed participants to the meeting and asked the ICCFASD members to introduce themselves. Dr. Powell thanked Drs. Anderson and Balachova for organizing the meeting and acknowledged the work of Dr. Marcia Scott as the former Scientific Coordinator and Executive Secretary. Dr. Balachova was formally introduced as the current Scientific Coordinator and Executive Secretary. Dr. Powell noted that Dr. Balachova was a leading expert in the prevention of alcohol-exposed pregnancies and FASD, with research ranging from intervention development to translation of empirically-supported practices into real-world settings.

Overview of ICCFASD Mission and Goals

Tatiana Balachova, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary

Dr. Balachova thanked members of the Committee and acknowledged the contribution of each member and their agencies to the ICCFASD. She thanked members of the committee who have recently retired or left the committee because of reassignments within agencies and welcomed Dr. Karen Sirocco as a new representative from NIDA.

Dr. Balachova discussed the aims of the ICCFASD, namely, to improve communication, cooperation, and collaboration among disciplines and federal agencies that address issues related to prenatal alcohol exposure. ICCFASD was created in 1996 in response to recommendations of an Expert Committee of the Institute of Medicine (IOM) of the National Academy of Sciences. In recognition of the seriousness of the consequences of prenatal alcohol exposure, the U.S. Congress mandated the IOM to conduct a study of FAS and related birth defects. The IOM-appointed Expert Committee identified the need to improve communication and cooperation among health, education, developmental disabilities, and social services disciplines and government agencies and recommended establishing an interagency task force, or other entity comprised of representatives from the relevant federal research, surveillance, and services agencies to be led by the NIAAA (Institute of Medicine, 1996). The ICCFASD was established to coordinate national efforts in FAS and other disorders associated with fetal alcohol exposure. The ICCFASD is administered by the NIAAA and includes agencies primarily within the Department of Health and Human Services (HHS), the Indian Health Service (IHS), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA),

Center for Medicare and Medicaid Services (CMS), Administration for Children and Families (ACF), Substance Abuse and Mental Health Services Administration (SAMHSA), and the National Institutes of Health (NIH) agencies, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), and National Institute on Drug Abuse (NIDA). Since 1996, the Department of Education and the Office of Juvenile Justice and the Delinquency Prevention (OJJDP) in the Department of Justice have also been active on ICCFASD; however, these agencies are currently not represented on the ICCFASD. The organizational chart of the ICCFASD is available on the ICCFASD [website](#).

The FASD-related work performed by the federal ICCFASD agencies addresses several topics including, basic and clinical research, best practices and patient treatment, health care delivery, adjustments for people with FASD in legal venues, education of children with FASD, and data for public health policies.

The ICCFASD holds two coordinating meetings annually and establishes working groups/ad hoc subcommittees to address specific topics of interest to the Executive Committee members. There have been several ICCFASD working groups since 1996. The working groups can involve experts to gain a broader perspective and more diverse knowledge about a topic. Presentations or reports are prepared by working groups for the ICCFASD to help agencies improve program development and implementation. One example is the Justice Issues Work Group (ICCFASD JI WG) which was established because of significant needs of families, children, and adults with FASD in the justice system and the need to increase attorneys' and judges' understanding of FASD and challenges that people with FASD face in the justice system. This work group was very effective. It took a gradual approach beginning with assessing needs and conducting a workshop as part of continuing legal education in collaboration with the American Bar Association and other organizations. In 2012, the American Bar Association Resolution of FASD was signed, which was established to enable legal professionals to better serve clients with FASD and to consider broader options for youths with FASD that appear in court. Dr. Balachova mentioned that she saw the positive impact of the 2012 Resolution when training for judges and legal professionals was conducted in Oklahoma. The FASD Guide for Judges was developed in collaboration with the National Council for Juvenile and Family Court Judges, ICCFASD JI WG, OJJDP, and NIAAA. More information about the Justice Issues Work Group is available on the ICCFASD [website](#).

Dr. Balachova stated that this is an important and challenging time for the ICCFASD, as recent studies indicate that the prevalence of FASD is higher than previously thought and the majority of FASD in children in the U.S. are under-recognized or misdiagnosed. While advances in science and technology are promising for improving recognition of FASD and services for individuals with FASD, challenges in the identification of affected children and adults remain. She introduced the focus of this ICCFASD meeting on recognizing and screening for FASD in children in primary health care, education, and other settings and invited agencies to report their FY 2018 FASD-related activities.

Reference:

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

Reports of Activities from FY2018: ICCFASD Agencies: ACF, IHS, NICHD, NIAAA, and NIDA

The Administration for Children and Families (ACF)

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

Dr. Newburg-Rinn spoke about the ACF work to address prenatal alcohol and other drug exposures in children in child welfare. In addition, the ACF has been conducting a study over the past few years in collaboration with Dr. Jacquelyn Bertrand, of the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD), whom Dr. Newburg-Rinn met through the ICCFASD. It is currently believed that many children who are in foster care have been exposed to alcohol or other drugs prenatally. However, a study by pediatrician Dr. Ira Chasnoff concluded that over 80% of children had a form of FASD that had been undiagnosed or misdiagnosed when they first entered foster care (Chasnoff et al., 2015). Many of these children are given an incorrect diagnosis of ADHD or another condition. A lack of appropriate services, critical to a child's development, further compounds problems such as an increased risk of maltreatment; a child's actions can be misinterpreted as bad behavior, rather than a health condition that may limit the child's abilities.

In the collaborative study carried out over three years so far, the goal is to learn more about how local child welfare agencies process children and families upon initial contact. How and when do child welfare agencies determine that a child should be screened for prenatal alcohol exposure, what is the level of documentation, and service determination that is currently performed? Intake and ongoing case workers need to be better educated about FASD to arouse suspicion regarding a potential case of FASD.

The current plan involves five states, which intentionally represent some diversity geographically (such as north, south, mid-Atlantic, midwest, and northwest) and demographically (urban/rural). Interviews, focus groups, and examination of file case notes were performed in about 30 local sites from several states. More in-depth data collection in two states will involve focus groups to determine where gaps exist in foster parent knowledge regarding how to work with FASD children/youth.

Dr. Newburg-Rinn reported that working with tribes has been more challenging, due to a certain level of mistrust of government services and the rural location of families. A tentative agreement with one tribe is already in place; nine tribal members potentially will be recruited as co-planners of the project. The current goal is to determine how to apply the tools that are currently being used with states to tribes. It is important to work consistently with local tribal customs.

A total of \$6 million in funding enables work to be carried out over the next five years. This funding includes \$5 million from the ACF and \$1 million from the CDC. Whereas the first phase

of this project will determine why child welfare agencies are typically not considering FASD as a potential concern, the second phase of the project, commencing this fall, will evaluate different tools. The project will either locate or develop and then, evaluate, tools that can be used for different groups of people to help social workers screen for FASD and/or help parents and medical professionals become more knowledgeable and equipped to manage FASD-related issues.

Reference:

Chasnoff IJ, Wells AM, King L. Misdiagnosis and Missed Diagnoses in Foster and Adopted Children With Prenatal Alcohol Exposure. *Pediatrics*. 2015 Feb 1;135(2):264–70.

The Indian Health Service (IHS)

Chris Fore, PhD, Director, Telebehavioral Health Center of Excellence, Division of Behavioral Health, IHS

The IHS serves 576 federally recognized tribes within the United States. The population is relatively impoverished, experiences health disparities and abnormally high levels of adverse childhood experiences (ACEs) that pose challenges regarding FASD and other issues.

The IHS is taking a more trauma-informed care approach and making the healthcare system more welcoming. Many tribes and their members suffer from historical trauma that still has modern-day consequences for both communities and individuals. The IHS, per se, does not have much funding for prevention currently. The prevention money that IHS has been allocated generally has gone out directly to the tribes, which administer prevention programs within their communities. Without much current funding for prevention, the IHS focusses on their healthcare treatment system, health care centers.

The IHS has a series of webinars on FASD to educate healthcare providers on the impact of FASD, screening, and recognition. Getting specialized treatment in tribal communities is a challenge. IHS is considering different ways to address that challenge. One example, a biweekly pediatric consultation clinic, is funded through the Indian Children’s Program. These funds are to help address developmental delays and other issues in native children. Any provider who is treating a native youth can call into the panel of experts and get a free consultation. With this clinic, the IHS hopes to help children and families with issues they experience, including FASD, autism, etc., and bridge the gap between healthcare providers and patients in remote areas.

IHS is also working on updating a manual—a book that was published about 25 years ago on the treatment of FASD within native communities. The book was comprehensive, and IHS is working on revising that and bringing it up-to-date to educate providers about the impacts of FASD and age-related screening and recognition tools; it will also contain suggestions relating to intervention.

Another project noted is the IHS collaboration with Johns Hopkins University on trauma-related pediatric integrated care clinics. There are 18 sites throughout the United States, and trauma-related care would certainly include screening for FASD.

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 in addition to child health, includes the support of a broader scope of research on typical development, nutrition, intellectual and developmental disabilities, trauma, critical care, prenatal, perinatal and neonatal health, pregnancy and maternal health, reproductive health, and rehabilitation across the lifespan. NICHD also includes the National Center for Medical Rehabilitation Research, which supports research on teratology, obstetric and pediatric pharmacology, global health, rare diseases, and demographic and population studies. At NICHD, support for FASD research typically involves indirect support of FASD research as a part of broader studies rather than support for specific projects looking directly at FASD.

NICHD supports large research networks and research cohorts that typically look at the collective impact of multiple exposures during pregnancy on multiple outcomes in childhood. NICHD also supports some basic science research using animal models and takes a lead role in a number of trans-NIH collaborations, including some around research methods, which may have relevance to FASD. An example is “Right from the Start,” a community-based cohort of over 5,000 pregnant women enrolled between 2002 and 2012, from eight metropolitan areas across the United States. Data from this cohort revealed that alcohol consumption in the 12 weeks prior to the first-trimester interview was similar in women reporting planned versus unplanned pregnancies. As most women stopped or dramatically decreased alcohol consumption early in pregnancy, only 6% of women reported current alcohol consumption at the time of the interview (Pryor et al., 2017). These data suggest that promoting early pregnancy awareness can play an important role in reducing prenatal alcohol exposure.

Dr. King emphasized the need to consider poly-substance use during pregnancy. In a cohort of women with opioid use disorder, the majority reported poly-substance use histories, with over half reporting alcohol use (Brogly et al., 2018). Many of the women also reported histories of physical or sexual abuse, incarceration, and hepatitis C infection. Therefore, any intervention to reduce substance use must include considerations of the diverse challenges faced by women engaging in high-risk behaviors.

NICHD supports some basic science research relevant to FASD. In one study, investigators used a mouse model of alcohol exposure to determine the effect of fetal alcohol exposure on blood vessels in the developing brain. Imaging analysis revealed that a single binge-like exposure to alcohol resulted in vessel constriction, suggesting that decreases in blood flow could be one mechanism contributing to the detrimental effects of alcohol on brain structure and function (Raghunathan et al., 2018).

Dr. King discussed how the U.S. Preventative Services Task Force considers evidence when deciding whether to recommend for or against screening for disorders. In some cases, a direct connection can be made between an actual screening event and a reduction in morbidity and mortality, for example, in colon cancer. However, the connection in childhood screening tends to be much less direct. NICHD is trying to find evidence in which screening leads to early detection of a target condition, which will then lead to a referral for treatment, and subsequent improvements in health outcomes. However, screening needs to be balanced against potential adverse effects and legal implications of both screening and treatment. NICHD recently held a workshop entitled, “Methods for Assessing the Impact of Screening on Childhood Health Outcomes.” This workshop included people with expertise in alcohol and substance abuse in adolescents. The workshop participants spoke about the context of screening and the manner in which people present during screening (affected individuals and family members) influenced the impact and effectiveness of screening.

References:

Pryor J, Patrick SW, Sundermann AC, Wu P, Hartmann KE. Pregnancy Intention and Maternal Alcohol Consumption. *Obstet Gynecol.* 2017;129(4):727–33.

Brogly SB, Saia KE, Werler MM, Regan E, Hernández-Díaz S. Prenatal Treatment and Outcomes of Women With Opioid Use Disorder. *Obstet Gynecol.* 2018;132(4):916–22.

Raghunathan R, Wu C, Singh M, Liu C-H, Miranda RC, Larin KV. Evaluating the effects of maternal alcohol consumption on murine fetal brain vasculature using optical coherence tomography. *J Biophotonics.* 2018;11(5):e201700238.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA)

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

NIAAA supports areas of FASD research that include interventions, etiology, prevention, and diagnosis. Over the past five fiscal years, the NIAAA research and training budget has steadily increased; \$387 million was allocated for FY2018. Over the past five fiscal years, 7-8% of the entire research and training budget supported research in FASD. In FY2018, 7.2%, or approximately \$28 million, supported 113 FASD-related grants. Of those grants, 27 were awarded for new research projects. These included epigenetics and neuroimmune function in FASD-related animal models, brain imaging in adults with FASD, sex differences in endocrine function in children with FASD, and sleep issues in children with FASD. Another category of the 27 grants is intervention and prevention studies, such as mobile health approaches to prevent alcohol-exposed pregnancies in Native American youth. A third new grant category includes studies related to diagnosing or identifying FASD as early as possible, including 3D brain and multi-modal brain imaging approaches and new physiological measures, like the cardiac orienting response, to screen children for PAE.

NIAAA continues to issue funding opportunities and notices with FASD-specific language on a variety of topics. In addition to individual research grants, NIAAA also supports larger research consortia. An example is the Collaborative Initiative on FASD ([CIFASD](#)), which consists of multi-disciplinary clinical and basic research projects. CIFASD was created in 2003 with the goal of enhancing the diagnosis of FASD at different stages of the lifespan, based on biological, physical, and behavioral assessments and improving outcomes in individuals with FASD.

Currently, the CIFASD is in its fourth iteration (CIFASD4). Major themes of CIFASD4 include 3D facial, brain, and fetal imaging, genetic studies on risk and resiliency factors, and developing screening tools and mobile health interventions. This phase led to the creation of an online registry of individuals with FASD and an adult health survey that is currently being conducted. Several projects are also looking at biomarkers in blood samples obtained individuals with FASD and their mothers.

Among 16 specialized research centers (P50s) that NIAAA funds, two have a major focus on FASD. The first is the New Mexico Alcohol Research Center ([NMARC](#); Dr. Dan Savage, Principal Investigator) that consists of five main projects, including three pilots and two cores that are involved in both pre-clinical and clinical studies addressing the neurobiological mechanisms underlying FASD-related behaviors. NMARC is the only P50 that is primarily focused on FASD. The second P50 with some focus on FASD research is the Developmental Exposure Alcohol Research Center ([DEARC](#); Dr. Terry Deak, Principal Investigator) at Binghamton University, State University of New York. DEARC has four pilots and main projects that primarily involve the use of animal models to understand the functional and neural effects of alcohol exposure throughout brain development, with a special emphasis on adolescence. An FASD-relevant focus of this center is to understand the detrimental effects of PAE on brain plasticity and the subsequent risk for teen alcohol abuse.

Larger research centers (P60s) include the FY2018-funded Native Center for Alcohol Research and Education ([NCARE](#); Dr. Dedra Buchwald, Principal Investigator), at Washington State University. NCARE's main focus is to compare the effectiveness of a culturally adapted intervention with American Indian women of reproductive age to reduce risky drinking and/or improve contraception use, with the goal to prevent alcohol-exposed pregnancies in a Cheyenne River Sioux population in South Dakota. This project, called Native Choices, combines motivational interviewing, contraceptive counseling, and supportive electronic messaging. NIAAA is also in the early stages of planning a consensus conference for which NIAAA hopes to involve national and international researchers and some federal partners in an attempt to harmonize various research classifications systems for both FAS and FASD. This meeting will be held on October 29th-30th, 2019, at NIAAA.

Lastly, NIAAA is involved in a trans-NIH initiative called the HEAL initiative that includes seven NIH Institute and Center Operations. As a part of the initiative, the NIAAA participates in the HEALthy Brain & Child Development Study (HBCD). The goal of the study is to examine normative cognitive, behavioral, and emotional development beginning prenatally through ages 9-10. The study will examine the long-term impacts of pre/postnatal drug exposures (opioids, marijuana, and alcohol) on brain and behavioral health and risk for substance use.

The National Institute on Drug Abuse (NIDA)

Karen Sirocco, PhD, Health Scientist Administrator, Prevention Research Branch, Division of Epidemiology, Services and Prevention Research, National Institute on Drug Abuse, NIH

NIDA investigates polysubstance use with much emphasis in the 1980s and 1990s on prenatal exposure to cocaine. With the opioid epidemic, NIDA's emphasis shifted due to the dramatic increase in the number of babies who were prenatally exposed to opioids—one neonate is born with neonatal opioid withdrawal syndrome every 15 minutes. The 2016 National Survey on Drug Use reported a decline in prenatal exposure to tobacco, but exposure rose again in 2017, perhaps due to the use of e-cigarettes. With legalization and medicinal use of marijuana, cannabis use during pregnancy is rising – NIDA and SAMHSA leadership are currently analyzing data from the 2017 National Survey on Drug Use and Health regarding prenatal exposure to cannabis.

Dr. Sirocco emphasized that polysubstance use measurement is an important consideration in prenatal drug exposure studies as the negative impact on fetal and neonatal outcomes may exceed exposure to a single drug. Variability in individual patterns of drug use throughout pregnancy should also be considered as previous studies have shown that use varies between preconception, pregnancy trimester, and postpartum periods. The isolation of drug-specific effects requires large sample sizes that are well characterized in terms of a variety of socioeconomic and other influences. As mothers do not always report drug use, NIDA prefers the use of toxicology reports over self-reporting of drug use.

Dr. Sirocco described recent studies that involved the evaluation of prenatal exposure effects. One of the examples, the HEALthy brain and Child Development Study (HBCD), is a multi-site longitudinally study of 7,500 pregnant women. The HBCD study will characterize developmental trajectories starting prenatally, through childhood, and determine the impact of pre/postnatal exposure to opioids, opioid treatment medication, cannabis, prescription medication, and illicit substances, alone or in combination, on developmental trajectories. The study will also delineate the roles of sex, genetic, epigenetic social and other environmental factors on risk/resilience related to structural and functional brain development, social/behavioral maturation, and substance use and mental disorders. R34 planning grant funding opportunities will be reviewed in July 2019 with a start date of September 2019.

Overview of 8th International FASD Conference

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

The 8th International FASD conference was held in March 2019 in Vancouver, Canada. The focus of the meeting alternates every other year; this year's meeting was focused on academic research and had over 800 participants. The meeting brings together global experts from diverse disciplines, including government officials, administrators, clinicians, family members with FAS and FASD, FASD specialists, lawyers, judges, physicians, policymakers, and scientists.

A pre-conference “Let’s Talk” session involved participants in roundtable discussions of four topics: epidemiology, alcohol use and prevention, diagnostics, and intervention. The focus of this session was to determine where the field should be in 20 years, in 2040. Electronic responses to this question will be collated into a published report.

The meeting included seven plenary sessions: (1) Intrauterine and Gut Microbiomes, (2) Cannabinoids, Alcohol, and Pregnancy, (3) Global Action on FASD Prevention Research, Policy & Practice, (4) CIFASD: A Research Update, (5) Registry Updates: Advancing Research through Participation, (6) Impact of PAE on Sleep/Healthy Sleep in FASD, and (7) Criminal Culpability through the Lens of FASD.

The meeting lasted three days, and at any one time, ten concurrent sessions could occur. The meeting [website](#) has videos of the plenary lectures. The next meeting will be held on April 22nd-25th, 2020, with a focus on issues and challenges that adolescents and adults with FASD face. The meeting is attended by a group of individuals with FASD called the “Changemakers,” who promote the saying “Nothing about us without us,” which reflects the idea that they would like to be more involved in FASD-related research. Dr. Dunty encouraged ICCFASD members to attend the 9th International Research Conference on Adolescents and Adults with FASD Review Respond and Relate: Integrating Research, Policy and Practice Around the World in April 2020.

Reports of Activities from FY2018: ICCFASD Agencies: CDC, SAMHSA, CMS, and HRSA (Continued)

Centers for Disease Control and Prevention (CDC)

Shin Y. Kim, MPH, Team Lead, Lead Health Scientist, Prenatal Alcohol, Opioid, and Substance Exposure Team, Prevention Research and Translation Branch, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

The National Center on Birth Defects and Developmental Disabilities has been reorganized recently. Dr. Kim said that she is in the Prevention Research and Translation Branch, in the Division of Congenital and Developmental Disorder. The team previously was called the FAS Prevention Team. The current initiative was expanded to include not only alcohol but opioids and other substance exposure; Dr. Kim leads the team. The CDC have partnered with academic institutions, medical societies, and national organizations to establish Practice and Implementation Centers (PICs). The PICs were funded from 2014–2018 to achieve practice and system changes in healthcare settings in six discipline-specific work groups: OB-GYNs, pediatricians, nurses, social workers, family practice physicians, and medical assistants.

The CDC FASD training [website](#) that went live in January 2018 included five online training courses:

- [Diagnostic Overview of FASDs: Recognition and Referral](#)
- [FASD Primer for Healthcare Professionals](#)
- [Implementing Alcohol Screening and Brief Intervention in Clinical Practice](#)
- [Interprofessional Collaborative Practice as a Model for Prevention of AEPs](#)

- [Preventing Alcohol-Exposed Pregnancies \(AEPs\)](#)

The website also includes published, relevant policy position statements, articles, and developed networks of champions.

In May 2019, the CDC published its fifth and final online course, [Interprofessional Collaborative Practice as a Model for Prevention of alcohol-exposed pregnancies \(AEPs\)](#) with the goal of giving practical insights and tips on how to design and implement interprofessional collaborative practice teams. Two micro-learnings, short videos focused on one objective, have been released to serve as supplements to the existing courses and are available online.

The CDC released four Notice of Funding Opportunity (NOFO) in 2018 for projects funded from 2019-2022 that build on PICs and partnerships.

- Promoting Resources for FASD Awareness and Prevention (National Organization on Fetal Alcohol Syndrome)
- Implementing Alcohol SBI in HC Systems Providing Women’s Health Services (Boston Medical Center, Henry Ford Health System, University of Alaska Anchorage, UConn Health Center)
- Reaching HC Professionals in the Prevention of FASDs through National Professional Organizations, including American Academy of Family Physicians (AAFP), the American College of Obstetricians and Gynecologists (ACOG), University of Alaska Anchorage, University of Nevada Reno, University of Texas-Austin)
- Pediatric Public Health Partnership on FASD which was funded to American Academy of Pediatrics (AAP)

Lessons learned from the PICs and partners include focusing the new NOFOs on concrete implementation efforts versus training, being more prescriptive regarding target audiences and activities, using a setting-specific approach focusing on practice and systems changes, being more focused and explicit regarding grantee activities, and retaining the champion concept that worked well with the current grantees.

CDC has a project called MAT-LINK (MATernaL and Infant Network) to understand outcomes associated with treatment for opioid use disorder during pregnancy. MAT-LINK will further the understanding of the spectrum of maternal, neonatal, and pediatric outcomes following treatment of opioid use disorder during pregnancy and may inform clinical management and prevention of these adverse outcomes. Data will be collected on all substances used during pregnancy.

CDC’s collaboration with ACF on assessing exposure to alcohol in social welfare settings resulted in one exploratory study of policies and practices that was completed recently, a multisite descriptive study replicating the exploratory study. A study of six states plus a tribal component is ongoing. (See the report from ACF and further discussion.)

A three-year interagency collaboration with SAMHSA and the National Committee on Quality Assurance is to promote the newly approved healthcare effectiveness data and information set (HEDIS measure; Unhealthy Alcohol Use Screening and Follow-up). HEDIS supports a quality improvement learning collaborative across four to five large and diverse health plans. The goal is to develop a toolkit on successful quality improvement approaches using electronic clinical data

systems and lessons learned and barriers for implementation. More information on the HEDIS measure is available on the CDC [website](#).

CDC is also interested in developing messages for healthcare providers to emphasize the importance of providing alcohol screening and prevention information to women of reproductive age and to inform the development of resources and tools to enhance patient-provider communication about alcohol and its risks during pregnancy. In 2017, the CDC awarded a communication contract to improve the way healthcare providers deliver messaging to patients about the risk of alcohol use during pregnancy. The messaging would also serve to engage healthcare providers in the delivery of alcohol screening and brief intervention for their patients, particularly women who are pregnant or might be pregnant. This is an 18-month contract with the American Institutes for Research. An online survey will be conducted with 500 healthcare providers, from those respondents, 36 healthcare providers will respond to in-depth interviews. In-depth interviews will also be conducted with 72 women of reproductive age. Based on the interview and survey findings, draft material concepts will be developed for healthcare providers.

CDC continues to monitor alcohol use among pregnant women using the Behavioral Risk Factor Surveillance System. CDC has worked with the National Ambulatory Medical Care Survey, which provides information on patient, provider, and visit characteristics. CDC has also worked with the DocStyles and SummerStyles surveys, which measures physicians' and consumers' knowledge, attitudes, and practices.

CDC has added questions on alcohol screening and brief intervention on the pregnancy risk assessment and monitoring survey on their opioid callback survey in seven states. Behavioral Risk Factor Surveillance System data collected from 2015-2017 in 50 states and D.C. indicated that one in nine pregnant women reported drinking alcohol in the past 30 days (Denny et al., 2019).

Reference:

Denny CH. Consumption of Alcohol Beverages and Binge Drinking Among Pregnant Women Aged 18–44 Years — United States, 2015–2017. *MMWR Morb Mortal Wkly Rep* [Internet]. 2019 [cited 2019 Oct 15];68. Available from: <https://www.cdc.gov/mmwr/volumes/68/wr/mm6816a1.htm>

The Substance Abuse and Mental Health Services Administration (SAMHSA)

Jon Dunbar-Cooper, MA, CPP, Public Health Analyst, Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration

In FY2018, SAMHSA underwent changes to improve business efficiency and to re-orient the organization to develop and implement a clinical, evidence-based focus in line with the current needs to advance the behavioral health of the nation. SAMHSA received a budget increase of 35%, which resulted in an increase in grant application volume from 1,350 to 3,500. The number of new grant awards increased from over 600 to over 1,500. SAMHSA streamlined the grant review process by reducing the application length from 25 to 10 pages and reducing

application questions from over 25 to 9. SAMHSA implemented a new system of national and regional technical assistance and training to focus on addiction, mental health, and substance abuse prevention.

The Office of the Chief Medical Officer was strengthened to enhance the ability of the organization to address clinical issues. The agency is currently focused more on treatment, screening, and diagnosing due to the opioid crisis. A new organizational unit, the National Mental Health and Substance Use Policy Laboratory, provides evidence-based resources. SAMHSA will soon release a guide, “Preventing Substance Misuse Among Young Adults,” and a guide relating to SAMHSA’s strategic prevention framework, which is the planning model for the prevention programs. Another policy guide will be “Preventing Marijuana Use: Focus on Women.”

SAMHSA launched the Opioid State Targeted Response Program, which awarded \$500 million to states to develop prevention, treatment, and recovery systems to address the opioid crisis. In this program, over 120,000 clients received services, 396 individuals were trained, and 1,300 funded organizations offered at least one form of medication-assisted treatment. Those programs train first responders and train pharmacists to make them aware of multiple prescriptions for opioids for one individual or to how to stop doctor shopping by individuals.

One billion dollars in additional funding was awarded to the State Opioid Response grant program with careful attention paid to enhance the clinical focus of the grant program, using additional language emphasizing the requirements to make FDA-approved medication available for the treatment of opioid use disorder.

SAMHSA has also implemented the Cures Act, requiring the establishment of the Interdepartmental Serious Mental Illness Coordinating Committee. Coordinating activities of this Committee include HHS, Justice, VA, Labor, HUD, Education, and the Social Security Administration. SAMHSA created five specific workgroups on: strengthening federal coordination; establishing evidence-based treatments; addressing populations involved in the justice system; closing the gap between what works and what is offered; and developing financial strategies to increase affordability and accessibility. Establishing evidence-based treatments is the main focus of SAMHSA efforts.

SAMHSA distributed over \$90 million in funding to tribal communities to prevent youth use of alcohol and illicit drugs, suicides, and to address historical trauma, children’s mental health needs, and other critical areas.

The Centers for Medicare and Medicaid Services (CMS)

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

CMS is not very active currently in FASD, despite the fact that the Center covers nearly half of pregnancy and birth care for women in the United States and covers a large amount of care for children with disabilities.

Applications for the Integrated Care for Kids (InCK) model were due on June 10, 2019. It is a child-centered local service delivery and state payment model aimed at reducing expenditures and improving quality of care for all children covered by Medicaid and CHIP (Children's Health Insurance Program), especially for those with, or at risk of developing significant health needs.

CMS wishes to improve performance on priority measures of child health, but current measures are not specifically related to alcohol use. The current measures focus on reducing avoidable inpatient stays and out-of-home placements, and the creation of sustainable alternative payment models. CMS will award to eight states up to \$16 million per award, for a seven-year performance period—two years of pre-implementation and five years of implementation. A state Medicaid agency must partner with a HIPAA-compliant lead organization, such as a hospital system or a large managed care organization. A partnership council would include representation from clinical care, schools and education, child welfare, etc. CMS will fund the creation of a mobile crisis response system if one is not already in place. The award will be announced in December 2019, and the pre-implementation phase will commence in January 2020.

The Maternal Opioid Misuse (MOM) model is currently an important topic for CMS. The MOM model is a patient-centered service delivery model that aims to improve the quality of care and reduce costs for pregnancy and postpartum care of Medicaid beneficiaries with opioid use disorder and their infants through state-driven care formations. The idea is to improve the quality of care, reduce cost, increase access to treatment, and improve service delivery capacity and infrastructure. This is important as evidence-based care is not always available to Medicaid participants, and even when it is, the organizations often do not serve pregnant women. Sustainable coverage and payment strategies would be developed so that a state can cover costs using their infrastructure. Maternity care, behavioral health, and primary care would be integrated with treatment for opioid, tobacco, and alcohol use disorders. CMS hopes to screen for and treat substance abuse disorders more broadly. Aside from tobacco, alcohol use is the most common substance used by pregnant women.

Children are much more likely to develop neonatal abstinence syndrome if there is a polysubstance use disorder. Therefore, the CMS programs cover women through labor, delivery, and then postpartum care, continue to provide behavioral health and primary care, opioid use disorder treatment, and try to promote evidence-based infant care. The CMS approach does not separate the mother and the baby as long as it is safe for them to remain together, encouraging skin to skin, rooming in, breastfeeding if the woman is not using illegal drugs or something else that might be incompatible with breastfeeding. There is a one-year pre-implementation period in the MOM model. The second year is called the transition year because CMS will fund services that are not currently funded under their Medicaid programs. By year three, the states are expected to have applied for waivers, which are exceptions to what is federally funded under Medicaid; therefore, these mechanisms should enable states to cover services themselves. CMS will award up to 12 cooperative agreements, but no formal announcement has yet been made.

CMS analyzed medical data to look at the diagnosis and treatment of substance abuse disorder among pregnant women in three state Medicaid programs. This was a descriptive study in which claims, vital records, and birth certificates were examined for 12 months before and after women gave birth to a live singleton infant in 2014 or 2015. The sample size was almost 38,000. 3.6% had a specified substance use disorder (SUD) before or during the delivery month; 1.7% had a specific SUD that was not diagnosed until after the delivery month, i.e., from one month after delivery through the full year after birth. 6% had an unspecified SUD, but the majority, 89%, did not have any SUD diagnosis. Alcohol use disorder (AUD) was the most common specific SUD diagnosis; 16% of women diagnosed with any SUD before or at delivery were diagnosed with AUD, and 24% were diagnosed with AUD after birth. This equates to 0.6% of pregnant women in the three state programs who had AUD diagnosed before delivery, and another 0.4% who had the disorder diagnosed after delivery. However, the approximate 1% of women with an AUD diagnosis is a very low estimate of alcohol misuse because it excludes not only undiagnosed AUD, but alcohol use during pregnancy or problematic use do not qualify as AUD. This is one of the disadvantages of using claims as they do not register whether or not a woman consumed any amount of alcohol during pregnancy.

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, Department of Health and Human Services

MCHB programs promote the mental health and well-being for maternal and child populations across the lifespan, aligning with the organization's mission to improve the health of America's mothers, children, and families. MCHB programs promote, prevent, screen, intervene, refer, treat, train, and support. The programs address mental and behavioral health issues on multiple levels, supporting providers, policies, state, and local systems, workforce training, patients and families, and innovations that harness technology-based solutions.

MCHB has one initiative focused on the prevention of FASD. Funding for this activity comes through Title V's special projects of regional or national significance or SPNs. MCHB integrates its FASD prevention into the existing training and technical assistance series, provided by the Healthy Start Initiative, eliminating disparities in perinatal health's EPIC technical assistance center (Healthy Start EPIC Center). The purpose of the Healthy Start Program is to improve outcomes before, during, and after pregnancy and reduce racial and ethnic disparities in rates of infant death and adverse perinatal outcomes.

The Alcohol and Substance-exposed Pregnancy Prevention (AStEPP) initiative focuses on increasing knowledge and skills among Healthy Start and federal home visiting grantees. The Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program focuses on increasing knowledge and skills related to prevention and early identification of fetal alcohol exposure or exposure to other drugs that impact maternal and newborn health outcomes. There is a special emphasis on the AStEPP program focused on American Indian communities and populations.

Available on the Healthy Start EPIC Center [website](#) are several useful resources, including a discussion guide, “[Increase Healthy Start and Home Visiting Staff Knowledge of Opioid Use among Pregnant Women](#).” There are six staff development group training videos that include questions for group discussion. These videos include the following topics:

- Using Preconception and Interconception Education and Services to Help Prevent Alcohol-Exposed Pregnancies
- Perinatal Depression: Screening, Support and Referral to Treatment
- Addressing Fetal Alcohol Syndrome in Native and Tribal Communities
- The Importance of Trust as a Tool for the Disclosure of Substance Use During Pregnancy
- Social Determinants of Substance Use During Pregnancy
- What I Wish For You: Community Health Workers’ Hopes for Their Healthy Start Clients

“[The Importance of Trust in Substance Use Disclosure During Pregnancy](#)” and “[Social Determinants of Substance Use During Pregnancy](#)” are videos that explore substance use during pregnancy in tribal communities. These were developed through a partnership with the Northern Plains Tribal Healthy Start Project.

A webinar series on FASD provides a basic overview of FASD, prevention strategies including referral for treatment for pregnant women, and screening and assessment for FASD in children. The webinars cover the following topics:

- [Addressing Fetal Alcohol Spectrum Disorders in the Context of Healthy Start: What do we need to Know?](#) (Presented live 2/21/17)
- [Using SBIRT in Healthy Start: Destigmatizing Addiction and Cultural Considerations](#) (Presented live 4/13/17)
- [Introduction to FASD Screening and Diagnosis](#) (Presented live 5/25/17)
- [What are the Long-term Effects and Impacts of Fetal Alcohol Spectrum Disorders \(FASD\) on Individuals and Their Families](#) (Presented live 9/5/17)
- [Ask the Expert: How does prenatal exposure to alcohol, marijuana, opioids and other substances affect maternal and child health outcomes?](#) (Presented live 12/12/17)

HRSA has just released three new funding opportunities to improve maternal health outcomes and to address disparities in maternal mortality and maternal morbidity. The State Maternal Health Innovation Program will invest approximately \$18 million through nine awards to states or a group of states working in concert with the State Title V agency. Successful recipients will receive \$2 million per year for five years to strengthen partnership and collaboration by establishing a state-focused maternal health task force, improving state-level data surveillance on maternal mortality and severe maternal morbidity, and promoting and executing innovation in maternal health service delivery. The second funding opportunity is the Supporting Maternal Health Innovations Program, which will invest approximately \$2.6 million through one award to support states and other stakeholders in reducing maternal mortality and severe maternal morbidity. Lastly, HRSA will fund one cooperative agreement for \$1.8 million per year for five

years for the Alliance for Innovation on Maternal Health program to develop and implement maternal safety bundles within community-based organization and outpatient clinical settings across the U.S. More information about these funding opportunities is available on the [HRSA website](#).

Special Panel Discussion: Considering, Recognizing, and Screening for Fetal Alcohol Spectrum Disorders (FASD) in Children in Primary Health Care, Education, Justice, and Social Service Settings

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

Engaging Parents/Caregivers in Early Childhood Development Monitoring: Resources From CDC

Karnesha Slaughter, MPH, Health Communication Specialist, "Learn the Signs. Act Early." Program, Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities

CDC's "Learn the Signs; Act Early" program offers free, parent-friendly tools, and other resources to help parents and other care providers track developmental milestones and act early on possible developmental concerns. The mission of the program is to improve early identification of developmental delays and disabilities, including autism, by promoting parent-engaged developmental monitoring, using developmental milestone checklists, and other resources into far-reaching programs and systems that serve families with young children. These tools do not replace developmental screening as recommended by the American Academy of Pediatrics at various ages, but they offer a parent-friendly way to educate parents about what to expect in a child's early development and encourage them to notice, track, and celebrate developmental progress. Finally, the tools provide clear, concrete guidance about what to do when there is a possible developmental concern.

Parent-engaged developmental monitoring tools are available as part of the CDC's Milestone Tracker app, which is free and available in English and Spanish. Each developmental milestone is categorized by domain: social/emotional, language/communication, cognitive, or movement/physical development. In the app, parents can check off milestones that their children reach, or become aware of alerts, that encourage parents to talk with their provider as soon as possible and ask for developmental screening. The checklists also include tips for parents to help them promote their child's development and an example scenario of when a provider may need to talk with a parent about possible developmental concerns for a child.

"Learn the Signs; Act Early" ambassadors are a group of people who are very well connected in their states and territories. They work to identify opportunities to integrate "Learn the Signs; Act Early" into statewide systems; 56 percent have reported integration. There are 54 ambassadors in 48 states and three territories. More information is available on the CDC [website](#).

Other free CDC resources available to help parents and caregivers and providers monitor children's early development are available in a wide variety of formats to make them accessible to as many people as possible, and in a variety of languages. In addition to English and Spanish, materials are also available in Vietnamese, simplified Chinese, Korean, Haitian Creole, and Brazilian Portuguese. Hopefully, through collaboration, the CDC can ensure that every child's development is closely monitored; that children with FASD, autism, and any other developmental disability are identified and connected with services as early as possible.

Recognizing Children with FASD in Primary Health Care

Yasmin Senturias, MD, FAAP, Professor of Pediatrics, Developmental and Behavioral Pediatrics Medical Director, Developmental and Behavioral Pediatrics of the Carolinas – Charlotte Clinic, Atrium Health, Adjunct Professor of Pediatrics at UNC Chapel Hill

In recent epidemiological studies, 1 to 5% of first-grade children in four diverse U.S. communities were diagnosed with some form of FASD; therefore, FASD is present in every primary care practice. FASD is the most common preventable cause of intellectual disability and behavioral disorders. FASD has lifelong effects that are more serious than those of other drugs or teratogens.

Gahagan et al. (2006) studied knowledge, training, and experience in the care of children with fetal alcohol syndrome among 879 pediatricians. The respondents almost universally knew the teratology and clinical presentations of FASD. However, whereas 62% and 50% of respondents felt prepared to identify and diagnose FASD, respectively; only 34% of respondents felt prepared to coordinate and manage treatment of FASD.

The American Academy of Pediatrics (AAP) conducted a study (Smith et al., 2017) that found among 436 pediatric providers (pediatricians, trainees, nurse practitioners; 71% pediatricians), 88.2% suspected that a child in their practice could have FASD. Only 29.2% of respondents felt comfortable with FASD diagnosis or referral, and only 11.5% felt comfortable with their current FASD knowledge base and practice behavior. Therefore, screening and diagnosis of FASD among medical professionals should be improved.

The AAP FASD toolkit is a free, downloadable, comprehensive one-stop resource for clinicians. It includes a flowchart for the screening process of children, management strategies, evidence-based interventions, and scripts that guide discussions with parents. Pediatricians should consider FASD evaluation when any of the following are presented:

- developmental, cognitive, or behavioral concerns (about 25% of pediatric visits)
- complex medical concerns (e.g., cardiac concerns)
- growth deficits
- history of maternal alcohol or drug use
- a sibling diagnosed with an FASD
- dysmorphic facial characteristics associated with FAS

The AAP Bright Futures kit that every pediatric resident is provided with, suggests the following screening questions to obtain information about the risk for prenatal alcohol exposure from a mother:

- How often do you drink beer, wine, or liquors in your household?
- In the three months before you knew you were pregnant, how many times did you have four or more drinks in a day?
- During your pregnancy, how many times did you have four or more drinks in a day?

Nash et al. (2006) created a screening tool to identify the FASD behavioral phenotype in a child. It was a small study, but it had 62.5% sensitivity for participants with FASD and 50% for prenatal alcohol exposure.

The AAP has two one-page handouts about the effects of prenatal alcohol exposure: “Developmental and Behavioral Effects of Prenatal Alcohol Exposure” and “Diagnosing Fetal Alcohol Spectrum Disorders: What Families Need to Know.”

Major challenges that remain in the FASD field include the fact that pediatricians are still not universally screening for FASD due to a lack of confidence in the recognition and management of FASD. There is a lack of FASD clinics that can provide a comprehensive evaluation and a lack of evidence-based methodologies to improve outcomes for children with FASD. Evidence-based interventions, such as Families Moving Forward and the MILE program are not available in every state or city. There is also bias and stigma about FASD and prenatal alcohol use that prevents pediatricians from even considering the diagnosis and discussing it with families. The FASD phenotype can overlap with other diagnoses, such as exposure to trauma.

Other AAP initiatives to help identify and manage FASD include:

- FASD Real Champion program (Champions lead and facilitate education and training)
- FASD webinars
- FASD ECHO program (telementoring program designed to create communities of learners by bringing together healthcare providers)
- FASD Continuity Clinic Project Implementation guides (residents are trained in screening for prenatal alcohol exposure)

Dr. Senturias reported the success of some of the AAP initiatives. For example, attending the webinars resulted in a 20% increase in knowledge of the primary facial dysmorphic features associated with FAS and knowledge of the criteria for neurobehavioral disorders associated with prenatal alcohol exposure. Knowledge of approaches/care strategies applicable to children diagnosed with FASD increased by 25% following the webinars.

Screening for Prenatal Exposure in Kids (Project SPEAK) was a study in which nine pediatric practices were assessed over several months. Baseline screening rates were low as electronic health record systems are not generally configured to support screening for prenatal alcohol exposure. However, the study showed that physicians were likely to implement universal screening for prenatal alcohol exposure. Dr. Senturias advocates for the inclusion of prenatal alcohol exposure as a vital sign, similar to tobacco use.

Dr. Senturias noted the needed for more patient and family strengths approaches and better utilization of Occupational, Physical, and Speech Therapists.

References:

Gahagan S, Sharpe TT, Brimacombe M, Fry-Johnson Y, Levine R, Mengel M, et al. Pediatricians' knowledge, training, and experience in the care of children with fetal alcohol syndrome. *Pediatrics*. 2006 Sep;118(3):e657-668.

Nash K, Rovet J, Greenbaum R, Fantus E, Nulman I, Koren G. Identifying the behavioural phenotype in Fetal Alcohol Spectrum Disorder: sensitivity, specificity and screening potential. *Arch Womens Ment Health*. 2006 Jul;9(4):181–6.

Smith VC, Matthias P, Senturias YN, Turchi RM, Williams JF. Fetal Alcohol Research Caring for Patients with Prenatal Alcohol Exposure: A Needs Assessment. *J Popul Ther Clin Pharmacol J Ther Popul Pharmacologie Clin*. 2017 Jan 27;24(1):e25–39.

Recognizing Children with FASD and Engaging School Systems

Molly N. Millians, DEd, Senior Associate, Department of Psychiatry and Behavioral Sciences, Emory Neurodevelopmental Exposure Clinic, Emory University Brain Health Center

Children with FAS or prenatal alcohol exposure are at high risk for global developmental delays, cognitive impairments, poor self-regulation, behavior problems, adaptive behavior function deficits, and poor social skills. These issues can cause academic failure, school underachievement, and legal problems.

Regulations for support for individuals with disabilities or special education services include the Rehabilitation Act (1973), the Americans with Disabilities Act (1990), and the Individuals with Disabilities Education Act (IDEA) which was updated in 2004 and is broken down into four parts. Parts B and C, deal with early interventions for young children in the school system and include “Child Find” a process to identify children who have disabilities or are at risk and may be eligible for services. Part B, which covers ages 3 to 21, helps with the identification of children who are eligible for special education services, multi-component evaluation, mandates, instruction, and different types of educational-related services. Part C is for children 0 to 3 and is more family-based. It is not academic-driven or school-driven. It has components for interagency collaboration and case management. Parts B and C also establish a technical system or dissemination network and provide fiscal support.

IDEA eligibility for special education services has 13 categories. However, schools are not medical providers; the eligibility categories are for educational purposes. Most school systems have put in place formal multi-tiered levels of interventions to make sure that children are provided support before they fail or need special education services. However, these screenings may not be appropriate if there are significant behavior problems, intellectual disabilities, or other disabilities that indicate a child may need immediate special education services.

There are differences between clinical and educational perspectives when dealing with learning disabilities, interventions, and treatment. Schools use multiple sources of information, academic benchmarks, or individual growth in relation to learning. Academic benchmarks and school expectations may not be consistent across states. Whereas the need for intervention/treatment of a suspected FASD is based on defined measures in the clinical setting (DSM-5 and ICD-10-CM criteria), academic benchmarks and school expectations may not be consistent across states.

Clarren et al. (2001) performed a two-year study to estimate the prevalence of FAS in 2110 children in 1st grade from two counties in Washington State. Prevalence could only be determined in one county in which almost all 1st graders were screened. Of 1,000 children, five received a diagnosis of FAS; eight were determined to be affected by prenatal exposures, and three were found eligible for intervention services/adjustment of services. In the second county, only 25 percent of the kids were screened because not every school wanted to participate in the project.

Poitra et al. (2003) examined the usefulness of a 32-item screening tool to identify children with behavioral problems or developmental disabilities for referral to a specialty clinic for diagnosis. This was a 9-year study that screened 1,384 children in North Dakota, South Dakota, and Minnesota. The estimated prevalence of FASD (using the Institute of Medicine Diagnostic Criteria) was one out of 230 kindergarteners, or 4.4 out of 1,000. The study concluded that the screening tool was time-efficient, cost-effective, and accurate.

Watson et al. (2011) examined 1,611 children (0-3 years of age) as part of three early-intervention programs in Massachusetts. The study found that the FAST screening tool had a 61% feasibility rate but an inconsistent fidelity across sites. School personnel reported feeling uncomfortable about asking caregivers about alcohol use during pregnancy. However, it did increase FAS awareness in school staff.

According to May et al. (2018), prevalence is between 1 and 5 percent; that is one to five out of 100 school-age children. Most likely, every classroom or every grade will have a child who's been affected by prenatal alcohol exposures. According to the special education statistics from the National Center for Educational Statistics, 50.7 million kids were enrolled in public school in 2018. In 2017, 14 percent were enrolled in special education services. There is no mention of FAS in data by the eligibility categories.

Dr. Millians stated one needs to think about how to collaborate with the U.S. Department of Education and how to get school systems to recognize FASD. Children with FASD have significant health, medical, and other issues that hinder learning. Would a national framework need to be developed for states and school systems to follow? Would it be feasible in a large school district? Can screening and special education services for these children be implemented? There are medical clinics in some schools that provide good care, which could potentially be used. Screenings are time-efficient. Schools would not be asked to do any medical diagnosis, just to inquire: is there possible prenatal exposure? It could be done.

However, studies indicate that there are challenges with maintaining screening fidelity, school personnel being vested, and schools really wanting to be part of it. Schools are very decentralized in some states. And states vary across the nation. If a child is not showing academic problems in a classroom or behavior problems, the child may not be eligible for services. One also has to consider the privacy and protection of health information and the stigma. Caregivers may continue to be reluctant, thinking their child may be treated differently in a classroom.

The Department of Education needs to be engaged, as well as early childhood professionals, and advocacy groups. One needs to get more on-board, have focus groups to do needs analysis to see how would this benefit education. One also needs to collaborate, possibly, with school-based health care systems.

Engaging schools in FASD recognition requires collaboration with the U.S. Department of Education, national organizations, early childhood advocacy groups, and the Council for Exceptional Children.

Suggestions to enhance FASD recognition include:

- Incorporating screenings for FASD within established school-based health centers
- Training school psychologists to screen for FASD
- Training social workers and education specialists to ask questions about prenatal exposures when kids come in, even when they transfer to new schools. This might include designating an FASD information specialist within the information network system. That way, there is someone to talk to who can refer a child and the family to support and services
- Changing the policy and the IEP process
 - adding a clarification statement under Other Health Impairment (OHI) and the IDEA, Part B
 - adding case management services

References:

Clarren SK, Randels SP, Sanderson M, Fineman RM. Screening for fetal alcohol syndrome in primary schools: a feasibility study. *Teratology*. 2001 Jan;63(1):3–10.

May PA, Chambers CD, Kalberg WO, Zellner J, Feldman H, Buckley D, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *JAMA*. 2018 06;319(5):474–82.

Poitra BA, Marion S, Dionne M, Wilkie E, Dauphinais P, Wilkie-Pepion M, et al. A school-based screening program for fetal alcohol syndrome. *Neurotoxicol Teratol*. 2003 Dec;25(6):725–9.

Watson E, Finkelstein N, Gurewich D, Morse B. The Feasibility of Screening for Fetal Alcohol Spectrum Disorders Risk in Early Intervention Settings: A Pilot Study of Systems Change. *Infants Young Child*. 2011 Jun;24(2):193.

Discussion

Nadia Carrell, PhD, FASD Advocacy and Support, stated that although schools always emphasize that they are not medical service providers, schoolchildren in the State of Maryland undergo vision and dental screenings. She suggested that screening for red flags for developmental disabilities (including FASD) would be appropriate. Dr. Carrell asked if a child is having difficulty with the school curriculum, why is that not enough for a referral for services, without a diagnosis of FASD. Dr. Millians replied that school teachers could be tolerant of some behavioral issues and that difficulty with the school curriculum would not equate to a need for services. Dr. Millians agreed that screening for developmental disorders should accompany the dental and vision assessments but noted that there is a stigma that prevents intervening in such situations. Dr. Carrell added that the Office of Special Education Programs, U.S. Department of Education (OSEP), had in the recent comments on IDEA clarified that they intended for FASD to be included under OHI (but specifications were not included. Dr. Carrell noted that the dyslexic and autism communities have been successful in the delivery of topic issue sheets to schools, and that has to be done at the state level because that would help the states to develop their policy.

Dr. Senturias asked whether traumatic brain injury, which is a category for an IEP, could be taken advantage of to address FASD? Dr. Millians responded that the criteria for traumatic brain injury include an after-birth event, so she has been unsuccessful using that category in the past. A medical diagnosis that is included in the DSM-5 would open up more opportunities. Dr. Senturias asked whether the use of the term neurobehavioral disorder would increase the potential for services because it has all the characteristics of FASD and has the added benefit of reduced stigma as it is a general term. Dr. Millians responded that a big issue is that schools do not deal with medical diagnoses. There is a poor bridge between education and the clinic, which needs to be changed by policies. But having ND-PAE in DSM-5 may open up some doors enabling schools and colleagues to provide services or get accommodations for these children.

Recognizing and Screening for FASD in Juvenile Justice Settings

Kenneth Lyons Jones, MD, Institute for FASD Discovery (IFASDD), Center for Better Beginnings University of California, San Diego, CA

Dr. Jones reported about a screening program at the Kearny Mesa juvenile detention facility in San Diego, one of two juvenile detention facilities in San Diego County. The screening program was conducted as a collaboration between the San Diego County Probation Department; the San Diego office of the primary public defender, the juvenile division; and the USCD Department of Pediatrics, the Division of Dysmorphology and Teratology. During this initial pilot screening program, from September 2013 through July 2016, all juveniles to the program were referred via the public defender's office. Obtaining consent for the examination from a parent or guardian was extremely challenging, and verbal assent from the juvenile was also required if they were of an appropriate age. Only a small percentage of those referred for screening by the public defender's office agreed to participate in the program.

The screening was performed by a nurse whom Dr. Jones had trained. She performed

measurements of height and weight, head circumference, palpebral fissure length, evaluations of facial features, the philtrum, upper lip, and palmar crease, contractures of the fingers and at the elbow, and the presence of a heart murmur. The screening took about eight minutes and was followed by a brief phone interview with a parent or guardian. If the screen was positive, the adolescent or child was referred to the FASD Clinic for diagnostic assessment by Dr. Jones. A total of 134 juveniles were screened, of which 32 (24%) screened positive; 14 (44% of 32) were evaluated, and 12 (86% of 14) were positive for FASD.

The 2018 publication "Prevalence of Fetal Alcohol Spectrum Disorders in 4 U.S. Communities." showed that the incidence of FASD in San Diego county was 2.3%. This prompted interest in another screening program that commenced in May 2019. Juveniles were automatically sent for screening if their head circumference was less than the tenth percentile, if there was a reliable history of prenatal alcohol exposure, or positive responses to questions ranging from school learning problems, history of mental health conditions, multiple admissions to juvenile hall, impulsive behavior, poor decision-making skills, aggressive behaviors, history of suspension or expulsion from school. In order to overcome problems of low rates of willingness to participate in an FASD screening program identified in an earlier pilot, the new program is working with probation officers to try and get more cooperation with the juvenile and the family to ensure that juveniles with FASD receive the proper support and care when they are released.

Dr. Jones also spoke about the importance of interacting with different components of the juvenile justice system to support a child with an FASD. In San Diego, these include the juvenile court judges and the head judge, the public defender's office, the district attorney, probation and reentry officers, and juvenile court-mandated schools. Another system that his program is involved with is the public health visiting nursing program, which is extensive in San Diego. In addition, they needed to involve the Department of Purchasing and Contracting of San Diego County for potential funding for the program.

Dr. Jones examined 16 individuals on death row, including one man with FASD who was executed. For another 15 men on death row, lawyers thought that an FASD diagnosis may be a mitigating factor due to maternal history of heavy alcohol use. Approximately one-quarter of the remaining 15 individuals on death row had their sentences converted to life in prison; intervention in the other cases is still ongoing at the time of the 2019 ICCFASD meeting.

Discussion:

Dr. Cross-Barnet asked how many girls in the juvenile justice system are there with these behavioral issues and whether girls who are in the juvenile system seem to be proportionally affected by FASD. Dr. Jones responded that he could probably count on one hand the number of girls he has seen in the juvenile justice system; the vast majority in the system are males. Out of the 16 individuals on death row, two are women. Dr. Jones believes that fewer girls commit crimes that cause them to end up in the juvenile justice system, but he thinks that it is a 50:50 chance that male or female offspring would have FASD following prenatal alcohol exposure. Dr. Sirocco asked if there is a difference in types of crime or other mental health disorders in girls with FASD compared to boys. Dr. Jones responded that he does not know about other mental health problems, but that depression is seen more in women than in men, and depression is a significant issue as far as pregnancy is concerned generally.

Promoting Recognition of FASD in Social Services Systems

Christopher Boys, PhD, LP, Associate Professor of Pediatrics, Department of Pediatrics, University of Minnesota Medical School

Dr. Boys reported on the general recognition of FASD, past collaborations and outreach, and the current state of FASD recognition in Minnesota (MN). The awareness of FASD in MN has developed through several years and has a multifaceted collaborative approach. A strong advocacy group, MOFAS (now called Proof Alliance), has driven connections between the university FASD clinic, a long-standing international adoption program at the University of Minnesota, and the counties and the school district to support screening mechanisms. That collaboration is remarkable in terms of the improved educational outcomes work with Minneapolis Public School. MOFAS funded a social worker within the school district that was FAS-specific and supported training with the school district and other childhood screeners. Past collaborations included a program similar to what Dr. Jones described, the SAMHSA FASD CE-supported Hennepin County Juvenile Justice Project, in which adolescents presenting for probation, for whom FASD was suspected, received an FASD evaluation and FASD-specific support services, as appropriate. We also have worked to assist in juvenile adjudication.

The University of Minnesota FASD Clinic has 450 evaluation slots for FASD annually. In addition to the clinical work, we have ongoing research programs and provide FASD training to school districts, which include behavioral modification and classroom management strategies. Approximately 50% of the referrals to the FASD clinic are from county social workers. Proof Alliance/MOFAS provides training to county social workers and foster care agencies. The rate of FASD in foster children is ten times higher than in the general population. An MN state law in 2017 mandated that newly licensed foster parents receive training on parenting strategies for children with FASD. Foster parents often request evaluations and education in FASD from social workers. There are some differences between the metro area and the rural areas, though, having foster parents, probation and juvenile justice, CPS workers, and even having the in the rural districts early childhood screeners crossing over between them and think about FASD in the context of more traditional children's mental health considerations is really important. It does not take long to branch out and spread information, and then the counties talk to their counterparts in other counties. In some of the rural counties, you have the public health nurse and two social workers, and that is the team. So, the outreach trainings that have been done in MN have been really important.

Discussion:

Mr. Dunbar-Cooper asked whether Native Americans were included in the MN populations. Dr. Boys responded that the MS FASD Clinic has a very significant population of Native American families, and his organization works pretty closely with a couple of specific tribal governments, White Earth, Red Lake, and the Mdewakanton Sioux and Shakopee. Mr. Dunbar-Cooper asked whether incidences of FASD are higher in those populations than in the general population. Dr. Boys said that was difficult for him to answer because his focus is on FASD and he does not see the whole community. Among children who are brought to his clinic, everyone has an FASD related concern, so it is hard to answer about a specific population group. Dr. Boys stated that

socioeconomic status, regardless of ethnicity, seems to be important in terms of family stressors and mental health and chemical dependency.

Allison Meisch, James Bell Associates, working on behalf of colleagues who do some research in prenatal alcohol exposure and thinking about it in the child welfare system, asked what the training for foster parents includes. Dr. Boys has not seen the whole training protocol in terms of the curriculum but stated that it includes both behavioral management strategies for kids that have FASD, and what behaviors may present. It is good training that is a backdoor into screening.

Dr. Senturias added that the foster care community is very strong, and if the information can be given universally to foster care families right from the get-go, there will be a lot of things that can take place that will promote recognition in primary care. Dr. Boys mentioned that in MN, newly licensed foster parents have to learn about FASD, but the law also mandated that FASD had to be an option for the continuing trainings. It may not be selected as an option, but formerly it was even not on the list of continuing training options. Nadia Carrell asked whether social workers in MN become aware of FASD during their training. Dr. Boys indicated that he was not certain, but the social work schools had not approached his organization on the matter. Dr. Carrell suggested that FASD should become part of the training that people have to take to become a licensed childcare provider, such as in Maryland. Dr. Boys said he was not well versed in the training for daycare and early childhood providers. Dr. Jones asked whether FASD is included in medical school lectures. Dr. Boys responded that he teaches psychiatry residents and fellows about FASD, not every year, but most years.

Open Discussion All ICCFASD Agency Representatives and Guests

Dr. Balachova asked Dr. Boys whether he has seen parents with FASD when he works with the child welfare system. Dr. Boys responded that there is a cycle of dependency and intergenerational FASD that he has seen in some families. Dr. Balachova said that she served on a Post-Adjudication Review Board (PARB) for many years and saw children in the foster care system whose parents had limited capacity and could not consistently commit to the treatment plan for their children. Some of the parents might have FASD or other conditions that have not been identified and addressed. Children remained in the system; both children and parents suffered. Dr. Boys stated that they work with proactive CPS workers who may become involved when parents have a chronic disorder or chemical dependency issues. There may be out-of-home placement for children for periods during which parents receive treatment. CPS is sometimes the access point to necessary resources for families.

Dr. Newburg-Rinn said that the Children's Bureau leadership is now focusing on trying to keep the children safely in their homes and providing whatever services are needed to accomplish that, such as counseling, housing, or food, rather than putting the children into foster care. Data from the Children's Bureau, a follow-up survey of the youth who leave foster care, showed that more of these youths were unemployed, had more drug or alcohol problems, and more were in jail. Dr. Newburg-Rinn thinks that such youth resemble children with FASD and stated that an international study indicated that 16.9% of the children in out-of-home care worldwide had an

FASD.

Dr. Carrell asked Dr. Boys whether his organization has done any training or any work with persons with FASD who have children themselves. Dr. Boys said it is something his organization is considering from an anecdotal clinic perspective. He said that people who present at the clinic do not do so of their own accord; they have been referred by someone else.

Mr. Dunbar-Cooper referenced a prior talk by Dan Dubovsky, who mentioned a screening tool used in clinical settings that treated women for substance abuse. The tool was also used to determine whether the women had FAS or FASD. The SAMHSA FASD Center for Excellence was going to promote the tool, but the SAMSA FASD program ended. Dr. Balachova believes that this tool has been evaluated by Dan Dubovsky and colleagues in Washington state, but she does not know what happened to the tool.

Dr. Carole Brown from the Education Department at the Catholic University of America commented that she was happy to hear Dr. Carrell's comments about a recent clarification from OSEP that they had intended for FASD to be considered under the OHI section of the 2004 IDEA. Dr. Brown noted that she was an education expert on the CDC-sponsored National Task Force's efforts related to education and the law that was published in 2004. She stated that the intent was always that FASD is considered part of OHI, unless there was another category that would fit a child's needs. She mentioned a Supreme Court ruling in a recent case, *Andrew versus the County of Douglas*, that is a huge shift for special education. The Supreme Court clarified that the law requires that children who are in special education make progress, and if they're not making progress, then the law is not being met. Dr. Boys said he reminds schools all the time that special education does not list every medical diagnosis for the category, so expressing that they have behavioral concerns or learning concerns, can be a diagnosis that can be used. Dr. Millians stated that in Georgia, eligibility classification technically does not guide placement or technical services, so once children are deemed eligible, the program can be structured based upon their individual needs.

Dr. Senturias stated that ADHD and autism are both neurodevelopmental disorders, and they are both in the DSM. Therefore, while there could be a conception that this could make it more psychiatric, there is also a neurological component to think about, because people do not necessarily think of it that way, DSM versus non-DSM.

Caitlin Cross-Barnet asked about the role of gender in diagnosis in terms of externalizing versus internalizing behaviors, and how one can make sure that girls are treated equitably in the justice system. Dr. Boys responded that it is important to have documentation of prenatal exposure, which could be achieved by early screening, which should be carried out for all children. Dr. Cross-Barnet asked whether most questions were based around externalizing behaviors. Dr. Boys replied that early screening would not be based on any presenting problem. Dr. Jones responded that he believes questions about alcohol use during pregnancy should be asked at the six-week check of the mother and baby after birth when there is a beautiful baby, and nothing is wrong. In Dr. Jones' experience, problems are first seen when children are about three years old. If the question regarding alcohol use during pregnancy had been asked at the six-week check, any alcohol use would already be documented in the chart when issues are first observed. Dr. Sirocco

asked what it would take to put that line of questioning into medical training to implement it in terms of standard screening. Dr. Jones responded that it would be very difficult to get a university to change what they teach, so the only way is to convince the people that write the tests that people have to take to become a pediatrician to include FASD on the tests. Dr. Jones did not believe that it would be difficult to achieve. Dr. Millians suggested that the section on FASD in medical textbooks be expanded. Dr. Senturias said that she was a member of the American Board of Pediatrics content development team, for developmental and behavioral pediatrics concerns and issues, and that FASD was included. She said that FASD should be addressed in graduate medication education, the Accreditation Council for Graduate Medical Education, and residency education. FASD is already included in the content specification for the American Board of Pediatrics, so every program should be approached to expand FASD content, from diagnosis to management. Dr. Balachova suggested that professional associations in psychology also can be approached. Dr. Boys stated that ACOG, the American College of Obstetrics and Gynecology, included FASD in their board exams.

Dr. King expressed a concern that pediatric residents do not have a lot of time to dedicate to learning about new topics. She asked how the structural barriers between systems, e.g., clinical and education systems, could be overcome. She said that even though relevant technology exists, privacy concerns would prevent the sharing of data. Dr. Senturias said that it is true that pediatric residents are already overloaded, but there is a mandatory one-month rotation for developmental-behavioral pediatrics. One champion among all developmental-behavioral pediatrics faculty in every single program actually could potentially make a difference.

Dr. Jones said that the American Academy of Pediatrics is coming around to the idea of asking questions about alcohol use during pregnancy at the six-week check.

Closing Comments

Dr. Powell remarked how useful the input from the federal and non-federal entities was. She said that comments and suggestions are welcome, not just at the meetings, but throughout the year.

Dr. Balachova thanked the speakers for excellent presentations and the agencies for their commitment to participating in the meeting. Dr. Balachova suggested that participants watch the NIH videocasts on previous ICCFASD meetings. Dr. Balachova thanked Dr. Anderson for organizing the meeting.

Adjournment

Dr. Powell adjourned the Spring 2019 ICCFASD meeting.