

FASD United Policy Forum



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FASD United
Affiliate Network

Affiliate Update





FASD United

THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NOFAS

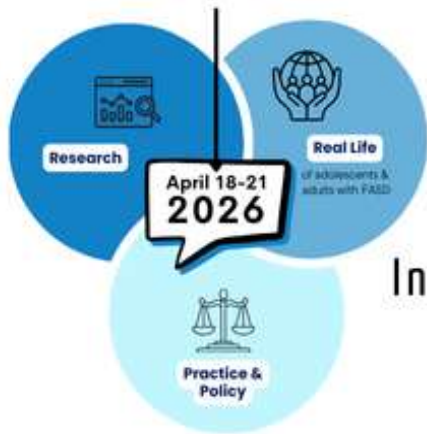
Organization Update



If you are excited about the work that the FASD United Policy and Training Center has done, please consider a tax-deductible contribution this holiday season.

We are committed to ensuring the sustainable and equitable implementation of FASD Respect Act programs, and this work is 100% funded by charitable donations from people like you.





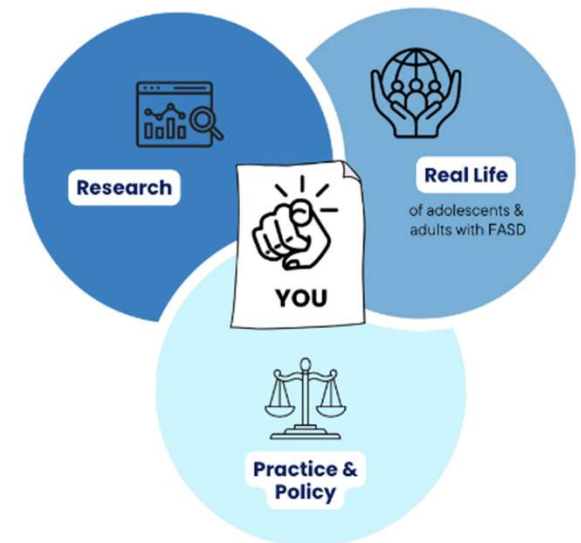
10th International Conference on
**Adolescents and Adults with
Fetal Alcohol Spectrum Disorders**
Integrating Research, Practice, and Policy Around the World



**Follow the link or QR code to
learn more and register!**



www.fasdunited.org/fasd2026/fasd-2026-registration





2026 Priorities

Quarter 1: Appropriations and Engagement



Current Calls to Action

Appropriations Form

Public Comment for PRAMS Extension



Submitting Public Comments

Why it matters and how you can help

Sec. 399H - Fetal alcohol spectrum disorders prevention, intervention, and service delivery program.

What it does:

- Establishes or updates federal programs for public awareness, service delivery, early intervention, training, and research
- Authorizes **grants**, contracts, and cooperative agreements for **States, Tribes, local governments, universities, and non-profit organizations**
- Includes **education and awareness, applied research**, and strengthening **diagnostic methods**

Why it matters:

- Congress has shown a **rededication to FASD from the perspective of support** and understanding by authorizing federal FASD programs for the first time in decades
- Provides a framework for consistent care across the nation and coordinates the federal and state response
- Funding for federal FASD programs had not been authorized since 2007, leaving the funding vulnerable

Sec. 399J - Authorization of Appropriations

What it does:

- Authorizes \$12.5 M per year (FY26-30). Congress still needs to formally appropriate this money.

Why it matters:

- Authorizations for FASD federal FASD programs expired in 2007, leaving funding extremely vulnerable. This protects what FASD has and provide a foundation to grow from.

Sec. 399I - Strengthening capacity and education for fetal alcohol spectrum disorders.

What it does:

- Provides **funds to build State, Tribal, and Local capacity to address FASD**. Public and nonprofit private entities are eligible
- Authorizes a **national clearinghouse** for evidence-based practices and resources
- Supports **workforce training, technical assistance, and best-practice dissemination**
- Encourages creation of **FASD State/Tribal Coordinator and Advisory Committee**

Why it matters:

- For the first time, States will be encouraged to assess and strengthen their systems of care and work toward making sure they are **FASD-informed**, leading to **systemic change**
- Organizations with demonstrated expertise will have the chance to receive funding

The FASD Respect Act



Status

Q1 Appropriations

Q2 State Agency Outreach

Q3 Legislative Outreach

Q4 State Legislation Introduction

***THE FASD RESPECT ACT
BECOMES LAW!!***



2026 Advocacy Impact Calendar



Make sure your state is prepared to implement FASD Respect Act programs and help secure increased funding for FASD

Things to Keep in Mind:

- The timing of your advocacy will be based on your state's current capacity, preparedness, and legislative calendar
- This kind of engagement works best as a coalition/group
- What's important is building relationships and making steady progress towards FASD-informed systems



Q1 Appropriations

Objectives

- Complete appropriation questionnaire
- Arrange meetings with legislators
- Follow up with contacts

Support

- Appropriation request form questionnaire
- Talking points
- Slides and presentations



Appropriations Form

Q2 State Agency Outreach

Objectives

- Connect with state agencies
- Determine where FASD fits into current state systems

Support

- State agency mapping tool
- Talking points
- Slides and presentations



Connect with State Agencies

Q3 Legislative Outreach

Objectives

- Identify State Champions
- Submit Awareness Month proclamation requests
- General outreach and awareness

Support

- Awareness Month Proclamation templates
- Slides and presentations



Identify and Engage with Potential Champion

Q4 State Legislation Introduction

Objectives

- Introduce state legislation for FASD State Coordinator and Advisory Committee

Support

- Draft language for legislation or executive order



Introduce State Legislation

The Whys



Why Appropriations Matter

Incremental increases to funding for FASD
creates sustainable & equitable systems

Why Coordination Matter

Coordination increases visibility & show
strength of FASD community

Why You Matter

Local impact & current state capacity highlight the
need

The Hows

Objectives

- Complete Appropriations Questionnaire provided by FASD United. This will include basic information about your organization, as well as ~3 sentences on the local need and impact.
- Contact and set meetings with federal legislators to discuss appropriations for FASD Respect Act programs
- Consider which State agencies to contact to discuss how FASD is currently addressed in your state.

FASD United Support

- A short form will be provided that will make it easy for you to highlight the local impact increased FASD funding would have.
- We will complete and submit the remaining sections of the Appropriation Requests. This includes precise request language, line-item references, and bill citations
- Talking points and presentations will be provided to support your meetings. FASD United can also attend any virtual meetings scheduled.

Public Comment Periods



Public Comments are how the public gives input on proposed actions by federal agencies.

What are agencies looking for?

- Federal employees review all input and identify **significant, relevant, and unique** points.
- Input is used to identify unknown impacts, ensure program is not duplicative, and strengthen the usefulness of current regulations

What makes a comment significant?

- Explains real world impact with data
- Highlights usefulness vs. burden of program

What is our Goal?

- Ensure systems are FASD-informed  Quality
- Increase visibility of FASD within federal agencies  Quantity

PRAMS Extension Public Comment



Pregnancy Risk Monitoring System (PRAMS)

Collection of **PRAMS** data set to expire **March 31, 2026**.

CDC is inviting public comments on the proposed extension of PRAMS for 60-days
(Closes January 20th)

Main Interests: Does this program have a cross-system impact? Does collecting data create an undue burden on individuals and systems? Is it cost effective? Is there a way to improve data collection?

Docket No. CDC-2025-0750

Can be found on
www.federalregister.gov

Crafting a Comment



Introduction

Why you are interested and what your experience is. How PRAMS relates to FASD.

Background & Analysis

Identify how PRAMS is used in your state or by your org, highlight FASD relevance.

Lay out argument for continuance: cross-system impact, non-duplicative data, allows for efficient and effective interventions, highlights service gaps, and identifies at risk populations.

Recommendation

Extend PRAMS, with monitoring conducted in non-stigmatizing way.

Conclusion

Reiterate main points and relevance to FASD

FASD United's Comment

- I. PRAMS Data is Necessary and Not Available from Other Sources
 - I. Cross-system impact
 - II. Non-duplicative
- II. PRAMS Has Practical Applications and Supports Cost-Effective Interventions
 - I. SBIRT
 - II. Protection against adverse birth outcomes
 - III. FASD and PAE specific data
- III. Burden-Conscious Methods
 - I. Anonymized data with limited burden on individuals
- IV. Non-Stigmatizing Monitoring Supports Authorized Programs
 - I. Ongoing monitoring is needed for implementation of authorized programs
- V. Conclusion

Calls to Action

Submit **Appropriations Form** to FASD United



<https://forms.monday.com/forms/9cbd307beac52ad8f9097aa207e2cb45?r=use1>

Submit a **Public Comment** on Extending

PRAMS



Docket No. CDC-2025-0750

www.federalregister.gov/documents/2025/12/15/2025-22751/proposed-data-collection-submitted-for-public-comment-and-recommendations