

FASD SYMPOSIUM

An Invitation to the Table



2026 Contributor's Handbook

www.FASDUnited.org

FASD SYMPOSIUM

AN INVITATION TO THE TABLE

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2026 SYMPOSIUM

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Thank you for attending the third **FASD Symposium** as part of 2026 National FASD Impact Week.

The **FASD Symposium** is FASD United's response to participant feedback from past Impact Weeks, and to the needs of the broader community of agencies, institutions, organizations, professionals, families, and individuals advocating for FASD.

PURPOSE

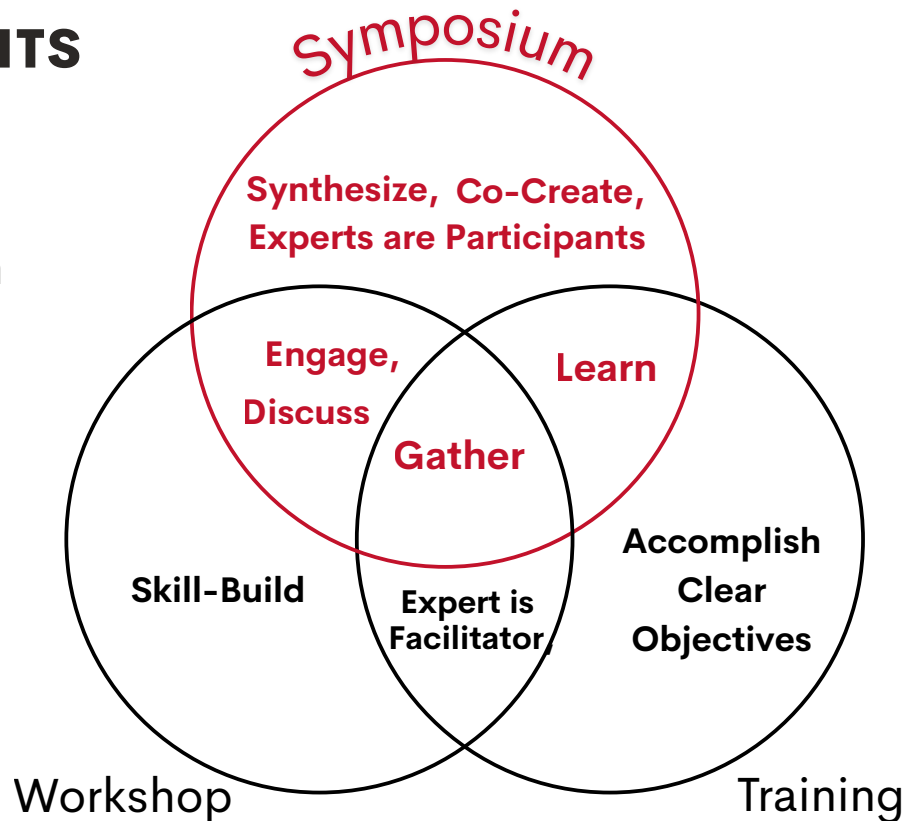
1. To offer space to **gather** and **engage** as a community.
2. To **co-create** a vision for collaborative progress that centers **living experience** and **support**.

WELCOME

WHY A SYMPOSIUM?

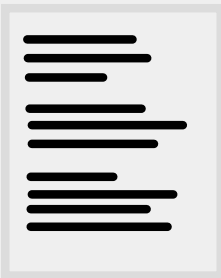
THE PARTICIPANTS ARE EXPERTS

A **Symposium** is a structured discussion among a group of diverse experts on a specific topic.



Call to Action

WHAT'S THE **GOAL** OF THE DISCUSSION?



After the Symposium, FASD United staff will publish an organized summary of discussion feedback as a **white paper** that represents a broad set of knowledgeable perspectives on FASD.

*ALL participants of the **FASD Symposium** have the option to be named as a Contributor.*

SYMPOSIUM CULTURE

ASSUMPTIONS

As we engage in discussions, there are three **assumptions** we should make about everyone in the room.

WE
KNOW



Participants have a proficient understanding of FASD basics.

WE
CARE



Everyone involved in FASD advocacy cares about FASD advocacy.

WE
**WORK
TOGETHER**



A comprehensive approach to FASD requires radical collaboration.

LANGUAGE & RESPECT

We understand there are language differences in the FASD community. Participants should be aware of language best practices to reduce harm caused by disrespectful language.

The language we use is powerful. It impacts the way people think, act, and feel and can be a **tool** for creating a more FASD-informed world.

- Person-first wording (for example, "person with FASD")
- Inclusive and accessible language
- Acknowledging harm without becoming stuck in it
- Highlighting strengths
- Asking the experts (people living with disabilities)



You can review the complete Language Guide by scanning the QR code.

INTRODUCTION

FASD WHITE PAPERS

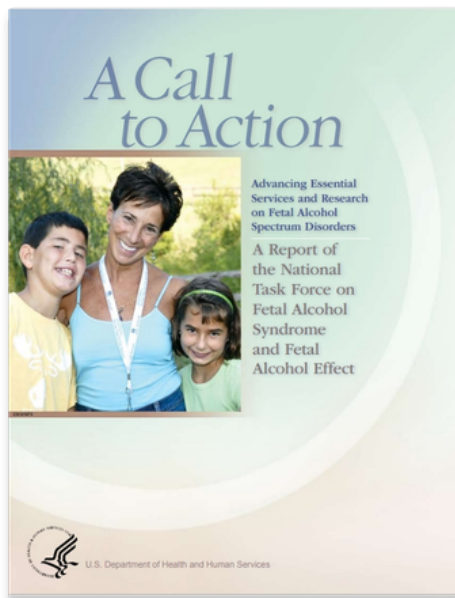
An Invitation to the Table

The goal of the White Papers is to revisit and update the existing 2009 FASD National Task Force Recommendations to reflect progress in the field and the broader, growing audience of the FASD movement. The 2009 National FASD Task Force Call to Action provided recommendations for agencies, research institutions, clinicians, and advocacy organizations. The report stressed that the "responsibility for addressing the many issues relevant to [FASD] transcends the mission and resources of any single agency or program."¹ We take on this responsibility by prioritizing more varied perspectives, especially those of people with living experience.

HOW DO WE PARTNER *WITHIN* THE FASD COMMUNITY TO PROGRESS *OUTWARD* ON THE NATIONAL, STATE, AND LOCAL LEVELS?

Each year, FASD United hosts the national **Symposium** in the Washington, DC area, among individuals with FASD, families, federal and state agencies, professionals, organizations leading FASD work in their communities, and researchers. The discussions are structured as individual sessions ending with feedback collection from attendees. That feedback is then analyzed, organized, and summarized into a White Paper. The White Paper created from today's activities will be the third of a 3-part series and is the resulting summary of FASD United's third annual FASD Symposium.

REFLECT



2009 NATIONAL TASK FORCE ON FASD'S CALL TO ACTION

Report for federal, state, and local agencies, researchers, clinicians, family support groups, and other partners on actions needed in FASD research, policy, and practice.

TASK FORCE RECOMMENDATIONS

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.
2. Improve diagnostic access by setting up screening systems for FASDs and increasing professional multidisciplinary diagnostic capacity in communities.
3. Intensify research initiatives and interagency coordination to: delineate the full fetal alcohol spectrum; continue study of alcohol mechanisms and biomarkers; carry out longitudinal descriptive studies; establish effective interventions; translate interventions to the community, and improve the quality and utilization of interventions in all service systems for those with FASDs.
4. Promote a comprehensive and accessible continuum of care for families raising infants, children, and adolescents with FASDs.
5. Promote a comprehensive and accessible continuum of care for youth, adults, and older individuals with FASDs.
6. Encourage comprehensive professional education on FASDs, and assessment of knowledge gained, within multiple service systems.
7. Enhance strong, collaborative, interagency leadership at state and national levels (that includes parent representation) to inform legislators, policymakers, and the public.
8. Recognize grassroots family support and advocacy organizations focused on FASDs, which are powerful and efficient agents of change.
9. Improve ongoing national surveillance systems to identify individuals with FASDs to better track prevalence, provide needed intervention, and assess the impact of prevention programs.
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.

FASD WHITE PAPERS

Plain Language of Volume 1.1

SCAN FOR FULL WHITE
PAPER 1.1 REPORT



Outcomes from 2024 FASD Symposium

DIAGNOSIS & SCREENING



2024 FASD Symposium Recommendation

Improve access to FASD screening and diagnosis by:

- using universal screening across all ages
- using standardized procedures
- providing in-depth, stigma-informed training for professionals

CONTINUUM OF CARE



2024 FASD Symposium Recommendation

Call for an in-depth and accessible continuum of care for individuals with FASD by:

- building research-backed supports and policies that ensure lifelong well-being, reduce stigma, and improve education and job training across all stages of life.

AGENCY COLLABORATION



2024 FASD Symposium Recommendation

Improve how federal agencies work together to bring FASD awareness & support into policies, education, and community resources across all states. To do this, agencies must:

- share leadership
- share objectives
- share efforts

FASD WHITE PAPERS

Summary of Volume 1.2

SCAN FOR FULL WHITE
PAPER 1.2 REPORT



Outcomes from 2025 FASD Symposium

PROFESSIONAL EDUCATION



2025 FASD Symposium Recommendation

Decide who should receive FASD education and how it can be shared with professionals working with people. The education materials should:

- center living experience
- include ways to measure FASD awareness

GRASSROOTS EFFORTS



2025 FASD Symposium Recommendation

Grassroots efforts should focus on connecting people to organizations and initiatives that they can support and stay connected to.

FASD DATA



2025 FASD Symposium Recommendation

Build confidence in the FASD community to understand and utilize relevant data. Priorities are:

- to track prevalence
- measure effective supports
- assess the impact of programs
- identify opportunities for sharing data among systems and the FASD community.

TIMELINE

01

September 2024



First FASD Symposium
was held

02

Spring 2025



White Paper
1.1 published

03

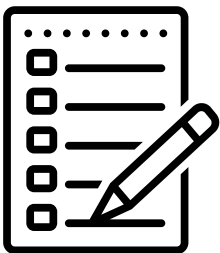
September 2025



2nd FASD
symposium

04

Summer 2026



White Paper
1.2 published

05

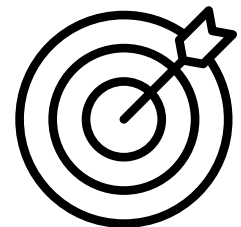
September 2026



3rd FASD
Symposium will
take place

06

2027



White Paper 1.3 will
be published



BACKGROUND

HELPFUL INFORMATION TO KNOW

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.¹ Individuals with FASD also show a wide range of strengths.

Prevalence & recent trends

Prevalence of FASD among children in the United States (US): **1 in 20**²

Prevalence of alcohol use during pregnancy among adults in the US: **More than 1 in 7**³

The prevalence of alcohol-exposed pregnancies has **increased** over time.⁴⁻⁷

Although **FASD is common**, it remains under-diagnosed and is often misdiagnosed.⁸

FASD across the lifespan

Prenatal alcohol exposure can affect how the brain and body develop, with lifelong impacts.⁹ Individuals with FASD can experience a wide range of whole-body health challenges.¹⁰ *Symptoms and support needs can change throughout the lifespan.*¹¹ Every person with FASD is impacted differently and has both unique strengths and support needs.¹²

Moving forward

We know that people with FASD can thrive and succeed when systems are **FASD-informed** and people with FASD are “given a seat at the table,” meaning their voices and needs are recognized and included. Recognition and accommodation of people with FASD and PAE is crucial. Modifications and shifts in practices and policies will better support the complex and unique needs of people with FASD.¹³

FASD-informed supports & systems

According to the FASD Respect Act¹⁴, **FASD-informed** is described as the use of interventions and resources that are culturally and linguistically informed, evidence-based or practice-based, and supportive of an improved quality of life for an individual with FASD and the family of such an individual.

Increasing the number of and access to FASD-informed agencies, professionals, and interventions can lead to more positive outcomes for people with FASD and their families.¹⁵

GLOSSARY OF TERMS

CAPTA	Child Abuse & Prevention Act: A federal law that provides funding to states to support the prevention, assessment, investigation, and treatment of child abuse and neglect. ¹⁶
Child Find	A State's obligation to locate, identify, and evaluate children who might need special education services, as required through IDEA. ¹⁷
DSM	Diagnostic and Statistical Manual of Mental Disorders: A publication by the American Psychiatric Association for the classification of mental disorders using a common language and standard criteria. ¹⁸
ICD-10	The 10th revision of the International Classification of Diseases, which is used to code and classify medical diagnoses and can be tied to medical billing. ¹⁹
IDEA	Individuals with Disabilities Education Act: A federal law that makes available public education and related services to eligible children with disabilities. ²⁰
Medicaid	A program in the United States that provides health insurance for adults and children with limited income and resources. ²¹

FASD NATIONAL FORUMS

Forums are gatherings where people come together to:



discuss important topics and issues



connect and collaborate



make decisions and recommendations



work toward shared goals

Within the FASD community, there are many examples of national forums, including special interest groups, conferences, collaboratives and committees, and social media networks. While the hosts, participants, and specific priorities may differ across these forums, they tend to share one overarching goal: create more FASD-informed spaces to uplift, empower, and support individuals and families impacted by FASD.

Community & Social Connections

- Facilitate peer support programs by creating structured peer mentoring programs that connect individuals with FASD to share experiences and build authentic friendships.
- Organize FASD respite camps. Supporting and funding camps would provide opportunities for social interaction and support while offering caregivers much-needed respite.

Mental Health & Well-Being

- Expand access to FASD-informed mental health services by standardizing professional development and/or certification training for mental health professionals to deliver FASD informed care.
- Promote evidence-based parenting interventions by supporting and funding positive parenting programs that utilize evidence-based practices tailored for families affected by FASD.

Education & Training

- Integrate FASD education in teacher training by mandating FASD training as a core component of teacher education programs.
- Ensure universal access to support through establishment of Family Navigators in every state.

Transition & Care Coordination

- Standardize transition protocols by developing and implementing standardized protocols for healthcare transition from pediatric to adult care, ensuring that there are clear measures of success for each individual's transition plan.
- Support Family Navigators nationwide by funding the establishment of Family Navigators in every state.

In/Inter-Dependence

- Develop comprehensive housing programs.
- Foster safe FASD communities through local partnerships and resources to perform mentorship and social services.

Policy & Advocacy

- Strengthen advocacy efforts at all levels by mobilizing advocacy efforts to push for policy changes that recognize FASD as a lifelong disability. This includes securing dedicated funding for FASD services and ensuring coverage through insurance and public health programs.
- Engage pharmaceutical companies: Encourage collaboration with pharmaceutical companies to develop treatments specifically for individuals with FASD.

Awareness & Stigma Reduction

- Launch national & state awareness campaigns: Develop a comprehensive media campaign aimed at reducing stigma around FASD, similar to those for autism.
- Implement standardized messaging: Create standardized messaging and signage laws in all 50 states to promote understanding of FASD, particularly concerning alcohol consumption during pregnancy.

Evidenced-Based Interventions

- Promote access to evidence-based programs. This includes expanding access to early intervention services and adult-based programs tailored to their specific needs.
- Establish research initiatives: Encourage research initiatives focused on developing and assessing new evidence-based interventions that cater specifically to adolescents and adults with FASD.

RESEARCH METHODS FOR PAE & FASD



Basic research seeks to advance fundamental knowledge and understanding without immediate concern for practical applications. It is generally focused on testing theories and concepts, and it advances understanding within academic fields. It describes, characterizes, and/or tries to understand mechanisms underlying a problem or challenge. Its findings are designed to later support applied research, technological innovation, policy development, or professional practice.²³

Examples of basic research related to FASD include the various studies done using animals like mice or zebrafish to better understand the effects of PAE. Animal studies allow researchers to systemically control and analyze measures of alcohol consumption on development in ways that are not possible when studying human beings. Studying animals like this also allows for faster results and cross-generational studies.²⁴ However, basic research is not limited to animals. Studies that use neuroimaging of the human brain or characterize neurobehavioral functioning of people with FASD are also examples of basic research. **Basic research helps scientists better understand how PAE can impact development and informs interventions and applied research.**



Applied research addresses specific practical problems and seeks to improve existing conditions or develop solutions that can be implemented in real-world settings. It takes theoretical knowledge gained by basic research and uses it to create tangible benefits for individuals, organizations, or society. It is solution-oriented, involves stakeholders (the people that will use the results), and evaluates effectiveness and impact of interventions.

Examples of applied research related to FASD include studies that examine the outcomes and effectiveness of programs designed for people affected by PAE. For example, researchers might study a specific behavioral intervention, such as a curriculum or skill development app, to determine the outcomes that participants experience. These studies measure things like improved executive functioning, reduction of disruptive behaviors, or changes to self-esteem.²⁵ **Applied research helps us find what works - or doesn't work - so that we can prioritize meaningful supports and resources.**

EMERGING RESEARCH: ACES & PACES

ACEs

Adverse Childhood Experiences

Potentially traumatic events that occur in childhood, including emotional, physical, and sexual abuse, emotional and physical neglect, exposure to family conflict and violence, exposure to household substance abuse, and separation from a caregiver.

- Extensive research has been done on adverse childhood experiences (ACEs).
- Higher rates of ACEs are associated with negative health outcomes across the lifespan, including poor physical and mental health.²⁶
- Research suggests that individuals with FASD generally have high rates of ACEs.²⁷

PACEs can reduce the impact of ACEs.²⁸

PACEs

Protective and Compensatory Experiences

Positive experiences that can increase resilience and protect against risk for mental and physical illness. Examples of PACEs are listed below.²⁹



unconditional
love from family



having a
best friend



volunteering/
helping others



having
enough food



having a
mentor



living in a safe,
clean home



being physically
active



having opportunities
to learn



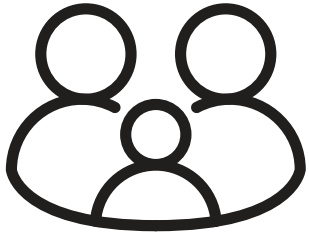
having a hobby



rules & routine

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 2: IMPROVING RESEARCH

Task Force recommendation #3:

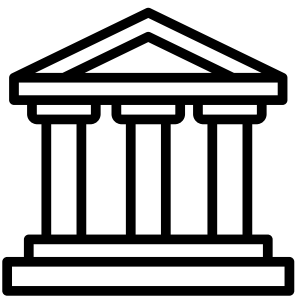
Intensify research initiatives and interagency coordination.



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 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.

SESSION QUESTIONS

SESSION 1: SUPPORTING FAMILIES

Leading Question: *If comprehensive supports were offered, what would make them accessible?*

Things to consider:

- What makes a support/resource accessible for families?
- What does comprehensive support look like? How is it delivered?

SESSION 2: IMPROVING RESEARCH

Leading Question: *Which of the scientific questions in our national priorities, if answered, would have the most impact on the FASD community?*

Things to consider:

- What steps would be needed to move those from theory to real-life practice?
- How do we honor people with FASD throughout the research process?

SESSION 3: NATIONAL FORUM

Leading Question: *What would an accessible and effective national forum look like?*

Things to consider:

- What focus areas should be prioritized? What would the goals be?
- How do we ensure all voices are included?
- How do we ensure there are meaningful outcomes?
- How could this work be funded?

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SYMPOSIUM AGENDA



Monday, September 28

Part 1

9:00 to 9:30 – Welcome and Introduction

9:30 to 9:45 – Intro to Session 1

9:45 to 11:00 – Session 1: Supporting Families

11:00 to 11:15 – Break (15 minutes)

11:15 to 11:30 – Intro to Session 2

11:30 to 12:45 – Session 2: Improving Research

12:45 pm to 2:00 – Lunch (75 minutes)

2:00 to 2:15 – Intro to Session 3

2:15 to 3:30 – Session 3: National Forum

3:30 to 4:00 – Wrap Up & Closing Remarks

Wednesday, September 30

Part 2

2:00 to 4:30 – Session 4: Federal Programs

4:30 to 5:00 – Reflections & Closing