



The FASD Respect Act Advancing FASD Research, Services, and Prevention

NEED FOR ACTION:

Harm to America’s children from prenatal alcohol exposure (PAE) is a significant public health problem and the most commonly known cause of developmental disabilities in the United States. Recent research 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). PAE is especially harmful to the developing brain impacting all facets of a child’s life. Research also shows that alcohol causes far greater harm to the developing brain than any other drug combined, yet recognition of the disability -- with appropriate supports and services -- can prevent secondary disabilities (e.g., dropping out of school, getting into trouble with the law, alcohol and drug use, etc.).

Alarming gaps in FASD-related diagnostic and clinical resources. Among medical and behavioral health professionals, inconsistent use or limited knowledge of diagnostic criteria and clinical guidelines result in many (if not most) children and adults living with FASD going undiagnosed or misdiagnosed. Families in every state, and especially in the child welfare system, struggle with FASD, and they cannot find systems of care that are familiar with or are equipped to diagnose and address FASD-related disabilities.

Federal funding for FASD prevention and intervention has declined from \$27 million in authorized in the Fetal Alcohol Syndrome Prevention Act of 1998 to just over \$12 million in FY2021. Also, existing FASD efforts are hindered by fragmented federal, state and local policy approaches and a lack of resources specifically dedicated to FASD prevention and intervention. Although many states and local communities have programs and policies to help support FASD prevention, FASD-informed intervention practices and services are limited in most systems of care around the country, and the United States itself lacks a national agenda to unite government efforts towards a common goal.

SECTION-BY-SECTION SUMMARY:

The “FASD Respect Act” authorizes \$50 million for FASD prevention efforts, screening and identification, and FASD-informed services by federal, state, local, tribal and private stakeholders. Most importantly, the bill creates a structure for the development of well-informed public policy on FASD and provides for a clear, ongoing societal commitment to advancing research and ensuring essential services for persons with FASD and their caregivers.

The bill reauthorizes and strengthens existing federal FASD programs, including the Interagency Coordinating Committee on FASD, replaces the defunct National FAS Taskforce with a National Advisory Council on FASD and establishes a FASD Center of Excellence as the go-to entity for state, tribal and local governments and non-governmental stakeholders seeking to develop new or improve existing best practices for FASD prevention, diagnosis, and intervention programs and services. The bill includes the following sections, as follows:

SECTION 1. SHORT TITLE - “Advancing FASD Research, Prevention and Services Act”.

SECTION 2. PROGRAMS FOR FETAL ALCOHOL SPECTRUM DISORDERS.

(a) Amends Part O of Title III of the Public Health Service Act by adding the following:

(a) DEFINITION. The terms ‘fetal alcohol spectrum disorders’ and ‘FASD’ mean the range of adverse effects that can occur in an individual who is prenatally exposed to alcohol. Such effects may include physical, mental, behavioral, and learning disabilities, with possible lifelong implications.

(b) RESEARCH ON FASD AND RELATED CONDITIONS (NIAAA). The Secretary, acting through the Director of the National Institutes of Alcohol Abuse and Alcoholism (NIAAA) shall: (1) establish a research program for FASD; and (2) award grants, contracts, or cooperative agreements to public or private nonprofit entities to pay all or part of carrying out research under the program established.

(c) SURVEILLANCE, PUBLIC HEALTH RESEARCH, AND PREVENTION ACTIVITIES (CDC). The Secretary, acting through the CDC’s Director of the National Center on Birth Defects and Developmental Disabilities, shall facilitate surveillance, public health research, and prevention of FASD in accordance with this section.

(d) BUILDING STATE FASD SYSTEMS (HRSA). The Secretary, acting through the Administrator of the Health Resources and Services Administration (HRSA), shall award grants, contracts, or cooperative agreements to States for the purpose of: 1) creating a state Advisory group to develop a statewide FASD strategic plan for FASD prevention and intervention programs and services; and, 2) establishing or expanding statewide programs of surveillance, screening and diagnosis, prevention, and clinical intervention, as well as training of health care (including mental health) providers on prevention and support services or programs for individuals with

FASD and their families and dissemination of FASD information to individuals with FASD and their families.

(e) PROMOTING COMMUNITY PARTNERSHIPS (HRSA). The Secretary, acting through the HRSA Administrator, shall award grants, contracts, or cooperative agreements to eligible entities to enable them to establish, enhance, or improve community partnerships for the purpose of collaborating on common objectives and integrating FASD services into existing programs and services available in the community for treatment, and provision of support services. Activities could include: needs assessment; screening for and diagnosing FASD; engaging in public awareness and outreach activities; or mentoring or providing other support services for those with FASD.

(f) DEVELOPMENT OF BEST PRACTICES (HRSA). The Secretary, acting through the HRSA Administrator, shall award grants to States, Indian tribes and tribal organizations, and non-governmental organizations for the establishment of pilot projects to identify, implement and evaluate best practices in educating children with FASD; educating numerous professionals (justice and child welfare) in identification, treatment and support of those with FASD.

(g) TRANSITIONAL SERVICES (HRSA) – SERVICES FOR ADULTS. The Secretary, in coordinating with the HRSA Administrator and 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 non-governmental organizations for the purpose of establishing integrated systems for providing transitional services for adults affected by prenatal alcohol exposure and evaluating such services for their effectiveness. Allowable activities include housing assistance, vocational training and placement services, medication monitoring, training and support for organizations providing family services or mental health programs for adults with FASD and providing trained mentors for individuals with FASD

(h) AUTHORIZATION OF APPROPRIATIONS. Authorization of expenditures for fiscal years 2022 through 2027.

(b) SERVICES FOR INDIVIDUALS WITH FASD. (Amends Subpart 2 of part B of title V of the Public Health Service Act). The Secretary may make awards to public and nonprofit entities, including Indian tribes and tribal organizations, for the purpose of providing FASD-informed services to individuals with FASD. Allowed services include screening to determine type and level of services, development of a comprehensive plan, mental health counseling, substance abuse services and treatment, coordinating services with other services and programming, vocational services,

health counseling, housing assistance, parenting skills training, overall case management, supportive services for families, respite care for caretakers, provides trained mentors and educational and supportive services for those with FASD.

(c) PREVENTION, IDENTIFICATION, INTERVENTION, AND SERVICES IN THE EDUCATION SYSTEM.

The Secretary of Education shall have responsibility over education-related issues with respect to children with FASD. The Office of Special Education and Rehabilitative Services shall conduct and disseminate training on a FASD surveillance campaign; disseminate evidence-based best practices effective in the education and support for children with FASD; ensure that in administering IDEA, parents, educators, and advocates for children with disabilities are aware that children with FASD have the right to access to the general curriculum under the least restrictive environment; collaborate with other federal agencies to include information or activities relating to FASD in maternal health and health education, and sex education; and, collaborate with the Secretary of HHS to ensure that FASD prevention grants (CDC) include education concerning FASD in sexual health education curricula of schools; and, support efforts with peer advisory networks of adolescents in schools to discourage the use of alcohol during pregnancy or while considering getting pregnant.

(d) PREVENTION, IDENTIFICATION, INTERVENTION, AND SERVICES IN THE JUSTICE SYSTEM.

The Attorney General shall direct the Office of Juvenile Justice and Delinquency Prevention (OJJDP) to develop screening procedures and conduct training on a nationwide FASD surveillance campaign in collaboration with CDC; introduce training curricula on effective methods of interacting with individuation in juvenile justice systems; investigate incorporating into justice professionals' credentialing requirements; promote the tracking of individuals entering the juvenile justice system with a high probability of having an FASD, especially whose mothers have a record of heavy or binge drinking during pregnancy as reported by a child protection agency; and, educate judges, attorneys, probation officers, child advocates, law enforcement officers, prison wardens, alternative incarceration administrators, and incarceration officials, on how to treat, respond to, and support individuals with FASD within the juvenile justice systems; conduct a study on the inadequacies of the current system of processing children with developmental delays and implement alternative methods of incarceration and treatment that are more effective for youth offenders with FASD; and, collaborate with FASD professionals and implement transition programs for juveniles with FASD.



(e) SUNSET PROVISION. Requires the Secretary of HHS to make recommendations to Congress whether programs shall continue no later than four years after appointment of members to the National Advisory Council on FASD.

SECTION 3. NATIONAL ADVISORY COUNCIL ON FASD.

The Secretary shall establish a 17-member advisory council to be known as the National Advisory Council on FASD to foster coordination and cooperation among all government agencies, academic bodies and community groups that conduct or support FASD research, programs, and surveillance, and otherwise meet the general needs of populations actually or potentially impacted by FASD.

1) advise Federal, State and local programs and research concerning FASD; review the 2009 National Task Force “Call to Action” Report and other research advances in FASD prevention and intervention ; make recommendations on a national agenda with the objective of reducing the prevalence and the associated impact of FASD and improving the quality of life for people living with FASD and their families. The Council will provide periodic reports to Congress with a final report summarizing the advances in research and an update to the national agenda no later than September 30, 2027.

SECTION 4. INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SPECTRUM DISORDERS.

The Secretary, acting through the Director of the National Institute of Alcohol Abuse and Alcoholism, shall provide for the continuation of the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders to 1) coordinate activities conducted by the Federal Government on FASD, including convening meetings, establishing work groups, sharing information, and facilitating and promoting collaborate projects among Federal agencies, the National Advisory Council on FASD and outside partners; and 2) develop priority areas considering recommendations from the National Advisory Council on FASD.

SECTION 5. FASD CENTER FOR EXCELLENCE.

The Secretary shall award up to four grants, cooperative agreements, or contracts to public or nonprofit entities with demonstrated expertise in FASD awareness, prevention, identification and intervention services to establish a Center of Excellence to build local, state, and national capacities to prevent the occurrence of FASD (including other defects or disorders related to the combined abuse of alcohol and other substances) and to respond to the needs of individuals and

their families. The Center will be the go-to resource for the federal government, states, local communities, Indian tribes and tribal organizations and nongovernmental organizations for receiving technical assistance in the development of best practices and community partnerships.

SECTION 6. APPROPRIATIONS

Authorizes appropriations for each year \$50,000,000 for FY2022 and such sums as may be necessary for each of fiscal years 2023 through 2027. Funding for the National Advisory Council on FASD shall not exceed \$2 million and for the Interagency Coordinating Committee on FASD shall not exceed \$1 million.

