

FASD SYMPOSIUM

An Invitation to the Table



Contributor's Handbook

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FASD SYMPOSIUM

AN INVITATION TO THE TABLE

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Thank you for attending the launch of the **FASD Symposium** as part of 2024 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

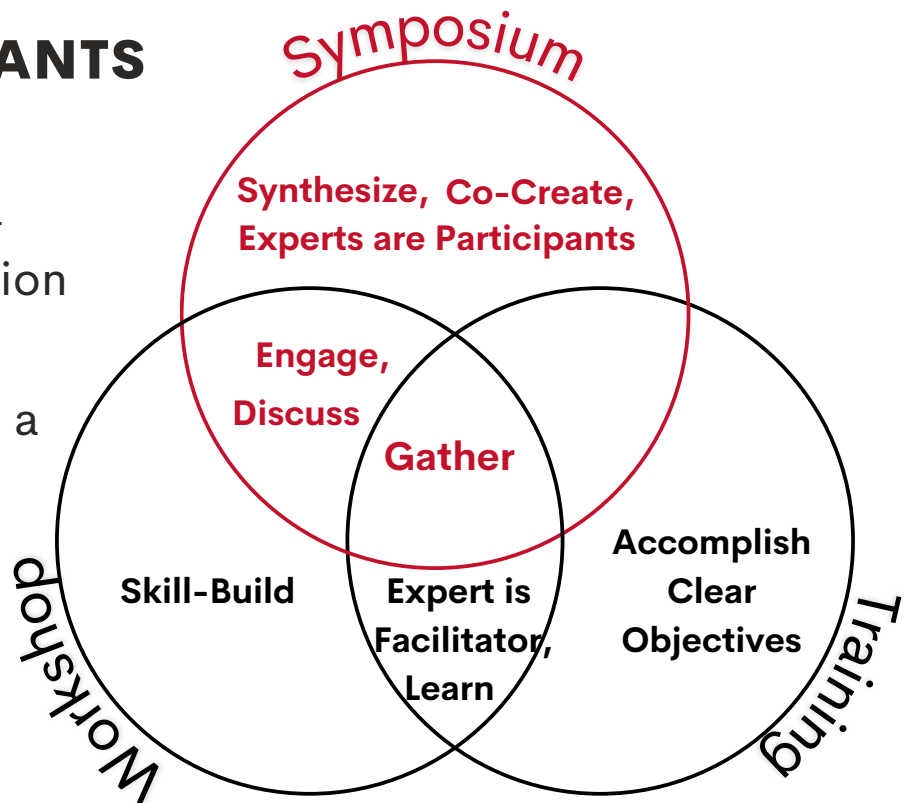
1. To offer space to **gather** and **engage** as a community.
2. To **co-create** a vision for collaborative progress that centers **living experience** and **support**.

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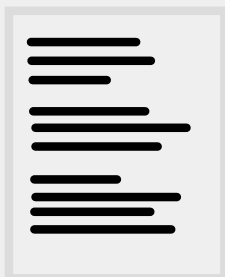
WHY A SYMPOSIUM?

THE PARTICIPANTS ARE EXPERTS

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



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 **3 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 & STIGMA

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

- Person-first wording
- Inclusive and accessible language
- Acknowledging stigma w/o becoming stuck in it
- Highlighting strengths
- Asking the experts (people living with disabilities)

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.

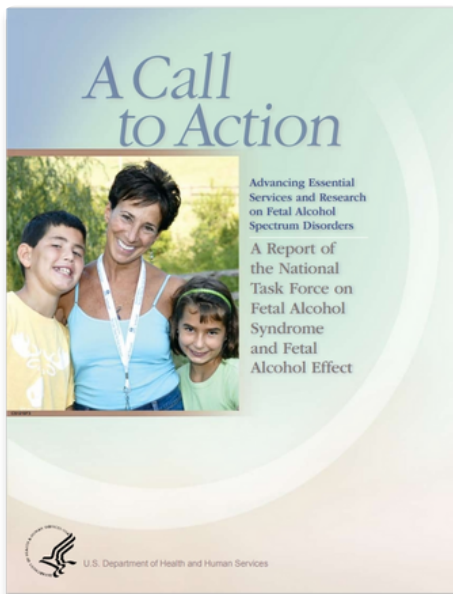
Let's help pregnant people feel safer asking questions about alcohol use during pregnancy or asking for help if they are having difficulties stopping their use.

Words and terms like:

- Suffering from FASD
- Damaged by FASD
- Innocent victims

falsely imply that people who drink while pregnant don't care about their children.

REFLECT



2009 CDC 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.

AGENDA



SESSION 1: DIAGNOSIS & SCREENING

Task Force recommendation #2: Improve diagnostic access by setting up screening systems for FASDs and increasing professional multidisciplinary diagnostic capacity in communities.

SESSION 2: AGENCY COLLABORATION

Task Force recommendation #7: Enhance strong, collaborative, interagency leadership at state and national levels (that includes parent representation) to inform legislators, policymakers, and the public.

SESSION 3: CONTINUUM OF CARE

Task Force recommendation #5: Promote a comprehensive and accessible continuum of care for youth, adults, and older individuals with FASDs.

Each session will be 60 minutes.

Your voice matters!

INTRODUCTION
FASD WHITEPAPERS

An Invitation to the Table



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

The 2009 CDC Task Force on FASD's Call to Action provided summarized 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" (page 15). This White Paper presents the perspectives and expertise of individuals and families with living experience, professionals with boots-on-the-ground, organizations leading FASD work in their communities, and representatives from national agencies and research efforts. The goal of this paper is to introduce collective feedback to the recommendations outlined in the 2009 CDC Call to Action. This paper presents insights contributed through various modes of feedback collection at the **FASD Symposium: An Invitation to the Table.**

TIMELINE

01

September 2024



First FASD Symposium

02

Fall 2024

Data review



03

Early 2025



White paper published

04

2025

2nd FASD
symposium



05

2026

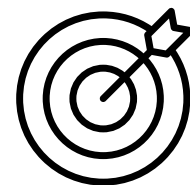


3rd FASD
Symposium

06

2027

Final white paper
published; revisit
themes and trends





BACKGROUND

Fetal alcohol spectrum disorders (FASDs) are a group of diagnosable medical conditions that can occur in a person who was exposed to alcohol before birth.

Effects are lifelong and can include mental health conditions, learning disabilities, sensory issues, and physical manifestations such as heart defects, hearing and visual impairments, and more.

Prevalence & recent trends

Rate of FASD the United States: **1 in 20**

Rate of alcohol use during pregnancy in the US: **1 in 7**

The estimated prevalence of FASD has **increased** over time.

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

FASD across the lifespan

Challenges through the lifespan may include:

Infancy: Birth defects, difficulty feeding, may be diagnosed as “failure to thrive”

Childhood: School challenges, developmental delays, behavioral issues

Adolescence: Behavioral issues, mental health struggles, challenges in school

Adulthood: Employment, housing, legal issues, mental health challenges

Research shows that parents and caregivers of children with FASD report wide-ranging strengths and positive influence. Common strengths of people with FASD can include: **loving, form close family bonds, social, want to be liked by others, trusting, warm, full of positive energy, creative thinkers.** Every person with FASD is unique.

Financial Costs of FASD:

According to a 2018 analysis of the economic impact of FASD, the annual cost for one individual with FASD is as much as \$24,308, including costs associated with health care, special education, residential care, and productivity losses. Supporting **early diagnosis** and **early interventions** may reduce these costs while improving quality of life for people with FASD. There is a significant need for **increased funding and resources** to support individuals, families, and communities impacted by FASD.

BACKGROUND

Social drivers of health

Social drivers of health (sometimes referred to as **social determinants of health** or SDOH) are factors that influence wellness, quality of life, and health outcomes. The World Health Organization describes SDOH as the conditions in which people are born, grow, work, live, and age. Sometimes social drivers of health result in better health outcomes, and sometimes they result in poorer health outcomes.

Social drivers of health include things like:



housing



education



health care



laws and policies



trauma

FASD & social drivers of health

- Social drivers of health like socioeconomic status, access to health care, and social relationships influence the rates of substance-exposed pregnancies.
- People with FASD, as well as their families, frequently experience stigma and discrimination. This may be compounded for those with multiple marginalized identities (such as being a person of color, female, or transgender).
- People with FASD experience higher rates of trauma and adverse life experiences.
- Students with FASD often have a challenging, disrupted school experience.
- People with FASD are disproportionately represented in the justice system.
- People with FASD face unique challenges in the workplace and have higher rates of unemployment compared to people without FASD.

BACKGROUND

6 REASONS TO SCREEN BEFORE 6-YEARS OLD

Research shows that **early identification** and diagnosis, especially before 6-years old, helps to reduce risks later on by:

1

Empowering parents with a sense of understanding

2

Identifying appropriate specialty care

3

Reducing the risk of maltreatment toward the child if behaviors are misunderstood

4

Making it easier to discuss accommodations or considerations in education

5

Increasing opportunities for interventions

6

Finding peer and community programs

Importance of diagnosis & interventions

People with FASD can thrive and succeed when systems are **FASD-informed** and FASD is given a seat at the table. Recognition and accommodation of people with FASD and PAE is crucial. Modifications and shifts in practices and policies will support the complex needs of people with FASD. Key systems include: Child Welfare, Education, Justice System, and Health. These systems are not yet fully capable of providing consistent FASD-informed services.

Importance of collaboration/interdisciplinary efforts

We aim to secure a presence for FASD and the support of healthy substance-free pregnancies in decision-making and discussion forums **across various fields**, including areas of study, professions, and societal sectors.



SOURCES

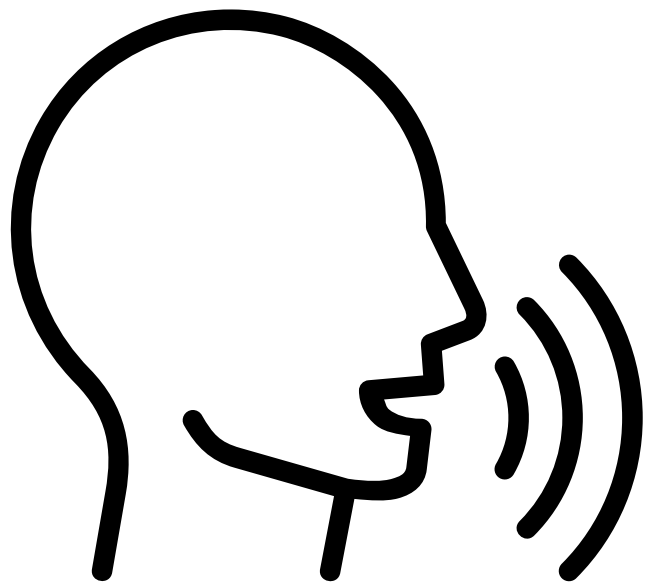
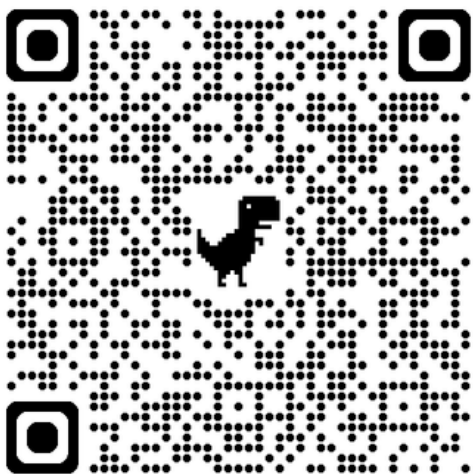
1. Carmichael Olson, H, et al. (2009). A Call to action : advancing essential services and research on fetal alcohol spectrum disorders : a report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect.
2. May, P.A., Chambers, C.D., Kalberg, W.O., Zellner, J., Feldman, H., Buckley, D., et al. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA*. 319(5):474–82.
3. Gosdin, L.K., Deputy, N.P., Kim, S.Y., Dang, E.P., Denny, C.H. (2022). Alcohol Consumption and Binge Drinking During Pregnancy Among Adults Aged 18–49 Years — United States, 2018–2020. *MMWR Morb Mortal Wkly Rep* 2022;71:10–13.
4. Centers for Disease Control and Prevention. (2023). Basics about FASDs. <https://www.cdc.gov/ncbddd/fasd/facts.html>
5. Waite, D., & Burd, L. (2023). Common developmental trajectories and clinical identification of children with fetal alcohol spectrum disorders: A synthesis of the literature. *Advances in drug and alcohol research*, 3, 10877. <https://doi.org/10.3389/adar.2023.10877>
6. Kautz-Turnbull, C., Adams, T. R., & Petrenko, C. L. M. (2022). The Strengths and Positive Influences of Children With Fetal Alcohol Spectrum Disorders. *American journal on intellectual and developmental disabilities*, 127(5), 355–368. <https://doi.org/10.1352/1944-7558-127.5.355>
7. Greenmyer, J. R., Klug, M. G., Kambeitz, C., Popova, S., & Burd, L. (2018). A Multicountry Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults. *Journal of addiction medicine*, 12(6), 466–473. <https://doi.org/10.1097/ADM.0000000000000438>
8. Fleming, L., Sheridan, C., Waite, D., Klug, M. G., & Burd, L. (2023). Screening for fetal alcohol spectrum disorder in infants and young children. *Advances in drug and alcohol research*, 3, 11125. <https://doi.org/10.3389/adar.2023.11125>
9. Rutman D. (2016). Becoming FASD Informed: Strengthening Practice and Programs Working with Women with FASD. *Substance abuse : research and treatment*, 10(Suppl 1), 13–20. <https://doi.org/10.4137/SART.S34543>
10. Mattson, S. N., Bernes, G. A., & Doyle, L. R. (2019). Fetal Alcohol Spectrum Disorders: A review of the neurobehavioral deficits associated with prenatal alcohol exposure. *Alcoholism, clinical and experimental research*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6551289/>
11. Wozniak, J. R., Riley, E. P., & Charness, M. E. (2019). Clinical presentation, diagnosis, and management of fetal alcohol spectrum disorder. *The Lancet. Neurology*, 18(8), 760–770. [https://doi.org/10.1016/S1474-4422\(19\)30150-4](https://doi.org/10.1016/S1474-4422(19)30150-4)
12. Weyrauch, D., Schwartz, M., Hart, B., Klug, M. G., & Burd, L. (2017). Comorbid Mental Disorders in Fetal Alcohol Spectrum Disorders: A Systematic Review. *Journal of developmental and behavioral pediatrics : JDBP*, 38(4), 283–291. <https://doi.org/10.1097/DBP.0000000000000440>
13. Popova, S., Lange, S., Burd, L., Nam, S., Rehm, J. (2016). Special Education of Children with Fetal Alcohol Spectrum Disorder. *Exceptionality*, 24(3), 165–175. doi: 10.1080/09362835.2015.1064415. Epub 2016 Mar 23. PMID: 27695197; PMCID: PMC5009761.
14. Sessa, F., Salerno, M., Esposito, M., Di Nunno, N., Li Rosi, G., Rocuzzo, S., & Pomara, C. (2022). Understanding the Relationship between Fetal Alcohol Spectrum Disorder (FASD) and Criminal Justice: A Systematic Review. *Healthcare*, 10(1), 84. <https://doi.org/10.3390/healthcare10010084>
15. Mela, M., Flannigan, K., Anderson, T., Nelson, M., Krishnan, S., Chizea, C., Takahashi, S., & Sanjanwala, R. (2020). Neurocognitive function and fetal alcohol spectrum disorder in offenders with mental disorders. *Journal of the American Academy of Psychiatry and the Law*.
16. Popova, S., Lange, S., Burd, L., Urbanoski, K., & Rehm, J. (2013). Cost of specialized addiction treatment of clients with fetal alcohol spectrum disorder in Canada. *BMC public health*, 13, 570. <https://doi.org/10.1186/1471-2458-13-570>
17. World Health Organization. (2024). Social determinants of health. <https://www.who.int/health-topics/social-determinants-of-health>
18. May, P. A., & Gossage, J. P. (2011). Maternal risk factors for fetal alcohol spectrum disorders: not as simple as it might seem. *Alcohol research & health : the journal of the National Institute on Alcohol Abuse and Alcoholism*, 34(1), 15–26.
19. Rockhold, M. N., Kautz-Turnbull, C., Handley, E. D., & Petrenko, C. L. M. (2023). The trauma experiences of children with fetal alcohol spectrum disorders: Developmental outcomes utilizing a threat/deprivation child adversity framework. *Alcohol, clinical & experimental research*, 47(9), 1722–1735. <https://doi.org/10.1111/acer.15144>
20. Lees, B., Riches, J., Mewton, L., Elliott, E. J., Allsop, S., Newton, N., Thomas, S., Rice, L. J., Nepal, S., Teesson, M., & Stapinski, L. A. (2022). Fetal alcohol spectrum disorder resources for educators: A scoping review. *Health promotion journal of Australia : official journal of Australian Association of Health Promotion Professionals*, 33(3), 797–809. <https://doi.org/10.1002/hpja.574>
21. Corrigan, P. W., Shah, B. B., Lara, J. L., Mitchell, K. T., Combs-Way, P., Simmes, D., & Jones, K. L. (2018). Stakeholder perspectives on the stigma of fetal alcohol spectrum disorder. *Addiction Research & Theory*, 27(2), 170–177. <https://doi.org/10.1080/16066359.2018.1478413>
22. Nankoo, M. M. A., Panton, K. R., Fitzpatrick, J. P., & Pestell, C. F. (2023). Scoping review of employment resources for individuals with fetal alcohol spectrum disorder and justice involvement. *BMJ open*, 13(2), e063860. <https://doi.org/10.1136/bmjopen-2022-063860>

FEEDBACK

SHARE YOUR STORY

Do you have more information or a personal story you want to share with FASD United?

Scan the QR code to share:



WHAT DID YOU THINK OF THE SYMPOSIUM?

Share your feedback and help us make next year even better!

Scan the QR code to fill out an evaluation form.

