

H.R. 4151, the *Advancing FASD Research, Prevention, and Services Act of 2021*

The Advancing FASD Research, Services, and Prevention Act of 2021 authorizes programs and funding to aid individuals and families affected by Fetal Alcohol Spectrum Disorders (FASD), including Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (FAS), Alcohol Related Neurodevelopmental Disorder (ARND), Neurobehavioral Disorders Associated with Prenatal Alcohol Exposure (ND-PAE), and related conditions. FASD is caused by prenatal alcohol exposure (PAE)—an enduring public health issue throughout the United States. A recent prevalence study identified that as many as 1 in 20 first graders across the country were found to have FASD. Most individuals affected by PAE show no outward physical symptoms, but experience internal damage that affects the developments on of the brain, kidneys, heart and other body systems. There is no cure for FASD, but research shows that early intervention treatment services can improve a child’s development. PAE is the leading known cause of neurodevelopmental disabilities and those with FASD face profound social, cognitive, and emotional challenges throughout their lifespan. In addition, nearly one out of four children in juvenile corrections has FASD. Nearly one in four youth with FASD are disproportionately overrepresented in the juvenile justice system.

The Institute of Medicine has stated that alcohol, of all commonly misused substances, causes greater long lasting harm to the developing fetus than other drugs. While the use of alcohol during pregnancy is more common than the use of other substances, over 40 percent of alcohol impacted pregnancies report the use of one or more other substances including, nicotine, cannabis, opiates, cocaine, and methamphetamines. Congress has recognized the need for preventing neonatal abstinence syndrome (NAS) because of the increased use of opioids during pregnancy to a rate of six out of every 1,000 live births. Prenatal alcohol exposure is documented at a rate of 1 in 9 live births. However, little is known about the long-term health effects on children prenatally exposed to multiple substances. The FASD Respect Act recognizes the need to have a comprehensive approach to all prenatal substance exposures and PAE is a significant health concern to our nation’s children and families.

This legislation:

- Creates the “National Advisory Council on FASD” consisting of parents, advocates, professional organizations, and experts in the field. The Committee will submit recommendations to the National Institute of Alcohol Abuse and Alcoholism and develop new recommendations for Congress pursuant to the 2009 National FAS Task Force “Call to Action.”
- Directs the Secretary of the U.S. Department of Health and Human Services (HHS)— acting through the Director of the National Institutes of Health and in coordination with the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders—to establish a research agenda for FASD, award grants, and enter into contracts and cooperative agreements with public or private nonprofit entities.
- Creates a program at the Health Resources and Services Administration to build State and Tribal systems to identify, treat, and support individuals with FASD. Grants will support States and Tribes to develop or update strategic plans to establish or expand FASD-informed clinical services and integrate them into existing systems of care.
- Authorizes FASD grant programs for medical experts, children, and their families
- Directs HHS to establish a Center of Excellence to build local, state, tribal and national capacities to prevent the occurrence of FASD—including disorders and birth defects related to combined abuse of alcohol and other substances. To establish the Center, HHS will award a grant or enter into a cooperative agreement or contract with a public or nonprofit entity with demonstrated expertise in promoting FASD awareness, prevention and intervention services.
- Authorizes the Departments of Education and Justice to address FASD-related issues and provides funding for training of professionals on the recognition and support for those with FASD.