H. R. 117TH CONGRESS 1ST SESSION

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 HOUSE OF REPRESENTATIVES

Ms. McCollum introduced the following bill; which was referred to the Committee on

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. FINDINGS.

Congress finds as follows:
(1) Fetal Alcohol Spectrum Disorders (referred to in this section as “FASD”), is a serious and complex public health issue impacting individuals, families, and communities throughout the United States, regardless of race, sex, culture, or geography. This Act provides an opportunity for our Nation to explore strategies to not only prevent the adverse effects of prenatal alcohol exposure (referred to in this section as “PAE”) but heal individual, historical, and cultural traumas.

(2) Exposure to alcohol has long-lasting consequences for a developing fetus, which may lead to a range of life-long physical, mental, social, and emotional problems. There is no known safe amount of alcohol use during pregnancy or while trying to get pregnant. There is also no safe time during pregnancy to drink. All types of alcohol are equally harmful, including all wines and beer.

(3) The most recent prevalence study identified as many as 1 in 20 first graders across the country are affected by PAE. Given that nearly 45 percent of pregnancies are unintended and women often don’t know that they are pregnant until they are 6 weeks along or more, it’s easy to understand how a woman could drink alcohol while expecting. Research
shows that solely focusing on individual women’s behavior as FASD prevention strategy perpetuates stigma and blame on biological mothers, individuals impacted by FASD, and the condition itself.

(4) Although research shows that white, college-educated, middle- to upper-class women are the most likely group to drink during pregnancy, one of the common misnomers about FASD is that it is an “indigenous issue”. Continued surveillance, stigmatization, and stereotyping of Indigenous populations may contribute to the misbelief that FASD is over-represented in these communities.

(5) In their recent landmark survey, “Lay of the Land: Equality vs Equity”, the FASD Changemakers, comprised of young adults with FASD, documented the social determinants of health that lead to the detrimental health disparities people with FASD often endure, including victimization resulting in incarceration, homelessness, reduced access to health care, vulnerabilities to substance misuse, and unemployment.

(6) The higher prevalence of FASD in criminal justice and foster care systems has been documented. Nearly 1 out of 4 children in juvenile corrections has FASD, and prevalence estimates among
children in the foster care systems range from 23 percent to 60 percent. Prevalence in adult corrections ranges from 11 percent to 25 percent.

(7) The National Academy of Medicine recommendations for a broad Federal response formed the basis of the Fetal Alcohol Syndrome and Fetal Alcohol Effect Prevention and Services Act of 1998 that authorized $27,000,000 for a National Task Force on Fetal Alcohol Syndrome and grant programs at the National Institute on Alcohol Abuse and Alcoholism, the Centers for Disease Control and Prevention, and the Substance Abuse and Mental Health Services Administration.

(8) In 2009, the National Task Force on Fetal Alcohol Syndrome reported FASD diagnostic capacity and FASD-informed services insufficient in the United States, resulting in countless individuals with FASD remaining unrecognized or misdiagnosed.

(9) Despite PAE remaining the leading preventable cause of birth defects and neurodevelopmental disabilities in the United States, the authority for the National Task Force on Fetal Alcohol Syndrome expired, SAMHSA funding for FASD ended in 2015, and other Federal and State FASD-related funding declined.
(10) FASD is preventable. Although there is no
cure for individuals impacted by FASD, research
shows that intervention services and supports that
include social, environmental, and educational strate-
gies can prevent subsequent trauma to the indi-
vidual, the individual’s caregivers, and society.

(11) Building coordinated State and Tribal
FASD systems of care that offer integrated cul-
turally-appropriate services and supports grounded
in best practices can mitigate the harms created by
historical and cultural trauma.

SEC. 3. PROGRAMS FOR FETAL ALCOHOL SPECTRUM DIS-
ORDERS.

(a) In General.—Part O of title III of the Public
Health Service Act (42 U.S.C. 280f et seq.) is amended
by striking section 399H and inserting the following:

"SEC. 399H. PROGRAMS FOR FETAL ALCOHOL SPECTRUM
DISORDERS.

"(a) Definition.—In this part—

"(1) the term ‘fetal alcohol spectrum disorders’
or ‘FASD’ means diagnosable developmental disabil-
ities of a broad range of neurodevelopmental and
physical effects that result from prenatal exposure to
alcohol. The effects may include lifelong physical,
mental, behavioral, social and learning disabilities,
and other problems that impact daily functioning
(such as living independently or holding a job), as
well as overall health and well-being; and

“(2) the terms ‘Indian Tribe’ and ‘Tribal organ-
ization’ have the meanings given the terms ‘Indian
tribe’ and ‘tribal organization’ in section 4 of the In-
dian Self-Determination and Education Assistance
Act.

“(b) RESEARCH ON FETAL ALCOHOL SPECTRUM
DISORDERS AND RELATED CONDITIONS.—

“(1) IN GENERAL.—The Secretary, acting
through the Director of the National Institutes of
Health, shall—

“(A) establish a research program for
FASD; and

“(B) award grants, contracts, or coopera-
tive agreements to public or private nonprofit
entities to pay all or part of carrying out re-
search under such research program.

“(2) TYPES OF RESEARCH.—In carrying out
paragraph (1), the Secretary, acting through the Di-
rector of the National Institute on Alcohol Abuse
and Alcoholism (referred to in this section as the
‘Director of the Institute’), shall continue to conduct
and expand national and international research in
consultation with other Federal agencies and outside partners that includes—

“(A) the most promising avenues of research in FASD diagnosis, intervention, and prevention;

“(B) factors that may mitigate the effects of prenatal alcohol and other substance exposure including culturally relevant factors and social determinants of health; and

“(C) other research that the Director of the Institute determines to be appropriate with respect to conditions that develop as a result of prenatal alcohol and other substance exposure.

“(3) AUTHORIZATION OF APPROPRIATIONS.—To carry out this subsection, there is authorized to be appropriated $30,000,000 for each of fiscal years 2022 through 2027.

“(c) SURVEILLANCE, PUBLIC HEALTH RESEARCH, AND PREVENTION ACTIVITIES.—

“(1) IN GENERAL.—The Secretary, acting through the Director of the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention, shall facilitate surveillance, public health research, and
prevention of FASD in accordance with this subsection.

“(2) SURVEILLANCE, PUBLIC HEALTH RESEARCH AND PREVENTION.—In carrying out this subsection, the Secretary shall—

“(A) integrate 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;

“(B) disseminate and provide the necessary training and support to appropriate medical and mental health professionals on the early identification of children with prenatal alcohol or other substance exposure as such children may require ongoing developmental and behavioral surveillance by their primary health care clinician which continues throughout their lifetime to access ongoing treatment and referral problems;
“(C) support applied public health prevention research to identify culturally-appropriate or evidence-based strategies for reducing alcohol and other substance exposed pregnancies in women at high risk of such pregnancies;

“(D) disseminate and provide the necessary training and support to implement culturally-appropriate or evidence-based strategies developed under subparagraph (C) to—

“(i) hospitals, Federally-qualified health centers, residential and outpatient substance disorder treatment programs, and other appropriate health care providers;

“(ii) educational settings;

“(iii) social work and child protection service providers;

“(iv) foster care providers and adoption agencies;

“(v) State or Tribal offices and other agencies providing services to individuals with disabilities;

“(vi) mental health treatment facilities;
“(vii) Indian Tribes and Tribal organizations;

“(viii) military medical treatment facility described in section 1073d(e) of title 10, United States Code, and medical centers of the Department of Veterans Affairs; and

“(ix) other entities that the Secretary determines to be appropriate;

“(E) conduct activities related to risk factor surveillance;

“(F) disseminate and evaluate brief behavioral intervention strategies and referrals aimed at preventing alcohol and substance-exposed pregnancies among women of childbearing age in special settings, including clinical primary health centers, outpatient clinics, child welfare agencies, and correctional facilities and recovery campuses;

“(G) document the FASD lived experience and incorporate the perspectives of individuals and their family members affected by FASD and birth mothers of individuals with FASD in the dissemination of information and resources;
“(H) disseminate comprehensive alcohol and pregnancy and FASD information, resources, and services to families and caregivers, professionals, and the public through an established national network of affiliated FASD organizations and through organizations serving medical, behavioral health, addiction, disability, education, legal and other professionals; and

“(I) coordinate FASD activities with affiliated State, Tribal and local systems and organizations with respect to the prevention of alcohol and other substance-exposed pregnancies.

“(3) Authorization of Appropriations.—To carry out this subsection, there is authorized to be appropriated $13,000,000 for each of fiscal years 2022 through 2027.

“(d) Building State and Tribal FASD Systems.—

“(1) In General.—The Secretary, acting through the Administrator of the Health Resources and Services Administration, shall award grants, contracts, or cooperative agreements to States and Indian Tribes for the purpose of establishing ongoing comprehensive and coordinated State and Tribal FASD multidisciplinary, diverse coalitions to—
“(A) develop systems of care for—

“(i) the prevention of FASD and other adverse conditions as a result of prenatal substance exposure; and

“(ii) the identification, treatment and support of individuals with FASD or other adverse conditions from prenatal substance exposure and support for their families;

“(B) provide leadership and support in establishing, expanding or increasing State and Tribal systems capacity in addressing FASD and other adverse conditions as a result of prenatal substance exposure; and

“(C) update or develop implementing and evaluating State and Tribal FASD strategic plans to—

“(i) establish or expand State and Tribal programs of surveillance, screening, assessment, diagnosis, prevention of FASD and other physical or neurodevelopmental disabilities from prenatal substance exposure;

“(ii) integrate programs related to prevention of FASD and interventions addressing the adverse effects of prenatal al-
cohol and other substance exposure into
existing State and Tribal coordinated sys-
tems of care which focus on the social de-
terminants of health, including systemic
racism, access to the Medicare program
under title XVIII of the Social Security
Act or to the Medicaid program under title
XIX of such Act, maternal and early child-
hood health, economic security, food and
housing, education, justice and corrections,
mental health, substance use disorder,
child welfare, developmental disabilities,
and health care;

“(iii) identify across-the-lifetime
issues for individuals and families related
to FASD and other adverse conditions re-
lated to prenatal substance exposure, in-
cluding historical and cultural trauma,
child abuse and neglect, mental health and
substance use disorder; and

“(iv) identify systemic and other bar-
riers to the integration of prenatal alcohol
and substance exposure screening, assess-
ment and identification of FASD into ex-
isting systems of care for individuals and families.

“(2) ELIGIBILITY.—To be eligible to receive a grant, contract, or cooperative agreement under paragraph (1), a State, an Indian Tribe, a Tribal organization, or a State-Tribal collaborative (referred to in this paragraph as an ‘eligible entity’) shall 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) evidence that the eligible entity designated in the application have or will have authority to implement programs described in this subsection;

“(B) evidence of the establishment of a State or Tribal FASD Advisory Group of State agencies or Tribal entities and, if available, a State affiliate of the National Organization on Fetal Alcohol Syndrome or similar Tribal or statewide FASD advocacy organization, to provide the leadership in building State or Tribal capacity in addressing prenatal alcohol and other substance exposure, including FASD prevention, identification, and intervention activities and programming, including—
“(i) the formation of a FASD advisory coalition of diverse, public and private representatives from multiple disciplines that may include—

“(I) State agencies or Tribal entities that are responsible for health, human services, corrections, education, housing, developmental disabilities, substance use disorder, child welfare, juvenile and adult justice systems, mental health and any other agency related to the adverse social impact of prenatal alcohol and other substance exposures;

“(II) public and private sector stakeholders, including individuals with FASD and their caretakers and entities that work with or provide services or support for individuals with FASD and their families, such as community-based agencies, law enforcement, the judiciary, probation officers, medical and mental health providers, substance use disorder counselors, educators, child welfare profes-
sionals, and other entities that address individual, family, community and society issues related to prenatal alcohol and other substance exposure throughout an individual’s lifespan; and

“(ii) the development of a State or Tribal strategic plan that—

“(I) contains recommendations, action steps, and deliverables for improving social determinants of health;

“(II) recommends actions for prevention of FASD and other conditions related to prenatal substance exposure;

“(III) integrates culturally-appropriate, best practices or evidence-based practices on screening, identification and treatment into existing systems of care;

“(IV) provides for FASD-informed clinical and therapeutic interventions;

“(V) provides for FASD-informed supports and services for fam-
ilies and individuals with FASD and other conditions from prenatal substance exposure across their lifetimes;

“(VI) identifies—

“(aa) existing FASD or other programs related to prenatal substance exposures in the State or Indian Tribe, including—

“(AA) FASD primary, secondary and tertiary prevention programs;

“(BB) prenatal screening, assessment or diagnostic services; and

“(CC) support and service programs for individuals with FASD and their families; and

“(bb) existing State, local, and Tribal programs, systems, and funding streams that could be used to identify and assist individuals with FASD and other conditions related to substance
exposed pregnancies, and prevent prenatal exposure to alcohol and other harmful substances;

“(cc) barriers to providing FASD diagnostic services or programs to assist individuals with FASD or reducing alcohol and substance exposed pregnancies for women at risk for alcohol or other substance exposed pregnancies, and recommendations to reduce or eliminate such barriers;

“(dd) barriers to FASD prevention, screening, assessment, identification, and treatment programs and to the provision of FASD-informed support services and accommodations across the lifespan, and recommendations to reduce or eliminate such barriers;

“(VII) integrates a public-private partnership of State, Tribal, and local communities to develop a comprehensive FASD-informed and engaged systems of care approach that addresses
social determinants of health, including systemic racism on health outcomes, economic security, food and housing; education, justice, and health care challenges experienced by individuals who have been diagnosed with FASD or other conditions as result of prenatal substance exposure;

“(VIII) describes programs of surveillance, screening, assessment and diagnosis, prevention, clinical intervention and therapeutic and other supports and services for individuals with FASD and their families;

“(IX) recognizes the impact of historical, cultural, and other trauma of individuals in the design and application of all programming; and

“(X) recognizes the lived experiences of birth mothers and those with FASD and their families in the design and application of all programming.

“(3) Restrictions on and use of funds.— Amounts received under a grant, contract, or cooper-
ative agreement under this subsection shall be used for one or more of the following activities:

“(A) Establishing or increasing diagnostic capacity in the State or Indian Tribe to meet the estimated prevalence needs of the State or Indian Tribe’s FASD population.

“(B) Providing educational and supportive services to individuals with FASD and other conditions related to prenatal substance exposure and their families.

“(C) Establishing a FASD statewide surveillance system.

“(D) Including FASD information in State medical and mental health care and education programs at schools of higher education.

“(E) Collecting, analyzing, and interpreting data.

“(F) Replicating culturally-aware or best practice FASD prevention programs, including case-management models for pregnant or parenting women with alcohol and other substance use disorders.

“(G) Training of primary care and other providers in screening for prenatal alcohol and other substance exposure in prenatal, pediatric,
early childhood or other child or teenage check-up settings.

“(H) Developing, implementing, and evaluating population-based and targeted prevention programs for FASD, including public awareness campaigns.

“(I) Increasing capacity of the State or Indian Tribe to deliver housing, economic and food security services to adults impacted by FASD or other conditions related to prenatal substance exposure.

“(J) Referring individuals with FASD and other conditions related to prenatal substance exposure to appropriate FASD-informed support services.

“(K) Providing for State and Tribal FASD coordinators.

“(L) Providing training to health care (including mental health care) providers on the prevention, identification and treatment of FASD and other conditions related to prenatal substance exposure across the lifespan.

“(M) Providing training to education, justice, and social service system professionals to
become FASD-informed and FASD-engaged in their practices.

“(N) Including FASD in training for workforce development and disability accessibility.

“(O) Supporting peer-to-peer certification programs for individuals with FASD.

“(P) Developing FASD-informed certification programs.

“(Q) Disseminating information about FASD and other conditions related to prenatal substance exposure and the availability of support services to families and individuals with FASD and other adverse conditions related to prenatal substance exposure.

“(R) Implementing recommendations from relevant agencies and organizations, including the State or Tribal FASD advisory group, on the identification and prevention of FASD, intervention programs or services for individuals with FASD and their families.

“(S) Other activities, as the Secretary determines appropriate or as recommended by the National Advisory Council on FASD under section 399H–1.
(4) **OTHER CONTRACTS AND AGREEMENTS.**—

A State may carry out activities under paragraph (3) through contracts or cooperative agreements with another State or an Indian Tribe, and with public, private for-profit or nonprofit entities with a demonstrated expertise in FASD and other conditions related to prenatal substance exposure prevention, screening and diagnosis, or intervention services.

(5) **REPORT TO CONGRESS.**—Not later than 2 years after the date on which amounts are first appropriated under paragraph (6), the Secretary shall prepare and 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 that contains a description of programs carried out under this section. At a minimum, the report shall contain—

"(A) information concerning the number of States receiving grants;

"(B) State and Tribal FASD diagnostic capacity and barriers to achieving diagnostic capacity based on State FASD surveillance data or the most recent estimated prevalence of FASD in the United States;
“(C) information concerning systemic or other barriers to screening for prenatal alcohol and other substance exposure in existing systems of care, including—

“(i) the child welfare system;
“(ii) maternal and early child health care and alcohol and other substance use disorder treatment programs;
“(iii) primary or secondary education systems; and
“(iv) juvenile and adult systems of justice;

“(D) information concerning existing State, Tribal, local government or community programs and systems of care and funding streams that could be used to identify and assist individuals with FASD and other conditions related to substance exposed pregnancies and the degree to which such programs are FASD-informed or to which there are systemic or other barriers preventing their use; and

“(E) information concerning existing State, Tribal, local government or community primary, tertiary, or secondary prevention pro-
grams on prenatal exposure to alcohol and other harmful prenatal substances.

“(6) AUTHORIZATION OF APPROPRIATIONS.—

“(A) IN GENERAL.—To carry out this sub-
section, there is authorized to be appropriated $32,000,000 for each of fiscal years 2022 through 2027.

“(B) ADMINISTRATIVE AND EMPLOYMENT EXPENSES.—Of the amount appropriated for a fiscal year under subparagraph (A), $12,000,000 shall be allocated to States and Indian Tribes for purposes of covering adminis-
trative costs and supporting the employment of FASD State and Tribal coordinators.

“(C) TRIBAL SET ASIDE.—Up to 20 per-
cent of the grants, contracts, or cooperative agreements awarded under this subsection shall be reserved for Indian Tribes and Tribal orga-
nizations.

“(e) PROMOTING COMMUNITY PARTNERSHIPS.—

“(1) IN GENERAL.—The Secretary, acting through the Administrator of Health Resources and Services Administration, shall award grants, con-
tracts, or cooperative agreements to eligible entities to enable such entities to establish, enhance, or im-
prove community partnerships for the purpose of collaborating on common objectives and integrating culturally-appropriate best practice services available to individuals with FASD and other conditions related to prenatal substance exposure such as surveillance, screening, assessment, diagnosis, prevention, treatment, and support services.

“(2) ELIGIBLE ENTITIES.—To be eligible to receive a grant, contract, or cooperative agreement under paragraph (1), an entity shall—

“(A) be a public or private nonprofit entity that is—

“(i) a health care provider or health professional;  
“(ii) a primary or secondary school;  
“(iii) a social work or child protection service provider;  
“(iv) an incarceration facility, or State or local judicial system for juveniles and adults;  
“(v) an FASD organization, parent-led group, or other organization that supports and advocates for individuals with FASD and their families;
“(vi) an Indian Tribe or Tribal organization;

“(vii) an early childhood intervention facility;

“(viii) any other entity the Secretary determines to be appropriate; or

“(ix) a consortium of any of the entities described in clauses (i) through (viii);

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 assurances that the entity submitting the application does, at the time of application, or will, within a reasonable amount of time from the date of application, provide evidence of substantive participation with a broad range of entities that work with or provide services for individuals with FASD.

“(3) ACTIVITIES.—An eligible entity shall use amounts received under a grant, contract, or cooperative agreement under this subsection to carry out one or more of the following activities relating to
FASD and other conditions related to prenatal substance exposure:

“(A) Integrating FASD-informed and culturally-appropriate practices into existing programs and services available in the community.

“(B) Conducting a needs assessment to identify services that are not available in a community.

“(C) Developing and implementing culturally-appropriate, community-based initiatives to prevent FASD, and to screen, assess, diagnose, treat, and provide FASD-informed support services to individuals with FASD and their families.

“(D) Disseminating information about FASD and the availability of support services.

“(E) Developing and implementing a community-wide public awareness and outreach campaign focusing on the dangers of drinking alcohol while pregnant.

“(F) Providing mentoring or other support to individuals with FASD and their families.

“(G) Other activities, as the Secretary determines appropriate, or in consideration of recommendations from the National Advisory
Council on FASD established under section 399H–1.

“(4) Authorization of Appropriations.—

To carry out this subsection, there is authorized to be appropriated $5,000,000 for each of fiscal years 2022 through 2027.

“(f) Development of Best Practices and Models of Care.—

“(1) In General.—The Secretary, in coordination with the Administrator of Health Resources and Services Administration, shall award grants to States, Indian Tribes and Tribal organizations, non-governmental organizations, and institutions of higher education for the establishment of pilot projects to identify and implement culturally-appropriate best practices for—

“(A) providing intervention and education of children with FASD, including—

“(i) activities and programs designed specifically for the identification, treatment, and education of such children; and

“(ii) curricula development and credentialing of teachers, administrators, and social workers who implement such
programs and provide childhood interventions;

“(B) educating professionals within the child welfare, juvenile and adult criminal justice systems, including judges, attorneys, probation officers, social workers, child advocates, medical and mental health professionals, substance abuse professionals, law enforcement officers, prison wardens or other incarceration administrators, and administrators of developmental disability, mental health and alternative incarceration facilities on how to screen, assess, identify, treat and support individuals with FASD or similar conditions related to prenatal substance exposure within these systems, including—

“(i) programs designed specifically for the identification, assessment, treatment, and education of individuals with FASD; and

“(ii) curricula development and credentialing within the adult and juvenile justice and child welfare systems for individuals who implement such programs;
“(C) educating adoption or foster care agency officials about available and necessary services for children with FASD, including—

“(i) programs designed specifically for screening, assessment and identification, treatment, and education of individuals with FASD; and

“(ii) on-going and consistent education and training for potential adoptive or foster parents of a child with FASD;

“(D) educating health and mental health and substance use providers about available and necessary services for children with FASD, including—

“(i) programs designed specifically for screening and identification, and both health and mental health treatment, of individuals with FASD; and

“(ii) curricula development and credentialing within the health and mental health and substance abuse systems for individuals who implement such programs; and

“(E) identifying and implementing culturally-appropriate best practice models for re-
ducing alcohol and other substance exposed pregnancies in women at high risk of such pregnancies.

“(2) APPLICATION.—To be eligible for a grant under paragraph (1), an entity shall prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

“(3) AUTHORIZATION OF APPROPRIATIONS.—To carry out this subsection, there is authorized to be appropriated $5,000,000 for each of fiscal years 2022 through 2027.

“(g) TRANSITIONAL SERVICES.—

“(1) IN GENERAL.—The Secretary, in coordination with the Administrator of the Health Resources and Services Administration and the Administrator of the Administration for Community Living, shall award demonstration grants, contracts, and cooperative agreements to States and local units of government, Indian Tribes and Tribal organizations, and nongovernmental organizations for the purpose of establishing integrated systems for providing culturally-appropriate best practice transitional services for adults affected by prenatal alcohol or substance
exposure and evaluating the effectiveness of such services.

“(2) Application.—To be eligible for a grant, contract, or cooperative agreement under paragraph (1), an entity shall prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may reasonably require, including specific credentials relating to education, skills, training, and continuing educational requirements relating to FASD.

“(3) Allowable Uses.—An entity shall use amounts received under a grant, contract, or cooperative agreement under paragraph (1) to carry out one or more of the following activities:

“(A) Provide housing assistance to, or specialized housing for, adults with FASD.

“(B) Provide FASD-informed vocational training and placement services for adults with FASD.

“(C) Provide medication monitoring services for adults with FASD.

“(D) Provide FASD-informed training and support to organizations providing family services or mental health programs and other organizations that work with adults with FASD.
“(E) Establish and evaluate housing models specially designed for adults with FASD.

“(F) Recruit, train and provide mentors for individuals with FASD.

“(G) Other services or programs, as the Secretary determines appropriate.

“(4) AUTHORIZATION OF APPROPRIATIONS.—

To carry out this subsection, there is authorized to be appropriated $5,000,000 for each of fiscal years 2022 through 2027.

“(h) SERVICES FOR INDIVIDUALS WITH FETAL ALCOHOL SPECTRUM DISORDERS.—

“(1) IN GENERAL.—The Secretary, in coordination the Assistant Secretary for Mental Health and Substance Use, shall make awards of grants, cooperative agreements, or contracts to public and non-profit private entities, including Indian tribes and tribal organizations, to provide FASD-informed culturally-appropriate services to individuals with FASD.

“(2) USE OF FUNDS.—An award under paragraph (1) may, subject to paragraph (4), be used to—

“(A) screen and test individuals to determine the type and level of services needed;
“(B) develop a FASD-informed comprehensive plan for providing services to the individuals;

“(C) provide FASD-informed mental health counseling;

“(D) provide FASD-informed substance abuse prevention services and treatment, if needed;

“(E) coordinate services with other social programs including social services, justice system, educational services, health services, mental health and substance abuse services, financial assistance programs, vocational services and housing assistance programs;

“(F) provide FASD-informed vocational services;

“(G) provide FASD-informed health counseling;

“(H) provide FASD-informed housing assistance;

“(I) conduct FASD-informed parenting skills training;

“(J) develop and implement overall FASD-informed case management;
“(K) provide supportive services for families of individuals with FASD;

“(L) provide respite care for caretakers of individuals with FASD;

“(M) recruit, train and provide mentors for individuals with FASD;

“(N) provide FASD-informed educational and supportive services to families of individuals with FASD; and

“(O) provide other services and programs, to the extent authorized by the Secretary after consideration of recommendations made by the National Advisory Council on FASD.

“(3) REQUIREMENTS.—To be eligible to receive an award under paragraph (1), an applicant shall—

“(A) demonstrate that the program will be part of a coordinated, comprehensive system of care for such individuals;

“(B) demonstrate an established communication with other social programs in the community including social services, justice system, financial assistance programs, health services, educational services, mental health and substance abuse services, vocational services and housing assistance services;
“(C) have a qualified staff of medical, mental health or other professionals with a history of working with individuals with FASD;

“(D) provide assurance that the services will be provided in a culturally and linguistically appropriate manner; and

“(E) provide assurance that at the end of the 5-year award period, other mechanisms will be identified to meet the needs of the individuals and families served under such award.

“(4) RELATIONSHIP TO PAYMENTS UNDER OTHER PROGRAMS.—An award may be made under paragraph (1) only if the applicant involved agrees that the award will not be expended to pay the expenses of providing any service under this section to an individual to the extent that payment has been made, or can reasonably be expected to be made, with respect to such expenses—

“(A) under any State compensation program, under an insurance policy, or under any Federal or State or Tribal health benefits programs; or

“(B) by an entity that provides health services on a prepaid basis.
“(5) DURATION OF AWARDS.—With respect to any award under paragraph (1), the period during which payments under such award are made to the recipient may not exceed 5 years.

“(6) EVALUATION.—The Secretary shall evaluate each project carried out under paragraph (1) and shall disseminate the findings with respect to each such evaluation to appropriate public and private entities, including the National Advisory Council on FASD.

“(7) FUNDING.—

“(A) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this subsection, there is authorized to be appropriated $10,000,000 for each fiscal years 2022 through 2027.

“(B) ALLOCATION.—Of the amounts appropriated under subparagraph (A) for a fiscal year, not more than $300,000 shall, for the purposes relating to FASD, be made available for collaborative, coordinated interagency efforts with the National Institute on Alcohol Abuse and Alcoholism, National Institute on Mental Health, the Eunice Kennedy Shriver National Institute of Child Health and Human
Development, the Health Resources and Services Administration, the Agency for Healthcare Research and Quality, the Administration for Community Living, the Centers for Disease Control and Prevention, the Department of Education, the Department of Justice, and other agencies, as determined by the Secretary. Interagency collaborative efforts may include—

“(i) the evaluation of existing programs for efficacy;

“(ii) the development of new evidence-based or best practice programs for prevention of prenatal alcohol and other substance exposure, and interventions for individuals with FASD and their families;

“(iii) the facilitation of translation and transition of existing evidence-based, best practices or culturally-appropriate prevention and intervention programs into general and community practice; and

“(iv) engaging in Tribal consultation to ensure that Indian Tribes and Tribal organizations are able to develop culturally-appropriate services and interventions for prenatal alcohol and other substance expo-
sure, and interventions for individuals with
FASD and other conditions related to pre-
natal substance exposure and their fami-
lies.”.

SEC. 4. NATIONAL ADVISORY COUNCIL ON FSAD.

Part O of title III of the Public Health Service Act
(42 U.S.C. 280f et seq.), as amended by section 2, is fur-
ther amended by inserting after section 339H the fol-
lowing:

“SEC. 399H–1. NATIONAL ADVISORY COUNCIL ON FASD.

“(a) In General.—The Secretary shall establish an
advisory council to be known as the National Advisory
Council on FASD (referred to in this section as the ‘Coun-
cil’) to foster coordination and cooperation among all Fed-
eral and non-Federal members and their constituencies
that conduct or support FASD and other conditions re-
lated to prenatal substance exposure research, programs,
and surveillance, and otherwise meet the general needs of
populations actually or potentially impacted by FASD and
other conditions related to prenatal substance exposure.

“(b) Membership.—The Council shall be composed
of 23 members as described in paragraphs (1) and (2).

“(1) Federal Membership.—Members of the
Council shall include representatives of the following
Federal agencies:
“(A) The National Institute on Alcohol Abuse and Alcoholism.

“(B) The National Institute on Drug Abuse.

“(C) The Centers for Disease Control and Prevention.

“(D) The Health Resources and Services Administration.

“(E) The Substance Abuse and Mental Health Services Agency.

“(F) The Office of Special Education and Rehabilitative Services.

“(G) The Office of Justice Programs.

“(H) The Indian Health Service.

“(I) The Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders.


“(2) NON-FEDERAL MEMBERS.—Additional non-Federal public and private sector members of the Council shall be nominated by the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders and appointed by the Secretary, and shall be staffed by the Office of the Assistant Secretary for Planning and Evaluation of the Department of
Health and Human Service. Such members shall include—

“(A) at least one individual with FASD or a parent or legal guardian of an individual with FASD;

“(B) at least one individual or a parent or legal guardian of an individual with a condition related to prenatal substance exposure;

“(C) at least one birth mother of an individual with FASD;

“(D) at least one representative from the FASD Study Group of the Research Society on Alcoholism;

“(E) at least one representative of the National Organization on Fetal Alcohol Syndrome;

“(F) at least one representative of a leading statewide advocacy and service organization for individuals with FASD and their families;

“(G) at least one representative of the FASD Center for Excellence established under section 399H–3;

“(H) at least 2 representatives from State or Tribal advisory groups receiving an award under section 399H(d); and
“(I) representatives with interest and expertise in FASD from the private sector of pediatricians, obstetricians and gynecologists, substance abuse and mental health care providers, family and juvenile court judges and justice and corrections programming and services, or special education and social work professionals.

“(3) APPOINTMENT TIMING.—The members of the Council described in paragraph (2) shall be appointed by the Secretary not later than 6 months after the date of enactment of the Advancing FASD Research, Services and Prevention Act.

“(c) FUNCTIONS.—The Council shall—

“(1) advise Federal, State, Tribal and local programs and research concerning FASD and other conditions related to prenatal substance exposure, including programs and research concerning education and public awareness for relevant service providers, reducing the incidence of prenatal alcohol and other substance exposure in pregnancies, medical and mental diagnosis, interventions for women at-risk of giving birth with FASD and beneficial services and supports for individuals with FASD and their families;
“(2) coordinate its efforts with the Interagency Committee on Fetal Alcohol Spectrum Disorders;

“(3) develop a summary of advances in FASD research related to prevention, treatment, screening, diagnosis, and interventions;

“(4) make recommendations for the FASD research program to the Director of the National Institute of Alcohol Abuse and Alcoholism;

“(5) review the 2009 report of the National Task Force on FAS entitled, ‘A Call to Action’ and other reports on FASD and the adverse impact of prenatal substance exposure;

“(6) develop a summary of advances in practice and programs relevant to FASD prevention, treatment, early screening, diagnosis, and interventions;

“(7) make recommendations on a national agenda to reduce the prevalence and the associated impact of FASD and other conditions related to prenatal substance exposure and improve the quality of life of individuals and families impacted by FASD or the adverse effects of prenatal substance exposure, including—

“(A) proposed Federal budgetary requirements for FASD research and related services
and support activities for individuals with FASD;

“(B) recommendations to ensure that FASD research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies, are not unnecessarily duplicative;

“(C) identification of existing Federal programs that could be used to identify and assist individuals with FASD and other conditions related to substance exposed pregnancies;

“(D) identification of gaps or barriers for individuals living with, or impacted by, FASD in accessing diagnostic, early intervention, and support services;

“(E) identification of prevention strategies, including education campaigns and options, such as product warnings and other mechanisms to raise awareness of the risks associated with prenatal alcohol consumption;

“(F) identification of current diagnostic methods and practices for the identification of FASD and identify gaps or barriers for achieving diagnostic capacity throughout the United
States based on current estimated prevalence of FASD;

“(G) recommendations for research or other measures to increase diagnostic capacity to meet the needs of the estimated number of individuals with FASD;

“(H) identification and enhancement of culturally-appropriate or best practice approaches and models of care to reduce the incidence of FASD; and

“(I) identification and enhancement of best practice approaches and models of care to increase support and treat individuals with FASD, and to make recommendations for a broad model comprehensive community approach to the overall problem of prenatal alcohol and other harmful substance exposure.

“(d) REPORT TO CONGRESS AND THE PRESIDENT.—The Council shall submit to Congress and to the President—

“(1) an update on the summary of advances described in paragraphs (3) and (6) of subsection (c), not later than 2 years after the date of enactment of the Advancing FASD Research, Services and Prevention Act;
“(2) an update to the national agenda described in subsection (e)(7), including any progress made in achieving the objectives outlined in such agenda, not later than 4 years after the date of enactment of such Act; and

“(3) a final report that provides a summary of advances described in paragraphs (3) and (6) of subsection (e), and an update to the national agenda described in subsection (e)(7), not later than September 30, 2027.

“(e) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section $2,000,000 for each of fiscal years 2022 through 2027.”.

SEC. 5. INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SPECTRUM DISORDERS.

Subpart 14 of part C of title IV of the Public Health Service Act (42 U.S.C. 285n et seq.) is amended by adding at the end the following:

“SEC. 464K. INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SPECTRUM DISORDERS.

“(a) IN GENERAL.—The Director of the Institute shall provide for the continuation of the ‘Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders’ (referred to in this section as the ‘Committee’) so that such Committee may—
“(1) coordinate activities conducted by the Federal Government on FASD, including convening meetings, establishing work groups, sharing information, and facilitating and promoting collaborative projects among Federal agencies, the National Advisory Council on FASD established under section 399H–1, and outside partners;

“(2) 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 in collaboration with other Federal and outside partners, and

“(3) develop priority areas considering recommendations from the National Advisory Council on FASD.

“(b) MEMBERSHIP.—Members of the Committee shall include representatives of the following Federal agencies:

“(1) The National Institute on Alcohol Abuse and Alcoholism.

“(2) The Centers for Disease Control and Prevention.

“(3) The Health Resources and Services Administration.
“(4) The Office of the Assistant Secretary for Planning and Evaluation.


“(6) Office of Justice Programs of the Department of Justice.

“(7) The Substance Abuse and Mental Health Services Administration.

“(8) The Office of Special Education and Rehabilitation Services.

“(9) The National Institute on Drug Abuse.

“(10) The National Institute of Mental Health.

“(11) The Indian Health Service.

“(12) The Eunice Kennedy Shriver National Institute of Child Health and Human Development.

“(13) Other Federal agencies with responsibilities related to FASD prevention or treatment or that interact with individuals with FASD, including education and correctional systems, alcohol and substance use disorder prevention and treatment programs, maternal health, the Medicare and Medicaid programs under titles XVIII and XIX, respectively, of the Social Security Act, child health and welfare, rehabilitative services, and labor and housing grant or entitlement programs.
“(c) Authorization of Appropriations.—There are authorized to be appropriated to carry out this section $1,000,000 for each of fiscal years 2022 through 2027.”.

SEC. 6. FASD CENTER FOR EXCELLENCE.

(a) In General.—Part O of title III of the Public Health Service Act (42 U.S.C. 280f et seq.), as amended by section 4, is further amended by inserting after section 339H–2 the following:

“SEC. 399H–2. FASD CENTER FOR EXCELLENCE.

“(a) In General.—The Secretary, acting through the Administrator of the Health Resources and Services Administration, and in consultation with the Assistant Secretary for Mental Health and Substance Use, the Director of the Centers for Disease Control, and the Chair of the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders, shall award up to 4 grants, cooperative agreements, or contracts to public or nonprofit entities with demonstrated expertise in FASD prevention, identification, and intervention services and other adverse conditions related to prenatal substance exposure. Such awards shall be for the purposes of establishing a FASD Center for Excellence to build local, Tribal, State, and national capacities to prevent the occurrence of FASD and other adverse conditions related to exposure to substances, 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 any of the following programs:

“(1) INCREASING FASD DIAGNOSTIC CAPACITY.—Initiating or expanding diagnostic capacity of FASD by increasing screening, assessment, identification, and diagnosis in settings such as clinical practices, educational settings, child welfare, and juvenile out-of-home placement facilities and adult correctional systems.

“(2) PUBLIC AWARENESS.—Developing and supporting national public awareness and outreach activities, including the use of all types of media and public outreach, and the formation of a diverse speakers bureau to raise public awareness of the risks associated with alcohol consumption during pregnancy with the purpose of reducing the prevalence of FASD and improving the quality of life for those living with FASD and their families.

“(3) RESOURCES AND TRAINING.—

“(A) CLEARINGHOUSE.—Acting as a clearinghouse for resources on FASD prevention, identification, and culturally-aware best prac-
tices, including the maintenance of a national data-based directory on FASD-specific services in States, Indian Tribes, and local communities.

“(B) INTERNET-BASED CENTER.—Providing an internet-based center that disseminates ongoing research and resource development on FASD in administering systems of care for individuals with FASD across their lifespan.

“(C) INTERVENTION SERVICES AND BEST PRACTICES.—Increasing awareness and understanding of efficacious FASD screening tools and culturally-appropriate intervention services and best practices by—

“(i) maintaining a diverse national speakers bureau; and

“(ii) conducting national, regional, State, Tribal, or peer cross-State webinars, workshops, or conferences for training community leaders, medical and mental health and substance abuse 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.

“(D) BUILDING CAPACITY.—Building capacity for State, Tribal, and local affiliates dedicated to FASD awareness, prevention, and identification and family and individual support programs and services.

“(4) TECHNICAL ASSISTANCE.—Providing technical assistance to—

“(A) communities for replicating and adapting exemplary comprehensive systems of care for individuals with FASD developed under section 399H(d) and for replicating and adapting culturally-appropriate best or model projects of care developed under section 399H(f);

“(B) States and Indian Tribes in developing statewide or Tribal FASD strategic plans, establishing or expanding statewide programs of surveillance, screening and diagnosis, prevention, and clinical intervention, and support for individuals with FASD and their families under section 399H(d); and

“(C) Indian Tribes and Tribal organizations in engaging in tribal consultation to ensure that such Tribes and Tribal organizations
are able to develop culturally-appropriate services and interventions for individuals with FASD and other conditions related to prenatal substance exposure and their families.

“(5) OTHER FUNCTIONS.—Carrying out other functions, to the extent authorized by the Secretary, after consideration of recommendations of the National Advisory Council on FASD.

“(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, including specific credentials relating to FASD expertise and experience relevant to the application’s proposed activity, including development of FASD public awareness activities and resources; FASD resource development, dissemination, and training; coordination of FASD-informed services, technical assistance, administration of FASD partner networks, and other FASD-specific expertise.

“(d) SUBCONTRACTING.—A public or private nonprofit may carry out the activities under subsection (a) through contracts or cooperative agreements with other public and private nonprofit entities with demonstrated expertise in—

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“(1) FASD prevention activities;
“(2) FASD screening and identification;
“(3) FASD resource, development, dissemination, training and technical assistance, administration and support of FASD partner networks; and
“(4) intervention services.
“(e) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section $8,000,000 for each of fiscal years 2022 through 2027.”.

SEC. 7. DEPARTMENT OF EDUCATION AND DEPARTMENT OF JUSTICE PROGRAMS.

(a) Prevention, Identification, Intervention, and Services in the Education System.—

(1) General rule.—The Secretary of Education shall address education-related issues with respect to children with FASD, in accordance with this subsection.

(2) Specific responsibilities.—The Secretary of Education shall direct the Office of Special Education and Rehabilitative Services to—

(A) support the development, collection, and dissemination (through the internet website of the Department of Education, at teacher-to-teacher workshops, through in-service trainings, and through other means) of culturally-appro-
priate best practices that are FASD-informed in the education and support of children with FASD (including any special techniques on how to assist these children in both special and traditional educational settings, and including such practices that incorporate information concerning the identification, behavioral supports, teaching, and learning associated with FASD) to—

(i) education groups such as the National Association of School Boards, the National Education Association, the American Federation of Teachers, the National Association of Elementary School Principals, the National Association of Secondary School Principals and national groups of special education teachers;

(ii) recipients of a grant under the 21st Century Community Learning Center program established under part B of title IV of the Elementary and Secondary Education Act of 1965 (20 U.S.C. 7171 et seq.) and other after school program personnel; and
(iii) parent teacher associations, parent information and training centers, and other appropriate parent education organizations;

(B) ensure that, in administering the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), parents, educators, and advocates for children with disabilities are aware that children with FASD have the right to access general curriculum under the least restrictive environment;

(C) collaborate with other Federal agencies to include information or activities relating to prenatal alcohol and other harmful substance exposure in programs related to maternal health and health education; and

(D) support efforts by peer advisory networks of adolescents in schools to discourage the use of alcohol and other harmful substances while pregnant or when considering getting pregnant.

(3) DEFINITION.—For purposes of this subsection, the term “FASD” has the meaning given such term in section 399H(a) of the Public Health Service Act, as added by section 3.
(4) Authorization of Appropriations.—
There are authorized to be appropriated to carry out
this subsection $5,000,000 for each of fiscal years
2022 through 2027.

(b) Prevention, Identification, Intervention
and Services in the Justice System.—

(1) In general.—The Attorney General shall
address justice-related issues with respect to youth
and adults with FASD and other
neurodevelopmental conditions as a result of pre-
natal substance exposure, in accordance with this
subsection.

(2) Requirements.—The Attorney General,
acting through the Office of Juvenile Justice and
Delinquency Prevention and the Bureau of Justice
Initiatives, shall—

(A) develop screening and assessment pro-
cedures and conduct trainings on demonstration
FASD surveillance projects in adult and juve-
nile correction facilities in collaboration with
the National Center on Birth Defects and De-
velopmental Disabilities and assistance from ap-
propriate medical and mental health profes-
sionals;
(B) provide culturally appropriate support and technical assistance to justice systems professionals in developing training curricula on how to most effectively identify and interact with individuals with FASD or similar neurodevelopmental disorders in the adult and juvenile justice systems, and such support may include providing information about the prevention, assessment, identification and treatment of these disorders into justice professionals’ credentialing or continuing education requirements;

(C) provide culturally appropriate technical assistance to adult and juvenile systems in addressing the integration of prenatal alcohol and substance exposure history into existing validated screening and assessment instruments;

(D) provide culturally appropriate technical assistance and support on the education of justice system professionals, including judges, attorneys, probation officers, child advocates, law enforcement officers, prison wardens and other incarceration officials, medical and mental health professionals, and administrators of developmental disability, mental health and alter-
native incarceration facilities on how to screen, assess, identify, treat, respond and support individuals with FASD and other conditions as a result of substance exposure within the justice systems, including—

(i) programs designed specifically for the identification, assessment, treatment, and education of those with FASD;

(ii) curricula development and credentialing of teachers, administrators, and social workers who implement such programs; and

(iii) how FASD and other neurodevelopmental disorders impact an individual’s interaction with law enforcement and whether diversionary sentencing options are more appropriate for such individuals;

(E) conduct a study on the practices and procedures within the criminal justice system for identifying and treatment of juvenile and adult offenders with neurodevelopmental disabilities, such as FASD, the impact of FASD on offenders’ cognitive skills and adaptive functioning, and identify alternative culturally-ap-
propriate methods of treatment and incarcer-
ation that have been demonstrated to be more
effective for such offenders; and

(F) collaborate with professionals with
FASD expertise and implement FASD-in-
formed transition programs for adults and juve-
niles with FASD who are released from adult
and juvenile correctional facilities.

(3) **ACCESS FOR BOP INMATES.**—The Attorney
General shall direct the Reentry Services Division at
the Bureau of Prisons to ensure that each inmate
with FASD or a similar neurodevelopmental disorder
who is in the custody of the Bureau of Prisons have
access to FASD-informed culturally appropriate
services upon re-entry, including programs, re-
sources, and activities for adults with FASD, to fa-
cilitate the successful reintegration into their com-
munities upon release.

(4) **AUTHORIZATION OF APPROPRIATIONS.**—For
the purpose of carrying out this subsection, there
are authorized to be appropriated $2,000,000 for
each of fiscal years 2022 through 2027.

(e) **DEFINITION.**—For purposes of this section, the
term “FASD” has the meaning given such term in section
1 399H(a) of the Public Health Service Act, as amended
2 by section 3.