

PUBLIC TESTIMONY

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Organization submitting testimony:

FASD United (formerly National Organization on Fetal Alcohol Syndrome)

Subcommittee:

Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Department and Agency:

Department of Health and Human Services

Centers for Disease Control and Prevention

Birth Defects, Developmental Disabilities, Disabilities and Health

Account: Fetal Alcohol Syndrome

Madam Chair and Subcommittee members, FASD United strongly supports an increase of at least \$2 million for FY 2023 for this line item in CDC's budget, together with report language to strengthen federally supported initiatives to prevent, diagnose, and improve service delivery for FASD, the nation's leading preventable cause of developmental disabilities and birth defects, and a leading cause of behavioral and learning problems. For many years, the line item has been labeled "Fetal Alcohol Syndrome". But the CDC typically uses the term "Fetal Alcohol Spectrum Disorders" or FASD as the umbrella term adopted in 2004 to describe the spectrum of developmental disabilities that result from prenatal alcohol exposure.

We request the following specific report language for the CDC's National Center for Birth Defects and Developmental Disabilities "to support expansion and strengthening of existing national community-based and professional fetal alcohol spectrum disorder (FASD) networks to disseminate best practices and technical assistance on diagnosis, treatment, intervention, peer mentoring, and other essential services."

BACKGROUND: Prenatal alcohol exposure (PAE) of our children is a silent public health crisis within our families and communities. PAE is a major known cause of birth defects, brain damage causing neurodevelopmental impairments and learning problems – commonly known as Fetal Alcohol Spectrum Disorders (FASD).

Recent CDC data show increasing use of alcohol during pregnancy with 14% (1 in 7 previously 1 in 9) pregnant people reporting current drinking of alcohol and about 5% or 1 in 20 pregnant people reporting binge drinking.

How common is FASD in the U.S.? Until recently, we did not have reliable prevalence figures. However, a study on prevalence of FASD published in the February 2018 Journal of American Medical Association (*JAMA*. 2018;319(5):474-482) shows a more startling and more accurate picture of the problem. Researchers assessed 6,639 first graders in four U.S. regions and found up to 1 in 20 children with an FASD. They also suspected substantial under reporting of

prenatal alcohol use and that “we are missing kids”. So, these results are likely to be a conservative estimate on FASD prevalence in the U.S.

Why was this prevalence study so important? First, researchers screened and did in-person assessments for FASD (other prevalence studies have been based on birth record reports and record reviews). Second, researchers learned that youth with this disability can be readily identified in U.S. mainstream populations. Third, neither race nor ethnicity and social economic status were significant factors – the youth with FASD mirrored the demographics of their community. Also important: this prevalence data is approaching two times higher than autism’s prevalence, yet autism federal funding is nearly 10 times greater. According to the National Institute on Alcohol Abuse and Alcoholism (NIAAA) Director Dr. George Koob, “The findings of this study confirm that FASD is a significant public health problem, and strategies to expand screening, diagnosis, prevention, and treatment are needed to address it.”

The study also confirmed that binge drinking is driving up the numbers of children with FASD. It provides useful data for targeted prevention efforts. Mothers of youth with FASD compared to a controlled population: 1) reported consuming significantly more drinks three months before pregnancy; 2) recognized that they were pregnant later; 3) had more first trimester alcohol consumption; 4) were more likely to binge with 5 or more drinks; 5) reported more drinking days in the past 30 days; and 6) reported that their husbands/partners consumed significantly more drinks per drinking day during pregnancy.

The above prevalence data, together with the increase in alcohol use during pregnancy, demands a renewed focus on the issue of binge drinking and other alcohol abuse and its harmful effects on our children.

Insufficient Federal Investment in FASD. In 1998, Congress first authorized federal FASD-related programs at \$27 million annually (nearly \$48 million in today’s dollars). Since then, however, federal funding for FASD-related programs has declined. Funding has flatlined for the Centers for Disease Control and Prevention (CDC) at \$11 million for what is the most dedicated public health focus on FASD to support clinical and epidemiological research, public health initiatives and networks, and expansion of clinical interventions. Besides the \$30 million (FY2022) for research through the National Institute of Alcohol Abuse and Alcoholism (NIAAA), the only other specific FASD funding is \$1 million at the Health Resources and Services Administration (HRSA), Maternal and Child Health Block Grant, Title V SPRANS Set-Aside).

There remains an alarming gap in FASD-related diagnostic and clinical resources. Among medical and behavioral health professionals, their inconsistent use or limited knowledge of diagnostic criteria and clinical guidelines result in many (if not most) children and adults living with FASD going undiagnosed or misdiagnosed. Families in every state, and especially in the child welfare system, struggle with FASD, and they cannot find systems of care that are familiar with or are equipped to diagnose and address FASD-related disabilities.

Cost of FASD. Economic impact studies (J Addict Med 2018;12: 466–473) show that the costs of FASD are significant, totaling \$205 billion in the United States (health care, special education,

residential care, productivity losses, and corrections). Costs to tribal communities over an individual's lifetime with FASD can range from \$850,000 to \$4 million, according to the National Congress of American Indians (NCAI; #REN-19-037). Yet, evidence shows these risks/costs can be significantly reduced by FASD-informed families, communities, and healthcare and other providers working together to create a system of early identification, stable environment with enduring relationships.

The alarming increase in prenatal alcohol consumption (41%) due to the COVID pandemic, and the already soaring rates of FASD, justify additional federal investment to strengthen CDC efforts to: expand prevention programs to heighten awareness of FASD and the risks associated with prenatal alcohol exposure; and increase existing national community-based FASD networks to expand access to diagnostic, treatment, intervention, and other essential services.

CDC's FY2023 Congressional Justification. Last year, the House-passed FY2022 Labor-HHS Appropriations bill included a \$1 million increase (from \$11 million to \$12 million) for the CDC's line item for FASD programs, but unfortunately the conference agreement retained the flatlined amount of \$11 million. With reference to the House-passed provision, the CDC included the following discussion in its FY2023 Congressional Justification:

“CDC appreciates the Committee’s support of awareness and prevention of fetal alcohol spectrum disorders (FASDs). CDC uses a comprehensive approach to address FASDs and the prevention of alcohol use during pregnancy. CDC conducts activities related to assessing trends in alcohol and polysubstance use in pregnancy and monitoring health care provider behaviors related to alcohol screening and brief intervention (SBI). CDC currently supports a network to reach health care providers across the nation to implement evidence-based strategies to reduce alcohol use during pregnancy and develop and disseminate FASD training and educational resources. In FY 2022, women of reproductive age within 67 health clinics across four health care systems have received appropriate alcohol screening and brief intervention services. In 2021, CDC also partnered with the MITRE Corporation to develop five clinical decision support (CDS) tools on alcohol SBI to help screen and offer evidence-based prevention strategies to those at risk. In FY 2022, two of these CDS tools were piloted to assess their use in a clinical setting.”

Notably, CDC's justification went on to state: “. . . in FY 2023, at level funding with FY 2022, CDC will continue to monitor trends in alcohol and polysubstance use in pregnancy and support partnership activities. **In the absence of additional resources, CDC lacks capacity to expand prevention efforts and extend the reach of its national partnership network.**” (Emphasis added.)

In conclusion, the enormity of the problem of FASD and its impact on families and communities in the United State and the increasing use of alcohol during pregnancy justify an increase in investment by the federal government. Thank you so much.