

# Give **FASD** a Seat at the Table

Affiliate Monthly Meeting  
November 20, 2025



**FASD United**  
*Affiliate Network*



**Doing Good Work,  
Together.**



# Welcome



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*Affiliate Network*

**For attendance, please put your full name and Affiliate name in the chat.**



**FASD United**  
*Affiliate Network*

# Updates from FASD United



# ACTION ITEM!

**The PRAMS program is set to end on 3/31/2026.**

The CDC is seeking a 3 year extension.

There is a public comment period until January 20<sup>th</sup>, 2026.

**We need this data.**



We need to hear from you!

# ANNOUNCEMENT!

## The 2025-2026 National Education Survey is LIVE!

WHO?

The survey is for self-advocates, parents and caregivers, and educators/professionals. *But this year, we are EXTRA focused on educators of all kinds.*

Even if you have taken the survey before, please take it again

### FASD AND SPECIAL EDUCATION SURVEY RESULTS



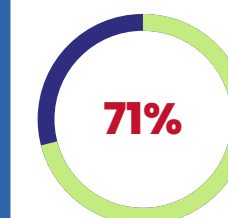
Fetal alcohol spectrum disorders occur in school aged children at a rate of

**1 in 20**

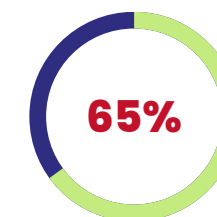
That's a child in every classroom.

<https://www.cdc.gov/fasd/data/index.html>

### STATISTICS



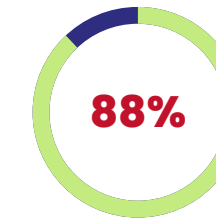
of self-advocates say not having appropriate FASD education accommodations is a **significant challenge**



of caregivers began noticing **educational challenges** in preschool



of self-advocates said the lack of recognition and understanding of FASD in schools is **discriminatory** for students with FASD



of professionals say students with FASD have a **more difficult time** obtaining educational accommodations compared to others with disabilities

May PA, Chambers CD, Kalberg WO, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA. 2018;319(5):474-482. doi:10.1001/jama.2017.21836

[bit.ly/FASDEdSurvey2025](https://bit.ly/FASDEdSurvey2025)



# SPREAD THE WORD

**Add to your  
newsletter**

**Tell your  
child's  
teacher**

**Take flyers to  
events**

**Make  
introductions**

**Share on  
social media**

**Invite us to a  
meeting**

**Share with a  
school  
administrator**

# What Happens Now?

Guidance, Resources, and Where  
You're At Sessions coming early 2026

NEXT POLICY FORUM:

JANUARY 28,  
2026



**JOIN JANUARY FASD  
POLICY FORUM**

[BIT.LY/POLICYFORUM26](https://bit.ly/policyforum26)





***IT'S TIME FOR  
APPROPRIATIONS  
REQUESTS!***

# What Happens Now?



Fill this form to have appropriations requests sent on your/your organization's behalf.



**FASD United**  
*Affiliate Network*

# Affiliate Network Updates

# AFFILIATE WORK GROUPS

You and others at your Affiliate (even if they are not primary contact) can join initiatives within the affiliate Network.

## **Connectivity Work Group**

Purpose: The Connectivity Work Group mission is to cultivate a sense of connection, build community, and promote collaboration within the FASD United Affiliate Network. The Connectivity work group members also moderate the FASD United Affiliate Network Facebook page.

## **Mental Health Work Group**

Purpose: The purpose of this work group is to provide clinicians with a deep understanding of brain-based differences (BBDs) to enhance mental health support related to assessment, treatment planning, and service delivery.

## **Widening the Circle Work Group**

Purpose: To deepen Affiliates' sense of connection and community with each other and provide learning opportunities and resources as we consider what it means to be advocates for access and engagement on behalf of people with FASD, their families, and communities in the broader access and engagement space.

# FASD United Events



**The Red Shoes Gala**  
Washington, DC  
September 28, 2026



**International Research  
Conference on FASD**  
Seattle, WA  
April, 2026



**Impact Week 2025**  
Washington, DC  
September 27 - 30, 2025

FASD UNITED

# Workgroups

CONFERENCES/EXPOS/MEETINGS  
AFFILIATE EXHIBITOR TOOLKIT



2026

**FASD** &  
FASD IS AN AND CONVERSATION

September is **FASD**  
**Awareness Month**

Plans of  
Safe Care  
CAPTA & FASD

**FASD** SYMPOSIUM  
& **WHITE PAPERS**

**FASD AND SPECIAL  
EDUCATION SURVEY  
RESULTS**

Fetal alcohol spectrum  
disorders occur in school  
aged children at a rate of

**1 in 20**

That's a child in every  
classroom.

<https://www.cdc.gov/fasd/data/index.html>

**STATISTICS**

**71%**

of self-advocates  
say not having  
appropriate FASD  
education  
accommodations is  
a **significant**  
**challenge**

**65%**

of caregivers  
began noticing  
**educational**  
**challenges**  
in  
preschool

**100%**

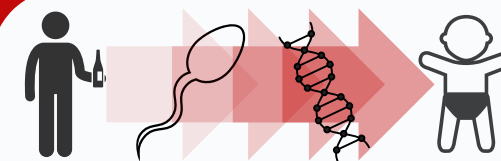
of self-advocates said  
the lack of recognition  
and understanding of  
FASD in schools is  
**discriminatory**  
for  
students with FASD

**88%**

of professionals say  
students with FASD have  
a **more difficult time**  
obtaining educational  
accommodations  
compared to others  
with disabilities

May PA, Chambers CD, Kalberg WO, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA. 2018;319(5):474-482.  
doi:10.1001/jama.2017.21856

**MICRO-LEARNING  
COMPONENTS**



**Alcohol Changes Sperm DNA**, which Transfers to  
the Embryo

**Alcohol  
& Men**

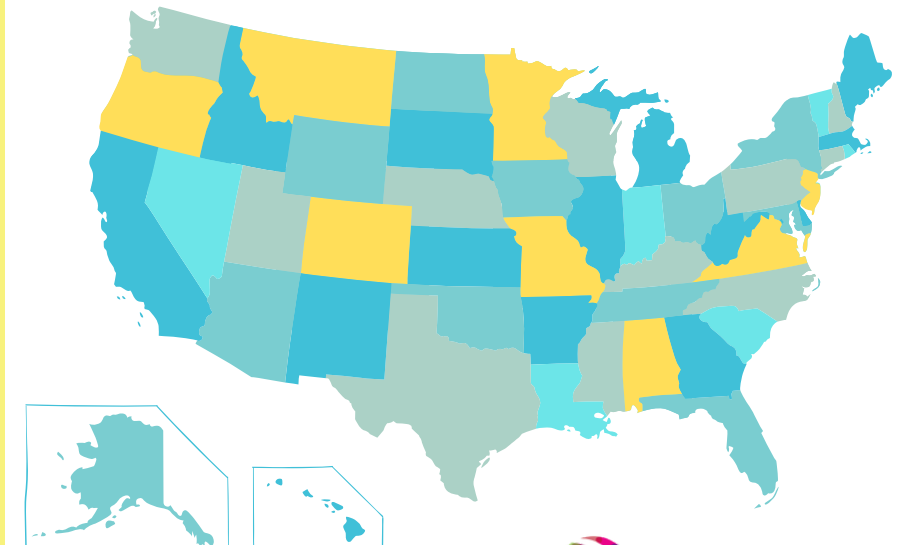
Preconception  
Alcohol Use in Men  
has Associations  
with:  
• Miscarriage  
• Neurobehavioral  
Issues in their  
Children



Preconception  
Counseling must  
include **Men**

**STATE DATA SHEETS**

See How Each State is Addressing FASD  
and Supporting Alcohol-Free Pregnancies:  
FASD United's State Data Sheets



**FASD United**  
THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS  
Forming Worlds



**LANGUAGE AND  
STIGMA GUIDE**

**FASD UNITED**

# Meetings



**FASD United**

*Affiliate Network*

**MEETING YOU**

***Where  
You're At***

As needed 30-min meetings for Affiliates

## POLICY DROP-IN

Every Wednesday except for  
Forum Days, 12:00 pm ET  
Requests for support with  
advocacy.

## POLICY FORUM

Last Wednesday of Each  
Month, 3:00 pm ET  
Updates on policy/advocacy

**FASD UNITED**

# Networks

Separate Networks that we are funded to do or participate in. We are limited in how we involve Affiliates in these groups, but want Affiliates aware of them so we know where we may be starting to recreate the wheel with Affiliate Work Groups/initiatives.



- Advisory
- Voice at the FASD SIG



**AUCD**

Association of University Centers on Disabilities

**SPECIAL INTEREST GROUP *on***  
**FETAL ALCOHOL SPECTRUM DISORDERS**

- Part of the planning committee
- Find linkages for the FASD Field

## COLLABORATOR'S DATABASE

- PLE's, self-advocacy opportunities
- Professionals



**CIFASD**

Collaborative Initiative on  
Fetal Alcohol Spectrum Disorders

- Promote Research Findings
- Recruit for Research

**FASD  
NATIONAL  
PARTNER  
NETWORK**



**CDC NPN**

- Public Health Dissemination
- Champions Network – for us, this is the Affiliate Networks

# EMERITI CIRCLE

- To acknowledge and honor community leaders
- Preserve institutional memory
- Maintain connectivity & relationships
- Leverage retired Affiliate Community leaders' valuable wisdom, perspectives, and ideas
- To provide a role for Affiliate Community leaders who retire to offer inroads to stay involved in FASD efforts.



**Eileen Bisgard, JD**



**Jdg Michael Jeffery**



**Jdg Susan Shepard  
Carlson**



**Sarah Messelt**



**Enid Watson**



**Ann S. Yabusaki,  
PhD, LMFT**



**Dr. Leigh Tenkku  
Lepper**



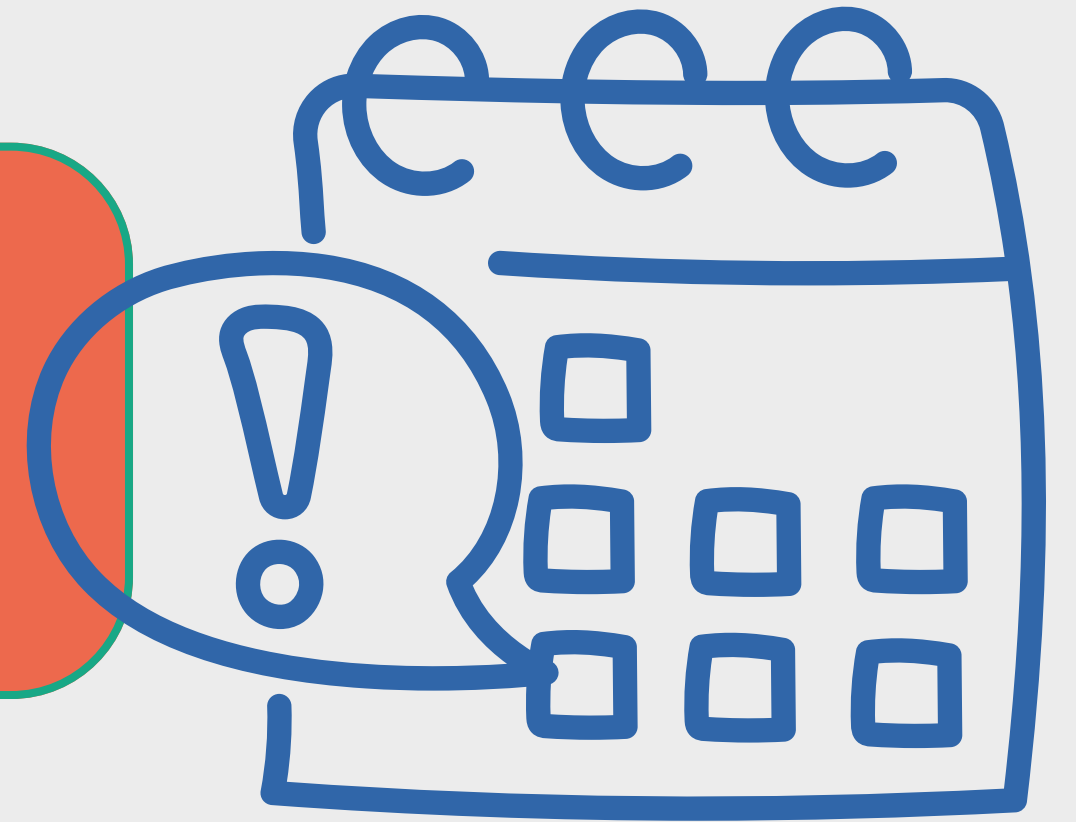
**Marilyn Pierce-  
Bulger**



**Peggy Way**



# ACTION ITEM!



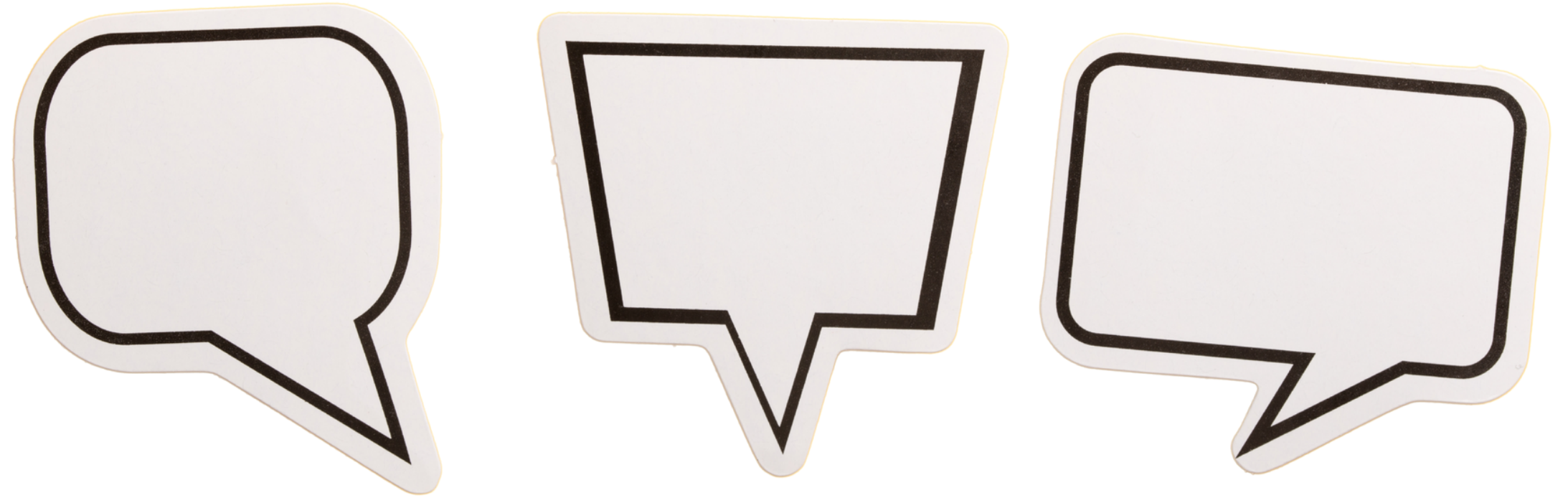
## 2026 Commitment Forms and Dues

*We are working to fix issues with the Affiliate Renewal Forms.*

We asked ANEC which **FASD United projects and initiatives** would see the most **IMPACT** on our community and movement from added **Affiliate involvement**.

# Breakout Discussion

What would it look like to focus on building capacity of the FASD movement, rather than individual organizations?





**FASD United**  
*Affiliate Network*

**CloseOut**

**More Questions?**