

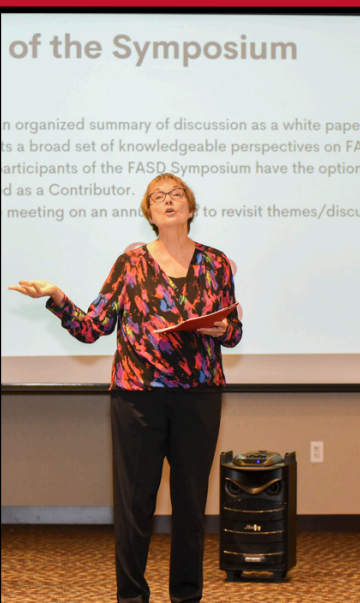
FASD SYMPOSIUM

WHITE PAPERS ↗

Co-Creating
Recommendations for
Progress in the FASD
Field and Community

An Invitation to the Table.

Volume 1.1
















WASHINGTON D.C.
SEPTEMBER 16, 2024

FASD SYMPOSIUM

AN INVITATION TO THE TABLE

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INTRODUCTION

FASD WHITEPAPERS

An Invitation to the Table

This White Paper presents the perspectives and expertise of individuals with FASD, as well as families, professionals in the field, 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 National FASD Task Force Call to Action. This paper presents insights¹ contributed through various modes of feedback collection at the **FASD Symposium: 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 National FASD Task Force 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 project intends to continue that work by bringing living experience to the center of the work.

GLOSSARY

| TERM | DEFINITION |
|---------------------------------|---|
| ADA | Americans with Disabilities Act. The ADA is a primary federal protection for people with disabilities. |
| Agencies | A term to refer to federal and state government organizations responsible for certain aspects of government-regulated work and policies. |
| Executives | A catch-all term to refer to insurers, medical companies, medical leaders, and any industries/corporations relevant to the FASD community and field. |
| IEPs/504 Plans | An Individualized Education Program (IEP) is a legally-binding, written plan that outlines specific educational goals and services for students with disabilities, tailored to their unique needs. A 504 Plan provides accommodations to ensure students with disabilities have equal access to education, but it doesn't involve the same specialized services as an IEPs. |
| Interdisciplinary | The practice of combining, integrating, or synthesizing information, data, and perspectives from multiple disciplines/fields. |
| Transdisciplinary | The practice of creating, and then utilizing, a new intellectual framework by integrating and transcending boundaries between natural, social, and health sciences. |
| Social Drivers of Health | Social drivers of health (sometimes referred to as social determinants of health or SDOH) are non-medical factors that influence wellness, quality of life, and health outcomes. |



BACKGROUND

Fetal alcohol spectrum disorders (FASD) 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 in the United States: **1 in 20** ²

Rate of alcohol use during pregnancy in the US: **1 in 7** ³

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

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

FASD Across the Lifespan

Challenges throughout the lifespan may include:

Infancy: Birth defects, difficulties in regulation, developmental delays

Childhood: Developmental delays, behavioral issues, academic and social challenges in school and with peers

Adolescence: Behavioral issues, mental health struggles, challenges in school and with peers

Adulthood: Employment, housing, legal issues, mental health challenges ⁹

Strengths and Positive Qualities:

Research shows that parents and caregivers of children with FASD often report a variety of strengths and positive qualities. Common strengths observed in individuals with FASD include: **being loving, forming strong family connections, being sociable, desiring acceptance from others, showing trust, warmth, energy, and creativity.** **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 the 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.¹² Sometimes social drivers of health result in better health outcomes, and sometimes they result in poorer health outcomes.

Examples of Social drivers of health:



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.¹³
- People with FASD, as well as their families, frequently experience stigma and discrimination.¹⁴ This may be compounded for those with multiple marginalized identities (such as being a person of color, female, and/or transgender).¹⁵
- People with FASD experience higher rates of trauma and adverse life experiences.¹⁶
- Students with FASD often have a challenging, disrupted school experience.¹⁷
- People with FASD are disproportionately represented in the justice system.¹⁸
- People with FASD face unique challenges in the workplace and have higher rates of unemployment compared to people without FASD.¹⁹

BACKGROUND

20

6 REASONS TO SCREEN BEFORE AGE 6

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

- 1 Empowering parents with a sense of understanding
- 2 Reducing the risk of maltreatment toward the child if behaviors are misunderstood
- 3 Increasing opportunities for timely interventions
- 4 Identifying appropriate specialty care
- 5 Making it easier to discuss accommodations or considerations in education
- 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.²¹ 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 academic disciplines, professions, and societal sectors.



METHODOLOGY

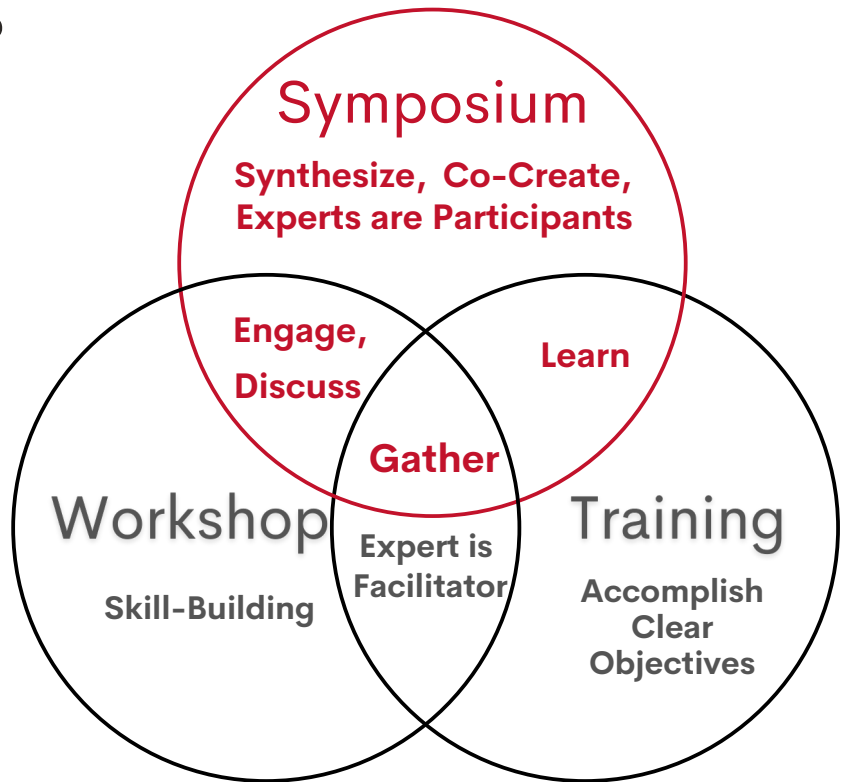
WHY A SYMPOSIUM?

The participants are experts.

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

Participants are named as **Contributors** in the resulting FASD Symposium White Paper.

Engagers are experienced professionals who help facilitate the discussions during the Symposium.



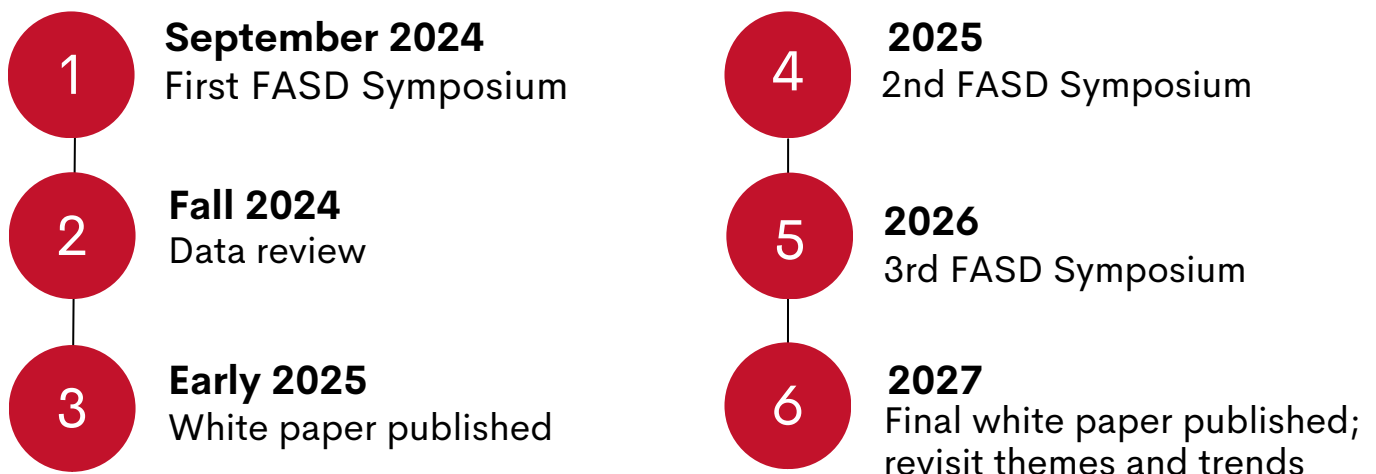
| | |
|------------------------|--|
| Symposium | A structured discussion among diverse experts on a specific topic. |
| White Paper | A white paper is a report or guide that informs readers concisely about a complex issue and presents the authors' perspectives on the matter. |
| Recommendations | A summarized suggested course of action or advice from the symposium aimed at advancing progress in the FASD community and field. |
| Action Items | Specific suggestions to the FASD community, field, and broader fields to <ol style="list-style-type: none"> 1) advocate for policy that accomplishes goals 2) conduct research to fill gaps of knowledge information 3) encourage further discussion or consensus around a topic. |

METHODOLOGY

ROLES

| | |
|---------------------|---|
| Contributors | Participants in the FASD Symposium discussions. Contributors are considered experts from living experience with FASD and/or professional expertise relevant to FASD. The first FASD Symposium brought in 75 representative Contributors. |
| Engagers | Facilitators of FASD Symposium discussions. Each discussion table has 1 Engager who has experience navigating conversations around FASD and ensuring all voices at the table are heard. |
| Reviewers | People with living experience with FASD and/or professional expertise relevant to reviewing technical information about FASD. Reviewers ensure content is evidence-based and accessible to our community. |
| Authors | Authors are responsible for designing the Symposium discussion, summarizing the Symposium data, and working with Engagers and reviewers to finalize the paper. |

TIMELINE



METHODOLOGY

Before the Symposium

The 2009 Recommendations



Original
Recommendation

Identify and understand the recommendations we will be updating. 3-4 Recommendations are updated per year.

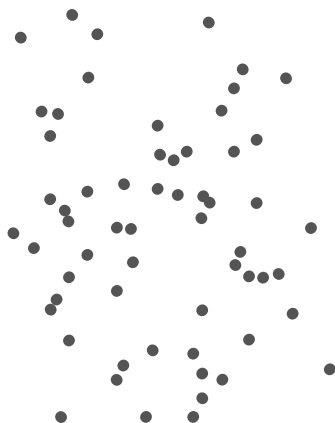
- FASD United selected 3 Recommendations from the *2009 National FASD Task Force Recommendations (TFR)*.
- The Background section of this paper was outlined based on the *2009 TFR*, and then fully updated with the most recent and relevant data.

Contributors' & Engagers' Guide

- The Contributors' Guide and Engagers' Guide were provided to support discussion for all 3 sessions.
- These guides were provided virtually before the Symposium, and physically the day-of.
- FASD United met with Engagers to walk through the Guide and understand the original Recommendations.

Data Collection

Data Points



Collect data utilizing diverse, representative feedback from the FASD field & community through a facilitated **Symposium** discussion. One session per recommendation.

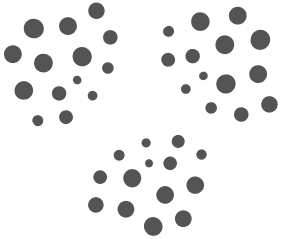
- Three Sessions were held at the FASD Symposium on September 16th, 2024 - One Session per Recommendation.
- In each Session, a Task Force Recommendation was deconstructed using a series of multi-modal, Socratic seminar-style discussions.
- People, or Contributors, sat approximately 10 per table, with a designated Engager to support meaningful discussion.
- At the end of each Session, the Contributors' feedback was collected using live individual surveys and written group feedback. The live surveys resulted in 80-100 "takeaways"/data points per session.

METHODOLOGY

After Symposium

Data Thematic

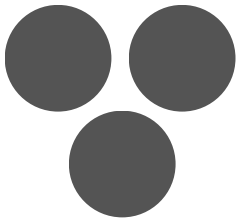
Data Themes



Identify and define themes in the data, and sort the data into the thematic categories.

Themes to Action Items

Agreed Action Items



Identify actionable recommendations from of each Theme.

Updated Recommendation

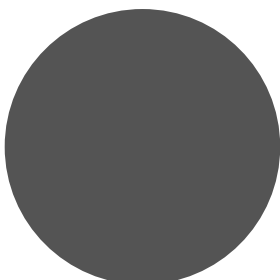


Summarize Themes into a single sentence, updated recommendation.

- For each Theme, FASD United drafted one Action Item. These are specific recommendations that organizations, institutions, and agencies can use to inform their work.
- A follow-up meeting was held virtually with the Engagers to discuss whether these Action Items accurately reflected the conversations they had the day of the FASD Symposium.

- Finally, FASD United took the Themes and Action Items to draft one Updated Recommendation.
- With the recommendations updates, the FASD White Paper was drafted and sent to our Research Review Team.

White Paper Published...



Repeat!

Every year, we will repeat the process of updating 3-4 of the original 2009 Task Force Recommendations. By 2026, we will have updated them all!

OVERVIEW

SESSION 1

Diagnosis & Screening



2009 FASD Task Force Recommendation

Improve **diagnostic access** by setting up **screening systems** for FASD and increasing professional multidisciplinary diagnostic capacity in communities.

2024 FASD Symposium Recommendation

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.

SESSION 2

Agency Collaboration



2009 FASD Task Force Recommendation

Enhance strong, collaborative, **interagency leadership** at state and national levels (that includes parent representation) to inform legislators, policymakers, and the public.

2024 FASD Symposium Recommendation

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.

SESSION 3

Continuum of Care



2009 FASD Task Force Recommendation

Promote a comprehensive and **accessible continuum of care** for youth, adults, and older individuals with FASD.

2024 FASD Symposium Recommendation

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.

SESSION 1

Diagnosis & Screening



2009 FASD Task Force Recommendation

Improve **diagnostic access** by setting up **screening systems** for FASD and increasing professional **multidisciplinary** diagnostic capacity in communities.

2024 FASD Symposium Recommendation

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.

**Universal
PAE
Screening**

**Enhanced
Professional
Training**

**Inter/Trans-
Disciplinary
Diagnostic
Capacity**

**Standardized
Diagnostic
Procedures**

SESSION 1: THEMES

**Increased
Funding &
Resources**

**Ongoing
Evaluation
& Support**

**Collaboration
on Best
Practices**

**Public
Awareness
& Stigma
Reduction**

UNIVERSAL SCREENING & DIAGNOSIS

THEMES AND ACTION ITEMS

Universal PAE Screening

- Create validated screening tool to be used in various settings: including prenatal care, newborn assessments, and routine childhood check-ups, to normalize inquiries about prenatal alcohol exposure and teach providers ways to ask these questions that reduce stigma.
- Work with national child-focused organizations to consider how screening for PAE or symptoms of FASD could appropriately be incorporated into the variety of settings in which children interact with professionals, such as WIC, child welfare, and educational settings..

Transdisciplinary Diagnostic Capacity

- Ensure every state has a clinic that can diagnose FASD, with a focus on accessible, person-centered services that consider the individual needs of patients across the spectrum.
- Promote the use of multidisciplinary approaches for the most complex cases and streamline standard diagnostic models to enhance efficiency.

Increased Funding & Resources

- Advocate for increased funding to support FASD research, training, and infrastructure development, ensuring financial feasibility for providers.
- Standardize and streamline reimbursement codes for FASD diagnostics and services to make it viable for more clinics to diagnose and serve.

Collaboration & Best Practices

- Encourage collaboration among researchers, healthcare providers, and educators to share best practices and utilize existing effective screening tools.
- Leverage insights from lived experiences to inform diagnostic practices and ensure a compassionate approach to care.

Enhanced Professional Training

- Develop and incentivize training programs for pediatricians, educators, mental health professionals, and child welfare workers to increase understanding and competency in FASD screening and diagnosis.
- Include training on trauma-informed and empathetic communication strategies to better engage families and reduce stigma.

Standardized Diagnostic Procedures

- Create a simplified and consensus diagnostic criteria and procedures across states, emphasizing a tiered model that addresses varying levels of support needs.
- Identify alternatives to requirement of confirmed prenatal alcohol exposure (PAE) to facilitate diagnosis and ensure that individuals can access necessary services.

Ongoing Evaluation & Support

- Implement routine re-evaluation of support needs over time, ensuring that individuals receive the necessary interventions as their circumstances change.
- Establish support groups for caregivers and families to provide resources and community connections.

Public Awareness & Stigma Reduction

- Initiate public education campaigns to normalize discussions around FASD screening and reduce associated stigma, making it a standard part of healthcare practice for all ages and demographics.

SESSION 2

2009 FASD Task Force Recommendation

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



Collaboration

2024 FASD Symposium Recommendation

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, treatment, and community resources across all states.

Collaboration
& Partnership

Leadership &
Coordination

Policy &
Legislative
Advocacy

Data Sharing &
Transparency

SESSION 2: THEMES

Education
& Training

Funding &
Resource
Allocation

Community
Engagement &
Empowerment

Access

COLLABORATION

Collaboration and Partnerships

- Build regional partnerships with businesses, grassroots advocates, and self-advocates to take action and mobilize communities, ensuring clear roles, goals, and decision-making processes.
- Empower self-advocates and parent-advocates to influence change, using social media to amplify their voices and connect agencies with communities.

Leadership & Coordination

- Create a national leadership structure, such as Center of Excellence, to guide states with clear goals, metrics, and a unified roadmap.
- Strengthen affiliates through nationwide training programs to ensure consistent leadership and support.

Policy and Legislative Advocacy

- Develop clear guidelines for FASD advisory committees and task forces, aligning them with state and federal policies.
- Push for greater understanding that individuals with an FASD are covered under the ADA and work to expand eligibility for other services and protections so they will always have a seat at the table.

Data Sharing and Transparency

- Set up a national platform to share data, objectives, and metrics, ensuring transparency and accountability.
- Link researchers and practitioners to ensure data is applied effectively in real-world solutions.

THEMES AND ACTION ITEMS

Education and Training

- Make FASD training mandatory in schools, healthcare, and social services to improve awareness and support.
- Include FASD education in teacher certification and school curricula to strengthen early intervention.

Funding and Resource Allocation

- Use Respect Act funds to create dedicated funding streams for FASD support with shared goals across agencies.
- Simplify funding processes and align priorities to encourage collaboration and resource-sharing.

Community Engagement and Empowerment

- Partner with large, broader disability groups to support caregivers and deliver actionable, easy-to-use resources for communities.
- Strengthen parent networks and ensure their voices are included in policies and community solutions.

Access

- Address barriers to collaboration by setting clear goals, focusing on strengths, and creating strong decision-making systems.
- Build capacity to overcome funding silos and other obstacles with structured, shared frameworks.

SESSION 3

Continuum of Care



2009 FASD Task Force Recommendation

Promote a comprehensive and accessible continuum of care for youth, adults, and older individuals with FASD.

2024 FASD Symposium Recommendation

To promote a comprehensive and accessible continuum of care for individuals with FASD, it is essential to implement coordinated, evidence-based interventions and policies that ensure lifelong support, reduce stigma, and enhance education and job training across all stages of life.

**In/Inter-
dependence**

**Mental
Health &
Well Being**

**Education
& Training**

**Transition &
Care
Coordination**

Access

SESSION 3: THEMES

**Community
& Social
Connections**

**Policy &
Advocacy**

**Awareness
& Stigma
Reduction**

**Family &
Caregiver
Support**

**Evidenced-
Based
Interventions**

CONTINUUM OF CARE

THEMES AND ACTION ITEMS

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.
- 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.

DISCUSSION

Since the 2009 Recommendations, some priorities of the FASD community have shifted. Below are some notable changes.

The **FASD White Paper 1.1** was reviewed by a team of 9 Reviewers who provided feedback on technical edits, design, content structure, and tone. Feedback that could not immediately be implemented is outlined below for future consideration by other individuals and entities.

ACCESS

In each session, Contributors are asked to submit a main takeaway. 16% of the Contributor data highlighted a need for increased access or the removal of barriers.

Named "barriers" included: expensive or complicated diagnoses as well as a lack of infrastructure and billing codes from insurance regarding FASD screening & diagnosis.

Contributors highlighted the importance of **universal screening** in pediatric appointments and schools to increase access. Contributors also encourage individuals and families to attend public agency meetings and advocacy events relevant to FASD.

DIAGNOSIS

Since 2009, researchers have moved away from standardizing a multidisciplinary diagnostic team. In the 2024 Symposium, there were several alternative suggestions including streamlining diagnosis for simpler cases. Some feedback highlighted the benefits of a tiered diagnostic model, according to the complexity of a case.

FUTURE COLLABORATIONS

Contributors and Reviewers highlighted the need for nurturing new or stronger collaborations with the following groups/industries:

- Insurance Companies
- Other disability and neurodiversity organizations
- State Agencies

DISCUSSION

AGENCIES & RESEARCHERS

Reviewers noted the value of attaching “measurable outcomes” to the Action Items and urge researchers to determine what action items require data, information, and/or research to fill gaps in our knowledge of FASD. This will provide the community with an understanding of our **current context**, making it possible to create measurable goals going forward.

With every FASD Symposium cycle, we intend to better understand our current context and make progress since the last FASD Symposium.

ORGANIZATIONS

We encourage you to understand how your work impacts the bigger picture. Under “Diagnosis & Screening”, there are Action Items about training as well as collaboration between researchers and organizations serving individuals & families. While we only tackle 3-4 Recommendations per year, all aspects of progress for FASD require all levels of participation.

What models for respite care currently exist? How can we improve models for respite services or nurture partnerships in communities where these are developed?

INDIVIDUALS & FAMILIES

Reviewers noted the power of Individuals partnering with organizations. Many initiatives are not possible if people with living experience and organizations do not partner every step of the way. Whether by using an organization’s services, joining a board, volunteering, or making yourself available to share your story, you have an impact on this progress.

Understand how to share your story. Reach out to local FASD and disability organizations, and learn how to advocate through your representatives.

ACKNOWLEDGEMENTS

Participants represent people with living experience, families, organizations, relevant professionals & clinicians, researchers, and government agencies. Post-nominals were left out to acknowledge the equal value of perspectives in this paper.

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Participation does not equal endorsement by organizations that the participants represent. Not all Contributors are named.

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Thank you to everyone who made this paper possible.



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