119TH CONGRESS
1ST SESSION

S. 139

To amend the Public Health Service Act to reauthorize and extend the Fetal Alcohol Spectrum Disorders Prevention and Services program, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JANUARY 16, 2025

Ms. MURKOWSKI (for herself, Ms. KLOBUCHAR, Mr. KING, Ms. HIRONO, Mr. MORAN, Ms. BALDWIN, Ms. CANTWELL, and Mr. CRAMER) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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A BILL

To amend the Public Health Service Act to reauthorize and extend the Fetal Alcohol Spectrum Disorders Prevention and Services program, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Advancing FASD Research, Services and Prevention Act'' or the ''FASD Respect Act''.

SEC. 2. SUPPORT FOR INDIVIDUALS AND FAMILIES IMPACTED BY FETAL ALCOHOL SPECTRUM DISORDER.

(a) IN GENERAL.—Part O of title III of the Public Health Service Act (42 U.S.C. 280f et seq.) is amended—

(1) by amending the part heading to read as follows: ''**FETAL ALCOHOL SPECTRUM DISORDERS PREVENTION AND SERVICES PROGRAM**'';

(2) in section 399H (42 U.S.C. 280f)—

(A) in the section heading, by striking ''**ESTABLISHMENT OF FETAL ALCOHOL SYNDROME PREVENTION**'' and inserting ''**FETAL ALCOHOL SPECTRUM DISORDERS PREVENTION, INTERVENTION,**'';

(B) by striking ''Fetal Alcohol Syndrome and Fetal Alcohol Effect'' each place it appears and inserting ''FASD'';

(C) in subsection (a)—

(i) by amending the heading to read as follows: ''IN GENERAL'';

(ii) in the matter preceding paragraph (1)—

(I) by inserting ''or continue activities to support'' after ''shall establish'';

(II) by striking ''FASD'' (as amended by subparagraph (B)) and inserting ''fetal alcohol spectrum disorders (referred to in this section as 'FASD')'';

(III) by striking ''prevention, intervention'' and inserting ''awareness, prevention, identification, intervention,''; and

(IV) by striking ''that shall'' and inserting '', which may'';

(iii) in paragraph (1)—

(I) in subparagraph (A)—

(aa) by striking ''medical schools'' and inserting ''health professions schools''; and

(bb) by inserting ''infants,'' after ''provision of services for''; and

(II) in subparagraph (D), by striking ''medical and mental'' and inserting ''agencies providing'';

(iv) in paragraph (2)—

(I) in the matter preceding subparagraph (A), by striking ''a preven-

tion and diagnosis program to support clinical studies, demonstrations and other research as appropriate'' and inserting ''supporting and conducting research on FASD, as appropriate, including'';

(II) in subparagraph (B)—

(aa) by striking ''prevention services and interventions for pregnant, alcohol-dependent women'' and inserting ''culturally and linguistically appropriate evidence-based or evidence-informed interventions and appropriate societal supports for preventing prenatal alcohol exposure, which may co-occur with exposure to other substances''; and

(bb) by striking ''; and'' and inserting a semicolon;

(v) by striking paragraph (3) and inserting the following:

''(3) integrating into surveillance a case definition for FASD and, in collaboration with other Federal and outside partners, supporting organizations

of appropriate medical and mental health professionals in their development and refinement of evidence-based clinical diagnostic guidelines and criteria for all FASD; and

''(4) building State and Tribal capacity for the identification, treatment, and support of individuals with FASD and their families, which may include—

''(A) utilizing and adapting existing Federal, State, or Tribal programs to include FASD identification and FASD-informed support;

''(B) developing and expanding screening and diagnostic capacity for FASD;

''(C) developing, implementing, and evaluating targeted FASD-informed intervention programs for FASD;

''(D) increasing awareness of FASD;

''(E) providing training with respect to FASD for professionals across relevant sectors; and

''(F) disseminating information about FASD and support services to affected individuals and their families.'';

(D) in subsection (b)—

(i) by striking ''described in section 399I'';

(ii) by striking ''The Secretary'' and inserting the following:

''(1) IN GENERAL.—The Secretary''; and

(iii) by adding at the end the following:

''(2) ELIGIBLE ENTITIES.—To be eligible to receive a grant, or enter into a cooperative agreement or contract, under this section, an entity shall—

''(A) be a State, Indian Tribe or Tribal organization, local government, scientific or academic institution, or nonprofit organization; and

''(B) prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including a description of the activities that the entity intends to carry out using amounts received under this section.

''(3) ADDITIONAL APPLICATION CONTENTS.—The Secretary may require that an eligible entity include in the application submitted under paragraph (2)(B)—

''(A) a designation of an individual to serve as a FASD State or Tribal coordinator of activities such eligible entity proposes to carry out through a grant, cooperative agreement, or contract under this section; and

''(B) a description of an advisory committee the entity will establish to provide guidance for the entity on developing and implementing a statewide or Tribal strategic plan to prevent FASD and provide for the identification, treatment, and support of individuals with FASD and their families.''; and

(E) by striking subsections (c) and (d); and

(F) by adding at the end the following:

''(c) DEFINITION OF FASD-INFORMED.—For purposes of this section, the term 'FASD-informed', with respect to support or an intervention program, means that such support or intervention program uses culturally and linguistically informed evidence-based or practice-based interventions and appropriate societal supports to support an improved quality of life for an individual with FASD and the family of such individual.''; and

(3) by striking sections 399I, 399J, and 399K (42 U.S.C. 280f–1, 280f–2, 280f–3) and inserting the following:

"SEC. 399I. FETAL ALCOHOL SPECTRUM DISORDERS CENTERS FOR EXCELLENCE.

''(a) IN GENERAL.—The Secretary shall, as appropriate, award grants, cooperative agreements, or contracts to public or nonprofit private entities with demonstrated expertise in the prevention of, identification of, and intervention services with respect to, fetal alcohol spectrum disorders (referred to in this section as 'FASD') and other related adverse conditions. Such awards shall be for the purposes of establishing Fetal Alcohol Spectrum Disorders Centers for Excellence to build local, Tribal, State, and nationwide capacities to prevent the occurrence of FASD and other related adverse conditions, and to respond to the needs of individuals with FASD and their families by carrying out the programs described in subsection (b).

''(b) PROGRAMS.—An entity receiving an award under subsection (a) may use such award for the following purposes:

''(1) Initiating or expanding diagnostic capacity for FASD by increasing screening, assessment, identification, and diagnosis.

''(2) Developing and supporting public awareness and outreach activities, including the use of a range of media and public outreach, to raise public awareness of the risks associated with alcohol consumption during pregnancy, with the goals of reducing the prevalence of FASD and improving the developmental, health (including mental health), and educational outcomes of individuals with FASD and supporting families caring for individuals with FASD.

''(3) Acting as a clearinghouse for evidence-based resources on FASD prevention, identification, and culturally and linguistically appropriate best practices, including the maintenance of a national data-based directory on FASD-specific services in States, Indian Tribes, and local communities, and disseminating ongoing research and developing resources on FASD to help inform systems of care for individuals with FASD across their lifespan.

''(4) Increasing awareness and understanding of efficacious, evidence-based screening tools and culturally and linguistically appropriate evidence-based intervention services and best practices, which may include by conducting nationwide, regional, State, Tribal, or peer cross-State webinars, work-

shops, or conferences for training community leaders, medical and mental health and substance use disorder professionals, education and disability professionals, families, law enforcement personnel, judges, individuals working in financial assistance programs, social service personnel, child welfare professionals, and other service providers.

''(5) Improving capacity for State, Tribal, and local affiliates dedicated to FASD awareness, prevention, and identification and family and individual support programs and services.

''(6) Providing technical assistance to recipients of grants, cooperative agreements, or contracts under section 399H, as appropriate.

''(7) Carrying out other functions, as appropriate.

''(c) APPLICATION.—To be eligible for a grant, contract, or cooperative agreement under this section, an entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

''(d) SUBCONTRACTING.—A public or private nonprofit entity may carry out the following activities required under this section through contracts or cooperative agree-

ments with other public and private nonprofit entities with demonstrated expertise in FASD:

''(1) Prevention activities.

''(2) Screening and identification.

''(3) Resource development and dissemination, training and technical assistance, administration, and support of FASD partner networks.

''(4) Intervention and treatment services.

''SEC. 399J. AUTHORIZATION OF APPROPRIATIONS.

''There are authorized to be appropriated to carry out this part such sums as may be necessary for each of fiscal years 2025 through 2029.''.

(b) REPORT.—Not later than 4 years after the date of enactment of this Act, the Secretary of Health and Human Services shall 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 of Health and Human Services to advance public awareness of, and facilitate the identification of best practices related to, fetal alcohol spectrum disorders identification, prevention, treatment, and support.

(c) TECHNICAL AMENDMENT.—Section 519D of the Public Health Service Act (42 U.S.C. 290bb–25d) is repealed.

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