

H.R. 5790, the *Advancing Fetal Alcohol Spectrum Disorders Research, Prevention, and Services Act*

The Advancing FASD Research, Prevention, and Services Act authorizes programs and funding to aid individuals and families affected by Fetal Alcohol Syndrome (FAS), Fetal Alcohol Spectrum Disorders (FASD), and related conditions. FAS is caused by prenatal substance abuse—an enduring public health issue throughout the United States—and Fetal Alcohol Syndrome is estimated to affect between 1 and 3 live births per 1,000. There is no cure for FASD but research shows that early intervention treatment services can improve a child’s development. FAS is the leading known cause of intellectual disabilities and children with FASD face profound challenges in understanding emotions, demonstrating a capacity for emotional understanding that lags two to five years behind their peers.

In addition to alcohol, the most common drugs involved in FAS are nicotine, marijuana, opiates, cocaine, and methamphetamine. Opioid use has been rising among pregnant women nationally and a recent study found that six out of every 1,000 live births were to women using opioids—up from 1.5 per 1,000 live births a decade ago. A 2016 study by the Journal of the American Medical Association (JAMA) suggested that children exposed to opioids in the womb may have heightened risks of long-term mental and physical health issues. Little is known about the long-term health effects on children born to mothers who abuse multiple substances.

This legislation:

- Creates an “Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders” 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.
- Directs the National Institute of Alcohol Abuse and Alcoholism to conduct research into the most promising avenues for FASD diagnosis, intervention, and prevention and other issues relating to conditions that develop as a result of in-utero substance exposure.
- Directs HHS to integrate into clinical practice an evidence-based standard case definition for diagnosis of fetal alcohol syndrome and—in collaboration with the Director of the National Institute of Alcohol Abuse and Alcoholism, the Director of the Centers for Disease Control and Prevention, the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders, and other experts in the field—develop standard, evidence-based clinical diagnostic guidelines and criteria for all other fetal alcohol spectrum disorders.
- Authorizes FASD grant programs for medical experts, children, and their families.
- Directs HHS to establish a Center of Excellence to build local, state, 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.