Enact S1800/HR3946 The FASD Respect Act

Ask: Promptly 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.

Diagnoses include:

- Fetal Alcohol Syndrome (FAS)
- Partial FAS (pFAS)
- Alcohol-related Neurodevelopmental Disorder (ARND)
- Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE)
- Alcohol-related Birth Defects (ARBD) with lifelong implications

Alcohol exposure during pregnancy can cause birth defects[1] and developmental disabilities[2], collectively known as fetal alcohol spectrum disorders (FASD)[3]. Alcohol exposure 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.

Up to 1 in 20 U.S. school children may have FASD

People with FASD can experience a mix of the following problems:

Physical Issues

- Low birth weight and growth
- Problems with heart, kidneys and other organs
- Damage to parts of the brain

Which leads to...

Behavioral & Intellectual Disabilities

- Learning disabilities and low IQ
- Hyperactivity
- Difficulty with attention
- Poor ability to communicate in social situations
- Poor reasoning and judgement skills

These can lead to...

Lifelong Issues

- School and social skills
- Living independently
- Mental health
- Substance use
- Keeping a job
- Trouble with the law

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-7 had alcohol in the past 30 days, of whom about a third engaged in binge drinking[13] (4+ drinks on at least one occasion over the past 30 days). Binge drinking creates a higher risk for more severe outcomes. Studies have shown that binge drinking among women of childbearing age during the Covid-19 pandemic 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

FASD costs the U.S. on average $205B per year.

The annual average cost per individual is $30,000

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.*

Investment in FASD Prevention & Intervention is Needed

Investment in prevention practices, early FASD identification and targeted FASD-informed interventions can reduce these costs. One WA state study[17] found that preventing prenatal alcohol exposure is 30% more cost effective than raising a child with FASD. *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]

Federal FASD Funding has decreased by 56% since 1998

FASD Expert Panel, Department of Health and Human Service, September 2019 [19]

In 2019, HHS convened a Technical Expert Panel (TEP) that 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

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 Screening

Develop screening tools or universal screening processes to identify individuals affected with FASD. Train frontline professionals for screening.

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.

Prevention Messaging

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.

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.

Juvenile Justice & Correction Systems Education

For critical staff within the corrections system to provide the appropriate services and support for inmates and paroles.

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

Sources

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*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).