

Meeting Summary

**Thursday, April 13, 2017**

National Institute on Alcohol Abuse and Alcoholism

5635 Fishers Lane, Terrace Level Conference Center, Rockville, Maryland

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# Welcome, Introductions, and Comments

*Kenneth R. Warren, Ph.D., Senior Advisor, National Institute on Alcohol Abuse and Alcoholism (NIAAA), National Institutes of Health (NIH); Chair, Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD)*

Dr. Warren welcomed participants to this meeting and asked the ICCFASD members to introduce themselves.

# Overview of ICCFASD Mission and Goals

*Marcia S. Scott, Ph.D., Division of Epidemiology and Prevention Research, NIAAA, NIH; Executive Secretary, ICCFASD*

Dr. Scott discussed the history and activities of the ICCFASD, which is made up of representatives of the federal agencies that address issues related to prenatal alcohol exposure. Its purpose is to help improve communication, cooperation, and collaboration around FASD education, prevention, and intervention. The committee has had several work groups, including the Justice Issues Work Group. More information is available on the [ICCFASD web page](http://www.niaaa.nih.gov/ICCFASD).

The committee’s members represent the U.S. Departments of Education, Health and Human Services (HHS), and Justice (DOJ). Most members come from HHS and represent the Indian Health Service, Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Agency for Healthcare Research and Quality, Administration for Children and Families (ACF), Substance Abuse and Mental Health Services Administration (SAMHSA), and NIH (NIAAA, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development [NICHD], and National Institute on Drug Abuse [NIDA]).

Activities of the committee focus on many types of issues, including basic, clinical, and survey research to provide data that inform public health policies; best practices for prevention and treatment; access to diagnostic information and services; and health care delivery for persons with FASD. The ICCFASD also addresses issues of appropriate education of children with FASD and promotion of recognition and fair treatment of individuals with FASD in judicial settings. The themes that underlie ICCFASD’s work are:

* Preventing drinking during pregnancy
* Intervening with children and families affected by prenatal alcohol exposure
* Improving methods for diagnosis and case identification
* Increasing research on etiology and pathogenesis
* Increasing information dissemination

# Update from the DOJ and the ICCFASD Justice Issues Work Group

*Scott Pestridge, M.P.P., Office of Juvenile Justice and Delinquency Prevention (OJJDP), DOJ*

Mr. Pestridge described recent FASD-related activities of OJJDP, whose vision is:

… a nation where our children are healthy, educated, and free from violence. If they come into contact with the juvenile justice system, the contact should be rare, fair, and beneficial to them.

This vision is closely linked to the work of the ICCFASD Justice Issues Work Group.

OJJDP recently published the [Fetal Alcohol Spectrum Disorders Listening Session Report](https://www.ojjdp.gov/pubs/249202.pdf). This report summarizes a listening session on June 13–14, 2013, and provides 76 action steps for government agencies and private organizations with expertise in FASD to best reach judicial, legal, juvenile justice, and other professions with FASD education and training. Through this training, stakeholders can identify ways to foster changes in the system to reduce recidivism and improve life outcomes for those with FASD.

A second recent important publication, [Fetal Alcohol Spectrum Disorders: Implications for Juvenile and Family Court Judges](https://www.niaaa.nih.gov/sites/default/files/publications/ICCFASD/NCJFCJ%20FASD%20Guide%20Final-12012016.SA_Access_FinalTC.pdf) (and <http://www.ncjfcj.org/FASD-Guide>), was co-funded by NIAAA and OJJDP and was issued by the National Council of Juvenile and Family Court Judges (NCJFCJ) in 2016.

The ICCFASD Justice Issues Work Group is working on disseminating these documents to the field. It will hold a panel presentation on FASD at the [Coalition for Juvenile Justice Annual Conference](http://juvjustice.org/events/conferences/2017-cjj-annual-conference) on June 14–17, 2017, in Washington, DC. The Work Group’s goal is to make participants (e.g., state advisory groups, organizations, juvenile justice practitioners, and service providers), who can affect change at the state level, aware of opportunities to assist FASD-affected individuals and the importance of doing so. A second panel presentation by the work group will take place at the [80th NCJFCJ annual conference](https://www.ncjfcj.org/80th-annual-conference) in Washington, DC, on July 16–19, 2017. The audience will consist of juvenile and family court judges, and this conference is very influential. In preparation for these conferences, the work group is developing an executive summary of the reports in lay language.

The work group is determining how to deliver its messages about FASD to other components of the juvenile justice community, and it welcomes suggestions. The challenge is communicating the importance of addressing deficiencies in the system around this important issue.

Ruth Richardson, J.D., a member of the Justice Issues Work Group, reported on the group’s webinar “Understanding Fetal Alcohol Spectrum Disorders (FASD): Promising Practices for System Involved Youth with FASD”, on April 12, 2017. Ms. Richardson moderated the program, whose panel members were Dr. Anderson; Eileen B. Bisgard, J.D., former president of the Colorado Affiliate of the National Organization on Fetal Alcohol Syndrome; Hon. Susan Carlson, J.D., Hennepin County, retired Minnesota Juvenile Court Judicial Referee; Mr. Pestridge; and Eileen Garry, Acting Administrator of OJJDP. Ninety-six individuals registered for the webinar, which provided basic information on FASD, case studies, and juvenile justice resources. The webinar has been archived on the MOFAS Web site. Link to it here “[Understanding Fetal Alcohol Spectrum Disorders (FASD): Promising Practices for System Involved Youth with FASD](https://attendee.gototraining.com/0m2w1/catalog/6132674919969558272)", or from the [ICCFASD web page](https://niaaa.nih.gov/about-niaaa/our-work/interagency-coordinating-committee-fetal-alcohol-spectrum-disorders).

The Justice Issues Work Group hopes that this experience will lead participants to seek more information on FASD. The group collected evaluation information from participants, and it hopes to use this feedback as the basis for additional webinars in the future.

# Reports of Activities of the ICCFASD Agencies: SAMHSA, NIAAA, and NIDA

## SAMHSA

*Jon Dunbar-Cooper, M.A., Public Health Analyst, Center for Substance Abuse Prevention, SAMHSA*

The Center for Substance Abuse Prevention (CSAP) no longer has the resources it used to have to dedicate to FASD activities. However, other parts of SAMHSA have some programs that contribute to efforts to reduce FASD. The Center for Substance Abuse Treatment (CSAT) at SAMHSA has some programs for women with alcohol use disorders and their young children that are specific to FASD. SAMHSA is focusing much of its attention and resources on opioid use prevention and treatment grants, and many women who use opioids also use alcohol. An opportunity exists to focus on alcohol, which is often the first substance used, and on poly-substance use within the $500 million SAMHSA will spend on treatment of opioid addiction and prevention of opioid overdose-related deaths.

The Center for Substance Abuse Prevention (CSAP) at SAMHSA maps prevention interventions to levels of risk (universal, selective, or indicated) based on the Institute of Medicine’s prevention model. CSAP is addressing issues related to opioid and alcohol use through, for example, training for families in administering naloxone during an overdose. SAMHSA is revising its [Fetal Alcohol Spectrum Disorders Among Native Americans publication](http://store.samhsa.gov/product/Fetal-Alcohol-Spectrum-Disorders-FASD-Among-Native-Americans/SMA06-4245), and the revised version will be available at the SAMHSA store.

Discussion

Dr. Warren said that universal prevention is useful for general education but does not have a major impact, whereas indicated prevention strategies have a substantial impact but are costly. He asked for clarification on selective prevention. Mr. Dunbar-Cooper explained that selective prevention targets individuals or population subgroups at high risk of mental or substance abuse disorders, such as runaway, homeless youth and students with high truancy levels who are not affected by universal prevention messages. Evidence shows that these individuals have a high risk of alcohol misuse, but when they are screened, they do not reach the level of indicated prevention because they might not drink frequently enough or they do not engage in binge drinking. These individuals might need motivational interviewing, which could be appropriate for those in the indicated or selective category. A challenge is obtaining payment for services for a person in the selective prevention group if that individual progresses to indicated status.

## NIAAA

*Dale Hereld, M.D., Ph.D., Program Director, Division of Metabolism and Health Effects, NIAAA, NIH*

NIAAA dedicates slightly less than 10% of its research and training budget to FASD, and this level has been stable since 2009. The total number of FASD grants ranged from 87 to 101 between 2009 and 2014. In general, NIAAA funds approximately 20 new FASD grants each year. Dr. Hereld listed the 17 new FASD awards in fiscal year 2015, which included studies on FASD prevention, diagnosis, etiology, and treatment. NIAAA currently has two active FASD-related program announcements:

* Effects of In Utero Alcohol Exposure on Adult Health and Disease (PA-12-291/292)
* Epigenetic Inheritance and Transgenerational Effects of Alcohol (PA-13-003/004)

In 2009, NIAAA issued four 5-year awards to develop FASD interventions in response to RFA-MH-09-161 (Novel Interventions for Neurodevelopmental Disorders). One of these studies is assessing the effects of postnatal choline supplementation in children with prenatal alcohol exposure, and three other NIAAA-funded studies of choline supplementation in children with FASD are also active.

NIAAA sponsors the Collaborative Initiative on FASD (CIFASD), a multidisciplinary consortium that conducts clinical and basic research to improve capabilities in FASD clinical case recognition as well as prevention and treatment interventions. One of these studies (Suttie et al. *Pediatrics* 2013;131: e779-88) used heat maps and morphing visualizations to distinguish between children exposed and those not exposed to alcohol in utero. This method might help clinicians use facial dysmorphology to identify children with FASD who lack the classic facial phenotype but have cognitive impairment. Another CIFASD study (Balaraman et al. PLoS One. 2016; 11(11): e0165081) found that levels of circulating micro-RNAs in maternal blood were significantly higher in the plasma of mothers of heavily prenatally exposed and affected infants than in mothers of heavily exposed but apparently unaffected infants and unexposed infants. These micro-RNAs have the potential to predict infant outcomes and classify subpopulations with forms of FASD that are difficult to diagnose. Furthermore, these micro-RNA’s have potential to distinguish between heavily exposed infants who are affected from those heavily exposed but with no apparent deficits. This will provide clinicians helpful information to assist their monitoring of exposed individual patients.

NIAAA collaborates with NICHD to support the Prenatal Alcohol in Sudden Infant Death Syndrome and Stillbirth Network. This international consortium is investigating the role of prenatal alcohol exposure in the risk of sudden infant death syndrome and adverse pregnancy outcomes, such as stillbirth and FASD, in 12,000 pregnant women in the United States and South Africa. The goal is to understand the genetic, molecular, physiological, and neurodevelopmental mechanisms associated with adverse pregnancy outcomes that might be related to maternal alcohol use. This study is wrapping up now, as is the Collaboration on FASD Prevalence (CoFASP), which is determining the prevalence of FASD among young children in three defined geographical areas in the United States.

## NIDA

*Cora Lee Wetherington, Ph.D., Women and Sex/Gender Differences Research Coordinator, NIDA, NIH*

Dr. Wetherington reported on NIDA’s concerns and studies of marijuana use and also presented information about the Adolescent Brain Cognitive Development (ABCD) study. To date, 29 states and the District of Columbia have legalized medical marijuana. Marijuana is the most widely used illicit drug during pregnancy, and its use is increasing. Past month marijuana use by pregnant women aged 18–44 years rose from 2% in 2002 to 4% in 2014, a 62% increase. Use is higher among those aged 18–25 than those who are older ([Brown, et al., *JAMA*, 2017 317(2):207-209](http://jamanetwork.com/journals/jama/fullarticle/2594398)).

Nora Volkow, M.D., NIDA’s director, was the lead author of a recent meta-analysis and review ([*JAMA* 2017;317(2):129-130](https://www.ncbi.nlm.nih.gov/pubmed/27992628)) showing that infants with in utero marijuana exposure were more likely to have anemia, have lower birth weight, and require neonatal intensive care than infants without such exposure. During school years, these children were more likely to have impaired higher-order executive functions, including impulse control, visual memory, and attention. Research shows that pregnant women with severe nausea are significantly more likely to use marijuana than those without severe nausea. The authors conclude that clinicians should advise pregnant women and those considering becoming pregnant to avoid using marijuana and other cannabinoids.

Nausea is a medical indication for medical marijuana in all states that have approved its use. Several websites recommend using marijuana to treat nausea in pregnancy, especially for hyperemesis gravidarum, and evidence shows that pregnant women with severe nausea are more likely to use marijuana than those without severe nausea. However, nausea, vomiting, and stomach pain are side effects of marijuana use and marijuana withdrawal, which potentially could increase risk for escalation of marijuana use by pregnant women. In addition, women progress to cannabis use disorder more quickly than men, and marijuana is now more potent than in the past. Furthermore, according to anecdotal reports, pregnant women are turning from smoking cigarettes to marijuana use because they believe that marijuana is less harmful than tobacco or not harmful.

NIDA is addressing the effects of opioids (heroin and prescription drugs) and new forms of nicotine (e-cigarettes and hookahs). New questions are arising about in utero drug exposure, such as its impact on infant behavior, brain development, maternal behavior, maternal–infant attachment, and long-term behavioral outcomes.

Dr. Wetherington highlighted the following NIDA funding opportunity announcements:

* Effects of Cannabis Use and Cannabinoids in the Developing Brain (PA-14-162/163/164)
* Women & Sex/Gender Differences in Drug and Alcohol Abuse/Dependence (PA-14-036/037/038)

NIDA plans to renew these opportunities for 3 more years.

The [Adolescent Brain Cognitive Development (ABCD) study](https://abcdstudy.org) will follow approximately 10,000 children, including 800 pairs of monozygotic and dizygotic twins, from ages 9–10 through early adulthood to identify factors that influence individual brain development trajectories and functional outcomes. In addition to NIDA, the many study sponsors include NICHD, NIAAA, many other parts of NIH, and also outside partners such as CDC and the National Institute of Justice**.** The original conception of this study was partially driven by the legalization of marijuana for recreational and medical use; likely resulting in an increase of marijuana use by adolescents; and concern about the effects of marijuana on the adolescent brain.

The study will develop national standards of normative brain development in youth and examine how exposure to different substances (including alcohol, marijuana, caffeine, and nicotine) affects various developmental and mental health outcomes and vice versa. In addition to data on drug use provided by the childrenenrolled in this study their parents will provide data on prenatal exposure to alcohol and other drugs. Recruitment of study participants began in September 2016 and will last 24 months. The ABCD sample has targets for sex, urbanicity, free/reduced priced lunch (as a proxy for socioeconomic status), and race/ethnicity to represent the rates in the U.S. population. The ABCD study will release to the scientific community curated, anonymized data starting 1 year after data collection begins and on an annual basis thereafter. In May 2017, the study will release its first batch of brain imaging data.

Discussion

Dr. Scott noted that one of the topics addressed by ICCFASD is poly-drug use because many people use more than one substance. The committee wants to address poly-drug use in risk assessments and improve coordination of interventions for multiple substance use.

# Special Panel: Overview of 7th International FASD Conference

Moderator: *Marcia S. Scott, Ph.D., NIAAA*

## Conference Overview

*Marcia S. Scott, Ph.D., NIAAA, NIH*

The theme of the 7th International Conference on FASD Research in March 2017 in Vancouver, Canada, was integrating research, policy, and promising practice around the world. The conference featured two preconference sessions (which were summarized after Dr. Scott’s overview) and six plenary sessions.

The first plenary session focused on the NIAAA-sponsored CoFASP, whose purpose is to determine the prevalence of FASD in three U.S. regions in a population with diverse ethnic/racial characteristics, education levels, and household incomes. During the plenary session, presenters described the challenges in establishing the prevalence of fetal alcohol syndrome (FAS) and FASD, including the subtle facial features associated with FASD that are easily missed and not always present, underreported prenatal drinking because of the associated stigma, and the lack of clinic-based studies reflecting the full range of physical traits and functional abilities of children in the general population. In addition, primary care physicians do not typically have the skills needed to assess dysmorphic features and cognitive, behavioral, and adaptive functioning deficits in children with FAS, and confirmation of prenatal alcohol exposure is difficult when the biological mother is absent or denies using alcohol during pregnancy.

CoFASP is enrolling first-grade children in four U.S. regions based on low height, weight, or head circumference and drawing a random sample from all children enrolled in study schools because they might have FASD even though they lack the associated physical features. This study will address the challenges in identifying prevalence because of the lack of consistency in facial features associated with different FASD categories and the fact that these features might not be present.

Study personnel measure the children’s physical growth, development, dysmorphology, cognitive and behavioral characteristics, and adaptive skills. The mothers are interviewed to determine whether they meet the minimum criteria for alcohol exposure and to answer questions about social or legal problems with alcohol use in the period around pregnancy. Data on the final outcomes will be published in the next few months.

A second plenary session featured the CIFASD, which is developing simple markers of alcohol exposure and prenatal alcohol effects at all stages of the lifespan as well as simple, low-cost methods to screen infants for FASD. The investigators are using shape analysis techniques and associated software to identify and measure atypical features associated with prenatal alcohol exposure in three-dimensional photographs. Other techniques being explored are whole-brain connectivity metrics and functional near-infrared spectroscopy. A decision tree that includes just four variables might be useful for determining which children with prenatal alcohol exposure need a referral, even if these children do not have a FASD diagnosis.

Other plenaries addressed the global picture of FASD, FASD prevention research, cutting-edge biomarkers and epigenetics, and long-term chronic disease outcomes after prenatal alcohol exposure. This last session featured a very moving presentation by young adults affected by FASD. Video recordings of these and other sessions are available on the [conference website](http://interprofessional.ubc.ca/initiatives/fasd2017/presentations).

## Preconference Workshop: FASD and The Law 2017: FASD Through the Criminal Justice System

*Sally M. Anderson, Ph.D., NIAAA, NIH*

The deficits associated with FASD that make it difficult for individuals with FASD to avoid involvement with the judicial system and/or navigate successfully through the system are in overall intellectual ability, planning and problem solving, attention and working memory, understanding others, impulse control, and socialization. Adults with FASD often lack organizational skills, have trouble keeping a job, have poor perceptions of money and time, have co-occurring mental health disorders and alcohol or other substance abuse, and cannot usually live independently. Because of these deficits, adults with FASD are at risk of exploitation by others.

People with FASD appear in every court docket in the United States, including civil, criminal, probate, and marriage dissolution courts. Their deficits are invisible and not generally recognized by the courts, making all dealings with the judicial system a challenge. Dr. Anderson focused her remarks on the involvement of people with FASD in juvenile and criminal justice courts.

Adolescents and young adults with FASD are highly susceptible to peer pressure, do not always understand the consequences of their actions, have a younger person’s level of understanding, do not know their rights, or sometimes confess to a crime to please the police officer. Three International FASD Conferences have featured a satellite meeting on FASD and the law. In 2013, a small group discussed current research and practices. The number of participants grew in 2015, when the focus expanded to include best practices and ethical considerations. The themes in 2017 were FASD throughout the juvenile and criminal justice systems and connecting resources to communities.

This year’s workshop drew approximately 200 participants, including individuals and families affected by FASD, researchers, lawyers, judges, probation staff, police officers, and corrections personnel. The meeting consisted of four sessions with very brief presentations and roundtable discussions on the following topics:

* Contact with the police
* Contact with the courts (lawyers)
* Contact with the courts (judges)
* Corrections and probate settings

Dr. Anderson focused the rest of her remarks on the first session, which featured a presentation by Constable Roberta Smallbones of the Lethbridge, Alberta, Police Service on the Youth FASD Justice Initiative, which is based in the prosecutor’s office. This program identifies offenders younger than 18 who have or might have FASD, diverts them from the court system when appropriate, and makes recommendations to the court for assessments. The program also proposes alternative measures or sentencing where appropriate; develops case management plans and/or presentencing reports; and provides advocacy for youth and their families, schools, and communities. Key elements of the program’s success are good relationships with school counselors, police officers, and school resource officers.

A newer program in Lethbridge, the FASD Adult Justice Project, serves adults with suspected or confirmed FASD who are in contact or in danger of contact with the justice system. The program offers training, education, monitoring, mentorship, advocacy, and coordination to help people navigate the justice system and avoid future justice system involvement through community supports. The program also provides recreational activities and assistance finding jobs. Sabrina Hacker, who leads this program, educates lawyers about FASD and the needs of clients with FASD. She also meets with homeless individuals with FASD to gain their trust and encourage them to engage with the program.

Discussion

Mr. Dunbar-Cooper asked how the FASD programs that Dr. Anderson described arrange for alternative penalties instead of prison time. Dr. Anderson said that decisions about alternative penalties are made by the prosecutor, who might consider whether prosecuting someone with FASD will benefit that individual and the community if that individual is not dangerous. Perhaps that individual can benefit from standard rehabilitation, or the person might need special training and special education.

Mr. Dunbar-Cooper suggested replicating the Lethbridge model in the United States. Dr. Anderson replied that major reforms are underway in juvenile justice systems throughout the nation. Mr. Pestridge agreed, adding that many national organizations want to change the system for processing children, and the publication of *Fetal Alcohol Spectrum Disorders: Implications for Juvenile and Family Court Judges* is a critical first step. A call with NCJFCJ will take place soon to discuss the guide with some judges. In addition, the Office of Justice Programs has commissioned a report by the National Academies of Sciences, Engineering, and Medicine on reforming the juvenile justice system as a follow-up to a 2014 report.

Dr. Anderson noted that no U.S. statistics are available on the proportion of people in juvenile detention with FASD. However, the Department of Education reports that more than one third of those in juvenile detention qualify for special education, and learning disabilities and other special education needs are strongly linked to FASD. A recent Canadian meta-analysis indicated that a juvenile with FASD is nine times more likely to be incarcerated than one without FASD, and many deficits in teenagers with FASD are highly correlated with delinquency. Adolescents with FASD, for example, are more likely to be incarcerated for shoplifting because they repeatedly fail to show up for probation appointments. Mr. Pestridge explained that the acting administrator of OJJDP will meet with the head of DOJ’s National Institute of Justice to discuss partnerships that can generate the needed data on FASD.

Mr. Dunbar-Cooper wondered whether Canadians with FASD face less stigma than those in the United States, and he asked about the effect of cultural norms in Canada on community mobilization in Lethbridge. In the United States, stigma is a major barrier to the supports that people with FASD need. Dr. Anderson explained that FASD-related services, resources, and public understanding differ throughout Canada’s 10 provinces and 3 territories. Just as some U.S. states have much more advanced FASD education programs, diagnostic networks, and justice programs than others, some Canadian regions have much more comprehensive supports for people with FASD than other regions. The Lethbridge example comes from a leader in Canada. Mr. Dunbar-Cooper pointed out that some excellent examples also exist in the United States, and Dr. Anderson agreed, pointing to programs in Alaska, Minnesota, Washington State, and California.

Mr. Dunbar-Cooper asked about primary prevention messages on drinking while pregnant. Dr. Anderson said that a key to implementing services is for a person in a position of authority to take an interest in FASD.

Dr. Warren pointed out that Alberta has a great deal of wealth and a sparse population, allowing the province to implement some novel programs. A province like Ontario, which has a denser population and fewer resources, does not have the types of services available in Lethbridge. Legal systems vary by locality, and what happens in one community will not necessarily happen in a neighboring jurisdiction. Furthermore, sharing of the latest technologies is less common in the legal community than in the medical community. No system needs attention to FASD more than the legal system.

##

## Preconference Workshop: Let’s Talk: Stigma and Stereotypes—Where Do We Begin?

*Diana R. Simmes*, *M.P.H., University of California, San Diego*

The purpose of this preconference session on stigma, which drew approximately 400 participants, was to challenge the thinking around stigma and stereotypes, broaden understanding of the science and roots of stigma, and engage delegates in discussions that can lead to the identification of directions for change. The session featured presentations on the following topics:

* Origins of Stigma and Intersectionality of FASD
* The Neuro Science of Addiction: Is it a Choice?
* What the Science Has to Say about Changing Stigma
* Living Stigma: Social Media Anonymity and Sustaining Stigma
* The Not So Pretty

During the discussions, participants suggested that the purposes of stigma include allowing people to avoid taking action, promoting power and control, and creating and maintaining dependency. Suggestions on what to do included providing evidence-based information; changing the stigma of use, misuse, and addiction; and changing drinking norms. Steps to begin changing stigma include improving the understanding of why pregnant women drink, demystifying the disability, modeling the desired changes, and teaching men that FASD is their business. Recommendations included discussing alcohol during all primary care visits, sharing good practices, supporting whole families, and building on lessons learned from efforts to destigmatize other conditions (e.g., substance use and mental health disorders).

This preconference started an awakening, with a focus on what can be done. Science is critical for understanding, but less attention has been paid to working with people who have lived experiences and learning from efforts to destigmatize other conditions. Stigma has harmful and multifaceted effects, and people might avoid engaging with health and social supports because of stigma. Stigma structures include stereotypes, prejudice, and discrimination, and types of stigma include public stigma, self-stigma, and label avoidance. Good stigma change is targeted (e.g., to healthcare professionals, parents, or schoolchildren), local, credible, and continuous.

Ms. Simmes described a project to reduce stigma associated with FASD that is funded by CDC through a supplement to support systems change in a CDC-funded Practice and Implementation Center for Pediatrics. This project is using a community-based participatory research approach with a team of birth mothers, adoptive mothers, pediatricians, nurses, midwives, and obstetricians. This team meets monthly to guide the project and leverage the unique perspectives of all team members. The results from focus groups with birth mothers, family members, pediatric care providers, and obstetric care providers will inform the development of an intervention that will include education and contact elements. This intervention will be launched in 2018 with the goal of increasing FASD screening and referrals in obstetrical and reproductive medicine departments. A curriculum is in development for birth mothers to address self-stigma and empowerment.

Ms. Simmes also mentioned a study that measured stigmatizing attitudes about biological mothers of children with FASD. The manuscript describing the results is currently in press.

Discussion

Elizabeth Parra Dang, M.P.H., explained that the ongoing FASD project that Ms. Simmes had described is one of four high-impact projects that are supplements to larger Practice and Implementation Centers. Each supplemental project lasts 2 years, and total funding per project is approximately $150,000.

Mr. Dunbar-Cooper asked about strategies for reaching out to fathers. He noted that women who drink while pregnant might be abused, and fathers might not recognize their own contributions to the stigma associated with FASD. Ms. Simmes called for more effective strategies for providing support to entire families. She described a collaboration with a hospital women’s auxiliary that is working with sororities and social clubs, such as fraternities, with male members. Resources are needed so that fathers can support their partners. Working with male-focused groups is an important way to spread the word, and some initiatives are doing this.

Deidra Roach, M.D., asked about initiatives in schools. When stigmatizing attitudes become engrained, they are difficult to change; the earlier initiatives start changing thinking around FASD, the better their chance of eliminating stigma. Ms. Simmes is working with an older sibling of a child with FASD who is interested in public speaking. The hope is that this sibling, who is in high school, will share her experiences with FASD in her social circle and at school. Social media are also a good way to reach a very broad audience.

# Discussion on Improving Our Messaging

*Sally M. Anderson, Ph.D., NIAAA, NIH, Moderator*

In 2005, the Surgeon General issued an advisory on alcohol use in pregnancy concluding that no amount of alcohol can be considered safe in pregnancy. The American Congress of Obstetricians and Gynecologists, CDC, and American Academy of Pediatrics have issued similar warnings. But despite these advisories, warning labels on beverages containing alcohol, and better targeted messages, 20–30% of women in the United States drink alcohol at some time during pregnancy. The ICCFASD has discussed this issue many times, and more discussions are planned.

Questions to consider are:

* Why has it been so difficult to get women to embrace these messages about not limiting their children’s future potential?
* Why is the rejection of these messages so charged with emotion and anger?
* How can we increase the number of pregnant women and physicians who accept these messages and act accordingly?

## Media Content Analysis of the 2016 CDC Vital Signs on Alcohol and Pregnancy

*Elizabeth Parra Dang, M.P.H., National Center on Birth Defects and Developmental Disabilities, CDC*

CDC publishes a new issue of *CDC Vital Signs* every month on any of a wide range of topics. These publications usually receive a great deal of media coverage. The February 2016 issue focused on FASD, and it received a much greater reaction than expected. To understand this reaction, CDC contracted with ICF Macro to analyze the reports published in traditional media, public discussions and reader comments on traditional media stories, and social media posts to derive lessons for future messaging.

ICF Macro analyzed 363 traditional media stories published in the month after publication. Of these stories, 38% were negative (e.g., were condescending or paternalistic), 33% were neutral, 21% were positive, and 8% were mixed. Only 10% of the articles included all seven *Vital Signs* key messages; most included four to six messages. Most stories portrayed the *Vital Signs* release as a CDC report on alcohol and birth control, not on alcohol and pregnancy. In fact, 41% of article headlines mentioned alcohol and birth control, and only 21% mentioned alcohol and pregnancy. In addition, 38% of the articles reported that the recommendation for women to abstain from alcohol if they are having sex and not using birth control is not practical. Of professional sources interviewed, 79% supported the release, but 82% of public sources interviewed did not. In addition, 52% of articles included secondary comments, such as expressing discontent with CDC because of the release, saying that CDC’s delivery of the release was wrong and ineffective, or claiming that women rejected or had a negative reaction to the release.

Reader comments on traditional media stories were split: approximately equal shares of readers framed the release in a positive (38%) or negative (26%) manner, thought the recommendations were practical (19%) or not practical (22%), and gave personal testimonies that supported (10%) or did not support (11%) the release. Males were significantly more likely than females to frame the release in a positive way and believe that the recommendations were practical. About half (52%) the comments mentioned secondary topics: 19% expressed discontent with CDC as a result of the release, and 6% expressed gratitude toward CDC; 10% mentioned a need for more research on alcohol and pregnancy; and 9% discussed men as part of the problem with alcohol use during pregnancy. As the number of key messages in the news articles increased, readers’ framing of the release became more positive. Readers who read reports with professional interviewees (which were dominantly supportive) had a more positive frame toward the release than readers who read news articles with public interviewees (who were primarily not supportive). There was no significant relationship between how the news article framed the release and readers’ framing of the release.

Only 4% of the more than 18,000 social media posts about the release were positive, 42% were negative, and 34% were neutral. Most of the positive Twitter posts were linked to an article on the Grio, a news website for the African American community. The infographic from the release showing the risks (e.g., injuries/violence, sexually transmitted diseases, and unintended pregnancies) of drinking too much alcohol for any woman was the top retweeted post that elicited the most negative reactions on social media. Major news organizations and Princeton University were the most influential Twitter participants in the *Vital Signs* conversation. The topic of birth control generated many more posts (more than 3,200) than the topic of pregnancy (1,630 posts). Those who engaged in these conversations were 33 times more likely to talk about feminism, 20 times more likely to talk about mental health, and 19 times more likely to talk about pregnancy in general.

The top recommendations based on findings were to:

1. Acknowledge that the message is difficult to convey
* Explicitly state the challenges and concerns in communicating difficult recommendations
* Pair difficult recommendations with other messages that increase an individual’s motivation and self-efficacy to carry out the recommendation
* Use strategic keywords that convey understanding to soften difficult message delivery
1. Frame the main message
* Strongly frame the message around the key concepts and avoid introducing secondary factors, such as birth control or violence, into the main message
* Link power words to the main message to increase its persuasiveness and influence readers’ tone in discussing the message
1. Test the messages
* Test messages on sensitive public health topics with the target audience and secondary audiences who are vocal on the topic or may be indirectly impacted by the message
* Understand audiences’ thoughts, attitudes, and behaviors toward the message before releasing it to ensure message effectiveness and avoid unintended effects

## FASD in the Medical Home

*Yasmin Senturias, M.D., Developmental and Academic Division Chief, Developmental and Behavioral Pediatrics, University of North Carolina at Chapel Hill*

The neurobehavioral characteristics of FASD include neurocognitive impairment, difficulties with self-regulation, and delayed or poor adaptive skills. Children with FASD often have restricted growth, minor facial anomalies, and medical needs (e.g., frequent infections and sleep problems).

Often, Dr. Senturias uses her first visit with the family of a child with FASD to describe the neurobehavioral characteristics using certain analogies, such as an emotional thermostat. She explains that these children might have a normal-range IQ but seem to be younger than their chronological age. Families are often particularly concerned about physical characteristics, including frequent infections, that are secondary to the brain characteristics.

Dr. Senturias tells families that in utero exposure can lead to any of the following:

* FAS
* Partial FAS (has some but not all of the features of FAS)
* Alcohol-related birth defects (congenital but not neurobehavioral or behavioral effects)
* Alcohol-related neurodevelopmental disorder (neurodevelopmental/behavioral effects without cardinal dysmorphic features)
* Neurobehavioral disorder associated with prenatal alcohol exposure (neurodevelopmental/behavioral effects regardless of cardinal dysmorphic features)

In addition to the types of effects, the levels of impairment are important. Some children do not need any special services, but others do because of various deficits.

Between birth and age 3, children with fetal alcohol exposure need careful monitoring for developmental milestones and early referral for developmental therapies if they have poor motor skills, language delays, sleep problems, or behavior problems, even if these problems are not yet severe. Pediatricians must advise families to provide a structured environment; avoid overstimulating the child; and ensure that the child sleeps well, eats a healthy diet, and gets plenty of exercise. Children with frequent ear infections, cardiac issues, or abnormal neurological examination findings need referrals. Emphasizing the child’s strengths when addressing their challenges is critical; children who can show off their strengths (e.g., by competing in Special Olympics) seem to do better and require fewer medications.

Potential neurobehavioral concerns in preschool and school-aged children with prenatal alcohol exposure are in neurocognitive abilities (e.g., learning, memory, and executive function), self-regulation (attention, sleep, and emotions), and adaptive skills (reading social cues and comprehension). The main medical concerns are attention deficit hyperactivity disorder (ADHD), mood problems, sleep problems, and poor growth. More research is needed on how best to support the families of these children. FASD certification for therapists or psychologists could be helpful for children in this age range. Sleep clinics might be appropriate for children with sleep problems; children who sleep well seem to have fewer behavioral problems. Dr. Senturias refers children to therapists to help them develop needed skills, and some children might benefit from pharmacologic therapy for ADHD and other issues. A structured environment is again critical, and these children usually need an individualized education program.

Neurobehavioral concerns in adolescents include poor judgement, learning and attention problems, social relationship challenges, and inappropriate expectations. Adolescents with prenatal alcohol exposure have a higher risk of substance abuse, comorbid mental illness (e.g., depression, anxiety, and ADHD), and inappropriate or risky sexual behaviors. Pediatricians should consider neuropsychological testing to assess higher-order neurocognitive deficits. These children need an environment that prepares them for adulthood, and families might consider applying for supported housing. Some of these teens can go to college, but they need supports. Those who cannot attend college need vocational skills and help finding jobs.

Pediatricians do not routinely screen their patients for FASD, possibly because of insufficient training and information as well as concern about potential stigma for the biological mother and child. However, many children with FASD have a foster mother. Dr. Senturias recommends that pediatricians focus on the facts and avoid being judgmental. They should remind the family that they care about them and their child, and they want to help the family reach a good place. Research is needed on how pediatricians can best communicate about FASD with children and families.

In general, pediatricians should refer children to developmental therapies when needed, work with school systems to ensure that the child’s needs are met, and develop relationships with local referral sources. Choline is a nutrient that can boost memory and spatial skills in animal models when administered prenatally and postnatally, and Dr. Senturias often recommends that children with prenatal alcohol exposure eat choline-rich foods. She discusses the medications that the children might need and shares tips and tools, including parenting strategies (e.g., modeling calm, and providing a calm environment).

## Discussion

Dr. Scott commented that very few people have expertise in messaging and unanticipated dissemination of information through social media. She asked Ms. Dang to expand on the recommendations she had listed. Ms. Dang said that it is difficult to determine whether the people who reacted negatively to the *Vital Signs* release were the target audience or simply people who were vocal and whether CDC should target its messages to the public or only to providers. Women are probably much less likely to be offended if their obstetrics/gynecology provider recommends that they use birth control if they drink alcohol than if this message comes from CDC. CDC would like to do more communications research on direct messaging for women.

In 2014, CDC suggested that women who want to avoid being pregnant discuss birth control with their doctor, and this message was not considered offensive. Either something has changed since then or the 2016 *Vital Signs* release was different—more research is needed to understand the difference. CDC would also like to examine direct messaging to women in light of the recommendation that providers deliver alcohol screening and brief intervention to female patients who are or could be pregnant.

Mr. Dunbar-Cooper asked whether CDC has identified other ways to disseminate the FASD key messages. Ms. Dang explained that CDC does not plan to modify the FASD *Vital Signs* release. She believes that part of the problem was that CDC included information on the effects of alcohol beyond during pregnancy, even though this information has been issued before. The combination of too many different messages (on alcohol, pregnancy, and birth control) is probably what upset people. The next round of communications research will address when to combine messages and how to deliver combined messages. Another option is to focus messages on providers and not the public.

Mr. Dunbar-Cooper suggested tying messages about underage drinking to messages about sexually transmitted diseases and violence. Ms. Dang said that CDC has not had problems in the past with its list of the effects of drinking too much. The problem was apparently the combination of the messages in the release.

Mr. Davis suggested that CDC capture the associated factors. Ms. Dang hoped that the next round of communications research will identify the most important components of contraception messaging.

Dr. Roach asked about gender differences in responses from the public. Ms. Dang replied that males tended to view the release’s messages more positively than females, perhaps because they did not think that the messages about birth control were aimed at them. Women were upset that men were not specifically included in the messages about birth control.

Dr. Warren shared the story of a gathering he attended in England. The pediatricians at the gathering said that they had never seen a patient with FASD, and they either did not believe in FASD or thought that none of their patients had it. These conversations happened just 20 miles from a meeting on FASD. This disorder has always been invisible because its features are subtle, leading to a great deal of denial that produces the types of responses to the CDC *Vital Signs* release that Ms. Dang had described. Many physicians and others have seen patients with FASD but did not know it, and this issue must be addressed to develop effective messages.

Dr. Warren added that some thought that the *Vital Signs* messages were patronizing. He finds warnings not to eat junk food patronizing, but he knows that these warnings are sound. He also argued that as long as people deny the existence of FASD, messages about it will generate negative reactions. People will think that they do not have to worry about this disorder and will not care what CDC and medical experts say. Women will tell themselves that they are safe drinking until they know they are pregnant, and cutting down their alcohol use at that time will prevent problems. This belief system is difficult to change.

Dr. Warren further agreed with Ms. Dang that targeting a single -message to two different audiences at the same time was probably not a good approach. The Surgeon General’s advisory, for example, was targeted only to physicians, even though the press discussed this advisory with the public. In some cases, messages might be more effective if they are targeted to the public. For example, if many established physicians in Great Britain do not believe the messages about preventing FASD, a more effective strategy might be to talk to the public about the risks of drinking in pregnancy. Fortunately, most physicians in the United States and Canada who can be reached with messages about FASD have already been reached. However, in most of the countries of the world the lack of knowledge about FASD is more like the situation in Great Britain.

Ms. Dang noted that the negative responses were not because the messages were wrong but, rather, because audiences did not believe them. Dr. Warren said that this attitude is what needs to change. The problem is not that members of the public have not been exposed to facts but, rather, that they did not believe the facts. Ms. Dang stated that when CDC advised pregnant women to avoid traveling to certain regions to avoid exposure to Zika virus, women were not offended. She wondered why the response was so different to the messages in the *Vital Signs* release. She added that the biggest takeaway from this experience is the continued lack of knowledge about FASD.

Dr. Roach called for education to start with school-aged children. People’s values and beliefs are established early and are difficult to change later in life.

Dr. Roach asked Dr. Senturias how to communicate with children about their diagnosis. Dr. Senturias said that the most appropriate way to communicate with children depends on their age and the family’s culture. If the parent gives permission, she sometimes tells young children that they, like their parents, sometimes find it difficult to do certain things. When this happens, they need to ask for help. For older children with an adoptive mother, she might explain that they were exposed to alcohol during the biological mother’s pregnancy and then describe the effects of this exposure. She emphasizes that these children have talents and strengths along with challenges like everyone else. She then encourages the child to ask questions and gives guidance on how to talk about their diagnosis. When parents are hesitant to discuss the diagnosis, Dr. Senturias gives them guidance and points them to websites.

# Reports of Activities of the ICCFASD Agencies: NICHD, CDC, ACF, and HRSA

## NICHD

*Maurice Davis, M.P.A. M.H.S.A., Health Scientist Administrator, Pregnancy Perinatology Branch, NICHD, NIH*

Mr. Davis reported that Marian Willinger, Ph.D., the NICHD representative on the ICCFASD, was retiring. Tracy King, M.D., M.P.H., a medical officer in NICHD’s Intellectual and Developmental Disabilities Branch, will replace Dr. Willinger after this meeting.

## CDC

*Elizabeth Parra Dang, M.P.H., National Center on Birth Defects and Developmental Disabilities, CDC*

The [March 30 issue of *Morbidity and Mortality Weekly Report*](https://www.cdc.gov/mmwr/volumes/66/wr/mm6612a1.htm)focused on screening for excessive alcohol use and brief counseling for adults based on 2014 data from the Behavioral Risk Factor Surveillance System. The results showed that 77.7% of adults reported that a primary care provider had asked them about their alcohol use, but only 32.9% reported that a provider had asked them about binge drinking. Furthermore, only 37.2% of binge drinkers reported being asked about alcohol use and advised about the harms of drinking too much, and only 18.1% had been asked about alcohol use and advised to reduce or quit drinking.

The 11 FASD Practice and Implementation Centers and National Partners will gather for a grantee meeting in Atlanta on April 24–25, 2017, to be followed by a meeting for nursing champions on April 26. CDC offers online courses on FASD, including a primer for health care professionals and a course on preventing alcohol-exposed pregnancies. Three more online courses are in development, and all will be posted on a website with materials for nurses and five other disciplines that CDC is targeting.

Health care plans use HEDIS® measures to monitor their progress, and a proposed new 2018 HEDIS measure, [Unhealthy Alcohol Use Screening and Follow-Up](https://www.ncqa.org/LinkClick.aspx?fileticket=6llhItcHo04%3D&portalid=0), will assess rates of unhealthy alcohol use screening and of counseling and other follow-up for members who screen positive for unhealthy alcohol use and receive brief counseling or other follow-up care. SAMHSA is the lead agency for this measure, which has completed the public comment period. If the measure is approved, it will be pilot tested starting in June 2018. CDC is working with SAMHSA to support a learning collaborative for health plans on implementation of the measure.

## ACF

*Sharon Newburg-Rinn, Ph.D., Office of Data Analysis, Research, and Evaluation, Children’s Bureau, ACF*

If health care providers do not diagnose FASD correctly, they might provide inappropriate or ineffective treatment. Some children with prenatal alcohol exposure are overmedicated with, for example, drugs for ADHD, anxiety, and depression. Children with FASD also have an increased risk of school failure, trouble with the law (as a victim or perpetrator), incarceration, unemployment, dependent living, inappropriate sexual behavior, injury, and poor health.

ACF collaborated with CDC on an exploratory study of knowledge, policies, and practices related to children with prenatal substance exposure receiving services through the Washington, DC, Child and Family Services Agency. The study collected data through interviews of key informants (e.g., administrators, clinical staff, educators, data management staff, and foster and adoptive parents), caregiver focus groups, and a case file review.

The results showed that no policies address identification of and education about children with prenatal substance exposure. Approaches tend to be informal and vary by case worker. Investigative and clinical staff estimated that 10–30% of cases involved prenatal substance exposure, and the agency relies heavily on positive toxicology reports to identify these children. However, these reports are not useful for alcohol, which is typically gone from the body within 12 hours. The only screener that includes prenatal substance exposure is for children from birth to age 3 years. Case management workers tend to learn about the topic on the job, from mentors or supervisors, or from their own pregnancy, sometimes perpetuating misinformation. Educators and trainers tend to focus their offerings on the hot topic of the day, but they acknowledged that education would be helpful. They also pointed out that training on how to recognize prenatal substance exposure without local referral sources for children with positive screening results is of little use. Caregivers said that having information on what to look for would have been helpful, and obtaining a diagnosis was a long and arduous process.

The analysis of 75 case files and notes found that information on prenatal substance exposure was in different places in each record and was most commonly noted in narrative fields. These fields are not searchable, so they cannot be easily used to assess prevalence. No single data element indicated prenatal substance exposure, and the most useful information was in contact notes and court reports. Finding this information was time consuming, tedious, and inefficient. Diagnostic information was embedded in medical visit notes and not in separate data elements.

The next step for this collaboration is to conduct a larger study to learn about policies and practices in a wider variety of agencies across the country, including tribal agencies. A national panel of experts will provide advice on the study’s design. Ultimately, the results will lead to recommendations for various changes, including training at agencies.

## HRSA

*Madelyn Reyes, M.A., M.P.A., R.N., Senior Nurse Consultant, HRSA*

The Maternal and Child Health Bureau at HRSA has a new 3-year initiative to integrate FASD prevention into existing training and technical assistance. The goal is to increase knowledge and skills among Healthy Start and home visiting grantees related to prevention and early identification of fetal exposure to alcohol or drugs that can affect maternal and newborn health outcomes. The program also provides knowledge of the assessment, diagnosis, treatment, and support needs of pregnant and parenting women who are affected by FASD. Another aim is to address the social, emotional, and environmental factors that affect the behavioral health of parents, children, and families and contribute to substance abuse before, during, and after pregnancy. This program includes all Healthy Start and home visiting grantees, and it emphasizes Native American populations.

The technical assistance center is conducting a literature review and environmental scan to gather resources on FASD for this initiative. The agency is also encouraging grantees to pool their knowledge and experience around FASD and behavioral health and to identify training and technical support needs. The Maternal and Child Health Bureau is creating an FASD advisory group, whose webinars will be archived on the Healthy Start EPIC website. A new online training program will address substance use prevention and will include prenatal alcohol exposure and FASD. Community workshops will bring grantees together with providers and other community resources to improve community service systems.

# An Update on Women, Drinking, and Pregnancy

*Deidra Roach, M.D., Division of Treatment and Recovery Research, NIAAA, NIH*

Epidemiology data show that between 1979 and 2006, the binge drinking rate increased by 30% among women aged 18–23 years. Between 2002 and 2012, the proportion of current drinkers and the prevalence of binge drinking grew among women in several age groups but not among men in those age groups. The prevalence of any alcohol or drug use among adolescent girls and boys is 21%, but 18% of these females and only 10% of these males have mood symptoms. These results point to the need to begin interventions much earlier than in current practice.

At the 12th Annual Conference of the International Network on Brief Interventions for Alcohol and Other Drugs (INEBRIA) on September 25, 2015 in Atlanta, Georgia, the ICCFASD Women, Drinking, and Pregnancy Work Group held a symposium on “Women, Girls, and Alcohol: Current Research on Screening and Brief Intervention”. Although no longer formally supported as part of the ICCFASD this group has continued to spread their message about the need for effective prevention, treatment and recovery services for women and girls with alcohol use disorders with support from NIAAA.

Symposia on screening, brief intervention, and referral to treatment for women and girls were held at the 2016 annual meeting of the American Society of Addiction Medicine and in 2017 at the Research Society on Alcoholism annual meeting. The group also collaborated with two major media events on drinking by women—an HBO special on risky drinking and an ABC 20/20 segment on a book by Elizabeth Vargas about her journey to recovery from alcohol use disorder and anxiety.

A 2013 white paper on research gaps in alcohol and other substance use informed a 2016 request for applications: Model Continuums of Care Initiative (MCCI) for Women and Girls at Risk and Living With HIV/AIDS and Harmful Alcohol and Associated Comorbidities. This community-based participatory, health systems/services research initiative will accelerate the translation of effective women and family-focused HIV as well as alcohol and other drug-related prevention and treatment interventions to community practice. Although this initiative does not focus on FASD, women and girls at risk of HIV are also at risk of alcohol- and other substance-exposed pregnancies.

Dr. Roach announced that a national conference on substance use among women and girls is planned for the fall of 2017, in Washington, DC. The conference goals are to disseminate the latest research findings on prevention and treatment of alcohol and other substance use among women (especially those of childbearing age), facilitate collaboration among potential implementation research partners, publicize findings from the Surgeon General’s report, build a coalition of stakeholder organizations to develop a blueprint for a coordinated public–private response to the epidemic of substance misuse among women and girls, recommend strategic actions tied to the Surgeon General’s report, and promote strategies to eliminate stigma and discrimination. The organizers are hoping for an audience of 400, consisting primarily of treatment providers, but also including policymakers and other public health officials, women and girls in recovery and their families, researchers, and insurers. All ICCFASD members are welcome to join the conference. Suggestions for conference speakers and participants are welcomed.

# Closing Comments

*Sally M. Anderson, Ph.D., NIAAA, NIH; ICCFASD Activities Coordinator*

*Kenneth R. Warren, Ph.D., Senior Advisor, NIAAA, NIH; ICCFASD Chairperson*

Dr. Warren pointed to the need for more collaborations like those between ACF and CDC, DOJ and NIAAA, and NIAAA and NICHD. He hoped that the ICCFASD could facilitate more of these partnerships in the future. Dr. Anderson thanked all participants for coming and the speakers for the effort they put into their presentations.

# Adjournment

*Marcia S. Scott, Ph.D., Division of Epidemiology and Prevention Research, NIAAA, NIH; ICCFASD Executive Secretary*

Dr. Scott explained that ICCFASD would receive the presentation slides and a summary from this meeting. The executive committee will meet in late 2017, and the next annual meeting will take place in the spring of 2018. She then adjourned the meeting.

# Appendix A: Participants

**ICCFASD Chairperson**

Kenneth R. Warren, Ph.D.

Senior Advisor

National Institute on Alcohol Abuse and Alcoholism (NIAAA), National Institutes of Health (NIH)

**ICCFASD Activities Coordinator**

Sally M. Anderson, Ph.D.

Office of the Director

NIAAA, NIH

**ICCFASD Executive Secretary**

Marcia S. Scott, Ph.D.

Health Scientist Administrator

Division of Epidemiology and Prevention Research

NIAAA, NIH

**ICCFASD Agency Representatives**

Elizabeth Parra Dang, M.P.H.

Behavioral Scientist, Fetal Alcohol Syndrome Prevention Team

National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention

Maurice Davis, D.H.A., M.P.A., MHSA

Health Scientist Administrator Pregnancy and Perinatology Branch

*Eunice Kennedy Shriver* National Institute of Child Health and Human Development, NIH

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

Public Health Analyst

Division of Systems Development, Center for Substance Abuse Prevention

Substance Abuse and Mental Health Services Administration

LCDR Mary Emanuele, M.S.N.

Senior Health Analyst

Health Resources and Services Administration

Dale Hereld, M.D., Ph.D.

Program Director

Division of Metabolism and Health Effects

NIAAA, NIH

Sharon Newburg-Rinn, Ph.D.

Social Science Research Analyst

Office of Data, Analysis, Research and Evaluation

Administration for Children and Families

Scott Pestridge, M.P.P.

Senior Policy Advisor

Office of Juvenile Justice and Delinquency Prevention

U.S. Department of Justice

CAPT Madelyn Reyes, M.A., M.P.A., R.N.

Senior Nurse Consultant

Health Resources and Services Administration

Deidra Roach, M.D.

Health Scientist Administrator

Division of Treatment and Recovery Research

NIAAA, NIH

Cora Lee Wetherington, Ph.D.

Women and Sex/Gender Differences Research Coordinator

Behavioral and Cognitive Neuroscience Branch, Division of Neuroscience and Behavior

National Institute on Drug Abuse, NIH

**Invited Special Guest Speakers**

Diana R. Simmes, M.P.H.

Academic Coordinator

Institute for Fetal Alcohol Spectrum Disorders Discovery

University of California, San Diego

Yasmin Senturias, M.D.

Medical Director and Academic Division Director

Carolinas HealthCare System

Adjunct Associate Professor

University of North Carolina Chapel Hill

Ruth Richardson, J.D.

Director of Programs & National Strategic Initiatives

Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)

St. Paul, MN

# Appendix B: Agenda

**Meeting of the Interagency Coordinating Committee**

**on Fetal Alcohol Spectrum Disorders**

National Institute on Alcohol Abuse and Alcoholism

5635 Fishers Lane ♦ Terrace Level Conference Center ♦ Rockville, Maryland 20852

<https://videocast.nih.gov>

**Thursday, April 13, 2017**

**AGENDA**

8:30 A.M. Welcome, Introductions, and Comments

*Kenneth R. Warren, Ph.D., Senior Advisor, NIAAA, NIH; ICCFASD Chairperson*

8:50 A.M. Overview of ICCFASD Mission and Goals

*Marcia S. Scott, Ph.D., Division of Epidemiology and Prevention Research, NIAAA, NIH; ICCFASD Executive Secretary*

9:00 A.M. Update from the U.S. Department of Justice and the ICCFASD Work Group on Justice Issues

*Scott Pestridge, M.P.P., OJJDP, DOJ*

9:15 A.M. Reports of Activities of the ICCFASD Agencies: SAMHSA, NIAAA, NICHD, NIDA

10:00 A.M. BREAK

10:15 A.M. Special Panel: Overview of 7th International FASD Conference, “Integrating Research, Policy and Promising Practice Around the World,” Vancouver, BC

*Marcia S. Scott, Ph.D., NIAAA, NIH, Moderator*

Presentations:

Conference Overview

*Marcia S. Scott, Ph.D.,**NIAAA, NIH*

Justice Pre-conference: ‘‘FASD-The Law Day“

*Sally M. Anderson, Ph.D., NIAAA, NIH*

Stigma Pre-conference: “Let’s Talk: Stigma and Stereotypes—Where Do We Begin?”

*Diana R. Simmes*, *M.P.H, University of California, San Diego*

11:45 A.M. **Lunch Break, Cafeteria/Grille, 1st floor, 5635 Fishers Lane**

12:45 P.M. Discussion on Improving Our Messaging

*Sally M. Anderson, Ph.D., NIAAA, NIH, Moderator*

Presentations:

Media Content Analysis of the 2016 CDC Vital Signs on Alcohol and Pregnancy

*Elizabeth Parra Dang, M.P.H., Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities*

FASD Recognition and Management in the Medical Home

*Yasmin Senturias, M.D., FAAP, Developmental and Academic Division Chief, Developmental and Behavioral Pediatrics, University of North Carolina at Chapel Hill*

Discussion:

*Speakers and all ICCFASD agency representatives*

2:15 P.M. BREAK

2:30 P.M. Reports of Activities of the ICCFASD Agencies: CDC, ACF, IHS, HRSA

3:30 P.M. Open Discussion

4:00 P.M. Closing Comments

*Sally M. Anderson, Ph.D., NIAAA, NIH; ICCFASD Activities Coordinator*

*Kenneth R. Warren, Ph.D., Senior Advisor, NIAAA, NIH; ICCFASD Chairperson*

4:30 P.M. Adjournment