



The FASD Respect Act



FASD RESPECT ACT BACKGROUND & RATIONALE

- ✓ **Fetal Alcohol Spectrum Disorders (FASD)** prevention and support programs first authorized in 1998 because of the 1996 Institute of Medicine (IOM) study that found that prenatal alcohol exposure causes far more harm to the developing fetus than any other substance.
- ✓ NIAAA funded research (JAMA, 2018;319(5): 474-482) shows an alarming prevalence of up to 1 in 20 first graders in the United States having the resulting disability of Fetal Alcohol Spectrum Disorders (FASD).
- ✓ \$27 million for FASD prevention and support programs appropriated in 2000 (FY2001) (see attached for more details).
- ✓ FASD authorization language expired in 2007.
- ✓ Funding for FASD programs has dramatically declined to \$11.5 million at CDC and \$1 million at HRSA (see attached for more detail); funding at NIAAA for FASD research, which was not a part of the 1998 authorization, but under NIAAA's authorization has remained steady with marginal increases through the years (\$30+M – FY2023).
- ✓ 117th Congress – FASD Respect Act (HR 4151/S 2278) introduced by Senators Lisa Murkowski and Amy Klobuchar (D-MN) and Representatives Betty McCollum (D-4-MN) and the late Don Young (R-AK) on June 21, 2021. By the conclusion of the 117th Congress, 76 members of the House and 10 of the Senate had signed on as co-sponsors. The legislation received over 200 national, state and local endorsements.
- ✓ 118th Congress - FASD Respect Act (HR 3946/S1800) introduced by Senators Murkowski and original co-sponsors Amy Klobuchar, Angus King and Jerry Moran along with Representatives Don Bacon (R-NE/02) and Betty McCollum (D-MN/4).
- ✓ FASD Respect Act reauthorizes expired programs for FASD prevention, research and services and authorizes such sums as necessary for FY2024- FY2028 funding for FASD prevention & intervention programs, including grants to build State and Tribal capacity and a FASD Center for Excellence.
- ✓ Prenatal alcohol exposure and the disability of FASD is unrecognized and misunderstood by existing systems of care funded by federal and state governments (health, education, substance use, mental health, justice, etc.) and as a result current funding streams do not address FASD. Funding to states along with technical assistance from FASD Center of Excellence will help states systemically address FASD prevention, screening, identification, intervention, and support programs and to infuse, modify and adapt FASD-informed prevention, service and support



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programs into existing systems of care. Funding will help address diagnostic capacity and health inequities for this population.

SECTION SUMMARY OF FASD RESPECT ACT

SECTION 1. SHORT TITLE - “Advancing FASD Research, Services, and Prevention Act or the FASD Respect Act.

SECTION 2. HHS PROGRAM ON FETAL ALCOHOL SPECTRUM DISORDERS.

(a) Amends Part O of Title III of the Public Health Service Act to reauthorize and extend the Fetal Alcohol Spectrum Disorders Prevention and Services program as follows:

- (1) Amends the heading to read as “Fetal Alcohol Spectrum Prevention and Services Program;
- (2) Strikes “Fetal Alcohol Syndrome and Fetal Alcohol Effect” and inserts “FASD” throughout the section;
- (3) Authorizes the Secretary to continue a comprehensive Fetal Alcohol Spectrum Disorders awareness, prevention, identification, intervention, and services delivery program” and updates and deletes obsolete language throughout the section.
 - (3) Adds integrating into surveillance practice an evidence-based standard case definition for fetal alcohol syndrome and, in collaboration with other federal and outside partners, support organizations of appropriate medical and mental health professionals in their development and refinement of evidence-based clinical diagnostic guidelines and criteria for all fetal alcohol spectrum disorders as a permissible program or activity;
 - (4) Adds building State and Tribal capacity for the identification, treatment, and support of individuals with FASD and their families as a permissible activity or program. Activities under this section may include - utilizing and adapting existing Federal, State or Tribal programs to include FASD identification and FASD-informed support; developing and expanding screening and diagnostic capacity for FASD; increasing awareness of FASD; providing training with respect to FASD for professionals across relevant sectors; and disseminating information about FASD and support services to affected individuals and their families.



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(b) Eligible entities – updates language regarding entities eligible for grants, cooperative agreements or contracts to include a State, Indian Tribe or Tribal organization, local government, scientific or academic institution or nonprofit organization, and provides that HHS Secretary may set guidelines for submission.

(c) Adds a definition of FASD-INFORMED with respect to support or an intervention program under this section.

Strikes sections of obsolete language for the establishment of a National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect.

Adds a new section 399I for the establishment of Fetal Alcohol Spectrum Disorders Centers for Excellence as follows:

SEC. 399I - FASD CENTERS FOR EXCELLENCE.

(a) Requires the HHS Secretary to award grants, cooperative agreements, or contracts to public or nonprofit entities with demonstrated expertise in FASD prevention and intervention services for the purpose of establishing FASD Centers for Excellence to build local, state, and national capacities to prevent the occurrence of FASD and other related conditions and to respond to the needs of individuals with FASD and their families.

(b) Allows funds awarded to be used for: (1) diagnostic capacity activities; (2) public awareness activities for the purpose reducing prevalence of FASD and improve outcomes of those with FASD and support for families; (3) clearinghouse for evidence-based resources, FASD-specific services in States, Indian Tribes, and local communities, dissemination of ongoing research and development resources on FASD to help inform systems of care; (4) increasing awareness of FASD screening tools and intervention services and best practices by conducting trainings for a number of professionals and providers related to FASD supports and services; (5) improving capacity for State, Tribal and local affiliates dedicated to FASD awareness, prevention and identification and family and individual support programs and services; and (6) providing technical assistance to grantees under Section 399H.

APPROPRIATIONS

Authorizes appropriations in such sums as may be necessary for each of fiscal years 2024 through 2028. Requires the Secretary of HHS to submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives a report on the efforts of the department to advance public awareness on, and facilitate the identification of best practices related to, FASD identification, prevention, treatment, and support no later than 4 years after the date of enactment of the Act.



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