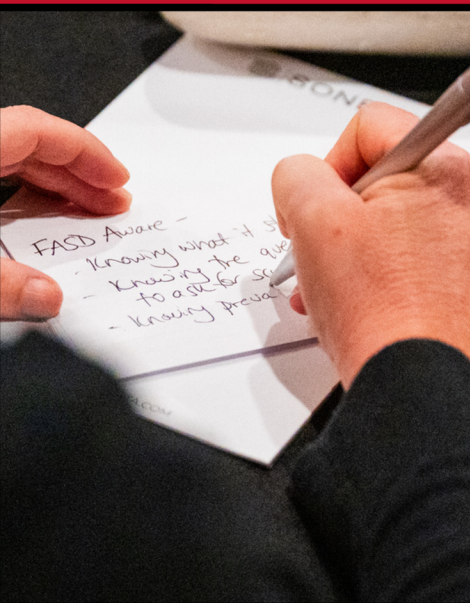


# FASD SYMPOSIUM WHITE PAPERS ↗

Co-Creating  
Recommendations for  
Progress in the Fetal  
Alcohol Spectrum  
Disorder (FASD) Field  
and Community

An Invitation to the Table.

Volume 1.2



WASHINGTON D.C.  
SEPTEMBER 15, 2025

A project of FASD United



# FASD SYMPOSIUM

AN INVITATION TO THE TABLE

## CONTENTS

|                                                                                     |                                                                                                                                                            |           |
|-------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
|    | <b>INTRODUCTION</b>                                                                                                                                        | <b>1</b>  |
|    | <ul style="list-style-type: none"><li>• FASD White Papers</li><li>• Summary of White Paper Volume 1.1</li><li>• Glossary</li></ul>                         |           |
|    | <b>BACKGROUND</b>                                                                                                                                          | <b>5</b>  |
|    | <ul style="list-style-type: none"><li>• Information about FASD</li></ul>                                                                                   |           |
|   | <b>METHODOLOGY</b>                                                                                                                                         | <b>8</b>  |
|  | <ul style="list-style-type: none"><li>• Before, During, &amp; After the FASD Symposium</li></ul>                                                           |           |
|  | <b>OVERVIEW</b>                                                                                                                                            | <b>13</b> |
|  | <ul style="list-style-type: none"><li>• 2009 Recommendations and 2025 Updated Recommendations</li></ul>                                                    |           |
|  | <b>SESSIONS &amp; ACTION ITEMS</b>                                                                                                                         | <b>14</b> |
|  | <ul style="list-style-type: none"><li>• Session 1: Professional Education</li><li>• Session 2: Grassroots Efforts</li><li>• Session 3: FASD Data</li></ul> |           |
|  | <b>DISCUSSION</b>                                                                                                                                          | <b>20</b> |
|  |                                                                                                                                                            |           |
|  | <b>ACKNOWLEDGEMENTS &amp; CITATIONS</b>                                                                                                                    | <b>22</b> |



# 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]<sup>1</sup> transcends the mission and resources of any single agency or program."<sup>1</sup> 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?

This White Paper is the second of a 3-part series and is the resulting summary of FASD United's second-annual **FASD Symposium**. Each year, FASD United hosts this national discussion in Washington, DC, 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 in the White Paper.

# FASD WHITE PAPERS

## Summary of Volume 1.1

SCAN FOR FULL WHITE  
PAPER 1.1 REPORT



### *Outcomes from 2024 FASD Symposium*

#### DIAGNOSIS & SCREENING



##### 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.

#### CONTINUUM OF CARE



##### 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.

#### AGENCY 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, and community resources across all states.



# GLOSSARY

## DEFINITIONS OF IMPORTANT WORDS & PHRASES

| TERM                     | DEFINITION                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>504 Plan</b>          | A Federal education accommodation plan under Section 504 of the Rehabilitation Act that provides supports and accommodations in school for students whose disabilities, including FASD, affect learning or other major life activities.                                                                                                                                                                                                                               |
| <b>Agencies</b>          | A term to refer to Federal and state government organizations responsible for certain aspects of government-regulated work and policies.                                                                                                                                                                                                                                                                                                                              |
| <b>Continuum of Care</b> | An integrated system of services that guides and supports an individual through various stages of a condition or life transition.                                                                                                                                                                                                                                                                                                                                     |
| <b>Evidence-Based</b>    | Research has shown that the program or practice works effectively.                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>FASD-Aware</b>        | Having a basic understanding of FASD, its general prevalence, and its potential impacts on individuals and families.                                                                                                                                                                                                                                                                                                                                                  |
| <b>FASD-Informed</b>     | <p>Understands the characteristics, challenges, and support needs associated with FASD and knows how to apply this knowledge in interactions or decision-making.</p> <p>Within the FASD Respect Act, FASD-informed is defined as the use of culturally and linguistically informed evidence-based or practice-based interventions and appropriate resources to support an improved quality of life for an individual with FASD and the family of such individual.</p> |
| <b>FASD-Trained</b>      | Has completed specialized education or professional training on FASD and can effectively implement FASD-responsive strategies, supports, or services.                                                                                                                                                                                                                                                                                                                 |

# GLOSSARY

| TERM                            | DEFINITION                                                                                                                                                                                                                                                                   |
|---------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>FASD Respect Act</b>         | Federal legislation passed in 2025 designed to improve diagnosis, prevention, research, and support services for individuals and families affected by FASD.                                                                                                                  |
| <b>FASD Surveillance</b>        | The ongoing systematic collection, analysis, and monitoring of data related to fetal alcohol spectrum disorders to track prevalence, identify risk factors and protective factors, and inform prevention and support services.                                               |
| <b>Grassroots Organizations</b> | Grassroots organizations are nonprofits and other groups focused on providing services, resources, and advocacy for the community.                                                                                                                                           |
| <b>National Framework</b>       | A national framework serves as a set of principles, regulations, and strategic directions established to address significant issues or achieve specific goals.                                                                                                               |
| <b>PAE</b>                      | Prenatal alcohol exposure. This term refers to people who have been exposed to alcohol during pregnancy but do not have access to confirmation of exposure or have not received an alcohol-related diagnosis.                                                                |
| <b>Task Force and Coalition</b> | A task force is generally a subject- or goal-focused group formed under local, state, and federal government agencies. A coalition is usually a broader, long-term partnership of organizations or stakeholders working together around a shared mission or common interest. |
| <b>Socratic Seminar</b>         | A formal discussion in which a facilitator asks open-ended questions, often based on a text (in this case, the 2009 FASD Task Force Recommendations).                                                                                                                        |
| <b>Stakeholder(s)</b>           | An individual, group or organization that is impacted by the outcome of a project. Stakeholders have an interest in the success of the project and can be within or outside the organization that is sponsoring the project                                                  |



# BACKGROUND

## HELPFUL INFORMATION TO KNOW

The CDC defines fetal alcohol spectrum disorders (FASDs) as a group of conditions that can occur in a person exposed to alcohol before birth. These conditions can affect each person in different ways and can range from mild to severe. People with FASDs can have lifelong effects, including problems with behavior and learning as well as physical problems.<sup>2</sup>

*Reviewers noted the need to consider a standard definition for FASD that is both accurate and encompassing of the strengths of people with FASD.*

### Prevalence & recent trends

Prevalence of FASD among children in the United States (US): **1 in 20**.<sup>3</sup>

Prevalence of alcohol use during pregnancy among adults in the US: **More than 1 in 7**.<sup>4</sup>

The prevalence of alcohol-exposed pregnancies has **increased** over time.<sup>5-8</sup>

Although **FASD is common**, it remains under-diagnosed and is often misdiagnosed.<sup>9</sup>

### FASD across the lifespan

Prenatal alcohol exposure can affect how the brain and body develop, with lifelong impacts.<sup>10</sup> Individuals with FASD can experience a wide range of whole-body health challenges.<sup>11</sup> Symptoms and support needs can change throughout the lifespan.<sup>12</sup> Every person with FASD is impacted differently and has both unique strengths and support needs.<sup>13</sup>

### 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.<sup>14</sup>

### The Impact of Grassroots Efforts

Grassroots efforts are initiatives where individuals engage with larger organizations and systems to create change. In 2025, thanks to the advocacy of families and self-advocates across the country, the FASD Respect Act was signed into law as a result of the Support Reauthorization Act. This milestone in FASD policy supports a comprehensive Federal response to prenatal alcohol exposure, empowering individuals and families impacted by FASD and enhancing our nation’s public health.



# BACKGROUND

## Definition of FASD-Informed

According to the FASD Respect Act<sup>15</sup>, which was enacted by Congress in 2025, **FASD-informed** is described as the use of interventions and resources that are:

- culturally and linguistically informed
- evidence-based or practice-based
- supportive of an improved quality of life for an individual with FASD and the family of such an individual.

Increasing the number of FASD-informed agencies, professionals, and interventions can lead to more positive outcomes for people with FASD and their families.<sup>16</sup>

## The Importance of FASD-Informed Professional Education



Students with FASD often have a challenging, disrupted school experience. Positive relationships with **FASD-informed educators, however, can promote greater success** for students with FASD.<sup>17</sup> However, many teachers report having limited knowledge about FASD and a need for more training.<sup>18</sup>



**Health professionals play an important role** in both PAE prevention and the care of people impacted by PAE. However, research shows many health professionals hesitate to discuss alcohol consumption with pregnant people due to limited confidence and insufficient clinical resources for diagnosis and integrated care.<sup>19</sup>



People with FASD are overrepresented in the justice system, yet FASD is often **unrecognized, undiagnosed, and misunderstood by legal professionals**.<sup>20</sup> Research shows that closing the legal field's gap in understanding of FASD can reduce recidivism (re-entry into jails/prisons).<sup>21</sup> Education is necessary among judicial officers, attorneys, and forensic mental health clinicians, highlighting the need for FASD-informed professional education and systems change.<sup>22</sup>

# BACKGROUND

## COLLECTING ROBUST AND ACTIONABLE FASD DATA

**Public health surveillance** is the ongoing, systematic collection, analysis, and interpretation of health-related information. It is used to plan and implement public health programs.<sup>23</sup> Several public health surveillance methods are used to collect information about PAE and FASD, including prevalence data. Brief descriptions of the four primary methods are provided below.

### ANALYSIS OF EXISTING ADMINISTRATIVE DATABASES

*Uses healthcare/insurance claims data, including diagnoses and procedures.*

**Strengths:** Large data source; efficient and cost-effective

**Weaknesses:** Undiagnosed cases may be missed; potential misclassification; not designed for research purposes.

**Examples:** (Dorsey, 2025)<sup>24</sup>, (Deputy, 2024)<sup>25</sup>

### MULTIPLE SOURCE RECORD REVIEW

*Reviews existing health, administrative, justice, or other records to identify characteristics of a child that meet a case definition consistent with an FASD.*

**Strengths:** Large data source; existing resources

**Weaknesses:** Requires coordination with state or local jurisdictions

**Examples:** CDC's FASSNet I and II<sup>26</sup>

### PUBLIC HEALTH SURVEYS

*Asks populations about health experiences.*

**Strengths:** Often recurring, captures a variety of experiences representative of a specific population

**Weaknesses:** Self-reporting bias, not always conducted longitudinally

**Examples:** Behavioral Risk Factor Surveillance System (BRFSS),<sup>27</sup> Pregnancy Risk Assessment Monitoring System (PRAMS)<sup>28</sup>

### IN-PERSON, ACTIVE CASE ASCERTAINMENT

*Works directly with communities to screen and evaluate individuals.*

**Strengths:** Detailed, standardized data collection; can identify previously undiagnosed cases.

**Weaknesses:** Time and resource intensive

**Examples:** (May, 2018)<sup>2</sup>



# METHODOLOGY

## HOW WE DID THIS PROJECT

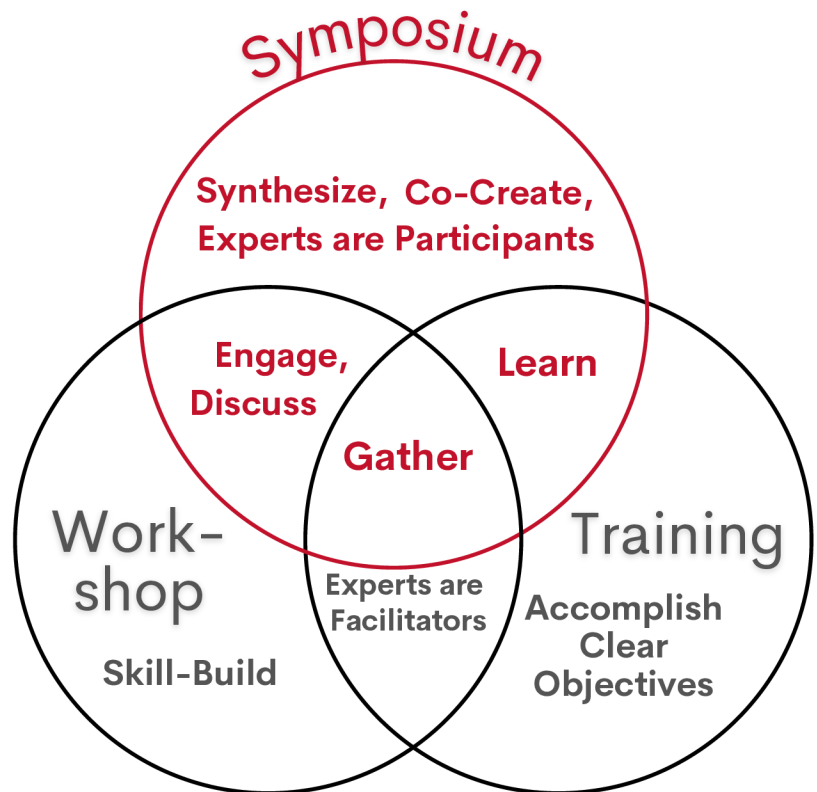
### WHY A SYMPOSIUM?

**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.



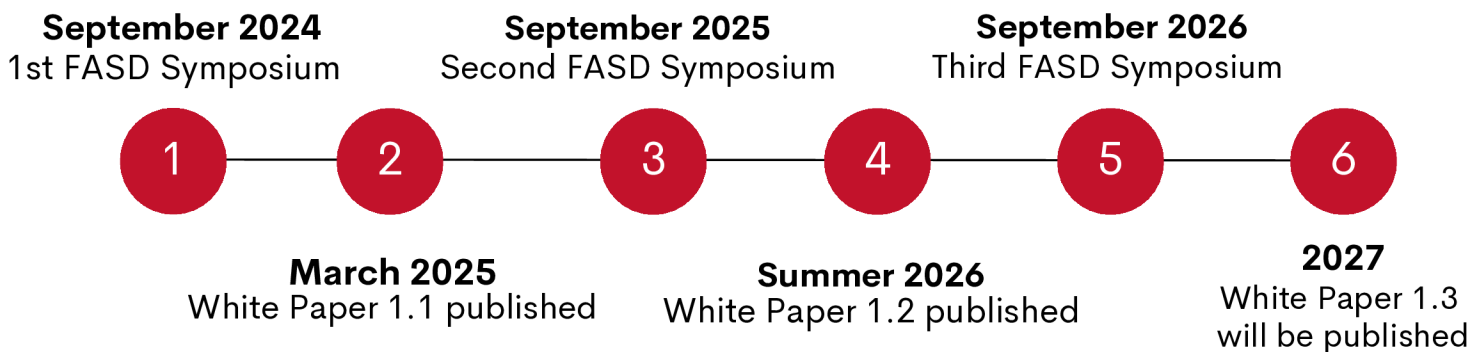
|                        |                                                                                                                                                                                           |
|------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>White Paper</b>     | A white paper is a report or guide that informs readers concisely about a complex issue and presents the authors' perspectives on the matter.                                             |
| <b>Recommendations</b> | 1-2 sentence goals for progress in the FASD community and field that were written by summarizing feedback from the Symposium discussions.                                                 |
| <b>Action Items</b>    | Specific suggestions to the FASD community, field, and broader audience to: 1) advocate for policy; 2) conduct research; and 3) encourage further discussion or consensus around a topic. |

# METHODOLOGY

## ROLES

|                     |                                                                                                                                                                                                                                        |
|---------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Contributors</b> | Participants in the FASD Symposium discussions. Contributors are considered experts as a result of having living experience with FASD and/or professional expertise relevant to FASD.<br>The 2025 Symposium included 119 Contributors. |
| <b>Engagers</b>     | 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. In 2025, there were 14 Engagers.               |
| <b>Reviewers</b>    | Reviewers ensure content is evidence-based and accessible to our community. They provide feedback on design, structure, proofreading, science & citations, accessibility, stigma, and plain language.                                  |
| <b>Authors</b>      | The Authors are FASD United staff responsible for designing the Symposium discussion, summarizing the Symposium data, and working with Engagers and Reviewers to finalize the paper.                                                   |

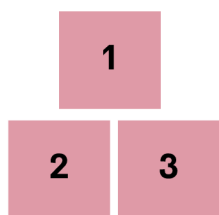
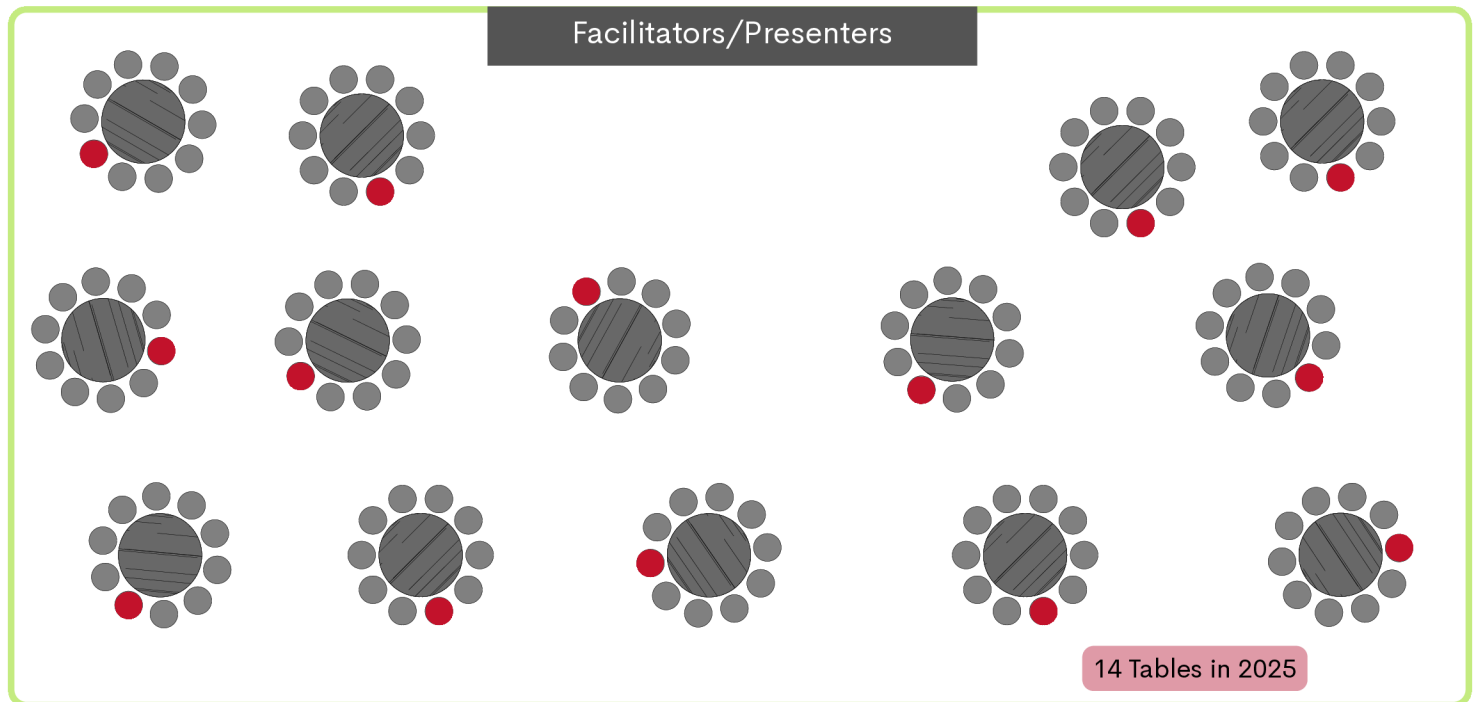
## TIMELINE





# METHODOLOGY

## ABOUT THE SYMPOSIUM SESSIONS



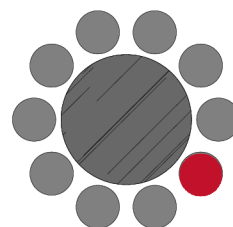
There were 3 discussion sessions; each centered on 1 Recommendation.



Each session started with a brief presentation to establish shared baseline knowledge on the topic.



Seat labels represent different perspectives (e.g., Social Work, Lived Experience, Research), fostering diverse discussions at each table.



Each table had 1 Engager to facilitate the activity and conversation.



Engagers guided activities and led discussions following the Engagers' Guide.



All participants were encouraged to submit personal takeaways from their table discussions, which informed the White Paper recommendations.

# METHODOLOGY

## Pre-Symposium

### The 2009 Recommendations



Original  
Recommendation

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

#### *2009 National FASD Task Force Recommendations (TFR)*

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

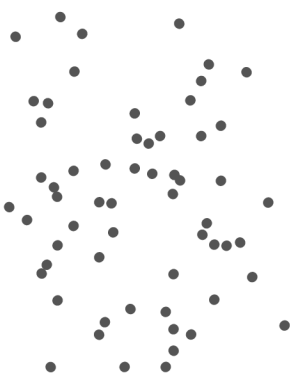
#### Contributors' & Engagers' Guide

- The Contributors' and Engagers' Guide were provided to facilitate discussion for all 3 sessions.
- These guides were distributed virtually before the Symposium and provided in print on the day of the event.
- FASD United met with Engagers to review the Guide and discuss the original Recommendations.

## Symposium

### Data Collection

#### Data Points



Conduct a facilitated symposium discussion with the FASD field and community. Identify and collect data that reflect the diversity of experiences within the FASD community.

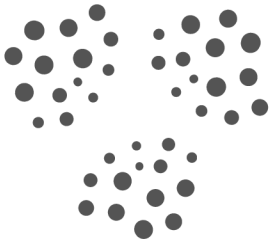
- Three sessions were held during the September 15, 2025 FASD Symposium, each dedicated to one recommendation.
- Each session deconstructed a *TFR* through multi-modal discussion and collaboration.
- Contributors were seated in groups of approximately 10 and engaged in facilitated socratic seminars led by Engagers.
- Contributors provided feedback through live individual surveys and written group responses.
- Each session generated approximately 80–100 takeaways (data points).

# METHODOLOGY

## Post-Symposium

### Data Thematic

#### Data Themes

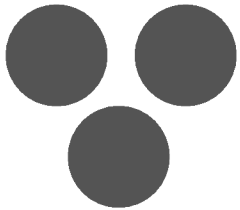


Identify and define themes in the data, and sort the data into the thematic categories.

- For each Session, Authors identified Themes in the dataset based on a) keywords from the original Recommendation, or b) by most-used words in the dataset using word-cloud generator.
- Authors then organized the individual data points into those Themes.

### Themes to Action Items

#### Agreed Action Items



Identify actionable recommendations from each Theme.

- For each Theme, Authors drafted one Action Item. These are specific recommendations that organizations, institutions, and agencies can use to inform their work.
- Action Items often reference specific data points in their wording or ideas.

### Updated Recommendation



Summarize Themes into a single sentence, updated recommendation.

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

## White Paper Published...



## Repeat!

Each year, we will repeat the process of updating 3-4 of the original 2009 Task Force Recommendations. By summer 2027, we will have reviewed and updated them all.

# OVERVIEW

## SUMMARY OF RESULTS

### SESSION 1

#### Professional Education



#### 2009 FASD Task Force Recommendation

Encourage comprehensive professional education on FASDs, and assessment of knowledge gained, within multiple service systems.

#### 2025 FASD Symposium Recommendation

Build out systems that can disseminate standardized curricula of FASD professional and public education across service systems. The priority should be to center living experience and include mechanisms for evaluating FASD awareness within communities.

### SESSION 2

#### Grassroots Efforts



#### 2009 FASD Task Force Recommendation

Recognize grassroots family support and advocacy organizations focused on FASDs, which are powerful and efficient agents of change.

#### 2025 FASD Symposium Recommendation

Create and sustain partnership opportunities with and among grassroots organizations focused on FASD to expand funding and resources to ensure longevity of programs and projects.

### SESSION 3

#### FASD Data



#### 2009 FASD Task Force Recommendation

Improve ongoing national surveillance systems to identify individuals with FASDs to better track prevalence, provide needed intervention, and assess the impact of prevention programs.

#### 2025 FASD Symposium Recommendation

Build confidence in the FASD community to understand and utilize relevant data. Priorities are to track prevalence, measure effective interventions, assess the impact of programs, and identify opportunities for sharing data among systems and the FASD community.





# SESSION 1

## Professional Education

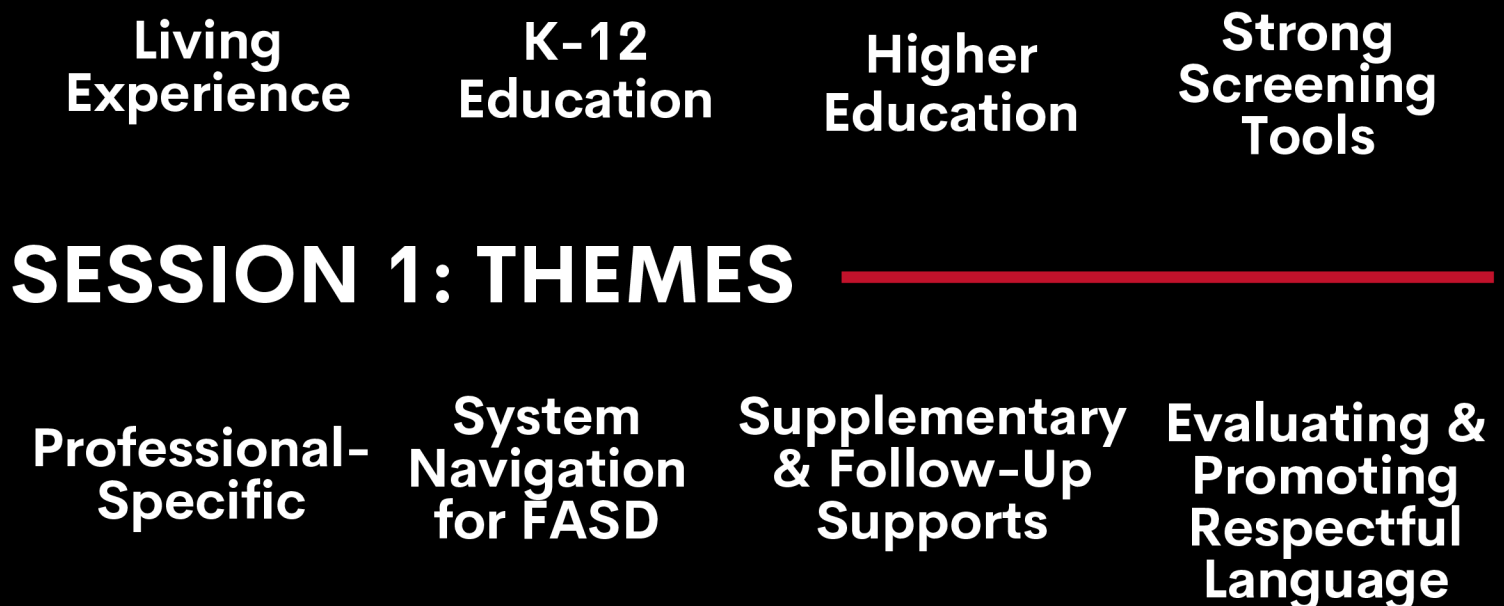


### 2009 FASD Task Force Recommendation

Encourage comprehensive professional education on FASDs, and assessment of knowledge gained, within multiple service systems.

### 2025 FASD Symposium Recommendation

Build out systems that can disseminate standardized curricula of FASD professional and public education across service systems that are informed by lived experience and include mechanisms for evaluating FASD awareness within communities.



# PROFESSIONAL EDUCATION

## THEMES AND ACTION ITEMS

### Living Experience

- Include people with FASD in the strategy, design, and review of education materials on FASD for every audience. Maintain an accommodating and open space that allows people with FASD to fully participate.
- Strategically offer compensation to people with FASD and birth parents for contributing living experience accounts and perspectives.

### K-12 Education

- Integrate age-appropriate foundational content on FASD into health and science curricula, emphasizing prevention, human development, and promoting respectful understanding of FASD among students.
- Provide in-school training and resources for teachers and school staff so they can recognize FASD-related support needs and leverage FASD-specific accommodations.

### Higher Education

- Bring FASD education into relevant degree programs (i.e., education, healthcare, human services, and criminal justice) to ensure future professionals understand diagnosis, support strategies, and prevention.
- Promote interdisciplinary research, campus awareness initiatives, and partnerships with community organizations to expand evidence-based practices and public understanding of FASD.

### Strong Screening Tools

- Form consensus around screening tools for PAE and FASD in respective fields (i.e., justice, human services, education.)
- Share screening training tools among associations and relevant organizations and work toward mandating training for certain fields.

### Professional-Specific

- Develop standardized levels of FASD competency for professions relevant to FASD, including clinicians, nurses, educators, social workers, therapists, first responders, and justice professionals.
- Incentivize FASD professional education through partnerships with professional associations, licensing organizations, and relevant agencies.

### System Navigation for FASD

- Organizations should be able to educate and support people and families impacted by FASD to access services and navigate service systems at the local, state, and Federal levels.
- Organizations and agencies must improve and update these materials as systems change.

### Supplementary & Follow-Up Supports

- Organizations should provide resources and forums for professionals to continue learning and access personalized support after receiving FASD training.
- Organizations providing services should create strong pipelines for referrals to/from professional associations and training organizations.

### Evaluating & Promoting Respectful Language

- Create systems to keep organizations, businesses, institutions, and agencies accountable in creating respectful content around FASD.
- Build out tools to evaluate and screen content for risk of harm caused by perpetuating stigma.

# SESSION 2

## Grassroots Efforts



### 2009 FASD Task Force Recommendation

Recognize grassroots family support and advocacy organizations focused on FASDs, which are powerful and efficient agents of change

### 2025 FASD Symposium Recommendation

Create and sustain partnership opportunities with and among grassroots organizations focused on FASD to expand funding and resources to ensure longevity of programs and projects.

**Community  
Support &  
Services**

**Policy & Local  
Relationships**

**Awareness &  
Media**

**Partnerships  
& Coalitions**

## SESSION 2: THEMES

---

**Training &  
Education**

**Diagnostics  
& Clinics**

**Justice System  
Support**

**Coordination  
with  
Research**



# GRASSROOTS EFFORTS

## THEMES AND ACTION ITEMS

### Community Support & Services

- Strengthen current community supports and services. This includes the creation of new programs and projects, especially by expanding geographical coverage and adult services.
- Develop “safe spaces” where people with FASD, birth parents, siblings, and caregivers can engage in structured interactions while also having opportunities for separate reflection and processing.

### Policy & Local Relationships

- Carry out relationship-building and relationship-maintenance at local, state, and Federal levels to grow representation of awareness in government that matches FASD’s prevalence.
- Service and advocacy organizations should be prepared to support service-users to understand the policy landscape that affects them.

### Awareness & Media

- Document lessons learned in communicating to the public, families, and professionals about FASD and PAE in consultation with people with lived experience.
- Seek ambitious partnerships with spokespeople, media agencies, and media/news outlets.

### Partnerships & Coalitions

- Create FASD networks that are supported by local government structures (task forces), and create mission-specific FASD networks to conduct collaborative initiatives (coalitions).
- Generate interest and engagement from outside the traditional FASD field/ community (i.e., corporate sponsors, agencies, etc.)

### Training & Education

- Grassroots organizations should be involved in establishing state and federal standards in professional education on FASD.
- Map out current training resources and coordinate strong networks of referrals to share existing resources and generate new training modules and content.

### Diagnostics & Clinics

- Service organizations and clinics should coordinate efficient systems of referrals to ensure people immediately access support.
- Grassroots organizations should be involved, whenever possible, in plans of safe care when it comes to responding to PAE and FASD.

### Justice System Support

- Grassroots organizations should partner with local Court Appointed Special Advocates (CASAs), judges, and attorneys to offer education, briefings, and connect systems to recent and relevant research.
- Strengthen parent networks and ensure their voices are included in policies and community solutions.

### Coordination with Research

- Grassroots organizations should be supported in accessing the most recent data and research to support people and families with FASD.
- Grassroots organizations should work in partnership with research institutions to inform them of community needs and build trusting relationships with self-advocates.

# SESSION 3

## FASD Data



### 2009 FASD Task Force Recommendation

Improve ongoing national surveillance systems to identify individuals with FASDs to better track prevalence, provide needed intervention, and assess the impact of prevention programs.

### 2025 FASD Symposium Recommendation

Build confidence in the FASD community to understand and utilize relevant data to track prevalence, measure effective interventions, assess the impact of programs, and identify opportunities for sharing data among systems and the FASD community.

**Integration  
with  
Systems**

**Partnered  
Studies**

**Surveillance  
Mapping**

**Long-Term,  
Effective  
Policy**

## SESSION 3: THEMES

---

**Novel  
Approaches**

**Generalized  
Screening  
Strategies**

**Reducing  
Harm**

**Building  
Confidence  
About Data**



# FASD DATA

## THEMES AND ACTION ITEMS

### Integration with Systems

- Embed FASD into existing systems of data and service systems (e.g., having FASD listed under "Other Health Impairments" in education so trends in prevalence and cost-effectiveness in services can be tracked).
- Develop partnerships within Medicaid and Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), acknowledging that public benefit program data may skew demographic data.

### Partnered Studies

- Seek out opportunities to partner on studies with related conditions and experience (e.g., autism, traumatic brain injuries, other exposures).
- Include people with FASD in research on interventions for other neurodiverse conditions and developmental disabilities to track varied outcomes and show a need for FASD-specific care.

### Surveillance Mapping

- Document current approaches in collecting data around PAE and FASD that can be used to strategize how to move forward.
- Outline what data should be collected across the lifespan of FASD (pre-exposure to the aging individual), and where that data can be accessed or asked for.

### Long-Term, Effective Policy

- Advocate for policies that reduce stigma and increase screening to allow for more identification, diagnosis, and tracking across an individual's life.
- Design policies within education, health, justice, and service systems to include people with FASD to encourage routine data collection within everyday operations (e.g., adding PAE screening to postnatal procedures).

### Novel Approaches

- Implement new screening and testing methodology to allow for more efficient screening and diagnosis, leading to more data.
- Build understanding around how the field can utilize paternal health and pre-conception data to gain a fuller understanding of FASD.

### Generalized Screening Strategies

- Build capacity to train medical and social/human service professionals on stigma-free screening for PAE and FASD to increase diagnostic and data collection rates.
- Continue to work toward universal screening at the county, state, and Federal levels.

### Reducing Harm

- Encourage non-punitive responses to alcohol exposure that encourage access to community services and support.
- Hold to higher-than-average organization/institutional standards for informed consent to protect people with FASD.

### Building Confidence About Data

- Researchers should understand and communicate to clients, patients, participants, and the general public where information is going and how it's useful to the field and community.
- Whenever data collection is involved, document how that knowledge can inform interventions, support, and current living experiences.

# DISCUSSION

The **FASD White Paper 1.2** was reviewed by a team of 12 Reviewers who provided feedback on technical edits, design, substance, and tone. Feedback that could not immediately be implemented is outlined below for future consideration by other individuals and entities.

## KEY TAKEAWAYS

The 2025 FASD Symposium emphasized that lasting progress requires more than awareness and expanded services. Contributors highlighted the need for collaborative, sustainable systems shaped by living experience. Key takeaways include:

- People with FASD and their families should help shape the systems, services, and policies that affect them.
- Grassroots organizations need sustainable partnerships and resources to grow their impact.
- FASD education should be practical, accessible, and informed by living experience.
- Data should be used to improve services, guide policy, and benefit the community.
- Progress requires stronger partnerships across healthcare, education, research, justice, and community organizations.

## LIVING EXPERIENCE AS A FOUNDATION

In the 2025 Symposium, across discussions on education, advocacy, and research, participants called for living experience to be incorporated into program design, professional training, research priorities, and public messaging. Contributors highlighted the need for meaningful compensation, accessible engagement opportunities, and accountability mechanisms that ensure living experience remains central to decision-making.

## PARTNERSHIPS ACROSS SYSTEMS

Contributors and Reviewers highlighted the need for nurturing new or stronger collaborations beyond traditional FASD organizations, including

- Schools
- Justice systems
- Government agencies
- First responders

# DISCUSSION

## RESEARCHERS

A notable sentiment from Contributors was a general mistrust and fear around “national surveillance efforts” and data collection. Researchers should consider how to build a sense of safety around community health data. Contributors highlighted the importance of collecting data that are meaningful to individuals and communities, while also ensuring transparency in how those data are used. For instance, an idea for facilitation was adding questions about FASD and alcohol exposure into existing surveys and studies. Contributors also noted that the FASD research community is tight-knit and generous with their work, but encourages researchers to seek partnerships across disciplines. People remarked on the work of the Adult Leadership Cooperative of FASD Changemakers, noting that people with FASD should be involved more in research design and processes.

## ORGANIZATIONS & AGENCIES

The “Grassroots Organizations” Recommendation changed fairly drastically since the audience of this paper changed from government agencies to the FASD community as a whole. It reads as a “to-do list” for organizations, but can also act as a map for how agencies can work with and fund organizations’ work around FASD.

Grassroots organizations should lean on each other to share information and resources, advocate, and strategize in areas where they are limited by funding, resource-strain, geographical barriers, and more. Sustained partnerships and resources can empower grassroots organizations to expand their impact and turn awareness into action.

## 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 work together 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 by sharing your experience with representatives and the community at large.

# ACKNOWLEDGEMENTS

## Lead Authors

Emma Baldwin

Sarah Brown

## Reviewers

Lead: Ruoxian (Susan) Huang

Heather Carmichael Olson

Michelle M. Cunningham

Olivia Gargiulo

Cierra Grant

Angela Freeman

Heather French

Andy Kachor

Chris Melfi

Kathryn Page

Christie Petrenko

Jackie Wille

## Symposium Facilitators

Emma Baldwin

Heather Carmichael Olson

Jennifer Wisdahl

## Engagers

Barb Clark

Tim Diffenderfer

Tom Donaldson

Olivia Gargiulo

Kendra Gludt

Casidee Gonzalez

Susan Huang

Annette Kunzman

Chris Melfi

Christie Petrenko

Julia Rivera

Rachel Sing

Sophie Sissi

Chris Troutt



# ACKNOWLEDGEMENTS

## Contributors

|                       |                           |                   |                    |
|-----------------------|---------------------------|-------------------|--------------------|
| Precious Alexander    | Debbie England            | Brenda McDade     | Mary Velasquez     |
| Naghum Alfulaij       | Kristen Eriksen           | Liz McHugh        | Kirk von Sternberg |
| Constance Alphonse    | Eric Flake                | Kathryn Meinhardt | Lewis Walker       |
| Jasmine Anderson      | Sidney Gardner            | Nicole Moore      | Amy Ward           |
| Kyle Apilado          | Lisa Ann Mushalko Glasgow | Heather Morris    | Holly Warren       |
| Anna Arno             | Lindsay Goeckeritz        | Anne Munson       | Jude Warren        |
| Rosa Arvizu           | Erin Goodman              | Angela Myles      | Tammy Wells        |
| Hope Barrett          | Cierra Grant              | Tami Pantano      | Jennifer Werden    |
| Lily Bastian          | Gianna Grant              | Amber Parks       | Kathryn White      |
| Crystal Bauer         | Jerry Grant               | Kristal Pollack   | Corrie Whitmore    |
| Clara Beery           | Angelle Gremillion        | Sherelle Porter   | Kayla Wright       |
| Ben Blanchard         | Coty Harrison             | Karen Poteet      | Carl Young         |
| Jessie Bollen         | Holly Helus               | Misty Pruner      | Malette Young      |
| Lauren Borchert       | Kelly Henderson           | Omar Rahman       |                    |
| Lara Bouse            | Cortney Heykoop           | Carina Rivera     |                    |
| Kate Boyce Reeder     | Claire Holder             | Nancy Roget       |                    |
| Guida Brown           | Katherine Holman          | Debra Ross        |                    |
| Tanya Browning        | Kathy Hotelling           | Hannah Ross       |                    |
| Tamra Cajo            | Yuka Imamura              | Yolanda Ross      |                    |
| Jamole Callahan       | Krista James              | Siara Rouzer      |                    |
| Susan Carlson         | Trasheki Shontae Johnson  | Emily Rusnak      |                    |
| Nadia Carrell         | Andy Kachor               | Teresa Russell    |                    |
| Konstance Causey      | Shannon Kaisler           | Jessica Sachs     |                    |
| Stacey Chart          | Roy Kendall               | Emily Schasteen   |                    |
| Katherine Chyka       | Katie King                | Amelia Schock     |                    |
| Rebecca Ciesielski    | Reuben Kittrell           | Yasmin Senturias  |                    |
| Elizabeth Cleveland   | Summer Krochta            | Amy Smith         |                    |
| Lynn Cole             | Katherine Kurima          | Nailah Smith      |                    |
| Melissa Curtis Cherry | Joshua Legg               | Shaneca Smith     |                    |
| Sandy Davis           | Lex Loutzenhiser          | Emily Speybroeck  |                    |
| David Deere           | Amanda Luning             | Guy Stephens      |                    |
| Jody Dickerson        | Amanda Mahnke             | Stacia Stribling  |                    |
| Arnold Eby            | Sarah Matthews            | Janet Thomas      |                    |
| Whitney Emerson       | Constance Mazelsky        | Rebecca Tillou    |                    |

# CITATIONS

1. Olson, H.C., Ohlmeiller, M.M., O'Connor, M.J., Brown, C.W., Morris, C.A., Damus, K., National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. (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. Centers for Disease Control and Prevention (CDC). (2025). About fetal alcohol spectrum disorders (FASDs). <https://www.cdc.gov/fasd/about/index.html>
3. May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., Kopald, D., Hasken, J. M., Xu, R., Honerkamp-Smith, G., Taras, H., Manning, M. A., Robinson, L. K., Adam, M. P., Abdul-Rahman, O., Vaux, K., Jewett, T., Elliott, A. J., Kable, J. A., Akshoomoff, N., ... Hoyme, H. E. (2018). Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *JAMA*, 319(5), 474–482. <https://doi.org/10.1001/jama.2017.21896>
4. Thomas, S.A., Gosdin, L.K., Terplan, M., Kim, S.Y., & Deputy N.P. (2026). Alcohol consumption during pregnancy among women aged 18–49 Years — United States, 2021–2024. *MMWR Morb Mortal Wkly Rep*, 75:280–284. DOI: <http://dx.doi.org/10.15585/mmwr.mm7522a2>.
5. CDC. (2012). Alcohol use and binge drinking among women of childbearing age—United States, 2006–2010. *MMWR. Morbidity and mortality weekly report*, 61(28), 534–538.
6. Tan, C. H., Denny, C. H., Cheal, N. E., Sniezek, J. E., & Kanny, D. (2015). Alcohol use and binge drinking among women of childbearing age – United States, 2011–2013. *MMWR. Morbidity and mortality weekly report*, 64(37), 1042–1046. <https://doi.org/10.15585/mmwr.mm6437a3>
7. Denny, C. H., Acero, C. S., Naimi, T. S., & Kim, S. Y. (2019). Consumption of Alcohol Beverages and Binge Drinking Among Pregnant Women Aged 18–44 Years – United States, 2015–2017. *MMWR. Morbidity and mortality weekly report*, 68(16), 365–368. <https://doi.org/10.15585/mmwr.mm6816a1>
8. 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. Morbidity and mortality weekly report*, 71(1), 10–13. <https://doi.org/10.15585/mmwr.mm7101a2>
9. Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135(2), 264–270. <https://doi.org/10.1542/peds.2014-2171>
10. Reid, N., Dawe, S., Shelton, P., Harnett, P., Warner, J., Armstrong, E., LeGros, K., & O'Callaghan, S. Systematic Review of Fetal Alcohol Spectrum Disorder Interventions Across the Life Span. *Alcohol. Clin. Exp. Res.* 2015, 39, 2283–2295.
11. Vanderpeet, C., Akison, L., Moritz, K., Hayes, N., & Reid, N. (2025). Beyond the brain: The physical health and whole-body impact of fetal alcohol spectrum disorders. *Alcohol Research*, 45(1). <http://doi.org/10.35946/arc.v45.1.05>
12. Hyland, M.T., Courchesne-Krak, N.S., Sobolewski, C.M., Zambrano, C., Mattson, S.N. (2023). Neuropsychological outcomes in FASD across the lifespan. In: Abdul-Rahman, O.A., Petrenko, C.L.M. (eds) *Fetal Alcohol Spectrum Disorders*. Springer, Cham. [https://doi.org/10.1007/978-3-031-32386-7\\_11](https://doi.org/10.1007/978-3-031-32386-7_11)
13. 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>
14. Flannigan, K., Pei, J., McLachlan, K., Harding, K., Mela, M., Cook, J., Badry, D., & McFarlane, A. (2022). Responding to the unique complexities of fetal alcohol spectrum disorder. *Front. Psychol.* 12:778471. doi: 10.3389/fpsyg.2021.778471
15. SUPPORT for Patients and Communities Reauthorization Act of 2025, Pub. L. No. 119–44, 139 Stat. 671 (2025). <https://www.congress.gov/bill/119th-congress/house-bill/2483/text>
16. Olson, H., Pruner, M., Byington, N., & Jirikowic, T. (2023). FASD-Informed Care and the Future of Intervention. 10.1007/978-3-031-32386-7\_13.
17. 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>
18. Reedman, B., Breen, K., & Wu, H. (2024). 'Trying differently' – Towards improving school experiences: Examining research on school experiences for students with FASD and their teachers. *Children and Youth Services Review*, 163. <https://doi.org/10.17605/OSF.IO/5BKU4>
19. Okurame, J. C., Cannon, L., Carter, E., Thomas, S., Elliott, E. J., & Rice, L. J. (2022). Fetal alcohol spectrum disorder resources for health professionals: a scoping review protocol. *BMJ open*, 12(9), e065327. <https://doi.org/10.1136/bmjopen-2022-065327>
20. Brown, J., Lewis, D. S., Kivisalu, T., Wartnik, A. P., Carter, M. N., Harr, D., Jozan, A., & Gilbert, D. J. (2024). Fetal alcohol spectrum disorder (FASD) and the criminal justice system: A guide for legal professionals. *International journal of law and psychiatry*, 97, 102029. <https://doi.org/10.1016/j.ijlp.2024.102029>
21. Bisgard, E.B., Fisher, S., Aduabato, S., & Louis, M. (2010). Screening, diagnosis, and intervention with juvenile offenders. *Journal of Psychiatry & Law*, 38(4), 475–506. <https://doi.org/10.1177/009318531003800406>
22. McLachlan, K., Mullally, K., & Ritter, C. (2020). Professional practices in FASD among international forensic mental health clinicians. <https://www.justice.gc.ca/eng/rp-pr/jr/ppfasd-etcafp/docs/professional-practices-fasd-forensic-mental-health-clinicians-eng.pdf>
23. Ali Shah, H., & Househ, M. (2024). Concepts, objectives and analysis of public health surveillance systems. *Computer Methods and Programs in Biomedicine Update*, 5, (100136), ISSN 2666-9900. doi.org/10.1016/j.cmpbup.2024.100136.
24. Dorsey, A. N., Downing, K. F., Deputy, N. P., Weber, M. K., & Howards, P. P. (2025). Prevalence of congenital heart defects among children with and without diagnosed fetal alcohol spectrum disorders, 2016–2022. *Drug and alcohol dependence*, 274, 112790. <https://doi.org/10.1016/j.drugalcdep.2025.112790>
25. Deputy, N. P., Grosse, S. D., Bertrand, J., Danielson, M. L., George, N. M., & Kim, S. Y. (2024). Administratively reported fetal alcohol spectrum disorders in commercially- and Medicaid-insured samples of children in the United States, 2015 – 2021. *Drug and alcohol dependence*, 263, 112420. <https://doi.org/10.1016/j.drugalcdep.2024.112420>
26. O'Leary, L. A., Ortiz, L., Montgomery, A., Fox, D. J., Cuniff, C., Ruttenber, M., Breen, A., Pettygrove, S., Klumb, D., Druschel, C., Frías, J. L., Robinson, L. K., Bertrand, J., Ferrara, K., Kelly, M., Gilboa, S. M., Meaney, F. J., & FASSNetII (2015). Methods for surveillance of fetal alcohol syndrome: The Fetal Alcohol Syndrome Surveillance Network II (FASSNetII) – Arizona, Colorado, New York, 2009 – 2014. *Birth defects research. Part A, Clinical and molecular teratology*, 103(3), 196–202. <https://doi.org/10.1002/bdra.23335>
27. CDC. (2025). Behavioral Risk Factor Surveillance System. <https://www.cdc.gov/brfss/index.html>
28. CDC. (2025). Pregnancy Risk Assessment Monitoring System (PRAMS). <https://www.cdc.gov/prams/index.html>