**Outside Witness Testimony – Fiscal Year 2025
Submitted by FASD United
Prepared for the U.S. Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Addressing the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Institute on Alcohol Abuse and Alcoholism, and
Health Resources and Services Administration**

Chairwoman Baldwin, Ranking Member Capito, and members of the Senate Appropriations LHHS Subcommittee, FASD United is pleased to submit this testimony as an outside witness. FASD United is a national, nonpartisan, nonprofit organization that supports individuals, families, and communities living with fetal alcohol spectrum disorders (FASD) and strives to prevent the lifelong developmental disabilities including brain damage resulting in neurodevelopmental impairments in cognition and behavior associated with prenatal exposure to alcohol and other substances harmful to human development.

Despite the known adverse effects of FASD, alcohol use during pregnancy is a rapidly growing and costly public health concern. According to the Centers for Disease Control and Prevention (CDC), 1 in 7 pregnant people report drinking alcohol and about 1 in 20 report binge drinking, and eight studies sponsored by the National Institute on Alcohol Abuse and Alcoholism (NIAAA) found that the average U.S. prevalence rate for FASD is 1 in 15 school-age children. These alarming findings demonstrate the dire price we are paying for neglecting FASD and require immediate and bold funding increases to expand FASD initiatives at CDC, NIAAA, and the Health Resources and Services Administration (HRSA).

Since the 1970’s NIAAA has supported biomedical and behavior research that has identified the underlying mechanisms of alcohol-induced impairment during gestational development. Basic and clinical research continues at NIAAA, however, enormous reductions in FASD funding throughout the Department of Health and Human Services have left diminishing and inadequate resources to translate research into public health measures and real-world diagnostic and intervention services.

In 2000, Congress authorized FASD programs at CDC and at the Substance Abuse and Mental Health Services Administration (SAMHSA). Beginning in 2001, a total of $27.5 million was appropriated annually between the CDC and SAMHSA FASD programs. In FY 2024, only $12.5 million was provided for non-research public health initiatives and services for individuals, a staggering 55% reduction in total dollars from 2001 to 2024 or a 74% reduction when adjusted for inflation. SAMHSA funding has been entirely eliminated, funding in 2024 at CDC is $11.5 million and $1 million is provided for FASD at the Health Resources and Services Administration).

The loss of investment has set back prevention and most importantly left individuals living with FASD without critical support and resources. As a result, families and communities face untreated medical and mental health impairments and spiraling costs, and public and private health, welfare, education, and other critical systems remain ill-equipped to address FASD-related disabilities.

To remedy the growing concern of FASD and the long-term decline in public resources for the disabilities, FASD United urges the committee to begin to restore investment in effective FASD services, public health, and research at CDC, HRSA, and NIAAA.

**Centers for Disease Control and Prevention**

CDC partners and collaborates with universities, discipline-specific associations, community-based organizations, and state agencies to improve practice and education, prevent alcohol use during pregnancy, and to help individuals living with FASD. In FY 2025, CDC will continue to strengthen partnerships in preventing alcohol use during pregnancy, improve support services and access to care, and improve identification and health of children with FASD and their families. CDC is modernizing data collection for children with FASD by analyzing person-level, de-identified claims data for children aged 0-17 years from a national sample of commercially insured enrollees, and Medicaid-ensured enrollees. This information complements in-person studies by providing more timely information about children with recognized and reported FASD from diverse populations. These findings also underscore the need for efforts to improve identification of and surveillance for children with FASD.

As noted by the agency in its justification of appropriations, “CDC appreciates the Committee’s support of fetal alcohol spectrum disorders (FASD). 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. CDC continues 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.”

The loss of investment in FASD has left individuals and families without critical support and resources. It also led to the elimination of the FASD Center of Excellence, a vital hub for the development and dissemination of best practices and resources among states and Tribes that from 2002 through 2015 successfully expanded clinical resources for children and adults. By restoring the FASD Center of Excellence, CDC will expand diagnostic capacity and family navigation, build continuity among care providers, and collect data to inform new practices and resources.

CDC’s efforts are making important progress, but FASD funding at the agency has stood still enabling the fast-growing increase in alcohol use during pregnancy and FASD prevalence rates. **FASD United recommends at least a $2 million funding increase for FASD at CDC to strengthen existing initiatives** to increase surveillance, expand partnerships to prevent alcohol use during pregnancy, and improve support services and access to care by disseminating practical resources and information through existing community-based local affiliates. **An additional $5 million is recommended for FASD at CDC to restore the FASD Center of Excellence.** The center will reestablish the national infrastructure to address FASD through the dissemination of best practices and assistance to states, Tribes, and existing FASD affiliates that will increase diagnostic capacity, develop resources for systems of care, train service providers and professionals, maintain a clearinghouse and data-based directory, and respond to the needs of individuals.

**Health Resources and Services Administration**

In 2008, Congress authorized a Fetal Alcohol Syndrome (FAS) set-aside in the HRSA/MCH/SPRANS (Special Projects of Regional and National Significance) account. In successive multi-year cycles, an alcohol screening and brief intervention quality improvement initiative among over 100 Community Health Centers, a project to train clinicians to support expectant mothers at risk for prenatal alcohol exposure, and an initiative to increase the use of screening, intervention, and referral processes for high-risk pregnancies by primary care providers has have been successfully implemented. However, over seventeen years FASD funding at HRSA has averaged only $600,000 annually.

**FASD United recommends a $1 million increase for the FASD set-aside in FY 2025 to continue current activities** and to increase access to support services for the 1 in 15 school-age children in the U.S. living with FASD. Enhancing the agency’s current Supporting Fetal Alcohol Spectrum Disorders (FASD) Screening and Intervention program will maximize the opportunity to increase accessible resources and expand individualized needs assessment and access to multidisciplinary care for children and families in rural and medically underserved communities.

**National Institute on Alcohol Abuse and Alcoholism**

Since NIAAA was established in 1970, the agency has supported a broad portfolio of research project grants, cooperative agreements, center grants, and training awards that collectively address FASD. This basic, translational, and clinical research provides valuable insight into improving strategies to prevent prenatal alcohol exposure and facilitate earlier diagnosis and more effective treatment of FASD.

Among NIAAA’s research portfolio is the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), a global consortium that coordinates research efforts across basic, behavioral, and clinical investigators to inform the development of effective prevention and treatment interventions for FASD. Recent CIFASD research includes investigating cardiovascular disease across the life span in patients with FASD and how prenatal alcohol exposure impacts stem cell regeneration and the onset of aging-associated diseases. CIFASD also supports research to train providers to use a FASD diagnostic telemedicine resource with the goal of improving precision and increasing access to screening and diagnosis.

Highlights of the institute’s half-century leadership role in the federal approach to FASD include the first national research workshop on fetal alcohol syndrome in 1977, the publication of the U.S. Surgeon General’s Advisory on Alcohol and Pregnancy in 1981, and, since 1998, NIAAA has sponsored and chaired the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD) to foster improved communication, cooperation, and collaboration among federal agencies that address issues related to prenatal alcohol exposure.

The soaring rates of fetal alcohol spectrum disorders (FASD) justify strengthening National Institute on Alcohol Abuse and Alcoholism (NIAAA) efforts to accelerate the translation and dissemination of evidence-based FASD prevention, diagnosis, and treatment research. **FASD United recommends at least a $2 million increase at NIAAA to boost the capacity of the ICCFASD to coordinate the federal response to FASD and investigate novel web-based and mobile health tools to assess FASD and increase the quality of life for children and adults living with FASD.**

FASD United appreciates the opportunity to present this testimony to the Committee. By restoring previous budget cuts, resources that reduce debilitating and costly secondary disabilities and foster stability and success among the FASD community can be expanded, easing the burden on families and providing children and adults faced with FASD with the support they deserve.

Thank you.