

From Momentum to Systems Change:

How the FASD Respect Act Got Done — and What It Means for the World

Presenters

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FASD United · United States

1 in 20

Americans with FASD

~20 yrs

From first bill to law

366–57

House vote, June 4, 2025

Dec 2025

Signed into law

The Problem We Had to Name

1 in 20

Americans have an FASD

More prevalent than autism

90%+

Undiagnosed
or misdiagnosed

Unsupported by systems of care

~20 yrs

Since federal FASD
authorization expired

SAMHSA funding cut to zero 10 years ago

Stigma

As a barrier to support and
systems change

Prevention was centered, not people

A Critical Reframe: From Prevention to Support

Old Framing

FASD as a problem of maternal behavior to be prevented. Prevention campaigns as the primary face of FASD. People already living with FASD rendered invisible.

New Framing — What Won

FASD as a lifelong neurodevelopmental disability. People with FASD and their families centered. Support, dignity, and lifespan systems change as the goal. NIAAA & CDC research as the foundation.


What Moved Decision-Makers: The Braided Approach

Three strands, woven together deliberately from 2021 — not sequenced, but simultaneous.



Positive Marketing Messaging

- Shift from blame to neurodevelopmental disability
- Dignity and Capability > Tragedy
- Reframed: prevention to support & systems
- FASD as public health opportunity, not moral failure
- Language guides built with self-advocates

 FASD can occur with alcohol use BEFORE recognition of pregnancy



Consistent Outreach


- Continued pressure and momentum
- Monthly policy forums kept advocates activated
- 40+ affiliates became constituency infrastructure
- Equipped advocates: talking points, training, legislative meeting prep
- Largest-ever Capitol Hill FASD day (Sept 2025)

 Contact your 2 Senators & 1 Representative regularly and often



Engagement of Self-Advocates, Parents & Caregivers

- Testified directly before Congress
- Co-designed policy language
- Reached through Facebook groups, task forces, affiliates
- Trained on solutions and science
- Living experience makes data human

 1 in 20. That's a student in every classroom

The braid started in 2021 and held for four years across three Congresses. Discipline in all three strands simultaneously — that's what made it unstoppable.

How the FASD Respect Act Was Passed

*Advancing FASD Research, Services & Prevention Act ("FASD Respect Act")
Section 104 · SUPPORT for Patients & Communities Reauthorization Act of 2025 (H.R. 2483)*

Signed Dec. 2, 2025

Bipartisan Authorship

- Senators Murkowski (R-AK) & Klobuchar (D-MN)
- Representatives McCollum (D-MN), Bacon (R-NE) & the late Don Young in House
- Carried across three consecutive Congresses

Stakeholder Mobilization

- Unified national voice
- Self-advocates, families, researchers, medical professionals
- Advocacy made approachable: templates, scripts, monthly forums

Embedded in Must-Pass Vehicle

- Attached to SUPPORT Reauthorization (H.R. 2483)
- Strategic decision: stop waiting for standalone
- Passed House 366–57; unanimous consent in Senate

Sustainability & Accountability

- HHS must report to Congress within 4 years, then annually
- \$12.5M/year authorized FY2026–2030 — a floor, not a finish line
- State & Tribal capacity building built into the statute

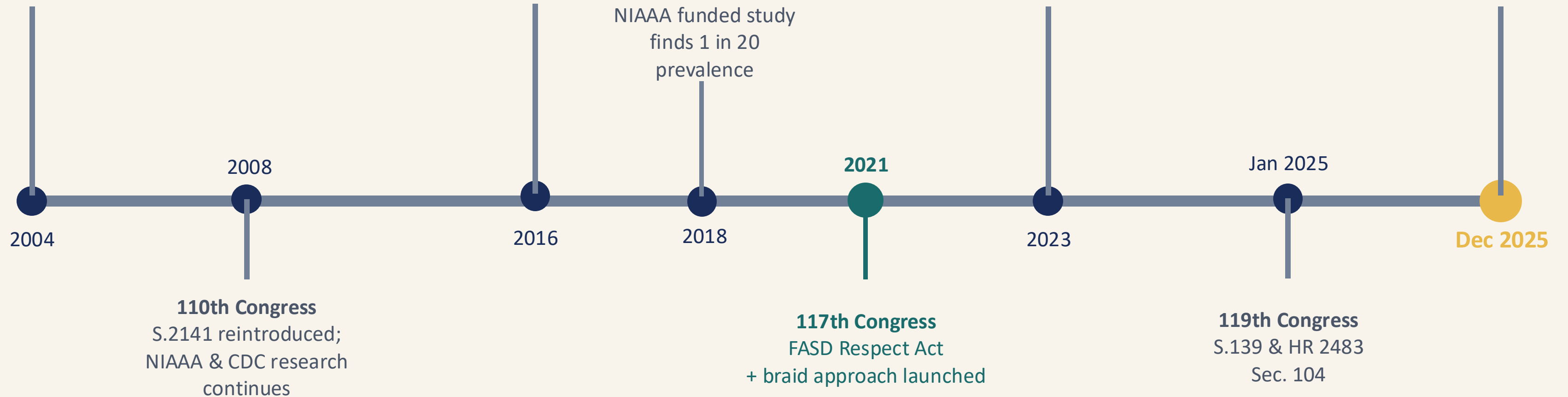
Decades of Persistence: Congressional Milestones

108th Congress
S.2741 — first
FASD reauth bill

114th Congress
SAMHSA FASD funding
reduced to zero

118th Congress
Committee approval —
closest yet

**SIGNED
INTO LAW ✓**
Dec. 2, 2025



2016: SAMHSA FASD funding cut to zero — programs gone, statutory authority lapsed

Legislation passes through sustained relationship-building, strategic timing, and a community that refuses to quit. Every generation of advocates made the next one possible.

The braid held for three Congresses. Science never stopped. Advocates never stopped. 2021 was the turning point.

What Section 104 of the SUPPORT Act Actually Does



§399H: Comprehensive Cross-Systems Program

Coordinates across foster care, social work, health services, education, vocational training, civil & criminal justice. Mandates State & Tribal capacity building



§399I: FASD Grants & Capacity Building

Authorizes grants to public/nonprofit entities to build local, Tribal, State & nationwide capacity — screening, diagnosis, intervention, training & technical assistance. NIAAA & CDC research gives grantees a strong foundation.



Funding Authorization — A Starting Point

\$12,500,000/year for FY2026–2030. First federal FASD funding since SAMHSA programs were eliminated. This is a springboard, not a ceiling. It establishes the federal commitment; making it match the need is the work ahead.



Congressional Accountability

HHS must report to Congress within 4 years and annually — covering public awareness, identification, prevention, treatment, and support for individuals and families with FASD. Accountability for support, not just prevention numbers.



Statutory FASD-Informed Definition

"Culturally and linguistically informed evidence-based interventions and appropriate resources to support an improved quality of life for an individual with FASD and the family of such individual." Quality of life. That is the reframe made law.

The Shift That Won

- FASD explicitly named in federal statute
- Lifespan support, not only prevention
- People with FASD centered in law
- Statutory FASD-informed definition: quality of life
- \$12.5M/yr — federal commitment established; the floor, not the ceiling
- Cross-sector mandate: health, education, justice, child welfare

What Nearly Stopped Us — And How We Navigated It

The Prevention Trap

Framing FASD as a maternal behavior issue left people already living with FASD unseen — and limited the political coalition

→ Reframed in 2021: FASD as a lifelong disability deserving support. Opened the door to disability rights, criminal justice reform, and child welfare allies. "Give FASD a Seat at the Table"

Stigma & Language

Outdated terminology and tragedy narratives repelled legislators and families alike

→ Enforced a positive messaging standard consistently across all FASD United communications and in advocate training. Not a tone preference: a strategic discipline built into the braid from day one.

Fragmentation

FASD spans health, education, justice, child welfare — no federal home, so no action

→ Turned the breadth into the argument. A condition this pervasive required a cross-sector statutory mandate. Section 399H reflects that argument directly by making FASD's reach a design feature, not a liability.

Congressional Inertia

Committee approval in the 118th Congress — meaningful progress, but no floor vote

→ Returned day one of the 119th Congress. Embedded in the SUPPORT Act. Four years of consistent advocate engagement allowed advocates to create moments, not wait for them.

The Work Ahead: The Pathway Forward

The law creates the mandate — implementation is where the gap between statute and lived experience is closed:

Challenges

Diagnosis Gap

90%+ remain undiagnosed. Grants under §399I must fund accessible diagnostic capacity — in rural communities, Tribal nations, and underserved populations, not only urban centers.

Adult Services Cliff

Lifespan framing is in the statute — infants to adults. But the service system largely collapses at 18. Translating statutory language into housing, employment, and justice supports is the next urgent fight.

Support Over Prevention Only

Implementation must serve people living with FASD now, not revert to prevention-only. Support without prevention abandons future children. Prevention without support abandons those already here.

Opportunities

Adapting Existing Systems

Identify gaps and barriers and connect to existing funding streams that should be addressing FASD.

Addressing the Eligibility Barrier

Work to ensure FASD is recognized by programs like IDEA so individuals and families can access the supports they need.

Fighting for Appropriations that Match the Need

Continued advocacy is what will make sure programs and services make it into communities. This will create sustainable funding to help states strengthen their capacity to address FASD.

Applicable to any national or regional advocacy context — drawn from the three braid strands:



Positive Marketing Messaging

ADOPT

Reframe toward support, dignity & quality of life for people with FASD now. Disability-affirming language expands your coalition. Prevention can be part of your message — not all of it. People with FASD are not a cautionary tale.

AVOID

Prevention-only framing that erases people already living with FASD. You cannot sustain a coalition on a message that makes your community invisible.



Consistent Outreach

ADOPT

Invest in equipping advocates — training them how to meet legislators, giving tailored talking points, making them part of the strategy. Show up every session. Relationships built before you need a vote are the ones that deliver.

AVOID

Episodic campaigns around a single bill or a single Hill Day. If your community only mobilizes when legislation moves, the relationships won't be there when the window opens.



Self-Advocate & Family Engagement

ADOPT

Center self-advocates, parents & caregivers as co-authors of policy — start in 2021, not 2025. The four-year investment is what filled Capitol Hill in September 2025 and moved the Senate. When they speak from their own lives, it changes what legislators hear.

AVOID

Treating lived experience as color commentary for expert testimony. Their voices are the expert testimony. Build their role into your strategy from the beginning.



Statutory Sustainability

ADOPT

Fight for statutory authorization AND mandatory reporting — and keep fighting after passage. Any funding you secure is a floor. Plan immediately for what adequate investment actually looks like and build the case for it.

AVOID

Thinking advocacy slows down once a bill passes. Sustained advocacy is what keeps funding growing and prevents it from being stripped away. Build advocacy into your infrastructure permanently.

The Work Continues.

Signed December 2, 2025 — the FASD Respect Act proves that positive messaging, consistent outreach, and self-advocates who refuse to be invisible can move federal law.

What does your country need to reach its own inflection point?

Message

With dignity — positive, affirming language in every piece of outreach and advocacy

Persist

Show up every session and invest in equipping your advocates to do the same

Center

Self-advocates, parents & caregivers as co-authors — from the beginning, not at the end

Embed

Fight for statutory accountability and funding — treat every authorization as a floor, not a ceiling