Talking Points

Meeting Template

Time	Role	Description
0-3 mins	Constituent host	**Introduce** advocates, thank staff/Member, ask how familiar they are with FASD, introduce **"the ask": Support FY27 appropriations of $21.5 million for CDC's FASD programs ($10 million increase over FY26)** and **$5 million in FY27 Defense Appropriations to continue the FASD prevention and clinical guidelines research project at the Uniformed Services University Center for Health Services Research.**
3-8 mins	FASD 101 Speaker	Share **basics of FASD** (description, prevalence, symptoms, impact on health and education)
8-9 mins	Pause for questions and comments	Make sure to keep staff/Member **engaged** throughout. Use this time to **summarize** the issue
9-14 mins	Living experience	Share **personal connection** to FASD, highlighting a specific **challenge** and what kind of **support** would be helpful
14-19 mins	Professional or Researcher	Share **insights from your field** or work with FASD. Highlight systems-level challenges or successes.
19-24 mins	Policy	Overview of FASD provisions passed as part of SUPPORT Reauthorization Act and how funding/appropriations will improve systems of care.
24-30 mins	Discussion	Engage with staff/Member

- Meetings are usually scheduled for 30 minutes, but you should always check how much time is available with the staffer or scheduler.
- While every meeting will look a little different, it is smart to plan ahead and have a meeting outline prepared. Depending on how many advocates are attending a meeting you need to make sure everyone has time to share their story, provide background information, and offer solutions.
- You will also want to allow time for questions and engagement; getting your Member of Congress and their staff interested in FASD is the goal here, so take every chance you get to capture their attention. The table above shows how a typical meeting runs.

Basics

Current federal funding for FASD programs does not match its prevalence or the need. Current efforts at the CDC and HRSA for screening and intervention, awareness, and capacity building are necessary but fall short. Increased funding will strengthen these current programs and will allow for the full intent of the new law to be carried out: building state and Tribal capacity to address FASD, coordinate work across systems and agencies, and fit FASD into systems of care. These updated provisions still need to be implemented, and that can be effectively and efficiently done with funding.

- **What it is:** Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person exposed to alcohol before birth. These neurodevelopmental conditions can affect each person in different ways. People with FASDs can have lifelong effects, including challenges with behavior and learning as well as physical problems. Individuals with FASD also show a wide range of strengths.
- **Not rare.** An estimated 1 in 20 Americans has an FASD. 1 in 7 pregnancies are alcohol exposed. FASD is more common than autism (1 in 31) and far more common than Down syndrome (1 in 640).
- **Underdiagnosed and misdiagnosed.** One study found 86.5% of youth with FASD in child welfare had never been diagnosed or had been misdiagnosed. Most people with FASD are being served by systems that do not know they have it.
- **Exposure often happens before a pregnancy is recognized.** FASD is a public health issue that crosses every geography, culture, and income level. It is not a character issue.
- **Compare to other prenatal exposures.** The Institute of Medicine found that, compared with other substances used during pregnancy, alcohol produces by far the most serious neurobehavioral effects on prenatal development. Despite this, FASD is rarely included when Congress addresses substance-exposed pregnancies.
- **Current efforts are disjointed.** There is no coordinated federal, state, and Tribal strategy. The FASD provisions enacted in Section 104 of the SUPPORT Reauthorization Act of 2025 were written to fix this.

The Cost of Inaction

- $215 billion a year. Estimated total annual U.S. expenditure associated with FASD across health care, special education, child welfare, corrections, and lost productivity (at 2% prevalence).

- $2.0 to $2.4 million per person over a lifetime, or $24,000 to $45,000 per person per year.
- $1.7 to $2.0 billion per birth cohort.

What the FASD Respect Act (Section 104 of the SUPPORT Reauthorization Act) Does

- **The FASD Respect Act language became law** on December 1, 2025**.** It was enacted as Section 104 of the SUPPORT for Patients and Communities Reauthorization Act of 2025 (Pub. L. 119-44), titled "Support for Individuals and Families Impacted by Fetal Alcohol Spectrum Disorder."
- **It restored a program that had been inactive since 2007.**
- It also created new provisions that still need to be implemented. This takes time, education, and greater funding. Advocates can help legislators understand the need to provide more funding in order to fulfill the intent behind the FASD Respect Act.
- **Intent:** Strengthen capacity to address FASD and support individuals and families by increasing coordination and understanding of FASD at the national level while supporting states and tribes in building up their own systems of care. State and Tribal capacity building allows for states and tribes to assess how they are currently addressing FASD to determine how to best fit it into existing systems of care.

What the law now authorizes:

- **A comprehensive national program** for FASD education, prevention, identification, intervention, and service delivery, reaching health profession schools and serving people with FASD from infancy through adulthood (Sec. 399H(a)(1)).
- **Research on diagnosis and prevention,** including culturally and linguistically appropriate prevention and interventions that address alcohol alongside other substances (Sec. 399H(a)(2)).
- **State and Tribal capacity building,** new to the law: adapting existing federal, state, and Tribal programs to include FASD, expanding screening and diagnostic capacity, evaluating interventions, training, and information dissemination (Sec. 399H(a)(3)).
- **Grants and technical assistance** to states, tribes and Tribal organizations, local governments, academic institutions, and nonprofits (Sec. 399H(b)).

- **A federal definition of "FASD-informed"** (Sec. 399H(c)), the first time the term appears in federal law. Puts emphasis on quality of life for individuals.
- **Nationwide prevention capacity grants** for public education, an evidence-based clearinghouse of FASD resources, awareness of screening tools and interventions, and technical assistance to other grantees (Sec. 399I).
- Grant applicants may be required to designate **a State or Tribal FASD Coordinator and establish an advisory committee** to guide a statewide or Tribal strategic plan (Sec. 399H(b)(3)).

$12.5 million authorized for each of FY2026 through FY2030, plus a report to Congress evaluating the program within four years and annually after that (Sec. 399J).

The law authorizes $12.5 million each year, but the actual funding comes from the appropriation process. **We are asking for $21.5 million to be able to fulfill the intent of the new law.** This is $10 million more than was appropriated for federal FASD programs at the CDC in FY26.

FASD Project with Uniformed Services University of the Health Sciences-FASD Prevention and Clinical Guidelines Research

This information can be shared with members on the **Appropriations Committee** or **Armed Services Committee**

We are asking for $5 million to continue and complete the FASD Prevention and Clinical Guidelines Research project. The Uniformed Services University (USU) Center for Health Services Research runs it in collaboration with FASD United to address FASD in the Military Health System. This was first funded in 2022-2023.

- **FASD is a military family issue.** More than 9.5 million service members, retirees, and family members, including nearly 2 million children, get care through the Military Health System. Alcohol use in the military runs higher than the national average.
- **This is a continuation of work, not a new project.** Since 2022, the Uniformed Services University Center for Health Services Research, in collaboration with FASD United, has run the FASD Prevention and Clinical Guidelines Research project. Before it, there were no studies of FASD in the Military Health System.

- Found **only 1,479 FASD diagnoses among 1.7 million military-connected children** (2016 to 2023), far below expected prevalence. Most military kids with FASD are undiagnosed, which highlights the need to expand capacity to diagnose.
- **Found no FASD-specific resources anywhere in the Military Health System.**
- **Trained more than 322 military providers** on FASD diagnosis and management.
- Partnered with Madigan Army Medical Center **to launch telehealth neurodevelopmental diagnosis** for remote bases.
- **Started a pilot telehealth consult model** for clinics beyond NDAA travel limits, aimed at helping Exceptional Family Member Program families take assignments at rural bases.
- Published six papers and held four annual USU/FASD United research workshops.
- **Military doctors want help**. A survey of 343 active-duty family physicians, published in 2026 in Military Medicine by USU researchers, found that only 4% answered all three basic FASD questions correctly, 62% rarely or never screen for prenatal alcohol exposure, and 80% had no FASD training since residency. 90% want FASD training and 94% want access to a developmental pediatrician for consults.

Appropriations Background

Congress authorized FASD programs in Section 104 of the SUPPORT Reauthorization Act of 2025. Now it's time to fund them. Authorizing a program is step one. Funding it is step two, and that has not happened yet.

- **Authorized is not the same as funded.** Last year Congress said FASD programs should exist and set a level of $12.5 million a year. But no money is actually put towards programs until the Appropriations Committees put dollars in the annual spending bills. Until then, the new state and Tribal capacity building, grants, and clearinghouse exist on paper but not in reality. Greater investment is needed so screening, intervention, awareness, and capacity building efforts can happen at scale.
- **Funding and awareness for FASD do not match its prevalence.** Right now the federal government spends about $12.5 million a year on FASD programs at CDC and HRSA. That is against $215 billion a year in costs to health care, education, child welfare, and justice systems.
- **Current funding was set before Section 104 of the SUPPORT Reauthorization Act passed.** Current funding pays for alcohol screening during pregnancy, public awareness campaigns, monitoring, and a small amount of FASD screening and

intervention. Not only are the current work and funding not enough to meet the needs of families and our systems, but it does not cover the intent of the new law. The intent is to start building state and Tribal capacity to identify and support people with FASD, allow for grants and technical assistance, and create an evidence-based clearinghouse. An updated response to FASD calls for an updated investment.

- **We know this approach works.** Sustained federal funding for autism trained professionals, built state capacity to screen and diagnose, and funded early intervention that offsets costs by $19,000 per child per year. FASD is more common than autism (1 in 20 versus 1 in 31), but federal funding works out to about $20 per impacted child for FASD compared to $211 for autism. The same proven approach can work for the FASD community with the modest increase requested for FY27.

The Asks (FY27)

The primary "asks" this year are focused on appropriations, or funding. The FASD Respect Act was enacted as part of the SUPPORT Reauthorization Act of 2025, and now it is time to fund it. If the Member you are meeting with sits on the Appropriations Committee in their chamber you can directly ask them to support appropriation requests in the **Labor-HHS and Defense spending bills.** Otherwise, you can ask them to send a letter of support to the Appropriations Committee urging them to include the appropriation requests.

- **Labor-HHS:** $21.5 million for CDC's FASD programs (a $10 million increase in the FAS line at NCBDDD), and continue the $1 million SPRANS FASD set-aside at HRSA for screening and intervention.
- **Defense:** $5 million to continue the FASD prevention and clinical guidelines research project at the Uniformed Services University.
- These Appropriations Requests were submitted to 24 Representatives and 6 Senators. Over 100 advocates and organizations also submitted Outside Witness Testimony in support of the Labor-HHS FY27 appropriations request the Senate Committee on Appropriations.
- **For Appropriations Committee Members**
    - They help write the spending bills. Ask them to put FASD funding in directly.
    - **Ask:** "Will you support $21.5M for CDC FASD programs and the $1M HRSA set-aside in the FY27 Labor-HHS bill?"
    - **Ask:** "Will you support $5M for the FASD research project at USU in the Defense bill?"
    - **Get the name of the staffer who handles appropriations.**

- **For Non-Committee Members**
    - They do not write the spending bills, but they can tell the appropriators that FASD matters to their constituents.
    - **Ask:** "Will you send a letter of support for this funding to the Appropriations Committee?"
    - **Ask:** "Will you support $5M for the FASD research project at USU in the Defense bill?"
    - Get the name of the staffer who handles appropriations.
- **For FY28**
    - **Ask: "**When your office submits FY28 appropriations requests next spring, will you include FASD funding at CDC, HRSA, and DOD? Can we please have the contact information for the person responsible for appropriations?"

What Will Be Built with this Investment

Investment into FASD programs at the Department of Health and Human Services (HHS) and the ongoing project with Uniformed Services University of the Health Sciences will lay the groundwork for the following:

- **One shared standard for FASD.** Medical associations, federal agencies, and disease classification systems agreeing on how FASD is defined and diagnosed, so a diagnosis means the same thing in every clinic and every state.
- **Clinical guidelines** for every specialty that touches FASD. Practical guidance for physicians, neurologists, psychologists, speech and occupational therapists, and other specialists, so providers know what to look for and what to do.
- **Billing codes** that let providers get paid for FASD care. Getting FASD-specific codes approved requires consensus definitions, clinical guidelines, and evidence. That is what the USU project and the new law can produce. With codes in place, screening, diagnosis, and treatment can be reimbursed. Right now, care that cannot be billed does not happen.
- **An FASD care model that works anywhere**. A proven clinical model replicated in primary care, hospitals, community health centers, and telehealth, so families do not have to travel to a handful of specialty clinics.
- **A national FASD hub.** A central clearinghouse to train providers, provide technical assistance, and share evidence-based and culturally appropriate practices and resources.

- **FASD systems in every state and tribe.** Advisory committees, strategic plans, and public-private networks so each state and Tribal nation has an FASD plan instead of a patchwork.

White Paper Recs

These are recommendations formulated and reworked by the FASD community based on 10 Recommendations for "Advancing Essential Services and Research on Fetal Alcohol Spectrum Disorders" from the 2009 FASD Task Force Call to Action.

- **Diagnosis and screening (2024)** Universal screening across all ages, standardized procedures, comprehensive stigma-informed training for professionals, and removal of barriers to diagnosis.
- **Continuum of care (2024)** A comprehensive, accessible continuum of coordinated, evidence-based interventions and policies ensuring lifelong support, reducing stigma, and improving education and job training at every stage of life.
- **Agency collaboration (2024)** A national framework for shared federal leadership, transparent objectives, and coordinated efforts to integrate FASD awareness and support into policy, education, and community resources across all states.
- **Professional education (2025)** Systems that disseminate standardized FASD curricula for professionals and the public across service systems, informed by lived experience, with mechanisms to evaluate community awareness.
- **Grassroots efforts (2025)** Sustained partnerships with and among grassroots FASD organizations to expand funding and resources and ensure programs last.
- **FASD data (2025)** Build the community's ability to use data to track prevalence, measure interventions, assess program impact, and share data across systems.

Fund FASD

Preventing Costs, Supporting People

State Data Sheets

FASD Factsheet

Talking About Prevention