



“Advancing FASD Research, Services, and Prevention Act”

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 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 alcohol causes far greater harm to the brain than other drugs, yet recognition of the disability -- with appropriate FASD-informed 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 exist in FASD-related diagnostic and clinical resources around the country. 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 equipped to diagnose and address FASD-related disabilities.

Meager Federal Funding for FASD prevention and intervention has declined from \$27 million authorized in the Fetal Alcohol Syndrome Prevention Act of 1998 to only \$12 million in FY2021, of which \$11 million goes to the Centers for Disease Control and Prevention (CDC). The National Institute of Health, through the National Institute on Alcohol Abuse and Alcoholism (NIAAA), has provided support for FASD research for several decades and continues that support in FY 2021 for a total of \$30 million.

Existing FASD efforts are hindered by fragmented Federal, State, Tribal and local policy approaches and insufficient resources dedicated to FASD prevention and FASD-informed intervention services. Though state and local communities have programs and policies to help support prevention efforts, FASD-informed intervention practices and services are limited in most systems of care, and the United States lacks a national agenda to unite government efforts toward the goal of advancing FASD research, services and prevention.

The FASD Respect Act lays the groundwork to construct that national agenda by enhancing programs and funding for FASD research, prevention, screening and identification, and FASD-informed services by federal, state, local, tribal and private stakeholders. Most important, the bill creates the structure for collaboration and development of well-informed public policy on FASD and a clear, ongoing societal commitment to advance FASD research and prevention programs and ensure essential FASD-informed services for persons with FASD and their caregivers.

The bill’s key provisions would: reauthorize and strengthen existing federal FASD programs, including the Interagency Coordinating Committee on FASD; replace the defunct National FAS Taskforce with a National Advisory Council on FASD; establish new FASD programs on Building State and Tribal FASD Systems, Community Partnerships, Best Practices and Models of Care, Transitional Services and Demonstration FASD-informed Services for Individuals with FASD; provide funding to the Departments of Education and Justice for FASD education awareness and training; and, establish 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, screening and identification, diagnosis, and FASD-informed intervention programs and services.

SECTION-BY-SECTION SUMMARY:

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

SECTION 2. FINDINGS.

SECTION 3. PROGRAMS FOR FETAL ALCOHOL SPECTRUM DISORDERS.

(a) DEFINITION. The terms ‘fetal alcohol spectrum disorders’ and ‘FASD’ mean diagnosable developmental disabilities of a broad range of neurological and physical effects that result from prenatal exposure to alcohol. Such effects may include lifelong physical, mental, behavioral, social and learning disabilities, and other problems that impact daily functioning (e.g., living independently or holding a job), and overall health and well-being.

(b) RESEARCH ON FASD AND RELATED CONDITIONS (NIAAA). Updated authorization for the Secretary, acting through the Director of the National Institutes of Alcohol Abuse and Alcoholism (NIAAA) to carry on its (1) research program for FASD, and (2) award of grants, contracts, or cooperative agreements to public or private nonprofit entities to pay all or part of carrying out research under the program established. Authorizes NIAAA \$30 million for each of Fiscal Years (FYs) 2022-2027.

(c) SURVEILLANCE, PUBLIC HEALTH RESEARCH, AND PREVENTION ACTIVITIES (CDC). Updated authorization for the Secretary, acting through the CDC’s Director of the National Center on Birth Defects and Developmental Disabilities, to facilitate surveillance, public health research, and prevention of FASD in accordance with this section. The CDC also must support: development of evidence-based clinical diagnostic guidelines and criteria for all fetal alcohol spectrum disorders; training and support of medical and mental health professionals on the early identification of children with FASD or other substance exposure; and, public health research to identify evidence-based strategies for reducing high risk alcohol and other substance exposed pregnancies. Authorizes CDC \$13 million for each of FY 2022-2027.

(d) BUILDING STATE FASD SYSTEMS (HRSA). The Secretary, acting through the Health Resources and Services Administration (HRSA), shall award grants, contracts, or cooperative agreements to States and Indian Tribes to establish on-going comprehensive and coordinated State and Tribal multi-disciplinary, diverse coalitions to:

- 1) develop systems of care on prevention of FASD and other adverse conditions from prenatal substance exposure and the identification, treatment and support of individuals with FASD or other adverse conditions from prenatal substance exposure and their families;

2) provide leadership and support in establishing, expanding or increasing State and Tribal capacity to address FASD and other adverse conditions as a result of prenatal substance exposure; and

3) update or develop, implement and evaluate State and Tribal FASD strategic plans.

Eligibility: States and Tribes designate a lead State agency or Tribal entity with authority to implement programming and provide evidence of the establishment of a FASD Advisory Group of relevant State agencies or Tribal entities and, if available, a statewide FASD advocacy organization to provide leadership in building State or Tribal capacity to address prenatal alcohol and other substance exposure through the formation of a public-private diverse multi-disciplinary FASD advisory coalition and development of a State or Tribal strategic plan for a comprehensive approach to State or Tribal FASD prevention, identification and intervention.

Activities funded: Enumerates eligible activities States and Tribes can undertake with grant funds, including increasing diagnostic capacity, training of professionals, prevention and intervention programming. Allows States and Tribes to contract with another State or States or Tribes to carry out activities under this section.

Report to Congress: Requires HRSA to submit a report to Congress on: the number of States receiving grants; State and Tribal diagnostic capacity and surveillance data or most recent FASD prevalence; data on systemic or other barriers to screening for FASD and other prenatal substance exposures; data on existing systems of care and funding streams that could be used to assist individuals with FASD and other conditions related to substance exposure.

Authorizes for subsection (d) \$32 million for each of FYs 2022-2027, with 20 percent of grants set aside for Tribes, and \$12 million allocated to States and Tribes to cover administrative costs and support employment of FASD State and Tribal coordinators.

(e) PROMOTING COMMUNITY PARTNERSHIPS (HRSA).

The Secretary, acting through HRSA, shall award grants, contracts, or cooperative agreements to eligible entities to enable them to establish, enhance, or improve community partnerships to collaborate on common objectives and integrate FASD-informed 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 FASD-informed support services for those with FASD. Authorizes \$5 million for each of FYs 2022-2027.

(f) DEVELOPMENT OF BEST PRACTICES AND MODELS OF CARE (HRSA).

The Secretary, acting through HRSA, shall award grants to States, Tribes and Tribal organizations, and non-governmental organizations to establish pilot projects to identify, implement and evaluate culturally informed best practices in educating children with FASD, and educating numerous professionals (justice and child welfare) in identification, treatment and support of those with FASD. Authorizes \$5 million for each of FYs 2022-2027.

(g) TRANSITIONAL SERVICES FOR ADULTS (HRSA).



The Secretary, in coordination with HRSA and the Council on Independent Living, shall award demonstration grants, contracts, and cooperative agreements to States, Tribes and Tribal organizations, and non-governmental organizations to establish integrated systems for providing transitional services for adults affected by prenatal alcohol or substance exposure and evaluating such services for their effectiveness. Allowable activities include: housing assistance or specialized housing for adults with FASD (includes developing and evaluating housing models specifically for those with FASD); FASD-informed vocational training and placement services; medication monitoring; FASD-informed training and support to organizations providing family services or mental health programs; and mentors for individuals with FASD. Authorizes \$5 million for each of FYs 2022-2027.

(h) SERVICES FOR INDIVIDUALS WITH FASD.

The Secretary, in coordination with the Assistant Secretary for Mental Health and Substance Use, shall make awards to public and nonprofit entities, including Tribes and Tribal organizations, to provide services to individuals with FASD. Allowable FASD-informed culturally-informed services include: screening to determine type and level of services; development of a comprehensive plan; mental health counseling; substance use 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; mentors and educational and supportive services for individuals with FASD. Authorizes \$10 million for each of FYs 2022-2027.

SECTION 4. NATIONAL ADVISORY COUNCIL ON FASD.

The Secretary shall establish an advisory council of 23 public and nonpublic members to be known as the National Advisory Council on FASD to foster coordination and cooperation among all federal 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.

The Council shall: 1) advise Federal, State and local programs and research concerning FASD; 2) coordinate its efforts with the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD); 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 NIAAA; 5) review the 2009 National Task Force "Call to Action" Report and other research advances in FASD prevention and intervention; and, 6) 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. The Council will provide periodic reports to Congress and a final report summarizing the advances in research and an update to the national agenda no later than September 30, 2027. Authorizes \$2 million for each of FYs 2022-2027.

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

The Secretary, acting through the NIAAA, shall provide for continuation of the ICCFASD to: 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 and outside partners; 2) support development of evidence-based clinical diagnostic criteria and guidelines for FASD; and 3) develop priority areas considering recommendations from the National Advisory Council on FASD. Authorizes \$1 million for each of FYs 2022-2027.

SECTION 6. FASD CENTER FOR EXCELLENCE.

The Secretary, acting through HRSA, 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 for the establishment of a Center of Excellence to build local, State, Tribal and national capacities to prevent the occurrence of FASD and other conditions related to prenatal substance exposure and to respond to the needs of individuals with FASD and their families. The Center will be the go-to resource for the Federal Government, States, local communities, Tribes and Tribal organizations, and nongovernmental organizations for receiving technical assistance in the development of best practices and community partnerships. Authorizes \$8 million for FYs 2022-2027.

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

(a) 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: disseminate culturally appropriate best practices that are FASD-informed 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 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 support efforts with peer advisory networks of adolescents in schools to discourage alcohol use during pregnancy or while considering getting pregnant. Section 7(a) authorizes \$5 million for each of FYs 2022-2027.

(b) PREVENTION, IDENTIFICATION, INTERVENTION AND SERVICES IN THE JUSTICE SYSTEM. The Attorney General, acting through the Office of Juvenile Justice and Delinquency Prevention and the Bureau of Justice Initiatives, shall:

- 1) develop screening and assessment procedures and conduct training on demonstration FASD surveillance projects in juvenile and adult correctional facilities in collaboration with the CDC;
- 2) provide culturally-appropriate technical assistance in integrating evidence of prenatal and substance exposure into existing screening and assessment instruments;
- 3) educate judges, attorneys, probation officers, child advocates, law enforcement officers, prison wardens, alternative incarceration administrators, and incarceration officials, on how to screen, identify, treat, respond to and support individuals within the justice system who have FASD and other conditions as a result of substance exposure;
- 4) conduct a study on existing justice system practices and procedures for identification and treatment of adults and juveniles with neurodevelopmental disabilities and identify alternative

culturally appropriate methods of treatment and incarceration that have been demonstrated to be more effective for such offenders; and

5) collaborate with professionals with FASD-expertise and implement FASD-informed transition programs for adults and juveniles from correctional facilities. The Reentry Services Division, Bureau of Prisons, must provide to all inmates with FASD or similar neurodevelopmental disorders access to FASD-informed culturally-appropriate services upon release and reentry into the community. Section 7 (b) authorizes \$2 million for each of FYs 2022-2027.

CONTACT INFORMATION:

House Lead Sponsors:

Representative Betty McCollum (D-MN-04):
Staff: Sophia.Schilling@mail.house.gov
(202) 225-6831

Representative Don Young (R-AK-At Large)
Health Staff: Jesse.VonStein@mail.house.gov
(202) 225-5765

Senate Lead Sponsors:

Senator Lisa Murkowski (R-AK)
Staff: Anna_Dietderich@murkowski.senate.gov
Cassidy_Hobbs@murkowski.senate.gov
(202) 224-6665

Senator Amy Klobuchar (D-MN)
Staff: Ashley_Bykerk@klobuchar.senate.gov
(202) 224-3244

**National Organization on Fetal Alcohol
Syndrome**

Tom Donaldson, NOFAS President
(FASD subject matter; federal involvement)
donaldson@nofas.org
(202) 785-4585, ext. 3

Susan Shepard Carlson
NOFAS Legislative & Policy Chair
(FASD subject matter; bill language & content)
Susca719@gmail.com
(612) 414-3125