

FASD United Policy Forum

Fund FASD

Wednesday
July 29th, 2026



***Policy & Training
Center***

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Agenda



➡ FASD United Updates

➡ White Paper

➡ Fund FASD

Org. Updates

FASD Awareness Month

- 2026 Toolkit
- Awareness Month Media
- More to be announced



<https://fasdunited.org/fasd-awareness-month-2026/>

Impact Week

- September 27th-30th, 2026 at Hyatt Regency Crystal City
- Symposium, Red Shoes Gala, Hill Day, Poster Reception, & more TBA!
- Hill Day Champions and Scheduling



<https://fasdunited.regfox.com/impact-week-2026>

FASD WHITE PAPERS

An Invitation to the Table

VERSION 1.2
NOW AVAILABLE!

FASD SYMPOSIUM WHITE PAPERS ↗

Co-Creating
Recommendations for
Progress in the Fetal
Alcohol Spectrum
Disorder (FASD) Field
and Community

An Invitation to the Table.

Volume 1.2



WASHINGTON D.C.
SEPTEMBER 15, 2025

A project of FASD United



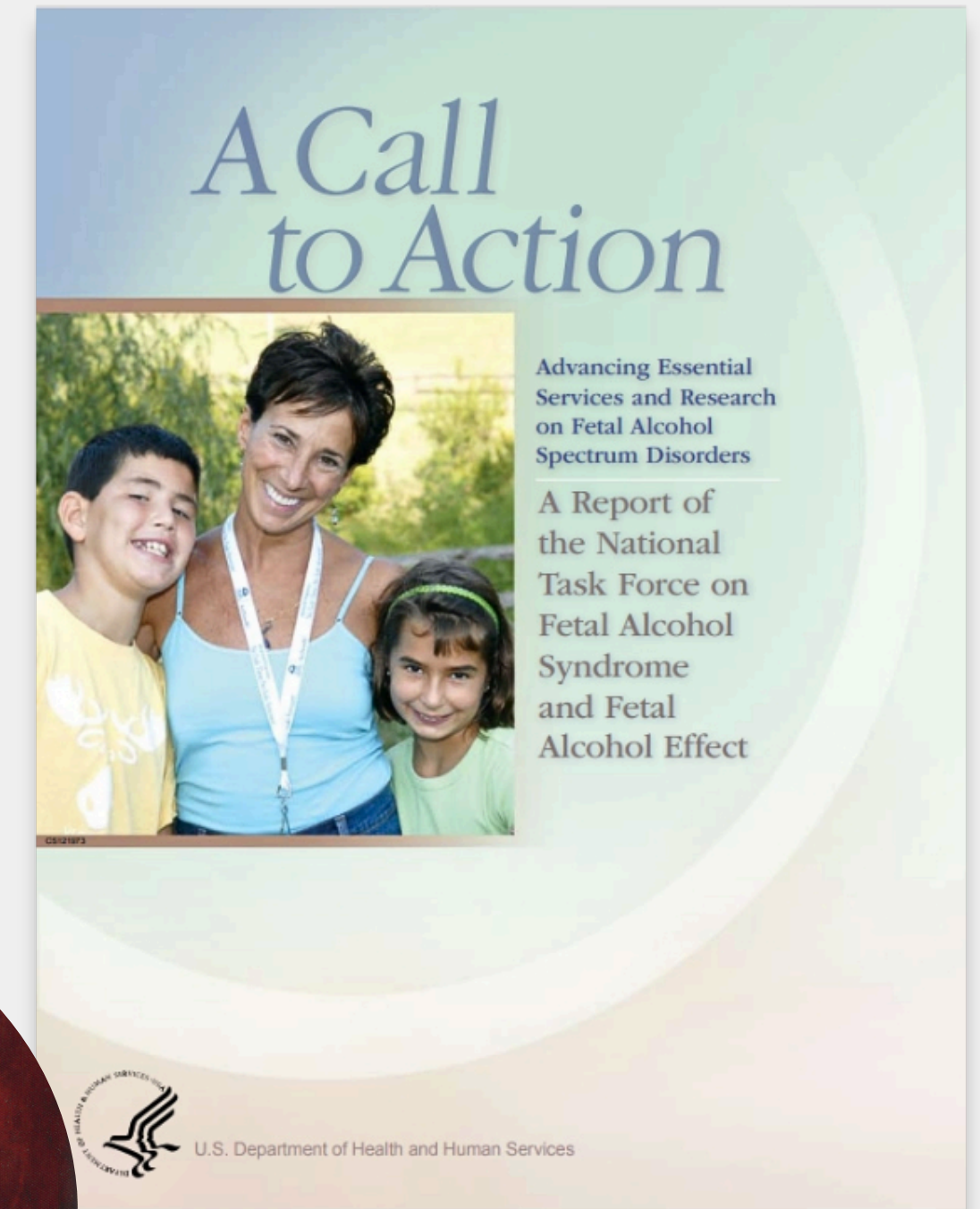
INTRODUCTION
FASD WHITE PAPERS
An Invitation to the Table
GOALS

1. Create continuity by returning to previous strategy in the FASD community/field and evaluating progress.
2. Generalize the national strategy created by federal agencies and researchers to be usable by organizations, professionals, families, and individuals with FASD.
3. Capture current attitudes, perspectives, and priorities of the FASD community/field.
4. Track progress and changes in the FASD movement's attitudes, perspectives, & priorities.

FASD SYMPOSIUM WHITE PAPERS ↗	Co-Creating Recommendations for Progress in the Fetal Alcohol Spectrum Disorder (FASD) Field and Community
An Invitation to the Table.	Volume 1.2
	
WASHINGTON D.C. SEPTEMBER 15, 2025 A project of FASD United 	

Task Force Recommendations

- From 2009 report "**A Call to Action: Advancing Essential Services and Research on FASD**"
 - Report for federal, state, and local agencies, researchers, clinicians, family support groups, and other partners on actions needed in FASD research, policy, and practice.
- 10 recommendations total



Task Force Recommendations

(simplified)

Set up screening systems in multiple professions in community & health services.



Promote continuum of care for families and individuals throughout the lifespan.



Make FASD eligible for government support and services.



Increase research about diagnosis, living experience, and effective interventions.



Encourage professional education on FASD.



Improve tracking of prevalence and support needs.



Recognize grassroots efforts focused on FASD as powerful agents of change.



Maintain a national forum involving parents, advocates, professional organizations, and experts.



Enhance agency collaboration on national AND state levels with representation from families/individuals.

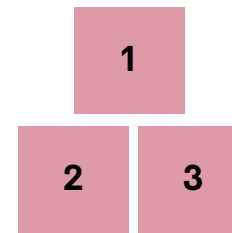
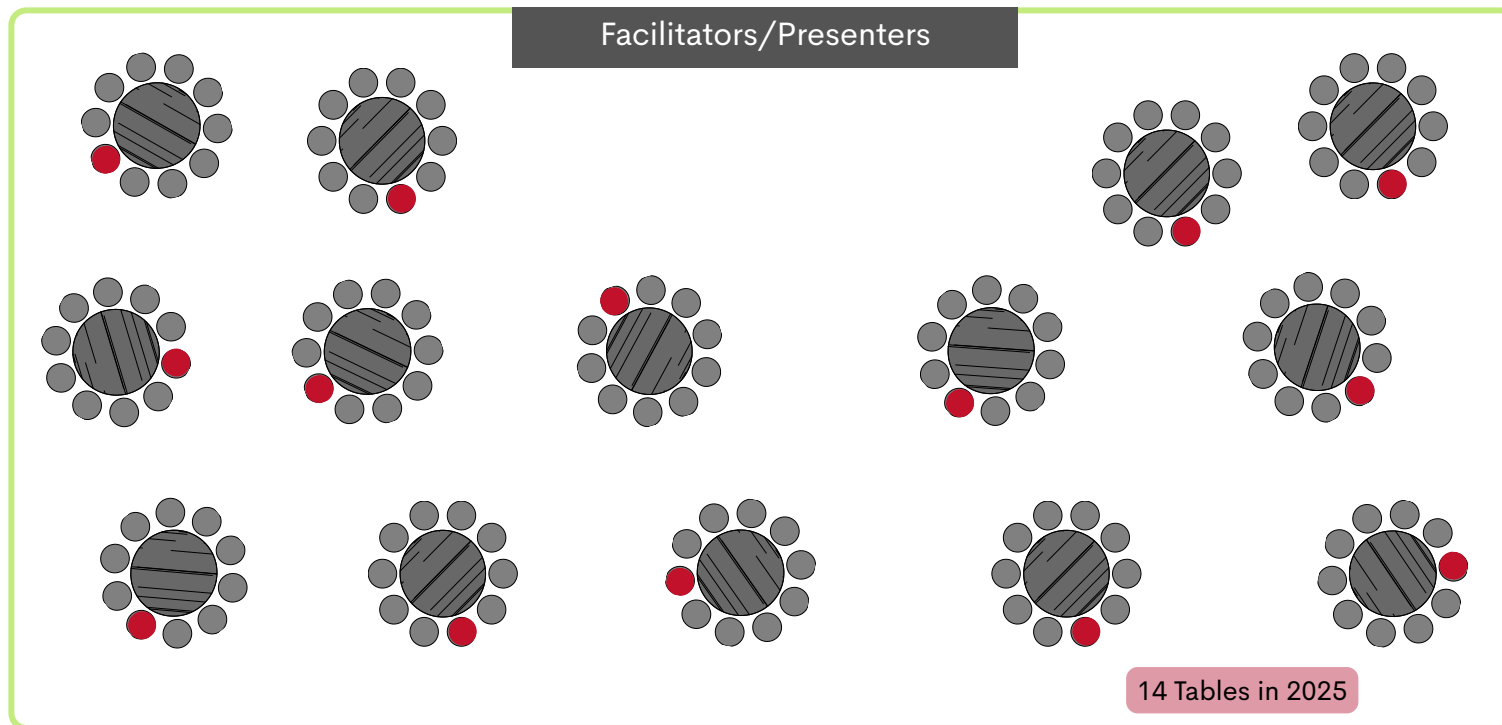




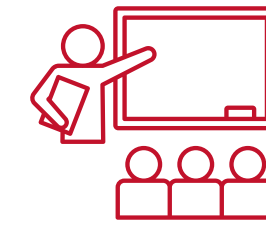
METHODOLOGY

HOW WE DO THIS PROJECT

ABOUT THE SYMPOSIUM SESSIONS



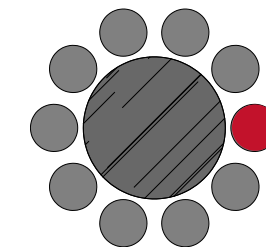
There were 3 discussion sessions; each centered on 1 Recommendation.



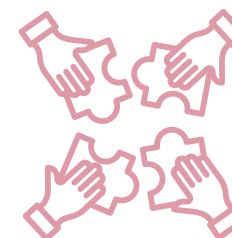
Each session started with a brief presentation to establish shared baseline knowledge on the topic.



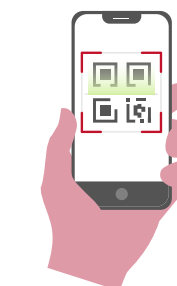
Seat labels represent different perspectives (e.g., Social Work, Lived Experience, Research), fostering diverse discussions at each table.



Each table had 1 Engager to facilitate the activity and conversation.



Engagers guided activities and led discussions following the Engagers' Guide.

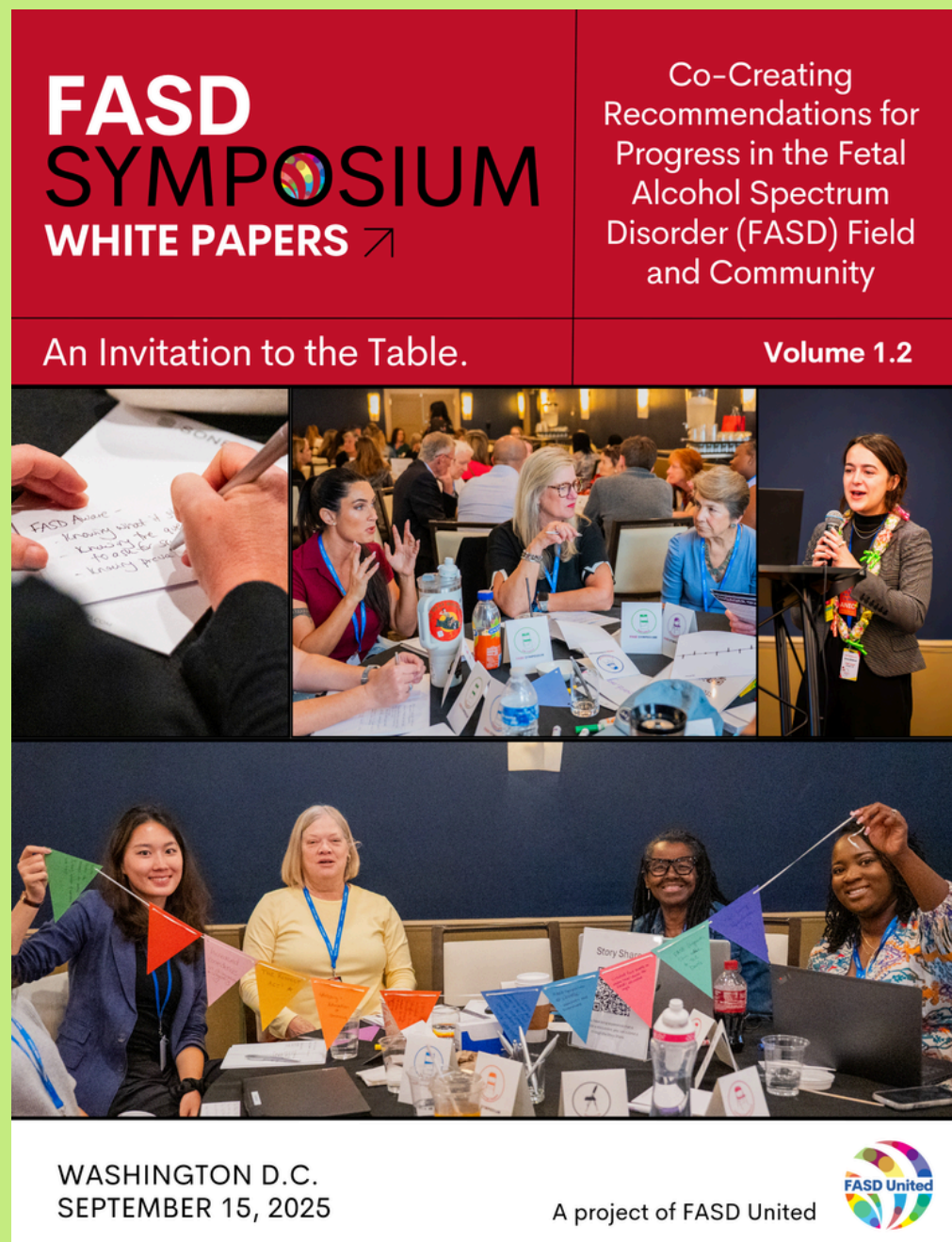


All participants were encouraged to submit personal takeaways from their table discussions, which informed the White Paper recommendations.

FASD WHITE PAPERS

Summary of Volume 1.2

Outcomes from **2025 FASD Symposium**



SESSION 1

Professional Education



2009 FASD Task Force Recommendation

Encourage comprehensive professional education on FASDs, and assessment of knowledge gained, within multiple service systems.

2025 FASD Symposium Recommendation

Build out systems that can disseminate standardized curricula of FASD professional and public education across service systems. The priority should be to center living experience and include mechanisms for evaluating FASD awareness within communities.

SESSION 2

Grassroots Efforts



2009 FASD Task Force Recommendation

Recognize grassroots family support and advocacy organizations focused on FASDs, which are powerful and efficient agents of change.

2025 FASD Symposium Recommendation

Create and sustain partnership opportunities with and among grassroots organizations focused on FASD to expand funding and resources to ensure longevity of programs and projects.

SESSION 3

FASD Data



2009 FASD Task Force Recommendation

Improve ongoing national surveillance systems to identify individuals with FASDs to better track prevalence, provide needed intervention, and assess the impact of prevention programs.

2025 FASD Symposium Recommendation

Build confidence in the FASD community to understand and utilize relevant data. Priorities are to track prevalence, measure effective interventions, assess the impact of programs, and identify opportunities for sharing data among systems and the FASD community.



Diagnosis & Screening

Enhance FASD screening and diagnosis by implementing universal screening across all ages, establishing standardized procedures, providing comprehensive, stigma-informed training for professionals, and removing barriers to diagnosis.



Professional Education

Build out systems that can disseminate standardized curricula of FASD professional and public education across service systems. The priority should be to center living experience and include mechanisms for evaluating FASD awareness within communities.



Continuum of Care for Individuals

Promote a comprehensive and accessible continuum of care for individuals with FASD, by implementing coordinated, evidence-based interventions and policies that ensure lifelong support, reduce stigma, and enhance education and job training across all stages of life.



Grassroots Efforts

Create and sustain partnership opportunities with and among grassroots organizations focused on FASD to expand funding and resources to ensure longevity of programs and projects.



Agency Collaboration

Enhance federal agency collaboration by establishing a national framework that promotes shared leadership, transparent objectives, and coordinated efforts among stakeholders to integrate FASD awareness and support into policies, education, and community resources across all states.

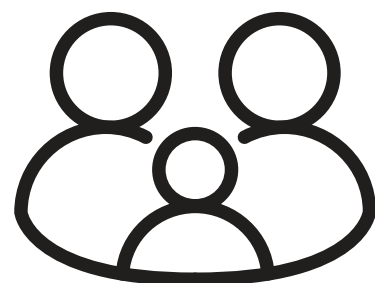


FASD Data

Build confidence in the FASD community to understand and utilize relevant data. Priorities are to track prevalence, measure effective interventions, assess the impact of programs, and identify opportunities for sharing data among systems and the FASD community.

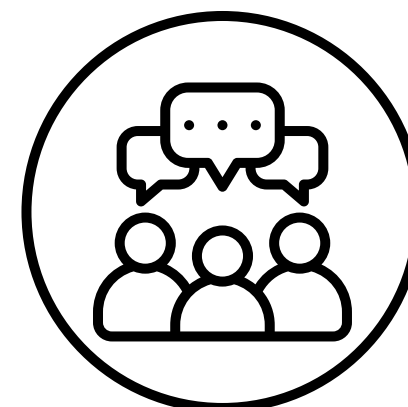
SESSION THEMES

2026



SESSION 1: SUPPORTING FAMILIES

*Task Force recommendation #4:
Promote a comprehensive and accessible continuum of care for families raising infants, children, and adolescents with FASDs.*



SESSION 3: NATIONAL FORUM

*Task Force recommendation #10:
Maintain a national forum in which parents, advocates, professional organizations, and experts in the field of FASDs can work to advance essential services and research for individuals with FASDs and their families.*



SESSION 2: IMPROVING RESEARCH

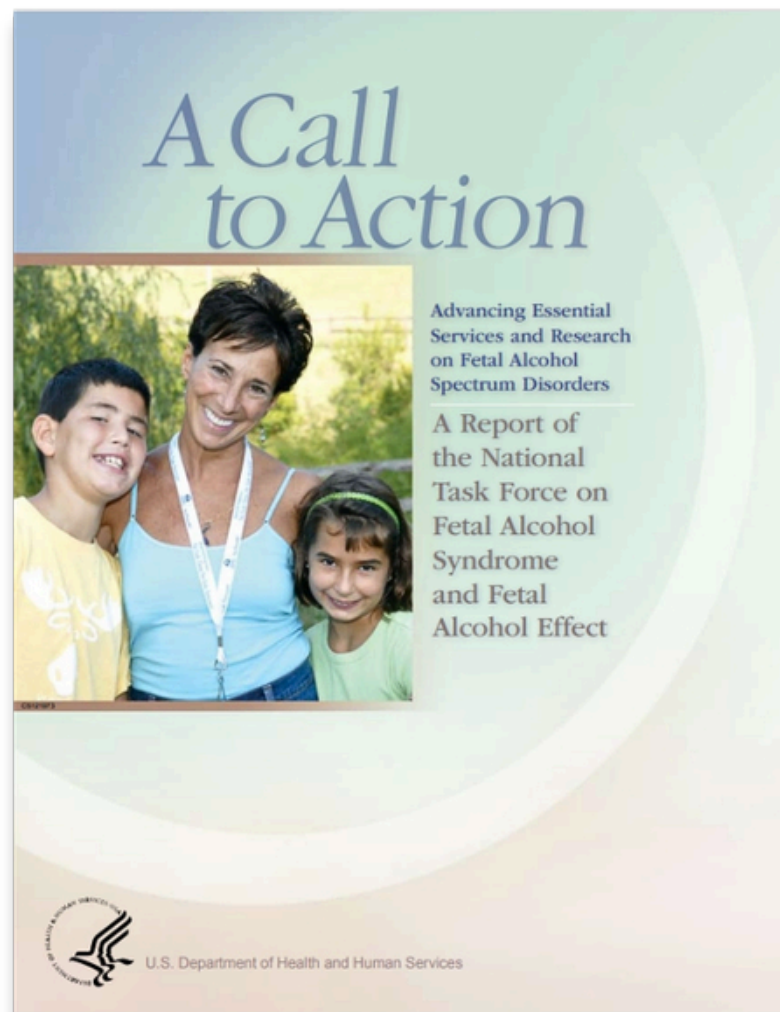
*Task Force recommendation #3:
Intensify research initiatives and interagency coordination.*



SESSION 4: FEDERAL PROGRAMS

*Task Force recommendation #1:
Modify eligibility and diagnostic classification systems to include FASDs so as to recognize FASDs as approved conditions under all federal disability-related benefit programs.*

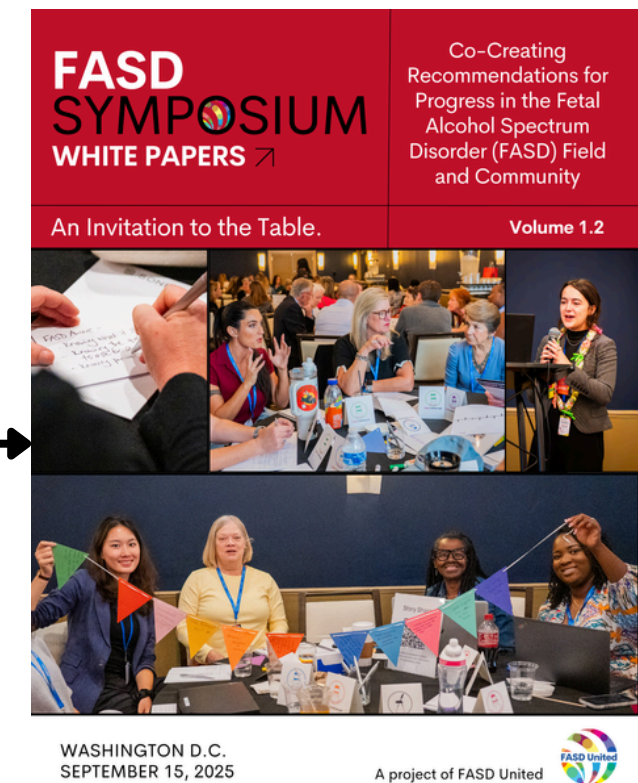
What will the result be?



2024 - Update 3 Recommendations



2025 - Update 3 Recommendations



2026 - Update final 4 Recommendations

FASD White Paper 1.3

FASD Respect Act

Authorization

- Programs for education, training, and awareness
- Development of improved diagnostic and intervention methods
- State and Tribal Capacity Building
- National clearinghouse to inform systems of care

Intent

- Address FASD through lens of support and coordination
- Strengthen states' abilities to include FASD in existing systems
- Acknowledge lack of awareness and gaps in support

Lay of the Land

Appropriations

- House approved FY 27 Labor-HHS-Education spending bill
- Senate still developing its own spending bill
- Fiscal year ends September 30

Calendar

- House and Senate in state/district August 10-30
- Need to pass all 12 appropriation bills by September 30
- Continuing Resolution likely



Meeting the Moment

Alabama Alaska Arizona Arkansas California Colorado Connecticut

Delaware Florida Georgia Hawaii Idaho Illinois Indiana Iowa Kansas

Kentucky Louisiana Maine Maryland Massachusetts Michigan

Minnesota Mississippi Missouri Montana Nebraska Nevada

New Hampshire New Jersey New Mexico New York North Carolina

North Dakota Ohio Oklahoma Oregon Pennsylvania Rhode Island

South Carolina South Dakota Tennessee Texas Utah Vermont Virginia

Washington West Virginia Wisconsin Wyoming

Meeting the Moment

Alabama Alaska Arizona Arkansas California Colorado Connecticut

Delaware Florida Georgia Hawaii Idaho Illinois Indiana Iowa Kansas

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Minnesota Mississippi Missouri Montana Nebraska Nevada

New Hampshire New Jersey New Mexico **New York** North Carolina

North Dakota Ohio Oklahoma Oregon Pennsylvania Rhode Island

South Carolina South Dakota Tennessee Texas Utah Vermont **Virginia**

Washington West Virginia Wisconsin Wyoming

What Now?

I have a meeting, but what do we talk about?

Fund FASD

You can support families and prevent prenatal alcohol exposure with:

- FY27 Labor-HHS Appropriations of **\$21.5 million for CDC's FASD programs** (\$10 million increase in FAS line at NCBDDD), and continue **\$1 million for SPRANS FASD set-aside at HRSA** to support screening and intervention
- Funding the **FASD prevention and clinical guidelines research project**, led by the **Uniformed Services University Center for Health Services Research**, for \$5 million

An Updated Response to FASD Calls for an Updated Investment

Congress authorized FASD programs in Section 104 of the SUPPORT Reauthorization Act of 2025 (Pub. L. 119-44). **Now it's time to fund them.**

Current funding at CDC and HRSA supports:

- Alcohol screening and brief intervention during pregnancy (CDC)
- Public awareness campaigns and partnerships to prevent prenatal alcohol exposure (CDC)
- Monitoring alcohol use during pregnancy (CDC)
- FASD screening and intervention (HRSA)

SUPPORT Reauthorization Act of 2025, Section 104 (Pub. L. 119-44) authorizes:

- Building state and tribal capacity to identify and support people with FASD and their families (adapting existing funds, expanding diagnostic capacity, providing training)
- Grants and technical assistance to states, tribes, local governments, and other organizations
- Evidence-based clearinghouse for FASD

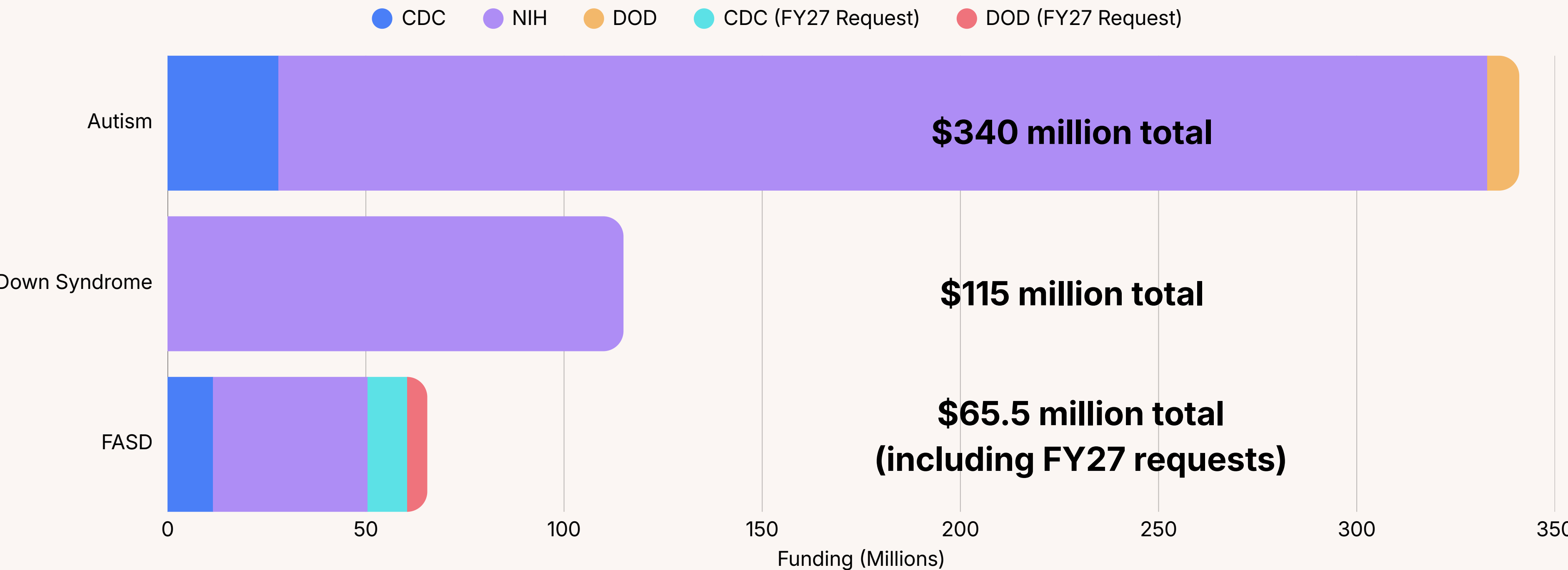
FASD is not rare. It is everywhere.

Compared to less prevalent disabilities, FASD receives a fraction of the funding, even though the costs associated with FASD are greater.

Condition	Prevalence	Lifetime cost per person	Federal funding per impacted child
Autism	1 in 31	\$1.4-2.4 M	\$211
Down Syndrome	1 in 640	No Data Since 1992	\$1,472
FASD	1 in 20	\$1.24-2 M	\$20

If FASD were funded at the same federal rate per affected person as autism, it would receive about \$535 million. A \$10 million increase at CDC is a much needed step in the right direction.

Federal Funding for FASD and Less Prevalent Disabilities



A Model that Works

Sustained federal funding for autism support and research has:

- Delivered supports to individuals and families
- Allowed for early intervention services that offset costs per child by \$19,000/yr
- Built state capacity to screen and diagnose.

This proven approach to better outcomes and systems can work for the FASD community with the modest increase in investment requested for FY27

The Next Step



What will **YOU**
do in the next 30 days?



Register for Impact Week and Hill Day

1. **Register** for Impact Week and Hill Day
2. **Contact** your Members' offices to request meetings
3. **Coordinate** with FASD United to attend meetings with your 2 Senators and 1 Representative