

Enact
**The Advancing Fetal Alcohol Spectrum Disorders
 Research, Services and Prevention Act (The FASD Respect Act)**

Ask: Promptly reintroduce and enact amendments to the Public Health Service Act to strengthen the National Agenda to address FASD

WHAT IS FASD?

FASD describes the range of adverse effects that can occur in a person who is prenatally exposed to alcohol. FASD includes diagnoses such as fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE) and a range of alcohol-related birth defects (ARBD) with lifelong implications, including congenital physical malformations as well as possible severe physical, mental, behavioral, and/or learning disabilities.

Alcohol use during pregnancy can cause [birth defects](#)¹ and [developmental disabilities](#)², collectively known as [fetal alcohol spectrum disorders \(FASDs\)](#).³ Alcohol use during pregnancy is also linked to other outcomes, such as miscarriage, [stillbirth](#)⁴, [preterm \(early\) birth](#)⁵, and [sudden infant death syndrome \(SIDS\)](#).⁶

Prenatal Alcohol and Other Drug Exposures

Current evidence indicates **prenatal alcohol exposure** is especially harmful to our nation’s children.

- The short and long-term effects of [prenatal alcohol exposure](#)⁷ are more severe and longer lasting than outcomes from prenatal exposure to other drugs.
- The [use of alcohol during pregnancy](#)⁷ is greater than the use of other substances and over [40% pregnant women](#)⁹ using alcohol report using one or more other substances.



Source: <https://www.cdc.gov/ncbddd/fasd>

The Prevalence of FASD in the US is a Significant Public Health Concern

In 2020, an [Adolescent Brain Cognitive Development Study](#)¹¹ found 25.9% or 1-in-4 youths had been exposed to alcohol *in utero*.

- A NIAAA-supported [2018 FASD prevalence study](#)¹⁰ of 6,639 first-graders in four US geographically-separated communities found 222 (3.3%) had FASD. The study estimated the prevalence of FASD ranged up to 1-in-20 children. Only 2 youths had a previous diagnosis within the FASD spectrum.
- [CDC researchers found](#)¹² among pregnant women (ages 18-44), 1-in-9 had alcohol in the past 30 days, of whom about a third engaged in binge drinking (4+ drinks on at least one occasion over the past 30 days). [Binge drinking](#)¹³ puts the fetus at greatest risk for severe problems. Studies have shown that binge drinking during the pandemic have increased by 41 percent.

A Disproportionate Number of Youths with FASD in Justice/Child Protection Systems

- A 2015 review of [studies on FASD in the justice system](#)¹⁵ found that adolescents affected by FASD are 19 to 40 times more likely to become involved in the juvenile justice system.
- The National Council of Juvenile and Family Court Judges FASD guide [states](#)¹⁵ 30% of school-aged children referred by child welfare agencies for assessment of behavioral problems met the diagnostic criteria for FASD. Significantly, 80% of those referred had no prior diagnosis within the FASD spectrum.

FASD is Costly to the United States

[A 2018 comprehensive review](#)¹⁶ of studies on the economic impact of FASD found an annual average cost of \$30,000/person (includes health care, special education, residential care, productivity losses, and adjusted by 30% to include corrections costs) or \$205B per year in the US.*

*Multiply the FASD prevalence of 2% times the US 2020 population of 331 million times the per individual economic cost of \$30,000 (2017 dollars).

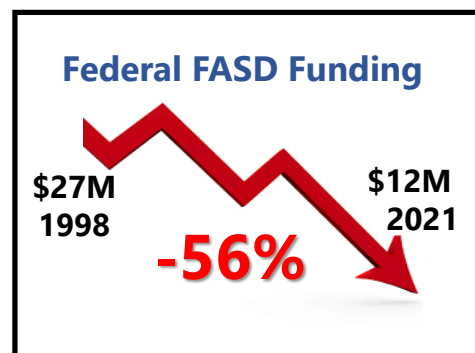
US prevalence studies estimate the average cost to the US for FASD is \$205B per year.

Investment in FASD Prevention and Intervention is Needed

Investment in prevention practices, early FASD identification and targeted FASD-informed interventions can reduce these costs. One WA state study found that preventing FASD is 30% more cost effective than raising a child with FASD.¹⁷ [Expert opinions from treating professionals, a wealth of family experience, compelling animal research, and pioneering intervention studies indicate the appropriate treatment of FASD can have a measurable, positive impact.](#)¹⁸

While some state and local communities have established policies and programs that support prevention and FASD-informed intervention, **the US lacks a national FASD agenda and adequate resources to effectively prevent FASD and lessen the harm to those with FASD, their families and our communities.**

Instead, federal funding for FASD programs has significantly **declined during the past decade.**





FASD Expert Panel, Department of Health and Human Service, September 2019

In 2019, HHS convened a [Technical Expert Panel \(TEP\)](#)¹⁹ who identified present-day gaps in the prevention, identification, intervention and treatment of FASD in individuals.

Our proposed legislation addresses many of the gaps and needs identified in the TEP report.

- 1) **Risk Factors** - Identify the risk factors for an alcohol-exposed pregnancy (AEP) to facilitate the development of a targeted prevention approach to FASD that focuses prevention efforts on women at greatest risk of an AEP. While factors such as pre-pregnancy alcohol consumption, homelessness, and abuse are noted as general FASD predictors, studies have yet to determine the role of age, race, and education level as AEP risk factors.

FASD Legislation - Section 2(b) would require CDC to conduct public health prevention research to identify evidence-based strategies that reduce alcohol and other substance exposures for pregnancies in women at high risk for alcohol and other substance-exposed pregnancies.

- 2) **Messaging for Prevention** – Research and implement effective messaging based on the results of identifying AEP risk factors. Currently, there is a lack of knowledge regarding which prevention messaging is most effective.

FASD Legislation - Research by CDC under Section 2(c)(B) and implementation by FASD Center for Excellence under Section 5(a)(2). Section 2(d)(4)(E) – Building State FASD Systems - authorizes use of grant funds for developing, implementing, and evaluating population-based and targeted prevention programs for FASD, including public awareness campaigns.

- 3) **FASD Screening** - Develop screening tools or universal screening processes to identify individuals affected with FASD. Train frontline professionals for screening.

FASD Legislation - Authorizes screening and training in Sections 2(a) to 2(f)] and 5.

- 4) **Diagnostic Capacity** – Develop, train, and use multi-disciplinary teams consisting of pediatricians, psychiatrists, occupational therapists, and special educators to diagnose and intervene in cases of FASD, especially children who are at risk for or have been diagnosed with FASD.

FASD Legislation - Section 5(a)(1).

- 5) **Tailored Interventions** – To implement behavioral interventions, providers must understand the needs of children with FASD at each stage of development. Experts recommend FASD interventions begin with a comprehensive neuropsychological examination to evaluate deficits and to create a tailored care plan.

FASD Legislation - Sections 2(c), 2(f), and 5(a)(3) and (4).

- 6) **Juvenile Justice and Corrections Systems Education** - For critical staff within the corrections system to provide the appropriate services and support for inmates and paroles.

FASD Legislation - Sections 2(d), 2(f), and 5.

“Of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”²⁰

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