

Fetal Alcohol Spectrum Disorders (FASD): History of Federal Response

The following document provides background and history on the federal response to Fetal Alcohol Spectrum Disorders and was prepared by The National Organization on Fetal Alcohol Syndrome (NOFAS). For questions or additional information pertaining to S. 2238/H.R. 4151, The FASD Respect Act, please go to <https://nofaspolicycenter.org/the-fasd-respect-act-for-legislative-staffers/>. Information on Fetal Alcohol Spectrum Disorders can be found at www.nofas.org.

Background on the federal response to Fetal Alcohol Spectrum Disorders - 1989-2021

1) Prenatal alcohol exposure-significant health concern. FASD is a significant public health problem requiring strategies to expand screening, diagnosis, prevention, and treatment to address it (National Institute on Alcohol Abuse and Alcoholism-NIAAA), May 2018). The harm to America's children from PAE was first recognized in the early 1970's.

2) US Surgeon General. The US Surgeon General issued the first public health advisory in 1981 (reissued in 2005) that alcohol during pregnancy was a cause of birth defects.

3) Initial congressional response. In 1988, Congress mandated that alcohol product labels include a warning about potential birth defects. Twenty-four states and the District of Columbia have now enacted laws requiring these warnings at the point of sale, including bars and restaurants.

4) Alcohol and Drug Abuse and Mental Health Administration Act of 1992. The Act authorized a study on Fetal Alcohol Syndrome (FAS) by the Institute of Medicine (IOM). The IOM study report defined the condition and found that **"of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus."** (Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment, National Academy Press; Washington, DC: 1996). The IOM report recommended that the federal government have an Interagency Coordinating Committee on FAS to improve communication and collaboration between agencies to address pressing issues related to FASD. Such a committee was created and is now the "Interagency Coordinating Committee on FASD" ([ICCFASD](#)) and its work is sponsored by the NIAAA.

5) Fetal Alcohol Syndrome Prevention and Control Act of 1998. The IOM made recommendations for a broad federal response that formed the basis of the Fetal Alcohol Syndrome Prevention and Control Act of 1998 (Pub. L. 105-168, §1(b), Apr. 21, 1998, 112 Stat. 43.) This act authorized \$27 million for a National Task Force on FAS and grant programs at the Centers for Disease Control and Prevention (CDC), and the Substance Abuse and Mental Health Services Administration (SAMHSA).

6) Origin of FASD Terminology. In 2004, in a meeting convened by the National Organization on Fetal Alcohol Syndrome (NOFAS), the National Institutes of Health, CDC, and SAMHSA and other experts in the field, developed a consensus definition on FASD to describe the spectrum of effects of PAE. "FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during

pregnancy. These effects include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD encompasses all other diagnostic terms, such as FAS, and is not intended for use as a clinical diagnosis.”

7) National FAS Task Force Report. In its 2009, “A Call to Action” Report (<https://www.cdc.gov/ncbddd/fasd/modules/calltoaction-P.pdf>) the Task Force found FASD diagnostic capacity and FASD-informed services insufficient in the United States, resulting in countless individuals with FASD remaining unrecognized or misdiagnosed.

8) HRSA FASD Quality Improvement Project in Federally Qualified Health Centers. A FY2005 congressional appropriation in the amount of \$840,000 created an alcohol screening, intervention, and referral initiative among federally qualified community health centers at the HRSA Bureau of Primary Health Care. In 2006, the project was moved to the Bureau of Maternal and Child Health, and by FY2008 funding was increased to \$972,000 before it was reduced to \$486,000 the following year. Funding for the FASD set-aside in the bureau’s block grant SPRANS account remained level until it was increased to \$1 million in FY2019.

9) NIAAA supported research on first active case ascertainment FASD study. In 2018, *JAMA*, the *Journal of the American Medical Association*, published a wide-ranging active case ascertainment cross-sectional study of over 13,000 first-grade students in four regions of the United States, that found the most conservative FASD of prevalence estimate of one in 20 children; using a weighted approach, the estimate prevalence was as high as one in 10 children (*JAMA* 319.5 (2018): 474-482). Studies show the FASD prevalence among children and adolescents in the child welfare and juvenile justice systems to be as high as one in five children (*Pediatrics* 132.4 (2013): e980-e995). According to the Center for Disease Control (CDC), the prevalence of FASD surpasses that of autism (1 in 59) cerebral palsy (1 in 323), and trisomy 21 (1 in 700).

10) Decline in federal funding. Despite findings that prenatal alcohol exposure remains the number one preventable cause of birth defects and neurodevelopmental disabilities in the United States (*Alcohol Research & Health*, Vol. 34, No. 1, 2011), the National FAS Task Force authority expired in 2007, annual SAMHSA funding of \$9.8 million was reduced to \$1 million in FY2014 and eliminated in FY2016, other FASD-related funding has declined and action has stalled on legislation to update federal statutes to address FASD specifically and strengthen federal programming to reverse the upward trend in prevalence and prevent FASD.

11) Current federal FASD-related funding.

- National Institute on Alcohol Abuse and Alcoholism (NIAAA) funding for FASD research has continued with appropriated funds from the National Institute of Health (\$18 million - FY2021; Federal Code authorization; discretionary funding used by NIAAA for FASD research - \$12 million; purpose of Institute §285n (b) (3)(B)).
- Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities (CDC) funding (\$11 million - FY2021) for FASD research, prevention, and surveillance; Federal Code authorization §247b–4.
- Health Resources and Services Administration (HRSA) funding for FASD screening and intervention (\$1 million - FY2021) [HRSA funding.](#)

