



Spring 2022 Public Meeting Summary

Friday, April 1, 2022

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ICCFASD Spring 2022 Public Meeting

A videocast of the ICCFASD Spring 2022 Public Meeting held on April 1, 2022, is available on the NIH videocast [website](#).

Meeting Participants on Zoom

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

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Invited Guest Speakers

FASD Changemakers, Adult Leadership Committee (ALC)

- Katrina Griffin
- Emily Hargrove
- Myles Himmelreich
- Anique Lutke
- Catherine Jill (CJ) Lutke
- Justin Mitchell
- Jan Lutke (moderator and organizer)

Meeting Participants on NIH Videocast

The meeting was NIH Videocast with 107 participants attending the live videocast. The archived meeting videocast is available at <https://videocast.nih.gov>.

ICCFASD Agenda

TIME	AGENDA
10:00 am	Welcome and Introductions <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i> <i>ICCFASD Members</i>
10:10 am	ICCFASD: Overview and Updates <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary</i>
10:20 am	Reports of Activities from FY2021: ICCFASD Federal Agencies ACF, ACL, ASPE, CMS
	Q&A, Discussion
	Break
11:20 am	Special Panel A FASD Changemakers’ Lay of the Land Survey: Equality vs Equity—What 468 Adults with FASD Want You to Know <i>(moderator Jan Lutke)</i> <i>CJ Lutke, Myles Himmelreich, Katrina Griffin, Justin Mitchell, Anique Lutke, Emily Hargrove</i>
12:00 pm	LUNCH BREAK
12:40 pm	Special Panel (Continued) A FASD Changemakers’ Lay of the Land Survey: Equality vs Equity—What 468 Adults with FASD Want You to Know; Discussion with FASD Changemakers <i>(moderator Jan Lutke)</i> <i>CJ Lutke, Myles Himmelreich, Katrina Griffin, Justin Mitchell, Anique Lutke, Emily Hargrove</i>
	Break
2:00 pm	Reports of Activities from FY2021: ICCFASD Federal Agencies (Continued) <i>NIAAA, NIDA, NICHD, NIMH</i>
	Q&A, Discussion
	Reports of Activities from FY2021: ICCFASD Federal Agencies (Continued) <i>CDC, IHS, SAMHSA, HRSA</i>
	Q&A, Discussion
	General Discussion
4:15 pm	Adjournment <i>Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair</i> <i>Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary</i>

Welcome, Introduction, and Comments

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

Dr. Patricia Powell, Deputy Director at NIAAA and Chair of the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD), welcomed participants to the annual ICCFASD meeting. She explained that this is a hybrid meeting, with ICCFASD members and speakers on Zoom, and others participating via the NIH Videocast site. She then explained how participants could submit questions and comments and said that the recording of the meeting would be archived on the ICCFASD website. She then gave an overview of the meeting's agenda and spoke about the presentation from the adult leadership committee of the FASD Changemakers, an organization of people who have FASD and who are also researchers and FASD experts. Dr. Powell then let the ICCFASD members introduce themselves and their agencies.

Overview of ICCFASD and 2021 Updates

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

Dr. Balachova introduced herself and gave an introduction about ICCFASD, focusing on updates for 2021. She spoke about the committee's purpose, which is to enhance communication, cooperation, and collaboration among federal agencies with programs related to FASD or with a special interest in FASD. She went on to talk about FASD as a public health concern and how ICCFASD members and agencies address this concern. Dr. Balachova then discussed the member agencies of ICCFASD and encouraged people to visit the ICCFASD website for more information about the member agencies.

Dr. Balachova spoke about an effective, evidence-based approach for reducing alcohol use during pregnancy—screening, brief intervention, and referral to treatment (SBIRT)—and emphasized that although effective, it is not widely practiced. One of the ICCFASD's priority areas is prevention of FASD, so in the fall of 2021, it created a working group, the Screening and Brief Intervention for Pregnant and Postpartum People Working Group. The working group's objectives are to exchange information and resources, identify gaps and opportunities for improved implementation and research, and expand collaboration and partnerships between federal agencies related to SBI and, when necessary, Referral to Treatment for pregnant and postpartum people.

Dr. Balachova then spoke about the Strategic Planning Working Group, which was formed in 2020. An outline draft of the ICCFASD's strategic plan was developed, with a main focus of addressing prevention of prenatal alcohol exposure and the needs of children and adults with FASD. The plan includes three major areas: prevent and reduce prenatal alcohol exposure, improve identification and surveillance of FASD, and mitigate the effects of prenatal alcohol exposure across the lifespan. Cross-cutting themes include addressing disparities, improving access to services, advancing research on FASD, and increasing education and training. Dr. Balachova spoke about the importance of engaging stakeholders and the request for information for public feedback on the proposed plan's framework. NIAAA hopes to finalize the plan by the end of 2022.

Dr. Balachova transitioned to the updates from the ICCFASD member agencies and reminded videocast participants how to submit feedback and questions during the meeting.

Reports of Activities from FY2021: ICCFASD Federal Agencies: ACF, ACL, ASPE, CMS

The Administration for Children and Families (ACF)

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

Dr. Newburg-Rinn introduced the Children's Bureau and said that many people in the child welfare field misunderstand important facts about alcohol, perhaps overlooking it as a problem, and may think that only other substances, such as opiates, need attention. However, according to the Institute of Medicine, when compared with other substances of abuse, alcohol "produces by far the most serious neurobehavioral effects in the fetus." According to another study, over 80% of foster children with FASD are overlooked when they enter foster care. Children with FASD often do not have visible physical features and can reach some developmental milestones, such as walking and talking, on time, so they may not appear unusual, but they may have damage to the brain and may exhibit behavioral problems such as executive function problems. Dr. Newburg-Rinn said that children with FASD may get into trouble with their parents and at school because it may appear that they are purposefully misbehaving, although they are not, and this creates a challenge in the field.

She then spoke about an FASD project that the ACF's Children's Bureau is working on jointly with the CDC. There is a group of expert consultants who support this project, with expertise in a variety of fields such as medicine, education, and research design. The project, which is divided into three phases, entails tracking what child welfare agencies do when they first have contact with a child and their family. During the first phase, ACF and CDC gathered data from a local child welfare agency and spoke to its staff. They found that no one was asking parents about fetal alcohol exposure, which illustrates that the child welfare field may not be tuned into the health risks of fetal alcohol exposure. During the second phase of the project, ACF and CDC gathered information from a broader group, expanding to a more geographically and demographically diverse set of people including various states and a tribe. They saw many of the same issues they saw in the first phase, including a general lack of understanding of the effects of alcohol exposure. The third phase of the project is underway, in which ACF and CDC are developing tools to help child welfare agencies identify and refer children who appear to need a full diagnostic evaluation for FASD. She emphasized that for a child to receive such an evaluation, the important question needs to be asked of whether the child could have been prenatally exposed to alcohol. They are starting to do an evaluation of the tools they are developing with state agencies.

Dr. Newburg-Rinn then spoke about her appointment to the White House Office of National Drug Control Policy, in which she specifically provides information on alcohol issues. She is also on a sub-group of the committee on Foster Care Prevention. Each person in the group was asked to provide two recommendations, and she spoke in detail about her two recommendations:

- To advise states that it may be counterproductive to define prenatal exposure to alcohol and other drugs as child abuse and that states should reconsider this stance, instead treating such exposure as a medical issue and not a moral or legal one.
- To create an information memorandum that describes FASD and the need for agencies to determine whether a child may have been prenatally exposed to alcohol so they can be eligible to receive needed services.

Dr. Newburg-Rinn spoke about the importance of a medical diagnosis, which can only occur after a child has been identified and evaluated, in allowing services to be covered by insurance and other social services. She then stated that by the time her recommendations had made it through the committee, they had been vastly simplified to remember to include alcohol, not just other drugs, when evaluating children. She also spoke about her idea to create informational flyers to give to families who come to the attention of the child welfare system that could describe the effects of prenatal alcohol exposure.

References:

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

Chasnoff IJ, Wells AM, King L. Misdiagnosis and missed diagnosis in foster and adopted children with prenatal alcohol exposure. *Pediatrics*. 2015 Feb;135(2):264-70. doi: 10.1542/peds.2014-2171. Epub 2015 Jan 12. PMID: 25583914.

Administration for Community Living (ACL)

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

Dr. Reichard spoke about how ACL supports people with FASD and their families. She first described ACL's belief about how all people, regardless of age or disability, have the right to self-determination, including making decisions about their homes and work and other aspects of life and that they have the right to live independently. She then spoke about ACL's mission, which is to maximize the independence, well-being, and health of older adults, people with disabilities, and their families and caregivers. She then listed ACL's four components and spoke about the services funded by ACL that are relevant to people with FASD and their families, such as aging and disability resource centers which serve as a gateway to a broad range of services and supports, and centers for independent living.

She then described the mission of NIDILRR, which is the research arm of ACL: to generate new knowledge and to promote its effective use to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. She described some of NIDILRR's activities, including funding research and development projects, providing training, and promoting the adoption of rehabilitation technology for people with disabilities. She emphasized that they are focused on whole-person rehabilitation research that is tied to long-term outcomes, such as independence, community participation, and employment.

Although NIDILRR does not have any current projects specific to FASD, she referenced a few publications that provide examples of types of research NIDILRR might fund related to people with FASD. One example study found that an FASD diagnosis in adulthood can benefit people by providing more access to supports/services and greater personal understanding and adaptation. The employment example found that people with FASD who were employed had increased autonomy through receiving an income, building self-esteem, developing social connections, and becoming an advocate for FASD. She also spoke about a health and function example, the findings of which suggest that formal training may help rehabilitation specialists better treat individuals with FASD.

References:

Temple VK, Prasad S, Popova S, Lindsay A. Long-term outcomes following fetal alcohol spectrum disorder (FASD) diagnosis in adulthood. *Journal of Intellectual & Developmental Disability*, 46(3), 2021.

Kapasi A, Makela ML, Flannigan K, Joly V, Pei JR. Understanding employment success in adults with fetal alcohol spectrum disorder. *Journal of Vocational Rehabilitation*. 51(3), 2019.

Birch SM, Carpenter HA, Marsh AM, McClung KA, Doll JD. The Knowledge of Rehabilitation Professionals Concerning Fetal Alcohol Spectrum Disorders. *Occup Ther Health Care*. 30(1), 2016. doi: 10.3109/07380577.2015.1053163. Epub 2015 Jun 26. PMID: 26115404.

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

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

Ms. West introduced herself and listed ASPE's roles, including advising the Secretary on policy development; coordinating the department's research, evaluation, and demonstration activities; and managing interagency planning activities. FASD is included in ASPE's broad substance abuse and prevention portfolio. She then spoke about ASPE publications that are relevant to FASD. In early 2022, ASPE published two briefs. One examined [different state's responses to the prevention, identification, and interventions related to FASD](#). The second was about [the role of different providers](#) from varied fields, such as education and criminal justice, in preventing FASD and in identifying people with FASD and providing services to them over their lifespan.

Ms. West then spoke about ASPE's work on [integrating substance use disorder \(SUD\) questions into OB/GYN care](#). Although the work was not specific to alcohol, it did include some questions on prenatal alcohol use. ASPE analyzed models of care that already integrate SUD care into OB/GYN and highlighted policy opportunities for states, particularly in expanding postpartum coverage in the American Rescue Plan, addressing stigma, and providing clinical and non-clinical services. She then described recent ASPE research that examined the effect of COVID-19 on child and adolescent mental health. They found that children with a disability diagnosis were more likely to have new or recurring mental health conditions after a COVID-19 diagnosis compared to children without a disability diagnosis. Ms. West said that findings in the report could be of help to school-based providers as children return to school.

Finally, Ms. West gave a broad overview of FASD-related topics that ASPE is following, including health equity in access to care, alcohol use among pregnant and postpartum people, trends in child mental health conditions before and after COVID-19, service use among children with prenatal substance exposure, and access to services following the pandemic among children with disabilities.

Centers for Medicare & Medicaid Services (CMS)

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

Dr. Cross-Barnet from CMS spoke about the results from the early evaluation of the Maternal Opioid Misuse (MOM) Model. Pre-implementation of the model ran from January 2020 through June 2021, and implementation began July 1, 2021. She is hopeful that next year she will be able to report on the first year of the model's operation. She then described the model. It focuses on pregnant and postpartum Medicaid beneficiaries with opioid use disorder (OUD) and their infants, and she described why the MOM Model is relevant to alcohol use among pregnant and postpartum people. Eight states are operating models, the overall goals of which are to improve care and reduce costs to Medicaid, expand access for people during pregnancy and postpartum, and create sustainable coverage through Medicaid programs for the services that are being offered under the MOM Model. Dr. Cross-Barnet also said that they hope programs operating within the MOM Model will integrate maternity and infant care with behavioral health care and wraparound services. She then spoke about the results of various aspects of the pre-implementation evaluation that was conducted with the support of contractors, including evaluating how awardees used the pre-implementation period to plan, prepare, and refine evaluation designs. She also described how the MOM Model is taking health equity into account and how it is part of the program's evaluation. Dr. Cross-Barnet mentioned the successes that have already come from the program, such as creating new partnerships, developing referral sources, and establishing payment policies through Medicaid program, but there are also challenges around hiring staff and developing contracts, having sufficient provider capacity, and having enough resources to address problems such as domestic violence, among others. Awardees are required to integrate data across their services, submit Medicaid claims, collect data on individuals, and provide a health-related social needs screening. Dr. Cross-Barnet then described one aspect of the MOM project that asked providers to give information about the challenges and barriers experienced by pregnant and postpartum people with OUD. They found that most beneficiaries have transportation barriers to seeking treatment and that barriers are worse for people in rural areas. Pregnant and postpartum people also face stigma and judgement (from parents, partners, children, providers, social services, law and court systems, and communities, as well as self-stigma). She then spoke about solutions to reduce stigma and other social support barriers, such as providers acting as a source of support so the beneficiary feels valued and that they can get care that meets their specific needs. She concluded by discussing a provider's hope that in 10 years, no one will remember a time when SUD treatment was not a key part of prenatal care and that it is just one of the things provided for a healthy birth.

Discussion

Dr. Balachova, the moderator for the first discussion session, thanked the presenters and reminded the audience how to submit questions over the videocast. She asked the first question from a videocast participant, which was

about how to address lack of information on prenatal alcohol use, especially in foster care and with those who have been adopted.

Dr. Newburg-Rinn answered by saying that the Children's Bureau is working on giving information and arranging training for child welfare agencies across the nation on how they can help families who may not understand what is happening. She also spoke about a SAMHSA's [TIP 58 on addressing FASD](#) that can help in this regard.

Dr. Dunty stated the second comment from the videocast which was about a need for ICD-10 codes for each of the separate FASD diagnoses, with qualifiers.

Ms. Kim from the CDC said that they think it's a very important issue, and they are doing an analysis of relevant ICD-9 and ICD-10 codes so that they can gain an understanding of how the codes are being used. They will also fund feasibility studies that will look at healthcare system data and information in order to inform ICD codes and provide better diagnostic codes in the future.

Dr. Dunty said that NIAAA continues to support technologies and novel methods for earlier identification of children with FASD, even in the absence of confirmed prenatal alcohol exposure. He described various methods and research studies that NIAAA has funded, such as 3-D photography to study facial dysmorphism and decision trees to identify children prenatally exposed to alcohol.

Dr. Powell asked Dr. Newburg-Rinn whether it is possible to implement a practice whereby once any trauma or other substance use has been identified, alcohol is also asked about.

Dr. Newburg-Rinn said that she has been saying that if a child has a positive toxicology screen at birth, that child should automatically be followed for possible FASD because there is such a high probability that if the child was exposed to other drugs, they were also exposed to alcohol. She spoke about a study using blood spots and another using meconium, but that it is not practical to perform these tests universally. She voiced her support for following a child who had been exposed to other substances prenatally for FASD assessment.

Dr. Dunty presented the next question from the public who asked whether the decision trees for early identification are available to the public. Dr. Dunty said they are still being developed, but people who are interested in learning more about them can go to the [Collaborative Initiative on FASD](#) website.

Dr. Balachova asked Dr. Reichard about how the [University Centers for Excellence on Developmental Disabilities](#) currently address FASD and how they could raise awareness among the various disciplines involved in health care.

Dr. Reichard said that they could help in a number of ways, such as educating families and referring families to services since the centers already work with families. These centers could also conduct relevant research with stakeholders who come into contact with children with FASD and their families.

Dr. Dunty asked a question from the videocast and opened it up to anyone who wanted to answer. The question was about what is being done to improve accessibility to FASD assessment, especially among youth in residential placement.

Dr. Newburg-Rinn said that the Children's Bureau, working together with the CDC, is trying to get this kind of testing available after agencies have referred. However, she stated that it is difficult to get the agencies to consider fetal alcohol exposure an important issue, so they often do not ask questions that might otherwise lead to a referral.

Dr. Balachova then announced the first break and the Special Panel's talk on "A FASD Changemakers' Lay of the Land Survey" which would occur after the break. She said that agencies' reports and discussions would continue after the panel.

Special Panel: A FASD Changemakers' Lay of the Land Survey: Equality vs Equity – What 468 Adults with FASD Want You to Know

Moderator Jan Lutke; Panelists Katrina Griffin, Emily Hargrove, Myles Himmelreich, Anique Lutke, CJ Lutke, and Justin Mitchell

Ms. Jan Lutke introduced the panel speakers, members of the Adult Leadership Committee (ALC) of the FASD Changemakers. She spoke about the Changemakers' survey study, which has gotten attention from institutions, governments, policymakers, researchers, and other organizations and helps focus research questions. One of their goals is to change outcomes for people with FASD. She said that one main objectives of the Adult Leadership Committee (ALC) is to undertake Lay of the Land Survey research on older teens and adults with FASD, as they believe little is known about this population beyond limited information from clinical samples. The ALC is trusted within the adult FASD community, so that gives them access to this population. The goal of the survey work is to bring the results to the attention of people in positions to focus research directions and to enact meaningful change to improve the lives of people with FASD.

The first survey was done in 2016 and 2017 and addressed health and physical issues of older teens and adults with FASD. The average age of the survey participants was 27.5. The survey results were published in 2020 as a chapter in the Handbook of Social Work and Addictive Behaviors and have received wide global attention. It found that rates of diseases, illnesses, physical issues, and syndromes are higher in this population than in the general population and higher than expected in a group of this age.

The second survey focused on the quality of life of older teens and adults with FASD. It was administered between August 2019 and December 2020, and the results were first released in March 2021.

Ms. Jan Lutke then spoke about the stigma surrounding FASD and emphasized the importance of not focusing only on primary prevention since that would not help people who have FASD. She said that the ALC and other Changemakers have been successfully challenging perceptions and redefining what it means to have FASD and the public perception of FASD.

Ms. CJ Lutke introduced the Lay of the Land #2 Survey. The ALC focused the survey on the quality of life of teenagers and adults with FASD.

She explained that when they first developed the survey, they knew they wanted to assess quality of life for adults with FASD. The ALC found two definitions of quality of life that resonated were:

- The degree to which a person is healthy, comfortable, and able to participate and enjoy life events.
- The degree to which a person enjoys the important possibilities in his or her life.

However, as the survey results started coming in, they realized that even more fundamental to quality-of-life concerns, the answers reflected a lack of equity (i.e., giving everyone what they need to maximize their potential) and equality (i.e., treating everyone the same), which precludes having a good quality of life. Ms. CJ Lutke outlined the difference between equality and equity, emphasizing that some people need more help than others. She stated that social equity is about the provision, implementation, and impact of services, programs, and policies within the political systems in place. She said that equity is essential if the chance to maximize potential is to be equally available to those with FASD.

Ms. CJ Lutke described the survey methodology. The survey contained over 300 questions, some of which were mandatory demographic questions. However, participants were not required to answer all the remaining questions, so response numbers for each question varied. Altogether, there were 490 respondents, but only 468 of them answered enough questions for their response to be considered valid for the purpose of data analysis. Moreover, the number of responses for each question was not always 468. The survey was disseminated widely through online FASD group websites, clinics, Facebook, Instagram, personally, and by email request.

Ms. CJ Lutke then spoke about the **demographics** of survey respondents, including their age, IQ, gender, and location. She also gave statistics for how many people had completed the survey on their own or with help.

Ms. CJ Lutke then spoke about the **respondents' diagnoses**. About a quarter of respondents (28%) indicated they had FASD, while another quarter (24%) said they had fetal alcohol syndrome (FAS), and others indicated they had alcohol-related neurodevelopmental disorder (ARND), partial fetal alcohol syndrome (PFAS), fetal alcohol effects (FAE), or another diagnosis. Unlike in the first Lay of the Land Survey, people without a formal diagnosis were allowed to participate in the second survey. They represented 20% of respondents and said they thought they had FASD but did not have a formal diagnosis. Responses varied as to who told them they might have FASD, including a family member or professional such as a social worker. The data from people with and without a formal diagnosis were combined. Ms. CJ Lutke then presented data on the age of diagnosis and emphasized that for the approximately 100 people who did not know their age at diagnosis, this meant that part of their history is missing.

Mr. Himmelreich then gave a brief preview of the topics raised by the survey and its answers, including external issues such as poverty, stress, stigma, victimization, lack of supports and eligibility for support in all areas, and lack of understanding. He also highlighted the internal problem of memory issues that he said affects everyone with FASD and cannot be fixed, unlike the external issues which can be addressed.

Ms. Hargrove then spoke about survey questions that dealt with **what people with FASD were told**, including whether anyone explained what FASD meant at the time of their diagnosis or since then. Additionally, a majority of survey respondents indicated that they would have liked to have had someone who has FASD to talk to when needed, indicating a gap in what people with FASD need.

Ms. Hargrove then spoke about **perceptions of FASD**, emphasizing that

- 97% of respondents answered “no” to whether people really understand their diagnosis.
- 82% believe their diagnosis has been used against them.
- 91% of people with FASD feel intellectually inferior to people without FASD.

Given these statistics, there is still a long way to go in destigmatizing FASD.

The next survey questions dealt with **friends**, and data reflected that most respondents believe friends with FASD understand them better than do friends without FASD. A vast majority also expressed that they would like to know more people with FASD and attend a conference for people with FASD. She spoke about how important community is for acceptance and understanding among people with FASD.

Mr. Himmelreich spoke about the **Adverse Childhood Experiences (ACE) scale**, which was developed in 1985 to assess childhood trauma through measurement of abuse, neglect, and household dysfunction. A physician asked the ALC to include the ACE scale in their survey, which they did, but in a modified form that had additional questions, some of which were about who was responsible for the ACE. The ALC acknowledged that answering ACE-related questions would be difficult for survey respondents; nevertheless, approximately 330 people answered the ACE-related questions. He spoke about the concerning number of ACEs that occurred in foster and adoptive homes, which is problematic since these homes are meant to be safe. He showed the survey statistics on various ACE questions, including the ones ALC added to the original ACE scale. He also spoke in greater detail about survey responses to questions about sexual abuse, noting that rates of sexual abuse in the surveyed population seem to be twice as common compared to the general population. He spoke again about high rates of abuse from foster and adoptive parents.

Next, Ms. Griffin spoke about **education**, including respondents still in school and respondents who are older than 18. She said that the data may indicate an improvement, as fewer high school students have no support. However, the data do not indicate whether the support is effective—for example, although more students have an individual education plan now than previously, the data does not show whether plans are adhered to or helpful. Fewer students are in a special education program or special education school, but it is unclear whether that is beneficial. For people who were over 18 and therefore not in high school, many indicated that they did not understand what was

taught in school, and of the people who said they did not finish, many said they thought they could have finished if they had received more support.

The survey also asked about **job skills programs, regular career training, and regular college/university**. In looking at the progression from entering a program, completing a program, and getting a job or remaining in a job in a person's area of study, there are low success rates. The data show that people with FASD clearly have the desire to get education or a job and the will to get them but have difficulty keeping the job. She then presented some specific examples of problems and associated challenges related to education:

- Problem: high school education is not meeting their needs.
 - Challenge: re-design education for adolescents and how it is delivered.
- Problem: adults with FASD cannot manage post-secondary education and employment the same way as those without FASD.
 - Challenge: develop ways and means for those who are able to get job skills or education to continue to be employed in their field of study.

Ms. Anique Lutke spoke about **paid employment**. Most adults with FASD want to work, and 85% of respondents have worked at some point. However, less than half who had worked at some time had a job at the time of the survey, and many jobs were temporary or self-employed. A majority of respondents (82%) indicated that they thought they could work if they had the right job and the right employer. Ms. Anique Lutke then presented information about being fired or quitting. She stated that there were high rates of being fired or quitting, with many people saying they had been fired or quit more than three times.

She presented data on why this happens, including work being overwhelming, things going wrong in other areas of life, worrying about doing the job properly, etc. Moreover, 62% keep their diagnosis secret from their employer, and 77% believe their diagnosis makes an employer unwilling or unlikely to hire them. The reasons for keeping the diagnosis secret were stigma, shame, fear, and a lack of understanding.

Mr. Himmelreich spoke about **financial disability assistance**, showing that 52% of respondents receive government financial disability funds. He posed the question of why the other 48% do not receive these funds, given that they are available in all western countries and that FASD is considered a permanent disability. He spoke about the difficulties in applying for this type of assistance. The ALC uses \$1,500/month as a benchmark for what someone can live on. 90% of respondents who received government financial disability assistance receive less than this amount, and 84% who were employed at the time of the survey earned less than this amount. Approximately a third of people who were currently employed when they filled out the survey earned enough to live on from employment alone. The survey also asked other **financial questions** related to disability, being taken advantage of, and a lack of money. Over 75% of respondents indicated that they receive regular financial help from informal sources such as family. Mr. Himmelreich posed questions about people who do not receive this extra type of financial help and what happens to people after this type of assistance is no longer available.

Mr. Mitchell spoke about **housing data**, emphasizing that the ALC asked survey questions to assess the stability of respondents' housing situations. Throughout this section, Mr. Mitchell spoke from both the survey results and his personal experience of being homeless. He showed statistics on where and with whom respondents lived at the time they filled out the survey. He said that these housing data are concerning since they raise the question of where the respondents will live after the people providing help are no longer able or willing to do so. He spoke about the importance of stable housing and how that can pave the way for receiving support and services. He also presented data about homelessness and evictions, noting that the rates of homelessness among those with FASD appear to be greater, based on survey responses, than for the general public, and that the survey did not ask about who gets "kicked out," which would probably have elicited different answers than the question on eviction. He showed statistics on how many respondents do not have enough money to pay rent and on how many people do not remember to pay rent. He spoke about the difficulties of finding acceptable housing when faced with these problems.

Dr. Balachova then announced the lunch break.

Special Panel (Continued): A FASD Changemakers' Lay of the Land Survey: Equality vs Equity – What 468 Adults with FASD Want You to Know

Dr. Balachova welcomed everyone back.

Ms. CJ Lutke then spoke about how the group's findings related to adverse childhood experiences led them to look at **adverse continuing experiences in adults (ACEs-A)** in people over 18. She showed survey responses to various adverse events that happened to respondents after the age of 18, broken down by gender. Examples included being manipulated by others, being physically assaulted, and being talked into sexual activity. She spoke in greater detail about three survey questions about sexual assault and how certain adverse events that are usually more commonly associated with female victims have a relatively high report rate among men. She spoke about the group's attempt to get a proxy measure for neglect and showed data from survey questions about housing, food, and clothing, pointing out that more than a quarter of respondents said they have to wear dirty clothing because they cannot afford laundry and that over a tenth of women are unable to purchase feminine hygiene products. She said that given these data, the ALC believes neglect is as high or higher among adults compared to individuals younger than age 18. She showed data that compared the occurrence of adverse events before age 18 to rates of occurrence after age 18. She concluded this section of the data by saying that growing up and hitting society's age goalpost does not protect against adverse events and said that it is problematic that there is no tool to look at and track adverse events in adults with FASD. She suggested that there is a need to develop a comprehensive tool to be used across all systems with which adults with FASD interact.

Ms. Griffin next spoke about **relationships**, including with birth, foster, and adoptive families; friends; and partners. She spoke about the respondents who had one long-term home and those who had multiple placements, as well as possible problems with interpreting some of the data, for example, because some respondents may not have counted a home or placement if they were there only for a few days. Only 19% of respondents had been raised solely by birth parents. Adoption information was shown, reflecting that 46% of respondents were adopted, some of whom did not know at what age, reflecting a problematic lack of history. Some respondents were adopted more than once or had an adoption break down. Respondents across all three family types (birth, foster, and adoptive) reported that relationships were difficult in childhood, got worse in adolescence, and improved for many in adulthood, with many respondents saying that their parents are a positive influence in their adult lives. Ms. Griffin spoke about how parents often provide most of the support for adults with FASD, but that this presents a problem since that support is not indefinite.

Ms. Griffin showed a slide on the problems that respondents indicated they have with friendships, such as it being difficult to keep friends and that being with people is exhausting. She drew attention to the fact that many said they are happier alone. Being alone, or interacting online rather than in person, makes it less likely that a person with FASD will be overwhelmed by social interactions. In terms of partner relationships, 43% were in a partner relationship and 14% were married at the time of the survey, but it is possible that these relationships are not stable or healthy, given the high rates of relationship issues shown by the ACEs-A questions.

Ms. Anique Lutke presented information on **parenting with FASD**, including data on questions related to whether respondents had children and if so, whether they were living together, and how many respondents had help and paid support. The vast majority (88%) of respondents indicated that they would find support from a nonjudgmental person to be helpful, but many also indicated that they are afraid that needing help could be used against them because it could put them on the radar of child protection services. Ms. Anique Lutke spoke about data on what happened to the children who do not live with their respondent parent. Respondents who were parents were asked whether their child had FASD or any other disabilities, and positive answers ranged from 20% to 40%. Respondents also indicated that their FASD diagnosis had been used against them in court by a partner or family member who does not have FASD to try to get custody of their children.

Ms. Hargrove spoke about **health issues**. She pointed out that the survey did not have many questions about health since that was the focus of the first Lay of the Land Survey, but that some measures were included since they affect quality of life. She discussed survey results that may reflect a continuing lack of knowledge in the medical

community about FASD. She then showed data from the first survey, including data on autoimmune and chronic immune problems, noting that many such diseases occur at higher rates in the surveyed population than they do in the general population. She spoke in greater detail about chronic ear infections, congenital heart defects and heart problems, endocrine disorders, and other health problems such as dementia and osteoarthritis. She emphasized that the average age of survey respondents was 27, so the higher rates of diseases, such as hypertension and diabetes, which may affect older people in the general population, is concerning. Ms. Hargrove then spoke about data from the previous survey about sensory problems which impact quality of life.

Ms. Hargrove next discussed survey results related to **mental health** and **sleep**. While anxiety is common among those with FASD, less than half of respondents said that they were on a medication to help with anxiety. About a quarter of respondents indicated that they were on medication for ADHD and about a third of respondents indicated that they self-medicate with street drugs or alcohol. Respondents also had high rates of feeling that life is hopeless, feeling like a failure, and not looking forward to the future. In terms of sleep, a high percent of respondents reported that they have difficulty sleeping that interferes with functioning during the day. Furthermore, 28% of respondents are afraid to fall asleep and 32% are on medication for sleep problems. The data raise the question of how well sleep issues are being treated in this population.

Mr. Mitchell presented data on **criminal justice** and **being a victim of crime**, again speaking both from personal experience and the survey data. He said that involvement with the criminal justice system is a well-known problem for those with FASD and that arrest rates, for example, are the same now as they were 25 years ago, indicating a lack of improvement. He emphasized that the majority of people with FASD are not bad people, but instead people who may make bad choices or mistakes due to their disability. He said that he does not think adults with FASD understand crime the way other people do, since, for example, it took him a long time to understand that his actions affected other people. He spoke about survey data relevant to various aspects of criminal justice, such as respondents agreeing with police that they had done something they did not do, being charged with crimes they did not commit, and being forced into committing a crime by other people. In terms of victims of crime, 54% reported that they had crimes committed against them, and Mr. Mitchell spoke about the categories of these crimes. About three fourths of victims did not report the crime to the police, possibly because they have had the experience of not being believed at some point in the past. Moreover, a quarter of the victims had authorities refuse to charge the person who committed the crime, and some of these victims were told it was because their FASD diagnosis made them unreliable. Lastly, a high percent of respondents (65%) who had ever been involved with the justice system said they did not understand the process.

In terms of past and current use of **drugs and alcohol**, current use was less than past use, with some respondents reporting that they were talked into using when they did not want to, that they used drugs and alcohol to fit in with people, or that they were using drugs or alcohol to cope with anxiety, trauma, or grief. Mr. Mitchell emphasized that this last reason speaks to the need to provide effective mental health treatment to help people deal with childhood ACEs and adult ACEs.

Ms. Anique Lutke presented data on **memory issues**, and how memory touches on every aspect of day-to-day life, from paying rent and bills, taking medication, doing laundry, being on time, and keeping appointments. Memory issues affect every area of life that the presentation had already touched on. She said that the problem with performing these tasks is not one of skill for people with FASD but a problem of memory. Memory is essential for adults to be successfully independent, and the problems many adults with FASD face with respect to being independent are not about laziness, lack of caring, or lack of willingness, but about memory. She spoke about more specific examples of how memory issues affect the lives of people with FASD.

Ms. Griffin spoke about **services**, emphasizing that although many respondents feel that life is hard for them and that they do not have control over things (while having control is important for quality of life), many would appreciate help with things they find difficult. Respondents answered questions about the top services they felt would be most helpful to improve the quality of their lives. The top five are listed here:

- A mental health clinician who specializes in FAS.
- A doctor or nurse practitioner who specializes in FASD.

- A person who can help when something goes wrong.
- A trusted person to give advice when needed.
- Enough money to live on each month.

Ms. Griffin stated that every agency, organization, service, program, policy, and government system, needs to consider how to provide these services. She emphasized that three of the top 10 services involve the word “trust,” something that is hard to develop and easy to lose, especially in a population such as people with FASD who have repeatedly been taken advantage of. The ALC also believes that doing something that is important to an individual is critical to quality of life for adults with FASD.

Mr. Himmelreich presented data on respondents’ feedback on **meaning, purpose, and satisfaction** with life. He said that in spite of their difficulties, most respondents still have hopes, dreams, and goals and feel that they contribute to the well-being of other people. However, about 36% of respondents indicated that they do not look forward to the future and about half indicated that they do not believe their ideas are listened to by those who make decisions.

Ms. CJ Lutke spoke about the following challenge: How to change the system NOW; fund it adequately NOW; and do the research in relation to service provision to meet the need on the basis of diagnosis and not IQ. The ALC believes that focusing on these issues now would be the fair and equitable thing to do. She urged listeners to consider the definitions of quality of life that were covered at the beginning of the presentation and emphasized that quality of life is not possible without equity, which is missing from the lives of people with FASD. She spoke about how FASD is an origin story, but that it should not be, and does not have to be, the destination. She emphasized the need for change and asked if change started today, where things would be in five or ten years. In urging change, she asked whether a person with FASD, at any age, can reasonably expect equity in life and whether people with FASD are worthy of efforts for systems to change.

Discussion

Moderators Jan Lutke and Dr. William Dunty

Dr. Balachova thanked the presenters and opened the discussion, which was moderated by Ms. Jan Lutke and Dr. Dunty.

Ms. Jan Lutke spoke about the importance of the work to be done as reflected in the survey results.

Dr. Dunty thanked the ALC. He asked them what surprised them the most about the survey results and how they hoped that making the public aware of the results would bring about change.

Ms. CJ Lutke said that she wasn’t too surprised since they had all already sensed that things were different for people with FASD. However, seeing the numbers in black and white was surprising, as it served as confirmation for what they had already thought was true.

Dr. Sarampote said he was struck by the fact that the number one need was mental health counselors with experience with FASD. He asked the ALC to talk more about what exactly it means to have a counselor who truly understood FASD and what advantage it would give.

Ms. Jan Lutke said that the group had discussed this issue together previously, and that standard mental health services, even if provided by people with a little training of FASD, is not sufficient. Instead, what is needed is mental health providers with a breadth and depth of understanding and experience. She said that an expert therapist in Vancouver had claimed that everything she had learned was of no use in working with people with FASD, and that instead, the therapist had to learn from working with people with FASD.

Mr. Himmelreich pointed out that typical therapy sessions, during which abstract questions are often asked, are difficult for people with FASD since they do better with concrete topics. He also suggested that a different format for therapy could be more helpful for people with memory problems. He emphasized that the burden for change should not be on people with FASD but rather on the people who support them.

Ms. Hargrove spoke about her experience working at a mental health clinic that focuses on FASD. She said that when families come into the clinic, they are often given an ACE score, but that since FASD does not stop at age 18, an important question is how to address issues beyond the age of 18. She pointed out that one of the valuable things about the survey was that it highlights that people with FASD have problems after age 18, underscoring the fact that FASD is not just a childhood issue. She urged mental health professionals to take this into account.

Ms. Jan Lutke said that supports are not present for adults with FASD in the same way that they may be available to children. She asked why supports are not available to adults, given that the disability is permanent. She said that providing such services for adults is well within the purview of social services systems. She also spoke about how memory issues can be perceived as the person not taking responsibility.

Ms. CJ Lutke spoke about sexual assault as measured by the ACEs-A. She asked why age 18 is the cutoff and said that for therapists to really understand adults with FASD, they need to work on understanding how an adult with FASD perceives a sexual assault.

Dr. Powell thanked the panel and asked what types of supports can be put into place more systematically, beyond mental health services and education of employers and law enforcement.

Ms. Jan Lutke said that it is critical that anyone providing support in any area should understand that people with memory issues are least able to use memory tricks and tips because using them requires that one remembers to do so. There was general agreement from the ALC about this.

Ms. CJ Lutke spoke about how memory issues impacted her work in retail stores.

Mr. Himmelreich spoke about how memory issues can impact a person's ability to access services since there are so many steps and very little support to getting services. He gave specific examples from his own experience, including how he is missing out on some financial benefits because he cannot remember how to do all the steps. He said that overall, the way disability services are set up are not conducive to people with FASD receiving benefits.

Ms. Jan Lutke pointed out that unlike most disabilities where people's IQ matches their need for support, this is not the case for people with FASD, as there is often a gap between their measured IQ and the other adaptive pieces. She spoke more about memory issues in people with FASD. She said that it may be the biggest issue for people with FASD because it gets in the way of everything but does not garner sympathy or support from society, especially if the person's IQ is over 70. She emphasized that typical ways that society supports memory do not work for people with FASD, so there is a lot of work that needs to be done in this area.

Ms. Griffin spoke about her personal experience with memory issues in daily life.

Ms. Anique Lutke spoke about her issues with memory and asked for the question to be repeated.

Dr. Powell explained that her question was about what services and supports the ALC members would like to see put in place.

Ms. Anique Lutke said that the ALC is working with the University of Rochester on developing an app for people with FASD to help with memory. She turned it over to Ms. Griffin to explain the app in greater detail.

Ms. Griffin listed specific aspects of the app, such as a medication tracker and a sleep tracker. She said the app's features are based on things that they as a group think would be helpful to have. She said that the thing that society could do to help would be to fund FASD to make it equitable and to move away from thinking of FASD as an IQ-based disability, but rather to ask what an individual person needs, whether that is a funded therapist, or a funded support worker.

Ms. Hargrove said that what would be helpful is not so much a specific service but a different philosophical approach that takes the humanistic approach into account. She pointed out that with the app, users do not have to be afraid that their disability will be used against them, but with other services, at least for her and as reflected in the survey, there is a fear that they will be perceived as stupid for needing services. She spoke about how services

should take a humanistic approach with the idea that if a person with FASD uses services, it would not be used against them, and that destigmatizing FASD would also be helpful.

Ms. Jan Lutke agreed with Ms. Hargrove. She said that the Changemakers want to change the whole perception around FASD so that it is not seen as a hopeless situation. She recognized that changing philosophies within systems takes a lot of work and that it has to be accepted that the disability is permanent, involves memory, and is not solely based on IQ. She said more of an emphasis needs to be placed on how memory issues will impact various aspects of daily life such as housing, employment, and parenting. She said systems and agencies need to change so that they do not require people with FASD to engage in activities that rely on memory and pointed out that while blind people are never expected to eventually see, people with FASD are treated in such a way that places the burden of doing things that rely on memory on them. There is a massive need for systems and agencies to understand that memory issues are permanent in people with FASD. She spoke about how high the vulnerability of people with FASD is because of their memory issues and contrasted memory issues in people with FASD to people with traumatic brain injury. She emphasized how important it is for systems to address memory issues in people with FASD.

Dr. Balachova presented a comment in praise of the presentation from a videocast participant and thanked the ALC for speaking and broadening everyone's knowledge of FASD. She announced a break.

Reports of Activities from FY2021: ICCFASD Federal Agencies: NIAAA, NIDA, NICHD, NIMH

The National Institute on Alcohol Abuse and Alcoholism (NIAAA)

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

Dr. Dunty introduced himself. He said that NIAAA supports four areas of FASD-related research through grants and other activities: etiology, interventions, prevention, and diagnosis. NIAAA funding for research and training grants has been on the rise for the last five years (2017-2021), with about \$425 million allotted to those activities last year. Over the same five years, awards to FASD researchers have remained steady and makes up 7-8% of NIAAA's total research and training budget. In 2021, over \$30 million supported 107 FASD-related grants, 20 of which were new in 2021. Dr. Dunty suggested that anyone interested in learning more about the research projects could use NIH RePORTER. He talked about the research topics covered by the new grants awarded in 2021. In the category of etiology, examples of topics are anxiety, sleep disruption, vascular development, and metabolic disruption. Topics related to intervention and prevention include mobile health tools for both adults with FASD and for women. In the category of diagnosis, topics included biomarkers and smartphone-based applications. Some projects have overlapping categories, such as etiology and interventions. He then spoke about the work of four NIAAA-funded consortia and centers:

- The Collaborative Initiative on FASD (<https://cifasd.org>).
- The New Mexico Alcohol Research Center (<https://hsc.unm.edu/nmarc>).
- The Developmental Exposure Alcohol Research Center (<https://www.binghamton.edu/centers/dearc>).
- The Native Center for Alcohol Research and Education (<https://ireach.wsu.edu/ncare>).

In 2021, NIAAA and NICHD issued a media advisory highlighting results from the Safe Passage Study, which followed nearly 12,000 pregnancies. The researchers found that women with combined exposure to drinking and smoking beyond the first trimester had an increased risk for stillbirths at week 28 or later compared to people who had no exposure or people who had quit before the end of the first trimester. Previously, these researchers had also found an increased risk for sudden infant death syndrome in pregnancies exposed to maternal drinking and smoking after the first trimester.

Dr. Dunty next spoke about NIAAA's current funding opportunity announcements (FOAs) in support of FASD research. They involve prevention and intervention approaches and navigating the pediatric-to-adult health care transition for those with intellectual and developmental disabilities. He directed interested persons to visit grants.nih.gov for more information.

In late 2019, NIAAA hosted a consensus conference on research classification to harmonize the various research classification systems for FAS and FASD. He described the benefits of having a single definition for FASD and a unified framework and said that NIAAA is finalizing an analysis plan to allow participants to evaluate the framework using their own datasets.

Lastly, Dr. Dunty spoke about NIAAA's outreach efforts. They promoted FASD Awareness Day in September and partnered with the American College of Obstetricians and Gynecologists (ACOG), the Centers for Disease Control and Prevention (CDC), and FASD United (formerly the National Organization on Fetal Alcohol Syndrome, NOFAS) to have a Twitter chat to raise awareness of the harms caused by prenatal alcohol exposure. NIAAA also released a brochure that provides answers to common questions about alcohol and drinking during pregnancy. NIAAA also participates in several trans-NIH pediatric initiatives, including the Adolescent Brain Cognitive Development Study and others.

To learn more about NIAAA's FASD research program, viewers are encouraged to visit NIAAA's page on [Fetal Alcohol Spectrum Disorders](#).

The National Institute on Drug Abuse (NIDA)

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

Dr. Prabhakar introduced herself and the alternate NIDA representative to the ICCFASD, Dr. Keisher Highsmith. She explained that NIDA does not fund research specifically on prenatal exposures to alcohol but rather that its portfolio focuses on a broad array of substances and poly-substance use. NIDA's research related to prenatal exposures touches on various fields including neuroscience, epidemiology, and interventions related to pregnant people. She described NIDA's extramural research programs that relate to this research.

Within the Division of Neuroscience and Behavior, NIDA has a grant to study the effects of prenatal cocaine use, either alone or in combination with other substances including alcohol, on brain connectivity and behavior. The Division of Epidemiology Services and Prevention Research has a grant studying whether improvement in maternal OUD services affects child health outcomes. One research project within the Division of Therapeutics and Medical Consequences focuses on developing and testing an SBIRT package for addressing substance use in pregnant and postpartum women through state-based home visiting programs.

NIDA is leading two key initiatives related to prenatal exposure: the [Adolescent Brain Cognitive Development \(ABCD\) study](#) and the [HEALthy Brain and Child Development \(HBCD\) study](#).

Dr. Prabhakar first spoke about the ABCD study, which began in 2015. It is a longitudinal study of about 12,000 children who were enrolled at ages 9-10. The study is assessing individual brain developmental trajectories and functional outcomes with the goal of understanding how the use of various substances affects developmental outcomes and trajectories, including what factors may lead to subsequent substance use in these children. Data from the study is publicly available. Papers have already been published using ABCD data. One found a [linear relationship between the number of adverse prenatal events a child is exposed to and their level of clinically significant psychopathology at ages 9-10](#). Another study found a relationship between [prenatal caffeine exposure and externalizing behavior problems](#), with the effect size for association of externalizing problems with prenatal caffeine exposure comparable with that reported for prenatal exposure to alcohol and cannabis.

Dr. Prabhakar then spoke about the HBCD study, which is a trans-NIH study. It is a prospective longitudinal study that begins during pregnancy and extends through the first 10 years of life, assessing brain, cognitive, and emotional development. It aims to determine how substance exposure and other environmental factors affect developmental

trajectories. Data from this study will be released annually. She then spoke about specific study objectives, including understanding the following:

- The typical neurodevelopmental trajectories and the normal range of variability in brain development.
- How biological and other environmental exposures affect developmental trajectories.
- How genetic influences interact with environmental factors to influence neurodevelopment and cognitive, emotional, and social behavior.
- How early life exposure to opioids, other substances, or other adverse environmental circumstances affects developmental trajectories.
- Whether there are key developmental windows during which adverse exposures influence later outcomes or during which ameliorating influences could be protective.

In 2021, NIDA funded 25 research sites across the country, as well as a data coordinating center and an administrative center, to undertake the study. The study will collect data on neuroimaging, environmental exposures, social and emotional assessments, and biospecimens. The centers have developed a coordinated protocol and enrollment will begin in 2022. Dr. Prabhakar then spoke about the timeline of the study and showed a list of some of the HBCD publications.

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

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

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

Dr. King noted that NICHD funds few awards that are focused specifically on children with FASD or alcohol use during pregnancy, but that it is involved in multiple ongoing initiatives and priority areas that have potential relevance to FASD. These include the Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE) Initiative, which focuses on reducing maternal morbidity and mortality; the Strategies to Enrich Inclusion and Achieve Equity (STRIVE) Initiative, which addresses issues of diversity, equity, inclusion, and accessibility (DEIA); an interest in the transition from pediatric to adult health care for adolescents with disabilities or chronic medical conditions; and an interest in improving reproductive health, pregnancy, and parenting for people with disabilities. She then spoke about each of these four initiatives or areas in greater detail.

Dr. King detailed the [IMPROVE Initiative](#), which focuses on addressing high rates of pregnancy-related complications and deaths in the U.S. and encompasses both foundational biology and social and biobehavioral research. Community partners are key to this project. The initiative is led by the NIH Immediate Office of the

Director, NICHD, and the NIH Office of Research on Women's Health, with additional support from other NIH Institutes, Centers, and Offices. IMPROVE focuses on cardiovascular disease, infection and immunity, and mental health and has an overarching theme of addressing racial, ethnic, age, and geographic regional disparities.

She explained the [STRIVE Initiative](#) in more detail. It has three interrelated themes: addressing diversity, equity, inclusion, and accessibility in NICHD's internal workforce; enhancing the diversity of its extramural workforce; and addressing health disparities and systemic racism in its research. STRIVE is meant to complement NIH-wide DEIA efforts.

NICHD is also interested in improving the transition from pediatric to adult health care for adolescents with disabilities and/or chronic medical conditions. Many adolescents and their families struggle with various aspects of this transition, including logistical, developmental, policy, and cultural obstacles. NICHD has led various efforts around improving the transition: hosting a [workshop](#), authoring a [publication](#), and issuing a [notice of special interest](#).

Dr. King next spoke about how people with disabilities are often not offered the same access to or quality of reproductive healthcare as persons without disabilities, which may result in disparities. Several recent efforts from NICHD highlight this problem: a [brief on Disability and Pregnancy](#) that was put out in conjunction with ACL, a [publication](#), a [workshop](#) and [request for applications](#), and a [notice of special interest](#).

The National Institute of Mental Health (NIMH)

Christopher Sarampote, PhD, Chief, Biomarker and Intervention Development for Childhood-Onset Disorders Branch, Division of Translational Research, National Institute of Mental Health, NIH

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

There are many areas of overlap between NIMH's interests and FASD. Prenatal alcohol exposure (PAE), even at levels lower than those associated with a formal diagnosis of FASD, increases the risk of adverse mental health outcomes and psychiatric symptoms, including emotional dysregulation, impulsivity, and impaired executive function. Additionally, children with PAE may respond differently to standard psychiatric treatments. Less is known about the long-term impact of PAE over the whole lifespan. Dr. Sarampote spoke about an NIAAA-funded study that showed PAE to be associated with greater rates of mental health disorders in middle adulthood and another that showed PAE predicts differences in brain activation during the development of memory networks in childhood. Studying how fetal alcohol exposure impacts development may lead to a better understanding of the underlying mechanisms of mental illness.

NIMH's scientific contribution to FASD is within collaborative efforts, such as the HBCD, which will establish a large cohort of pregnant women from different regions of the U.S. affected by the opioid crisis. HBCD's findings will improve understanding of normal child brain development and of the long-term impact of prenatal and postnatal opioid and other drug and environmental exposures including nicotine and alcohol. This is of interest to the FASD community because opioid use is comorbid with alcohol abuse. NIMH has a strong interest in this study because it will help the understanding of normative brain development and what factors can affect such development. NIMH is contributing funds and scientific expertise to HBCD to figure out the best study measures and designs. NIMH may perform secondary analysis on HBCD data to examine how fetal alcohol exposure is involved in risk and resilience.

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Discussion

Dr. Balachova welcomed everyone back, announced the discussion section, and thanked the NIH presenters for their agency updates. She reminded the videocast audience how to submit questions.

Dr. Powell asked how much NIH research is focusing on memory issues, since the Changemakers talked about how important memory issues are to their quality of life.

Dr. Sarampote said that NIMH has studies on cognitive memory formation and cognition in relation to development and to components of other psychological disorders. However, they do not have any studies that look specifically at FASD.

Dr. Powell asked how well researchers are doing at teasing apart what is behavior and what is actually memory issues.

Dr. Sarampote said it's probably difficult to separate those two, although there is a comprehensive battery.

Dr. Prabhakar explained that ABCD has measures that follow neurocognitive behaviors like memory and brain development. But she agreed with Dr. Sarampote that it is difficult to tease the two apart. She said that NIDA has studies on memory and substance use, although not specific to FASD. These studies look at meta memory, or one's own confidence about their own memory, which may be relevant to what the Changemakers spoke about.

Dr. Dunty added that NIAAA funded studies that aim to connect the dots between things such as sleep regulation and memory impairment, but there is no data yet since these are new grants.

Dr. King said that NICHD has long had an interest in developing better outcome measures and agreed with the Changemakers that IQ does not capture memory issues so it can be misleading as a way to label people with disabilities. She said that NIMHD is interested in developing measures that would better characterize disabilities by teasing out different aspects.

Dr. Balachova asked about how well people with FASD are represented in research, not necessarily as research subjects, but as advocates who can help plan research and formulate goals.

Dr. Dunty said that some NIAAA-supported researchers, because the Changemakers had publicized some of their survey data in the past, now understand that adults with FASD need to be made part of research efforts in order to find solutions. He mentioned the app that Ms. Anique Lutke and Ms. Griffin had described in their presentation and said that the Changemakers are serving as advisors on the grant so that the app can address challenges that they face. This is one concrete example where people with FASD are really influencing NIH-funded research.

Dr. King spoke about the problems posed to researchers who are interested in studying disabilities when large studies have inclusion or exclusion criteria that exclude people with disabilities. In these situations, it is hard for researchers studying disabilities to know how the findings from such studies generalize to their specific populations of interest. Dr. King said that NICHD is beginning to look at such exclusions as a lost opportunity for large cohort studies, although she acknowledged the difficulties in including a less homogenous population in such studies.

Dr. Balachova spoke about the importance of including individuals with FASD in research, including listening to individuals who have the condition being studied during the formative phases of a research project.

Dr. Dunty announced a comment from the videocast that expressed thanks for the work being done on PAE and translational research and asked what effects the COVID-19 pandemic has had on studies such as ABCD or HBCD.

Dr. Prabhakar explained that the planning phase of HBCD coincided with the pandemic, so researchers had to pivot to remote assessments; therefore, some data collected from pregnant women and their children does reflect the

effects of COVID-19. The study will continue gathering data so that researchers can measure the impacts of the pandemic on neurodevelopmental and maternal outcomes. Each site within the HBCD study has peer navigators, people who have lived experience using substances. The navigators will interact with both the research team and study participants.

Dr. Dunty asked another question from the videocast—do the studies on pregnancy in persons with disabilities include data on postpartum health or the incidence of child protective service involvement due to parental emotional or cognitive issues?

Dr. King explained that NICHD's initiatives around pregnancy and parenting among people with disabilities are all new so they do not have any data yet.

Ms. Jan Lutke suspects that no one is collecting that type of data because of issues around how issues are looked at within child protective services. She said, however, that she would expect a higher rate of mental health issues in women with disabilities during and after pregnancy. She spoke about women with other disabilities and asked how many of them have their children removed compared to mothers with FASD. She emphasized that it is important to look at what women with FASD need to support their pregnancies and postpartum periods.

Dr. Reichard said that people with developmental disabilities have a greater risk of postnatal depression. One reason the ACL does not know more about FASD is because the data they have from national studies do not include an indicator for FASD. She acknowledged her colleagues who are working to get disabilities included as a variable on certain surveys.

Dr. Cross-Barnet cautioned that based on experience with the MOM Model, the legal system as a whole may not have good policy or education about substance abuse exposure. Therefore, the mother's situation may be decided on an ad hoc basis by the judge based on whatever the judge thinks is right for that case. For example, although someone who is on medication to treat an addiction is considered to be in recovery medically, the legal system may view that person as having substituted one addiction for another and treat them as if they were still addicted. She said that she thinks this sort of ad hoc approach probably also happens a lot with people with developmental disabilities in terms of how they are treated by a social worker or a judge.

Ms. Lutke explained that many adults with FASD have IQs that are too high to fit legal definitions of someone who is disabled. She spoke more about the limitations of definitions of disability and adaptive function as relates to people with FASD.

Reports of Activities from FY2021: ICCFASD Federal Agencies: CDC, IHS, SAMHSA, HRSA

Centers for Disease Control and Prevention (CDC)

Shin Y. Kim, MPH, Team Lead, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Ms. Kim started by talking about CDC's surveillance efforts. She discussed data showing that 1 in 7 pregnant people in the U.S. reported drinking alcohol and that 1 in 20 reported binge drinking. She also talked about a study that showed nearly 3 in 4 physicians screen their patients for alcohol misuse, but that the rates of brief intervention are much lower. Only 20% of patients who were screened for alcohol use and reported binge drinking at their last checkup were advised to reduce their drinking. CDC also analyzes data on alcohol use during pregnancy, screening and brief intervention, and polysubstance use, and Ms. Kim spoke about three of these efforts.

CDC's current activities related to awareness and prevention include having a cooperative agreement with four health systems to focus on alcohol screening and brief intervention implementation within health systems that provide women's health services. The aim of these projects is to reduce excessive alcohol use among women of reproductive age. One of the four grantees developed a [podcast about alcohol and pregnancy](#).

Since September 2019, CDC has been working on developing standards-based clinical decision support (CDS) tools for alcohol SBI based on evidence-based guidelines. Tools have been developed for screening instruments and brief intervention aids, and all these tools are available to the public on [CDS Connect](#). A pilot study is underway to test the integration of an alcohol screening CDS and a brief intervention CDS with electronic health records in a particular health system.

CDC also has cooperative agreements with professional organizations that focus on promoting the prevention of FASD. Goals include raising awareness of risky alcohol use, including any use during pregnancy, and promoting clinical guidelines and policies that promote alcohol SBI.

CDC has also been working with FASD United (formerly NOFAS) since the 1990s. Currently, the purpose of their cooperative agreement is to raise awareness about the risks of prenatal alcohol exposure; to improve understanding about individuals living with FASD; and to promote the prevention of FASD and care of affected individuals. One accomplishment that has come from this agreement is that ACOG and FASD United paired ob/gyn champions with a member of the FASD United Speakers Bureau to provide joint Grand Rounds. The ob/gyn champions have found that their co-presenters, who have the lived experience of having FASD, are very impactful at these talks.

Ms. Kim spoke about CDC's work in developing messages for healthcare providers on the importance of providing alcohol SBI to patients and on alcohol's risks during pregnancy. They are working with a contractor to develop final products for a CDC guide on FASD-related messaging and for patient-provider communication materials.

CDC is promoting FASD identification and care in pediatric settings by collaborating with the American Academy of Pediatrics (AAP) to provide training and education. AAP's efforts are focused on improving the health and developmental outcomes of children with PAE and prenatal exposure to other drugs. The activities of the partnership between CDC and AAP fall into four categories: awareness, education, and resources for pediatric providers; FASD Champions Network composed of 10 AAP fellows with expertise in FASD; Neurodevelopmental Extended Communities Health Outcomes (ECHO) project; and a Continuity Clinic Resident Training Project.

Lastly, CDC has [two new funding opportunities related to FASD](#): one addresses prenatal alcohol and other substance use and fetal alcohol spectrum disorders, and the other is aimed at understanding clinical data and pathways to inform surveillance of children with FASD. Findings from these will be used to inform future public health surveillance activities.

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The Indian Health Service (IHS)

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

Mr. Kinlacheeny started by describing IHS. IHS's mission is to raise the physical, mental, social, and spiritual health status of American Indians and Alaska Natives (AI/IN) to the highest level. Its vision is healthy communities and quality healthcare systems through strong partnerships and culturally responsive practices. The three strategic goals of IHS are to

Ms. Andrea Harris, an alternate representative from SAMHSA on the ICCFASD, added information to Mr. Dunbar-Cooper's presentation about SAMHSA services that are relevant to FASD. Many of SAMHSA's SBIRT programs focus on pregnant and postpartum people and women of childbearing age. SAMHSA also has grants to study SUD in pregnant and postpartum women and to help their children.

Ms. Jan Lutke returned to the topic of eligibility for services based on adaptive vs cognitive measures. She said that the adaptive functioning tools that are used in assessment are often off base when it comes to people with FASD. She emphasized that since people with FASD have such high cognitive levels, it generally does not occur to people that there are still cognitive issues that need real consideration. Dr. Powell suggested that this issue sounds like a research question and invited comments.

Dr. Balachova asked the ALC to explain more about the top two needs of adults with FASD based on the survey (mental health and doctors or nurse practitioners who specialize in FASD). She asked whether it is necessary to have providers who specialize in FASD or if it would be sufficient to generally increase knowledge about FASD among providers.

Ms. CJ Lutke explained her own personal experience that illustrated how she has trouble navigating certain aspects of daily life related to navigating medical services. Her examples illustrate the fact that adults with FASD may understand information differently and that it would be helpful to have providers explain things to her in a way that makes sense to her.

Ms. Griffin pointed out that there are providers who specialize in disabilities, and asked why there is not an FASD specialization. She pointed out that while there is a relatively large amount of information about FASD in children, there is much less information about FASD in adults. This underscores a concern common among many Changemakers about what will happen to them in 20 or 50 years. She would like to know what to look out for, in terms of medical conditions such as dementia, when she is 60 years old. She expressed frustration that so little information is known about FASD in adulthood.

Ms. Jan Lutke, speaking from her experience working with adults with FASD in the medical system, said that it is important to continually educate doctors and to look at the diseases and disorders that seem to be overrepresented in the adult FASD population compared to the general public. She believes there are enough people with FASD that there should be a medical specialty in FASD, and stated that physicians should know to check some things regularly in their patients with FASD whether or not the patient is complaining about them because the patient may not remember that something is wrong. She gave examples of medical conditions that had gone undetected for a long time in some of the ALC members. According to her, family physicians cannot be expected to have deep knowledge about FASD since they provide services to such a broad audience, but since there are so many common conditions that often get worse among people with FASD, it is important to have a specialty in medicine for FASD. She and Ms. CJ Lutke spoke about examples of medical issues from their own family members with FASD and her own family's physician. Ms. Jan Lutke, stating her opinion based on her experiences and what she has heard from many people, said that there is a need for physicians with FASD expertise because of the importance of specific skills in diagnosing and treating adults with FASD.

Dr. Powell asked whether there should be something in electronic health records to prompt providers, once a patient is known to have FASD, that the provider should be looking for certain things. She also said there needs to be systemic change and spoke about how certain chronic conditions are sometimes dismissed and that medicine needs to do better, especially for vulnerable individuals.

Dr. Dunty addressed some of the things Ms. Jan Lutke brought up. NIAAA is funding an adult health survey to help establish the medical literature that will cover some of the things brought up in the ALC's presentation. The study is currently recruiting individuals affected by PAE in the United States and Canada to study its effects in midlife.

Dr. Balachova pointed out that some of the difficulties being raised may be related to the fact that the diagnosis of FAS was first established in the middle of the 1970s, so there are few older adults who have been observed since childhood. It is a relatively new field of knowledge. She reiterated the study that Dr. Dunty had spoken about that is investigating health conditions in adults.

Dr. Powell asked whether there were any questions for the panelists from SAMHSA, IHS, HRSA, or CDC.

Dr. Dunty read a question from the videocast as to whether there are any studies on healthy foods in aiding the care or treatment of people with FASD. He said that he was not aware of any such studies, and Ms. Jan Lutke indicated that she also was not aware of any.

Mr. Dunbar-Cooper pointed out that for people with FASD, unless they have the facial features, one cannot tell whether a person has the disability. He said that educating the public and doctors is important. He said that it's like a catch-22 predicament for adults with FASD, because the more they fit into society, the more people think there is not a problem. He said that overall people just do not think FASD is a big problem. He disagreed with Ms. Jan Lutke's point on having a medical specialty in FASD. He said that the conditions are not sufficiently known because there isn't enough surveillance in that area. Additionally, it is critical to discuss FASD continuously to know the numbers of people with FASD and to educate people about its implications. He emphasized that it is challenging to get the message across to healthcare workers and to the public that people with FASD really do have problems. He expressed disappointment with the lack of change in the field since he started working in FASD in 2010.

Ms. Jan Lutke spoke about her frustration with the societal expectation that someone with a mental disability has to look a certain way and with prevailing thought, even in the medical field, that people with full FAS will not be able to accomplish anything. She also expressed frustration at service providers who question whether an adult with FASD "still has it" and ask for a re-diagnosis. In the public, there is a lack of understanding that this disability does not go away.

Mr. Dunbar-Cooper spoke about a past SAMHSA program that supported mothers who drank during pregnancy. The mothers and the children who had PAE, through the program, gave talks around the country, and he said that was important. However, the program no longer exists.

Dr. Reichard pointed out that many of the issues discussed during this meeting seem similar to those of many other invisible disabilities such as traumatic brain injury. People with these other disabilities often say that the general public and their providers do not really understand how their disability affects their lives, similar to what the ALC had said about FASD. She wondered whether there is any value in aligning FASD with other invisible disabilities in terms of advocacy and raising awareness. She said that in the disability community, progress has been made in the past when different groups joined together. She spoke about how different groups have had success in bringing attention to the invisible nature of traumatic brain injury.

Ms. Jan Lutke spoke about one disability group that was not willing to work jointly because of the stigma associated with FASD. She pointed out that for other invisible disabilities, there is not a known preventable and stigmatizing cause as there is in FASD. She spoke about messages on prevention of FASD and how prevention is related to social determinants of health and stigma in complex ways.

Dr. Reichard expressed appreciation for what Ms. Jan Lutke said and suggested that she and the other ICCFASD members would be able to educate their own federal agencies with this information.

Ms. CJ Lutke spoke about how society wants people with FASD to look different in order to validate someone else's shame. She expressed frustration with difficulty qualifying for services based on looking like everyone else.

Dr. Dunty read two comments from the videocast. The first was a woman who had asked a neighbor, a general practitioner, whether he ever treated anyone with FASD. He said that he treats adults so he does not have any concerns with FASD. The second comment came from a parent of an adult child with FASD and expressed appreciation for the Changemakers' presentation.

Adjournment

Dr. Powell thanked everyone who joined the meeting today, the presenters, Dr. Balachova, the IT support staff, and the ALC presenters. She said that the ALC presentation sets out a path of things that need to be done. She emphasized the importance of keeping this dialog open.

Appendix: Abbreviations

Abbreviation	Term
AAP	American Academy of Pediatrics
ABCD	Adolescent Brain and Cognitive Development study
ACF	Administration for Children and Families
ACL	Administration for Community Living
ACOG	American College of Obstetricians and Gynecologists
AI/IN	American Indians and Alaska Natives
ASPE	Office of the Assistant Secretary for Planning and Evaluation
CDC	Centers for Disease Control and Prevention
CDS	Clinical decision support
CMMI	Center for Medicare & Medicaid Innovation
CMS	Centers for Medicare & Medicaid Services
DEIA	Diversity, equity, inclusion, and accessibility
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECHO	Extension for Community Healthcare Outcomes
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
FOA	Funding Opportunity Announcement
HBCD	HEALTHY Brain and Child Development study
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
ICCFASD	Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders
ICD	International Classification of Diseases
ICP	Indian Children's Program
IHS	Indian Health Services
IMPROVE	Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone
MCHB	Maternal and Child Health Bureau
MOM	Maternal Opioid Misuse (Model)
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NICHD	The <i>Eunice Kennedy Shriver</i> National Institute of Child Health and Human Development
NIDA	National Institute on Drug Abuse
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NOFAS	National Organization on Fetal Alcohol Syndrome
ODD	Opioid Use Disorder
PAE	Prenatal Alcohol Exposure
PCP	Primary care provider
SAMHSA	Substance Abuse and Mental Health Services Administration
SBI	Screening and brief intervention
SBIRT	Screening, brief intervention, and referral to treatment
SFASDSI	Supporting Fetal Alcohol Spectrum Disorder Screening and Intervention program
STRIVE	Strategies to Enrich Inclusion and Achieve Equity
SUD	Substance Use Disorder