Find your seat at the table



Education



Child Welfare



Research



Mental Health



Policy



Maternal Health



Justice System



Neurodiversity



Substance Use



Disability



Healthcare



FASD SYMPOSIUM

An Invitation to the Table

Today's Presenters



Jennifer Wisdahl
Chief Operating Officer,
FASD United



Heather Carmichael Olson
Clinical Professor,
University of Washington
School of Medicine



Emma Baldwin
Director of Partnerships,
FASD United



Bill Dunty
NIAAA/NIH

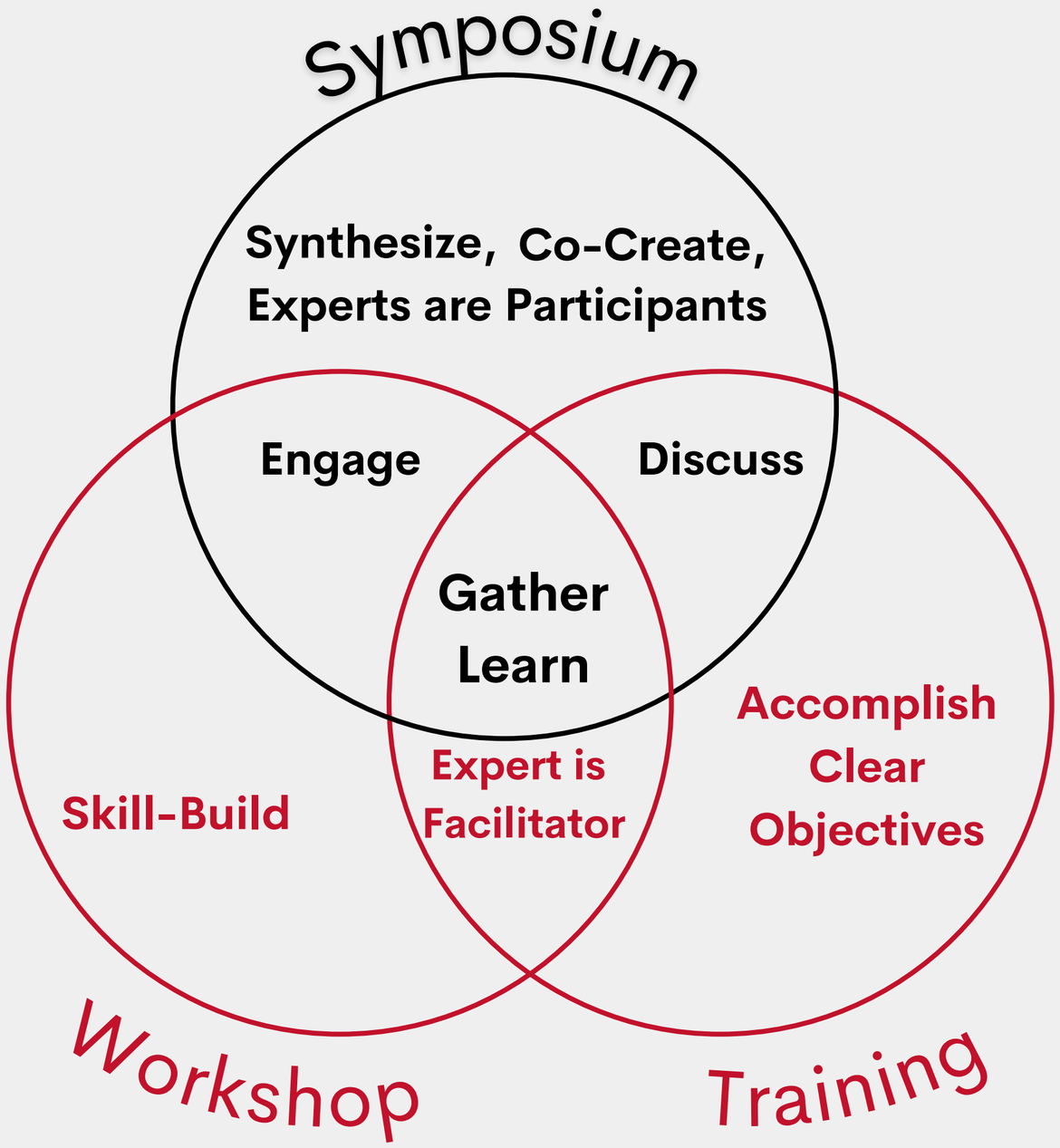


Tatiana Balachova
NIAAA/NIH

Why a Symposium?

THE PARTICIPANTS ARE EXPERTS

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



Overall Goals

FASD SYMPOSIUM



1. Publish an organized summary of the discussion as a white paper that represents a broad set of perspectives on FASD in order to **co-create a national plan for advancing the FASD community and field.**

2. Continue meeting on an annual basis to revisit themes/discussion.

   Publish a complete update on the original National FASD Task Force Recommendations.

Goals of **TODAY**:

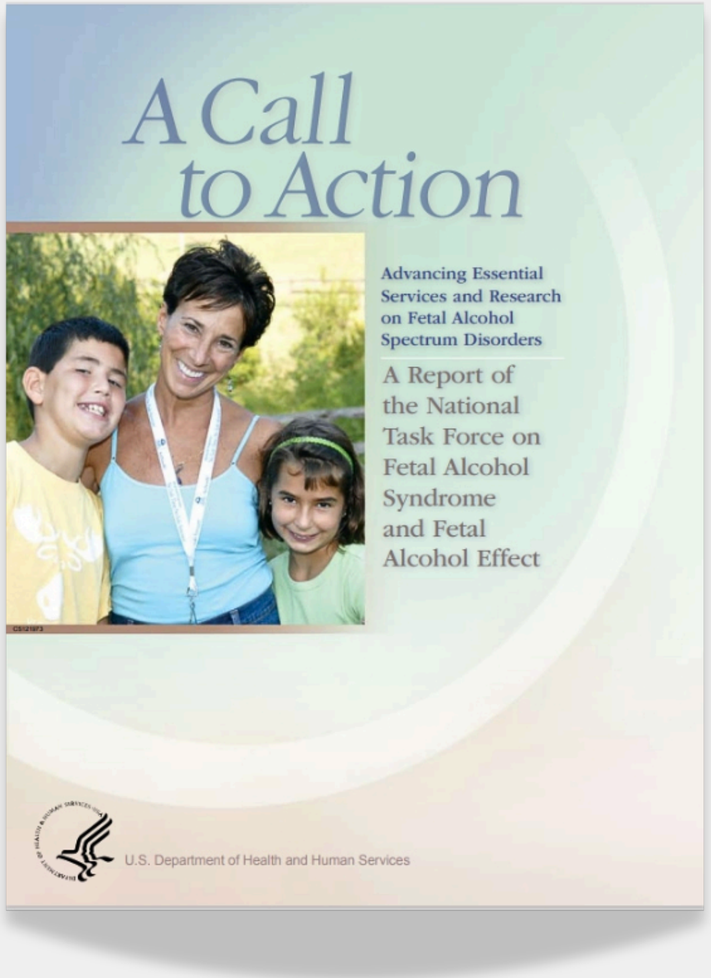
- Engage as a community
- Co-create a vision for collaboration that centers living experience
- Have meaningful and empowering discussions
- Understand our path forward



Task Force Recommendations

From 2009 FASD Task Force Report "**A Call to Action: Advancing Essential Services and Research on FASD**"

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



Task Force Recommendations

(simplified)

Improve access to diagnosis by standardizing procedures and enforcing universal screening.



Enhance agency collaboration through shared leadership, transparent objectives, and coordinated efforts with living experience and communities.



Promote a continuum of care for individuals with FASD that is evidence-based, lifelong, and reduces stigma.



Make FASD eligible for government support and services.



Increase research about diagnosis, living experience, and effective interventions.



Encourage professional education on FASD.



Improve tracking of prevalence and support needs.



Promote a continuum of care for families and caregivers affected by FASD.



Recognize grassroots efforts focused on FASD as powerful agents of change.



Maintain a national forum involving parents, advocates, professional organizations, and experts.



2026 Symposium Priorities

Improve access to diagnosis by standardizing procedures and enforcing universal screening.



Enhance agency collaboration through shared leadership, transparent objectives, and coordinated efforts with living experience and communities.



Promote a continuum of care for individuals with FASD that is evidence-based, lifelong, and reduces stigma.



Make FASD eligible for government support and services.



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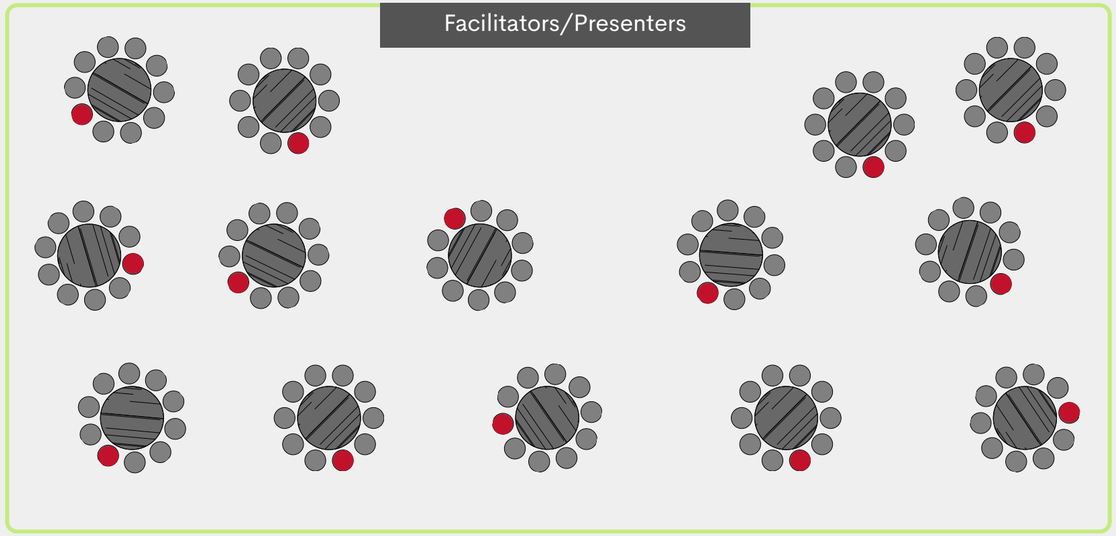


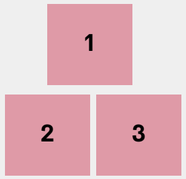
Maintain a national forum involving parents, advocates, professional organizations, and experts.



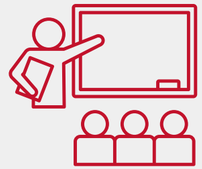
Methodology

ABOUT THE SYMPOSIUM SESSIONS





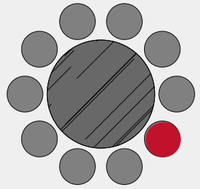
There are 3 discussion sessions; each centers on 1 Recommendation.



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



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



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



Engagers guide activities and lead discussions, following the Engagers' Guide.



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

Methodology

- The Symposium is focused on collecting **qualitative data** through a scientific process

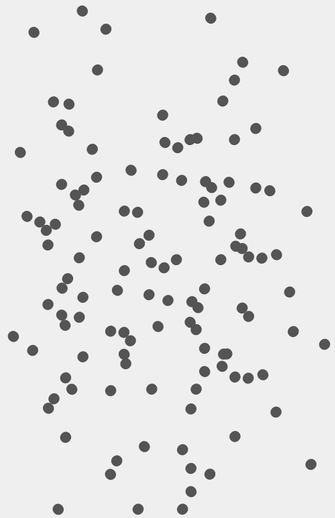
- Data is collected through multiple outlets:
  - Group discussions / notes
  - Multimodal activities
  - **Individual submissions through Slido**

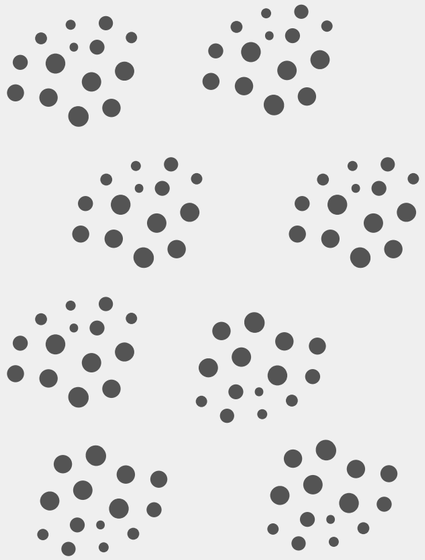
YOU are the experts!

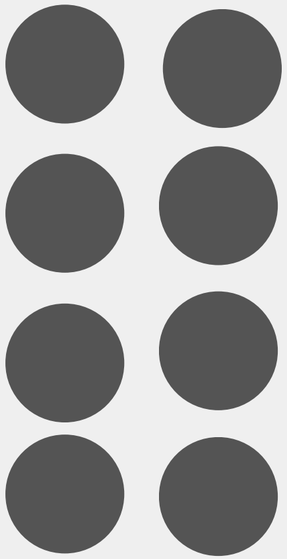
Make your voice heard by completing the data collection opportunties.

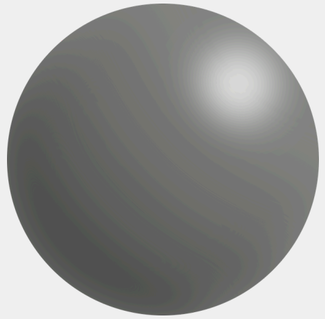
Methodology











Phase 1

The 2009 Recommendation

Identify and understand the recommendation we will be updating.

Phase 2

Data Collection

Collect data from a diverse representative of the FASD field & community through a facilitated **Symposium** discussion session.

Phase 3

Data Thematic

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

Phase 4

Themes to Recommendations

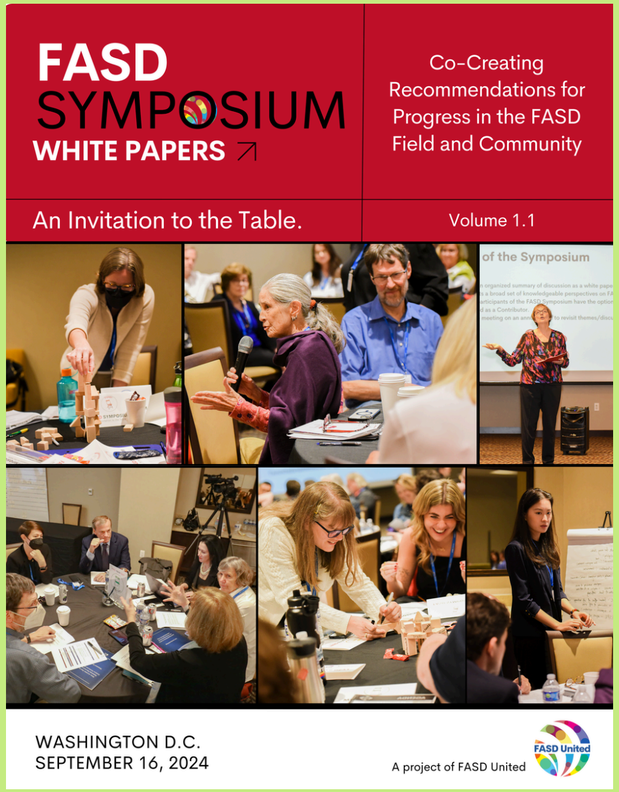
Create 1-2 actionable recommendations out of each Thematic Category.

Phase 5

Updated Recommendation

Synthesize broken-down recommendations into a single-sentence, updated recommendation.

White Papers



- Based on data collected at the FASD Symposia
  - White Paper 1.1: 2024 Symposium
  - White Paper 1.2: 2025 Symposium
  - White Paper 1.3: 2026 Symposium

- Presents the perspectives and expertise of individuals with FASD, as well as families, professionals in the field, organizations leading FASD work, and representatives from national agencies

- Offers new perspectives and recommendations on the 2009 National FASD Task Force Call to Action

Today’s Focus



Supporting Families



National Forum

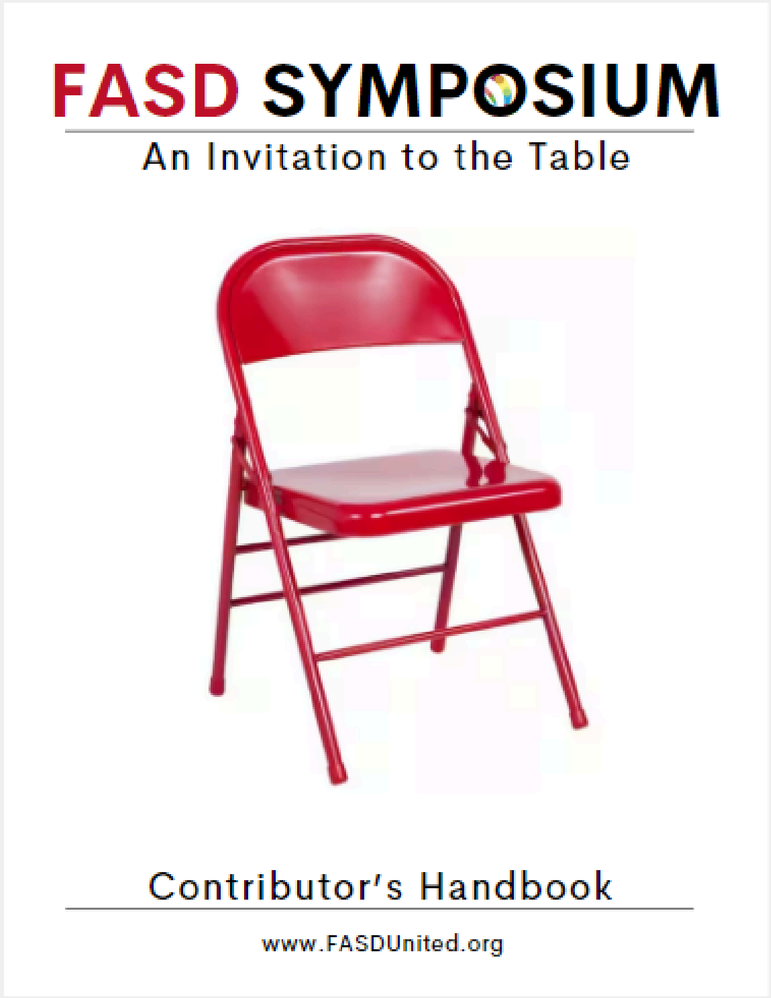


Improving FASD Research

Contributor’s Handbook

Helpful information throughout the day, including:

- Symposium Culture
- Past White Papers
- Taskforce Recommendations
- Agenda
- Background Information
- Session Themes & Questions



SYMPOSIUM AGENDA

Part 1

9:00 to 9:30 – Welcome and Introduction

9:30 to 9:45 – Intro to Session 1

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

11:00 to 11:15 – Break (15 minutes)

11:15 to 11:30 – Intro to Session 2

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

12:45 pm to 2:00 – Lunch (75 minutes)

2:00 to 2:15 – Intro to Session 3

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

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

WEDNESDAY SESSION

Part 2

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

- Coding & Billing
- ND-PAE/ ICD-10 Codes
- IDEA
- CAPTA

4:30 to 5:00 – Reflections & Closing

Notetaking

Please select 1-2 people who can take notes for your table.

- Try to write in full sentences. We understand conversations can move quickly.
- Rely on the Engager. Feel free to ask them for clarification.
- Notes can be taken on paper, your phone, or laptop.
- Notes will be collected at the end of each session.

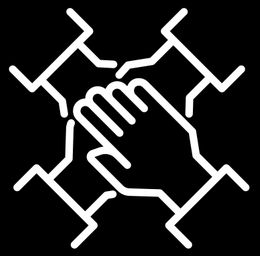




1) Participants have a proficient understanding of FASD basics. ***We know***.



2) Everyone involved in FASD advocacy cares about FASD advocacy. ***We care***.



3) FASD must be approached from a transdisciplinary lens where boundaries between research, policy, and service areas are flexible. ***We work together***.

Guiding Principles

Honoring Stories and Experiences.

*Let's practice self care **and** community care*

Today's conversations may bring up heavy feelings in a short time frame.

Please be respectful of everyone's experiences.

Your voice matters; **YOU MATTER.**

FASD United is grateful for our Mental Health First Aid volunteers. Please see a FASD United staff member if you require access to help/support during Impact Week.

Story Share

If you have living experience that is relevant to a discussion, you can submit it through the Story Share.

Session 1

Supporting Families



Task Force recommendation: Promote a comprehensive and accessible continuum of care for families raising infants, children, and adolescents with FASDs.

Introduction to Session 1

Task Force recommendation: Promote a comprehensive and accessible continuum of care for families raising infants, children, and adolescents with FASDs.

Similar to Recommendation #5: "Promote a comprehensive and accessible continuum of care for youth, adults, and older individuals with FASDs," which was **addressed at 2024 FASD Symposium**

Here is what the group recommended then

Themes for Continuum of Care* from 2024 Symposium

Independence/ Interdependence	Mental Health & Wellbeing	Education & Training	Transition & Care Coordination	Access
Community & Social Connections	Policy & Advocacy	Awareness & Stigma Reduction	Family & Caregiver Support	Evidence-Based Interventions

*continuum of care = high-quality care across the lifespan tailored to an individual's needs

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.

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.

Education & Training

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

You can find this information on page 11 of your Contributor's Guide

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.

Independence/Inter-Dependence

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

You can find this information on page 11 of your Contributor's Guide

Session 1: Introductions

Please share your name and one community program that you know of that helps address families' needs.

Session 1: Leading Question

Task Force recommendation: Promote a comprehensive and accessible continuum of care for families raising infants, children, and adolescents with FASDs.

If comprehensive supports were offered, what would make them <u>accessible</u>?

<u>accessible</u> = easy to use

Session 1: Activity



Community & social connections (blue)



Mental health & well-being (purple)



Education & training (dark orange/red)



Transition & care coordination (yellow)



Independence/interdependence (white)



Policy & advocacy (brown)



Awareness & stigma reduction (light orange)



Evidence-based interventions (green)

If comprehensive supports were offered, what would make them <u>accessible</u>?

Session 1: Data Collection

Task Force recommendation: Promote a comprehensive and accessible continuum of care for families raising infants, children, and adolescents with FASDs.

What is a major takeaway from your discussion? Tell us on Slido.

Now is the time to make your voice heard!

Slido submissions and written notes are our main "data buckets."

E-mail notes to brown@fasdunited.org.

Slido #2972805

Break

11:00 to 11:15

Session 2

Improving FASD Research



Task Force recommendation: Intensify research initiatives and interagency coordination.

A CALL TO ACTION, REVISITED:
ADVANCING FASD RESEARCH AT NIAAA

Bill Dunty, PhD | NIAAA FASD Research Coordinator

Program Director - Divisionof Metabolism and Health Effects

National Institute on Alcohol Abuse and Alcoholism

In 2009, the Call to Action asked for a major expansion of FASD research

Where are we now — and what still needs attention?



A lay of the land
NIAAA'scurrent priorities and research on FASD

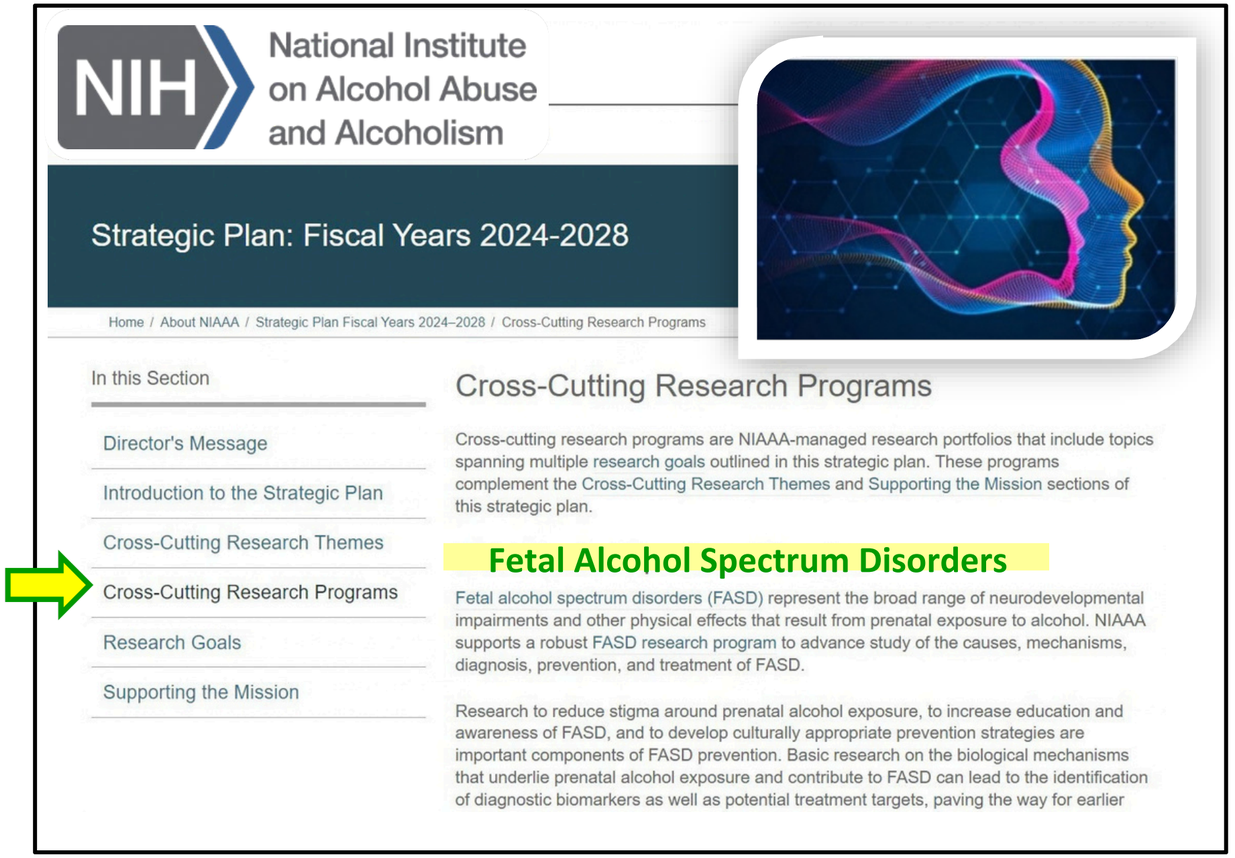


How well have we **Intensified Research Initiatives**?



Several areas of research are changing how we think about FASD

FASD as a cross-cutting research program at NIAAA



3 Objectives

- Advance the prevention of prenatal alcohol exposure
- Improve early identification and treatment interventions for FASD
- Identify mechanisms, diagnostic biomarkers, and potential treatment targets

For more info

FASD and NIAAA's Strategic plan

National Institute on Alcohol Abuse and Alcoholism

National Institutes of Health
U.S. Department of Health and Human Services

FASD research at NIAAA today

FY 2025

- 99 grant projects
- ~$31.5M total funding
- 20 different types of grants

FY: 2025
Category: FASD Extramural only

Admin IC: AA
Mech: R/U/T/P K/F/RDC
Status: Awarded with subs

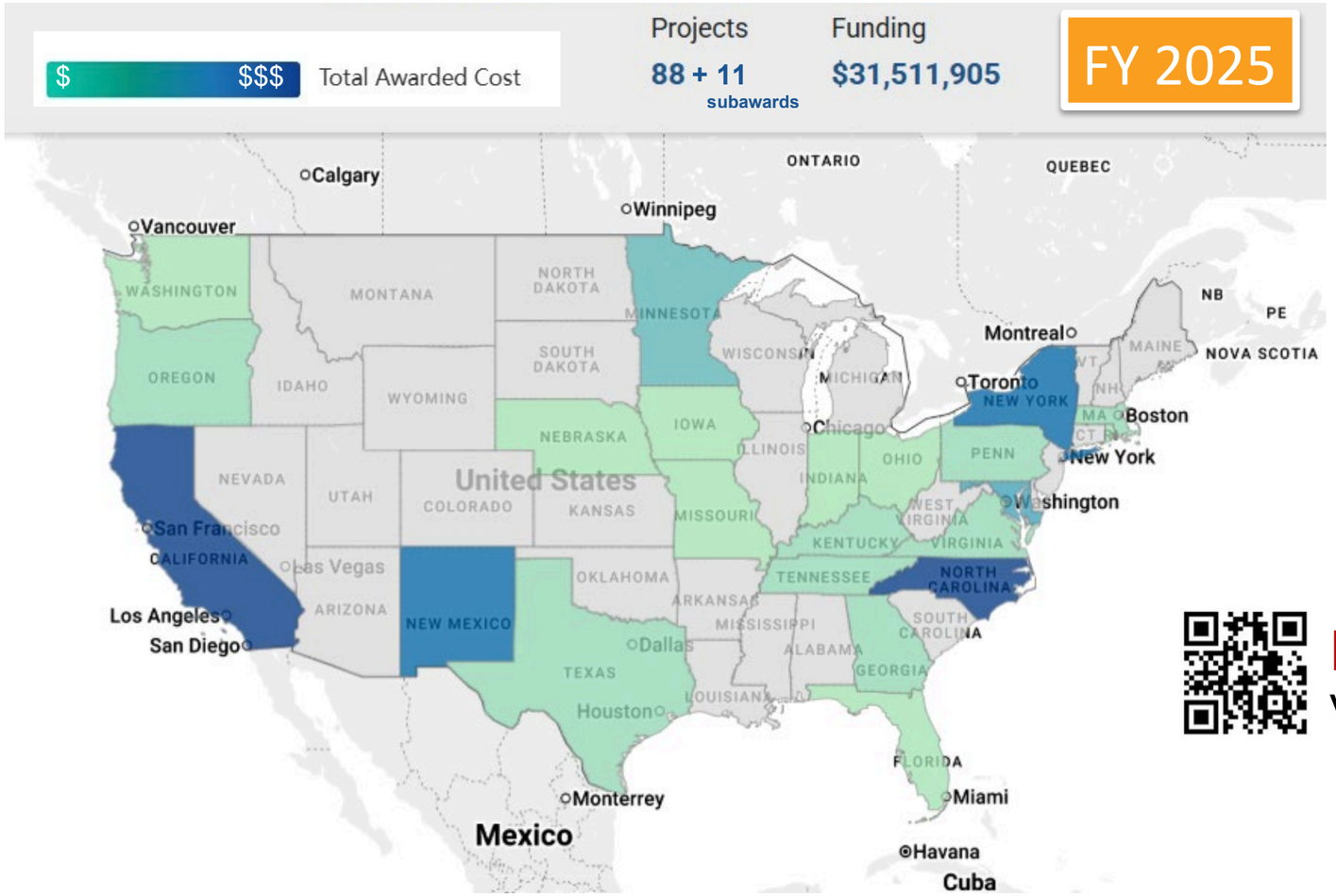


For more info:
Visit NIH RePORTER
(select *FASD* under NIH Spending Category)

National Institute on Alcohol Abuse and Alcoholism

National Institutes of Health
U.S. Department of Health and Human Services

NIAAA supports FASD research at institutions across the US

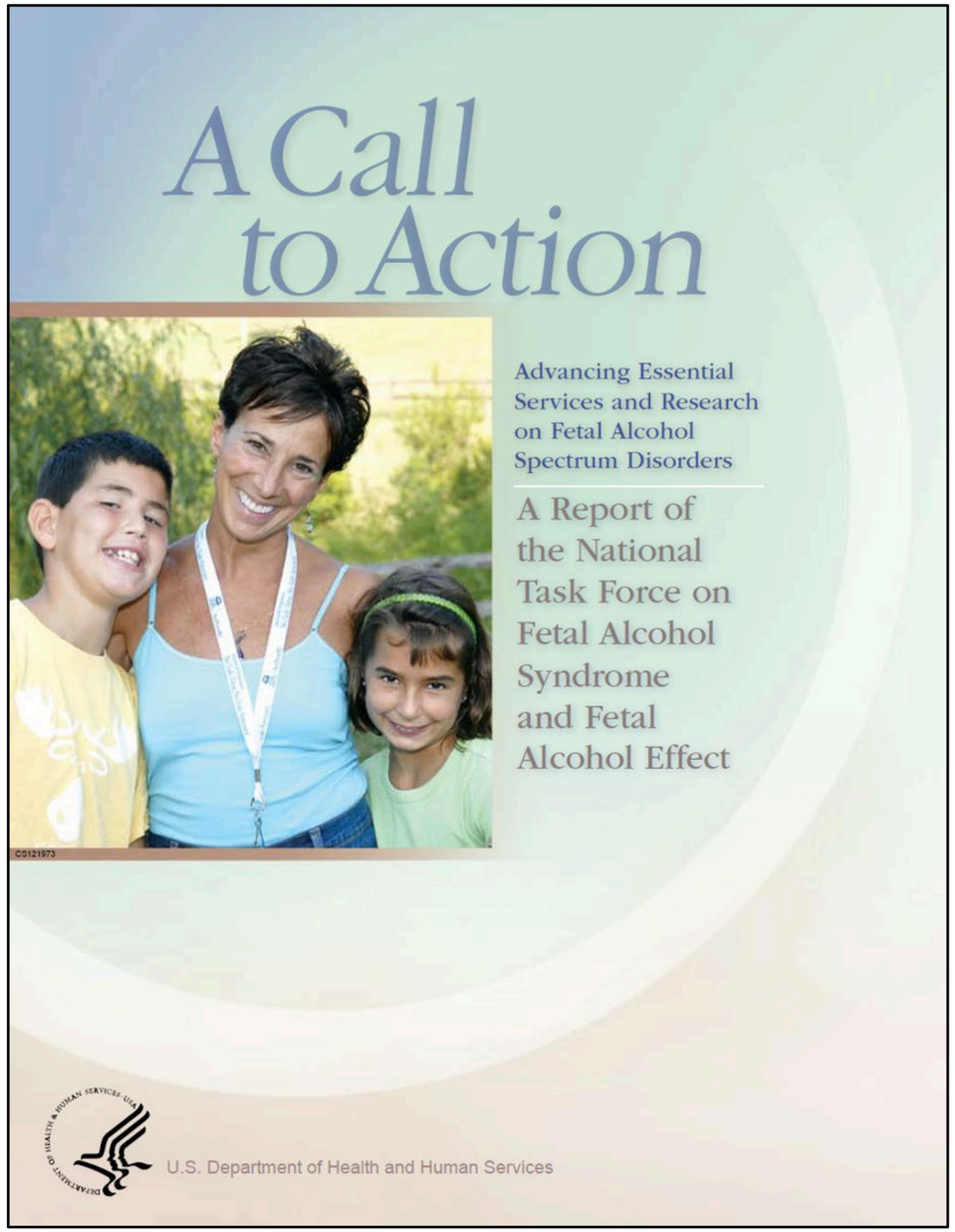




For more info
Visit NIH RePORTER

National Institute on Alcohol Abuse and Alcoholism

National Institutes of Health
U.S. Department of Health and Human Services



*Rec #3 and its 11 actions □ 4 concise themes in plain language

What **Recommendation #3** asked research to accomplish:

Understand FASD

- define the spectrum
- understand development and brain/body effects

Identify FASD earlier

- improve diagnosis
- develop useful biological markers

Improve lives

- test interventions, teaching strategies, and protective factors
- study outcomes across the lifespan

Make research usable

- bring effective approaches into communities
- improve services and supports

Selected FASD research challenges:

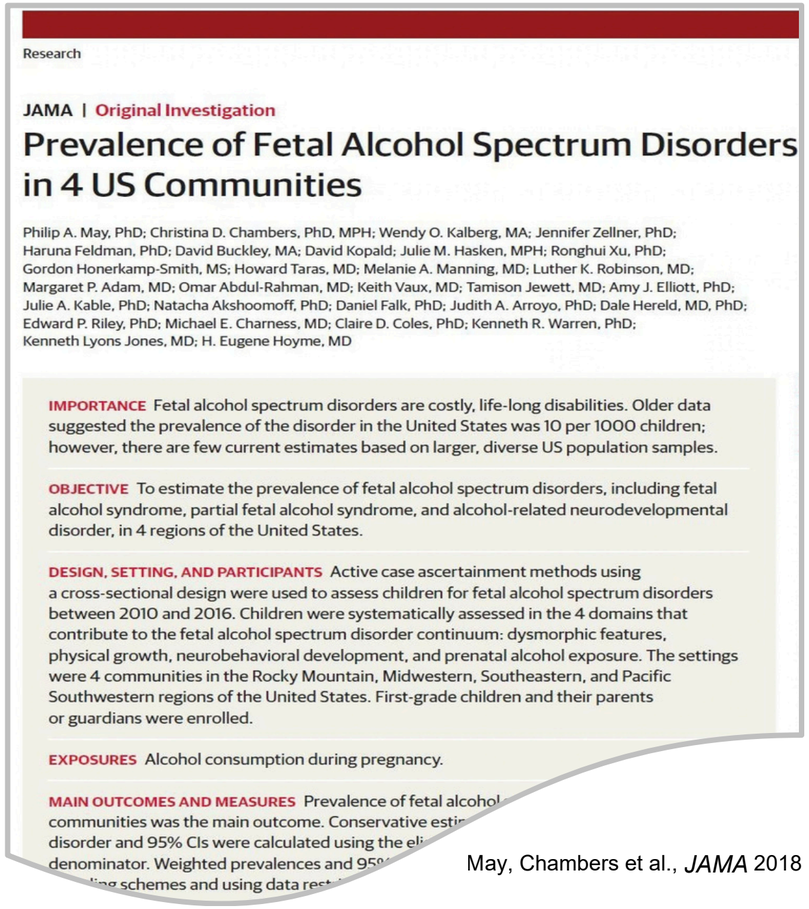
Progress since 2009

1. **How common** are FAS and FASD?
2. How does alcohol exposure during pregnancy **cause harm**?
3. How can we **better identify** infants and children exposed to alcohol before birth?
4. Can **choline supplementation** improve outcomes after prenatal alcohol exposure?
5. What **new prevention** and **intervention approaches** show promise?
6. How does prenatal alcohol exposure affect **health across the lifespan**?
7. How do **alcohol** and **other exposures** together affect child development?
8. Can alcohol use **before conception** by **fathers** affect child health?

NIH National Institute on Alcohol Abuse and Alcoholism

National Institutes of Health
U.S. Department of Health and Human Services

Challenge: How common is FASD?



Research

JAMA | Original Investigation

Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities

Philip A. May, PhD; Christina D. Chambers, PhD, MPH; Wendy O. Kalberg, MA; Jennifer Zellner, PhD; Haruna Feldman, PhD; David Buckley, MA; David Kopald; Julie M. Hasken, MPH; Ronghui Xu, PhD; Gordon Honerkamp-Smith, MS; Howard Taras, MD; Melanie A. Manning, MD; Luther K. Robinson, MD; Margaret P. Adam, MD; Omar Abdul-Rahman, MD; Keith Vaux, MD; Tamison Jewett, MD; Amy J. Elliott, PhD; Julie A. Kable, PhD; Natacha Akshoomoff, PhD; Daniel Falk, PhD; Judith A. Arroyo, PhD; Dale Hereld, MD, PhD; Edward P. Riley, PhD; Michael E. Charness, MD; Claire D. Coles, PhD; Kenneth R. Warren, PhD; Kenneth Lyons Jones, MD; H. Eugene Hoyme, MD

IMPORTANCE Fetal alcohol spectrum disorders are costly, life-long disabilities. Older data suggested the prevalence of the disorder in the United States was 10 per 1000 children; however, there are few current estimates based on larger, diverse US population samples.

OBJECTIVE To estimate the prevalence of fetal alcohol spectrum disorders, including fetal alcohol syndrome, partial fetal alcohol syndrome, and alcohol-related neurodevelopmental disorder, in 4 regions of the United States.

DESIGN, SETTING, AND PARTICIPANTS Active case ascertainment methods using a cross-sectional design were used to assess children for fetal alcohol spectrum disorders between 2010 and 2016. Children were systematically assessed in the 4 domains that contribute to the fetal alcohol spectrum disorder continuum: dysmorphic features, physical growth, neurobehavioral development, and prenatal alcohol exposure. The settings were 4 communities in the Rocky Mountain, Midwestern, Southeastern, and Pacific Southwestern regions of the United States. First-grade children and their parents or guardians were enrolled.

EXPOSURES Alcohol consumption during pregnancy.

MAIN OUTCOMES AND MEASURES Prevalence of fetal alcohol
communities was the main outcome. Conservative esti
disorder and 95% CIs were calculated using the eli
denominator. Weighted prevalences and 95%
ling schemes and using data rest

May, Chambers et al., *JAMA* 2018

- **The CoFASP study:** a NIAAA-supported prevalence study of ~ 6,600 1st graders across 4 U.S. communities
- Researchers actively evaluated children rather than relying only on existing diagnoses
- <u>Findings</u>:

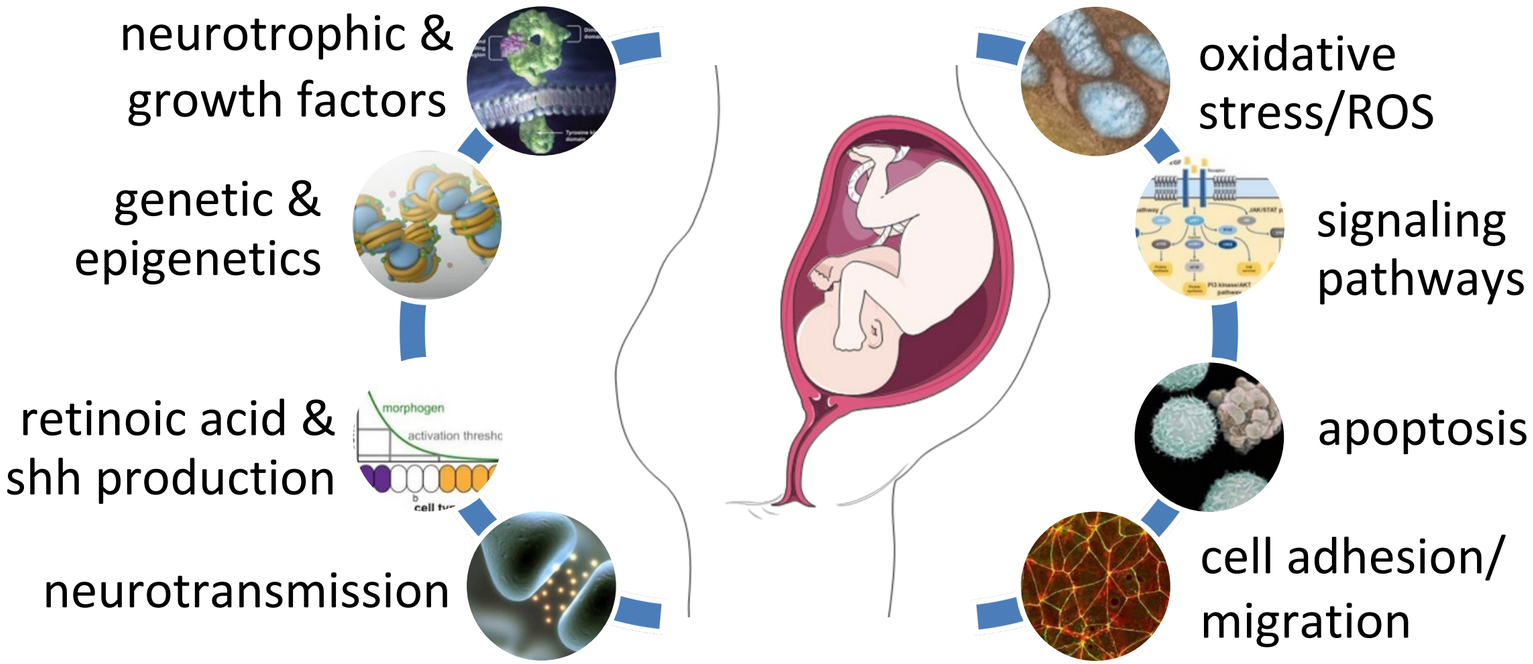


1-5% of 1st grade children may have FASD

May, Chambers et al., *JAMA* 2018

Challenge: How does alcohol exposure during pregnancy cause harm?

Partial reference List
Ahlgren et al., 2002
Aoto et al., 2008
Bearer et al., 1999
Bhave et al., 1997
Blader et al., 1998
Cartwright et al., 1995
Cheema et al., 2000
Chen et al., 1996
Climent et al., 2002
Cuzon et al., 2008
de la Monte et al., 2005
Deltour et al., 1996
Dunty et al., 2001
El Fatimy et al., 2014
Flentke et al., 2011
Garic et al., 2011
Garic-Stankovic et al., 2005
Haycock et al., 2009
Henderson et al., 1995
Hong et al., 2012



Partial reference List
Ikonomidou et al., 2000

Kaminen-Ahola et al., 2010
Kietzman et al., 2014 Kot-Leibovich et al., 2009 Li et al., 2004
Liu et al., 2009
McAlhany et al., 2000
McCarthy et al., 2013
Muralidharan et al., 2018
Olney et al., 2002
Ramachandran et al., 2003
Ramanathan et al., 1996
Shabtai et al., 2018
Sulik et al., 1981
Swartz et al., 2014
Tang et al., 2006
Wang et al., 2010
Yan et al., 2010
Young et al., 2008
Zhou et al., 2011

Alcohol can affect development through many biological pathways; there is no single mechanism that explains FASD

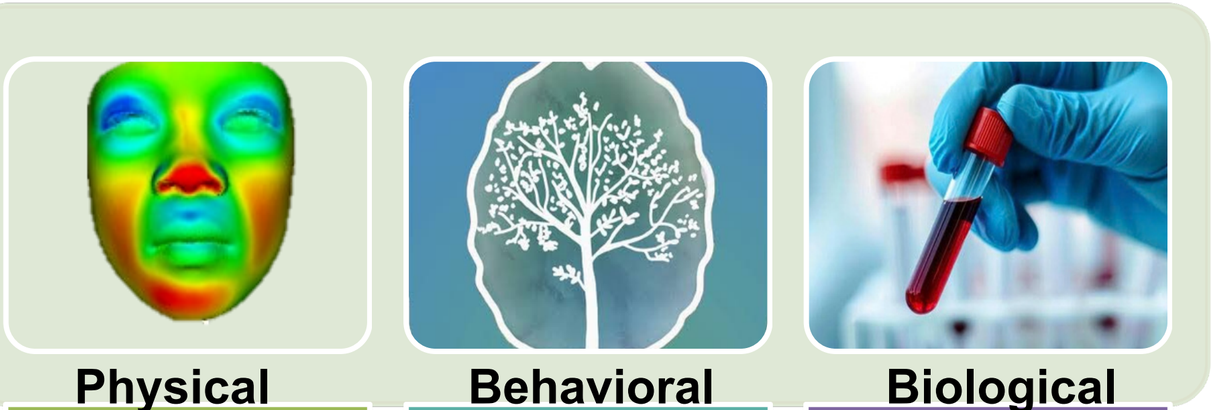
National Institute on Alcohol Abuse and Alcoholism

National Institutes of Health
U.S. Department of Health and Human Services

Challenge: How can we better identify infants and children exposed to alcohol before birth?



For more info on CIFASD



Physical

3D facial imaging and eHealth approaches to identify features not obvious to clinicians

Suttie et al., 2013, 2018; Del Campo et al., 2024.; Li et al., 2026

Behavioral

Online screening tools to help identify children with PAE in an efficient and cost-effective way

Mattson et al. 2013,2023, 2026; Goh et al., 2016; Bernes et al., 2022; Hyland et al., 2023

Biological

Novel blood-based biomarkers that identify PAE early and predict outcomes

Bodnar et al., 2018, 2020; Sowell et al., 2018; Salem et al., 2020; Mahnke et al., 2021; Pinson et al., 2023

NIH National Institute on Alcohol Abuse and Alcoholism

Challenge: Can choline supplementation improve outcomes after prenatal alcohol exposure?



*Illustrates intervention research; **not a clinical recommendation.**

Choline during pregnancy

- choline given to 69 women & initiated early in pregnancy
- Infants showed catch-up growth in weight & head circumference at 6.5 and 12 months; improved visual recognition memory at 12 months
- Larger brain volumes in 6 brain regions at 1 month of age

Choline in young children

(Wozniaketal.2020,2025;Fuglestadetal.,2022;Gimbel et al., 2022)

- choline or placebo in 60 children ages 2½ to 5 with FASD for 9 months
- 4-year follow-up shows sustained benefit for non-verbal intelligence, visual-spatial skills, memory, and behavior; 7-year follow-up shows benefits on executive functioning and brain development
- Greater benefit in younger kids; no sex differences or dose response

Challenge: What new prevention and intervention approaches show promise?

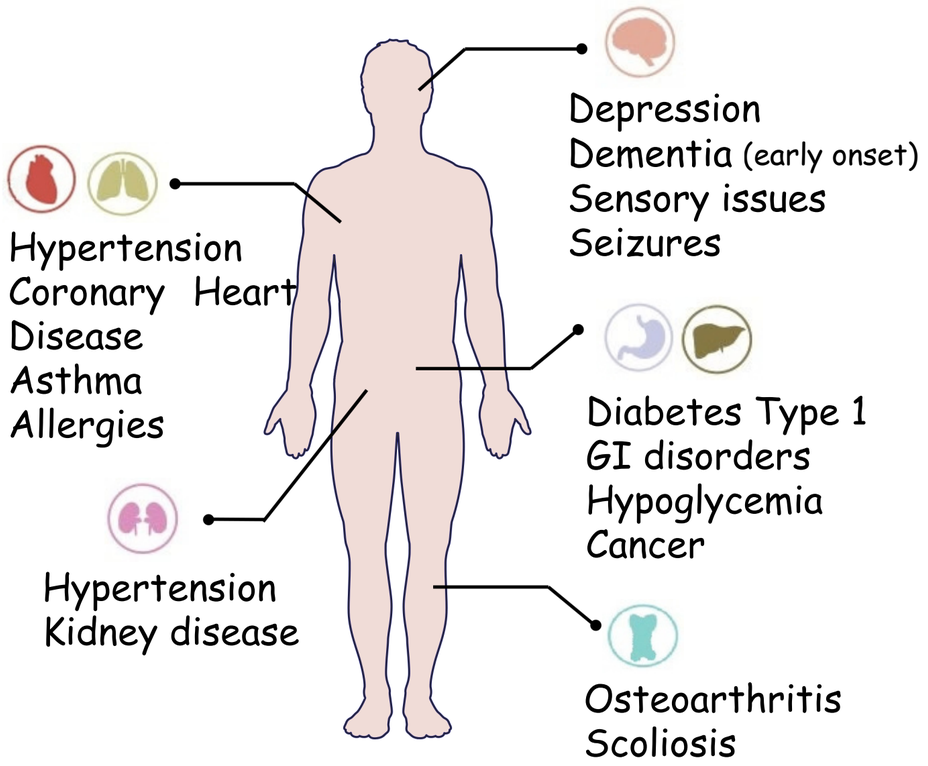


- NIAAA continues an initiative soliciting projects on interventions for people with FASD and approaches intended to prevent prenatal alcohol exposure
- As of August 2026 -- **10 grants have been awarded**
- **New studies** underway are testing supports that matter in daily life
  - Early family support for infants and toddlers
  - FASD-informed person-centered planning
  - Sensory-processing and music-based approaches
  - Prevention approaches designed to reduce stigma & work with communities

For more info
Visit NIH RePORTER
PAR-25-158 / PAR-25-159
PAR-24-067 / PAR-24-068
PAR-21-097 / PAR-21-098

Challenge: How does prenatal alcohol exposure affect health across the lifespan?

FASD is a whole-body disorder

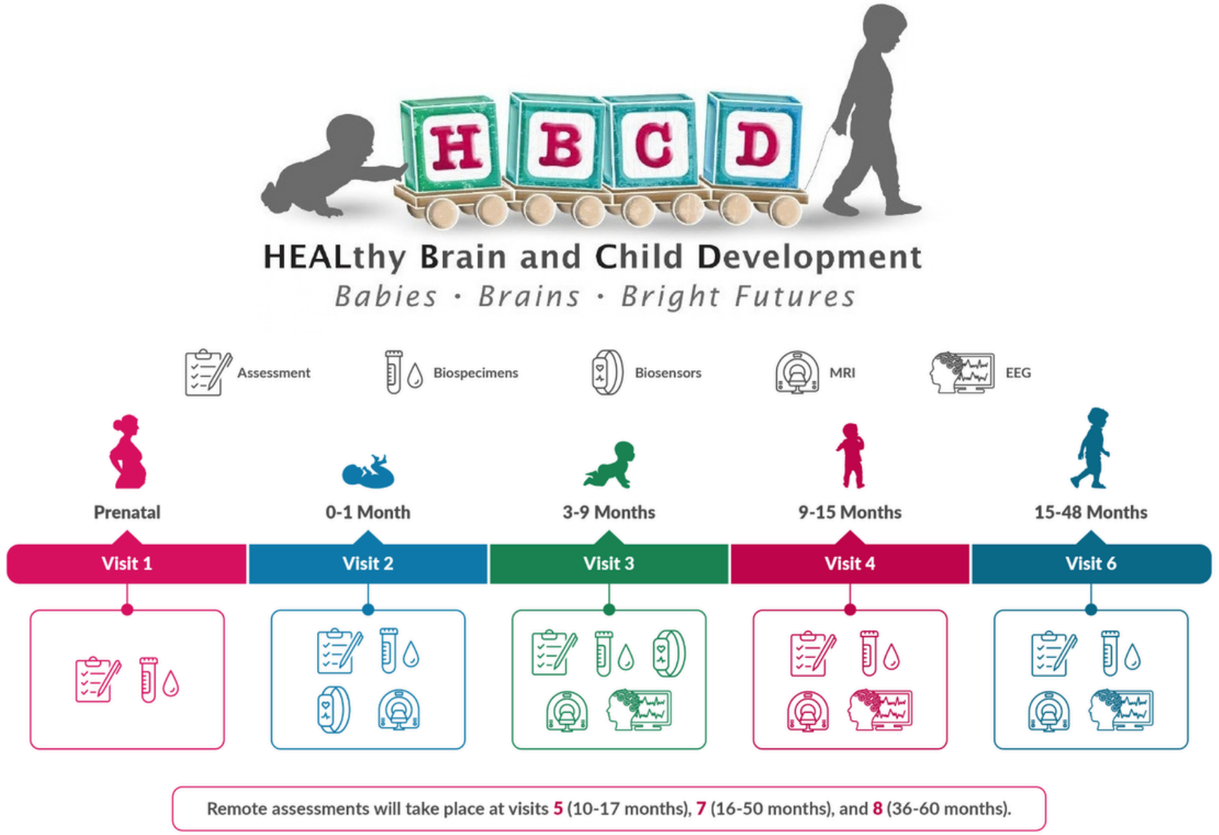


Source: Myles Himmelreich, C.J. Lutke and Emily Travis Hargrove *The Routledge Handbook of Social Work and Addictive Behaviors* 2020

Recent studies indicate:

- In 2017, a group of adults with FASD (*FASD Changemakers*) conducted a community-based health survey alerting NIAAA to many health co-morbidities not typically associated with PAE (Himmelreich et al., 2020)
- Emerging research suggests that PAE is now associated with comorbidities in many organ systems and domains (Akisonet al.,2019;Attellet al.,2025; Coleset al.,2024,2022;Vanderpeetet al.,2025;WeinbergandMoritz, 2026)
- Screening and early identification of comorbidities may improve health outcomes for individuals with PAE
- These are health concerns under study; they are not outcomes that every person with FASD will experience

Challenge: How do alcohol and other exposures together affect child development?



- The largest long-term study of early brain & child development (birth to age 10) in the US
- Goal: To better understand how brain and behavior usually develop and how they are affected by **exposure to opioids or other substances** (e.g., alcohol, cannabis, tobacco), stressors, trauma and other environmental influences.
- HBCD will greatly add to our efforts to understand polysubstance use to inform prevention and treatment efforts
- HBCD 2.1 contains data from more than 3,500 participants.

For more info:
hbcdstudy.org

National Institute on Alcohol Abuse and Alcoholism

National Institutes of Health
U.S. Department of Health and Human Services

Challenge: Can alcohol use before conception by fathers affect pregnancy or child health?



Most evidence so far comes from animal studies.
Human evidence is still emerging.

Recent studies indicate:

- Pre-clinical studies of alcohol exposure before conception in male suggest effects on a variety of health outcomes not previously recognized (Chang et al.,2017;2019;Conneretal.,2020)

•What recent animal studies show:

- changes in how the placenta develops and work
  (Thomas et al,, 2021; Bhadsavleetal, 2024)
- decrease embryo survival & pregnancy success
  (Roachetal.,2023)
- changes in facial shape
  (Thomas et al.,2023; Higgins et al., 2024)
- changes in cell energy and signs of faster aging
  (Baseletal.,2024)

•What human research is examining:

(reviewed by McBride and Johnson, 2016)

- sperm health
- changes inhow genes are regulated
- how partners may influenceeach other's drinking
- relationshipcontext & support

NIH National Institute on Alcohol Abuse and Alcoholism



We have learned more -- but much has not yet reached everyday practice

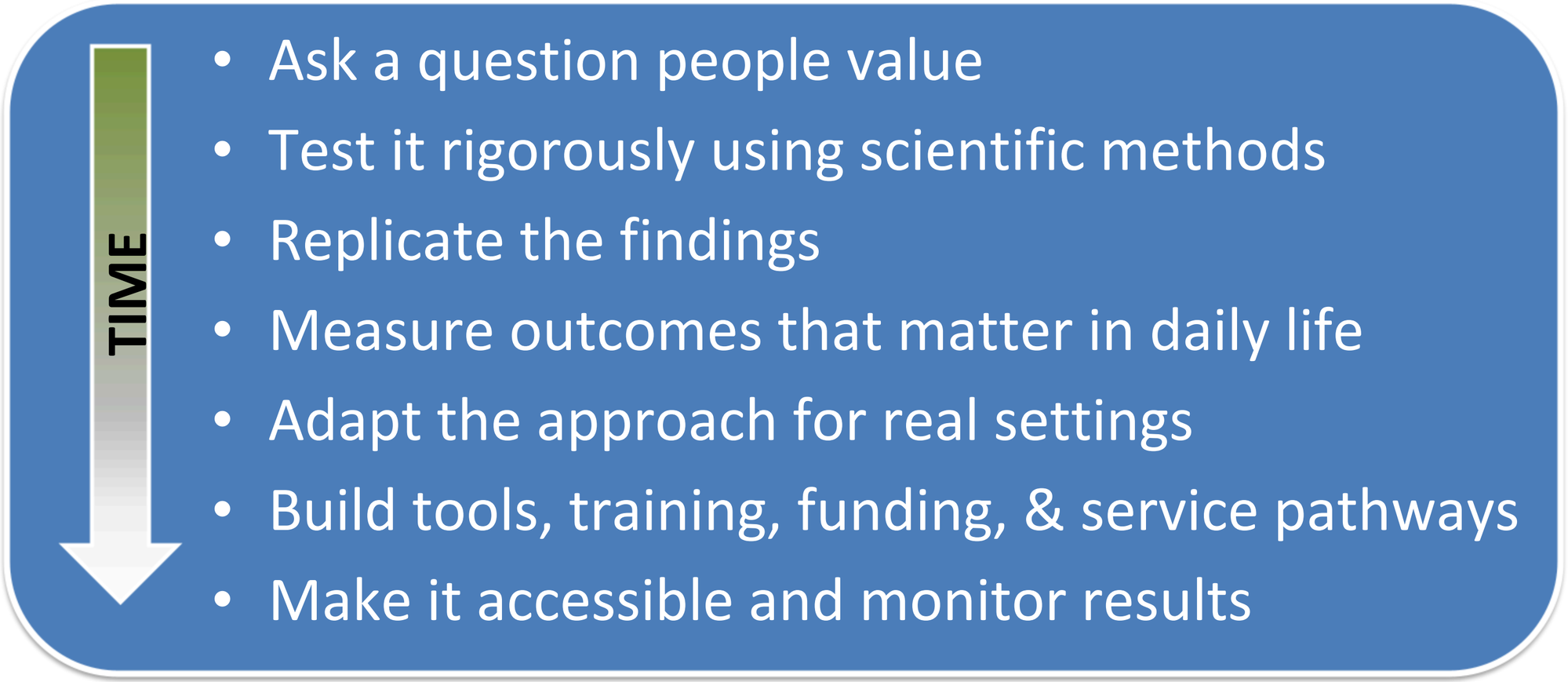
Substantial Gains

- Better prevalence estimates
- More knowledge of brain and body effects
- Promising screening approaches
- More intervention studies
- Greater attention to daily-life outcomes

Important unfinished work

- More consistent approaches to diagnosis
- Clinically useful biomarkers
- Stronger lifespan evidence
- Broadly validated treatments
- Moving evidence into communities & systems

Evidence-to-Practice: Research is not finished until people can use it



People with FASD, families, and communities should help shape the question, the outcomes, and how the results are used

In Closing



We know much more than we did in 2009

Research has improved our understanding of howc ommon FASD is, how prenatal alcohol exposure affects development, how we might identify FASDearlier, and what kinds of supports may help.



Important gaps remain

We still need more consistent diagnosis, useful biological markers, stronger lifespan research, better-tested treatments, and ways to bring evidence intoeveryday services.



The measure of success is what changes in people’s lives

Research should lead to better health, autonomy, participation, relationships, and quality of life — outcomes defined with people with FASD and families.

National Institute on Alcohol Abuse and Alcoholism



Thank you

For more info:
NIAAA's FASD research program

ALCOHOL RESEARCH *Current Reviews*

Topic Series on FASD (2023-2025)

To download: reviews

- **Impact of low to moderate PAE on neurodevelopmental outcomes** - Dr. Gretchen Bandoli and colleagues
- **Biomarkers and screening tools for PAE and affected children** - Drs. Julie Kable and Ken Jones
- **Ways to reduce PAE and the incidence of FASD** - Dr. Grace Chang
- **Exploring FASD as a whole-body disorder** - Dr. Natasha Reid and colleagues
- **Teratogenic mechanisms of PAE exogenous to the embryo/fetus** - Dr. Susan Smith

NIH National Institute on Alcohol Abuse and Alcoholism

National Institutes of Health
U.S. Department of Health and Human Services

Session 2: Introductions

Please share your name and your familiarity with research related to FASD.

Session 2: Leading Question

Task Force recommendation: Intensify research initiatives and interagency coordination.

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

Which of the scientific questions, if answered, would have the most impact on the FASD community?

Please rank the research questions, with 1 being the most impactful.

You can rank all 9,
or only rank the ones that are most important to you (i.e., your top 3).

Be sure to hit “Send” when done ranking.

Session 2: Activity



How do we honor people with FASD throughout the research process?

On the heart shapes, write recommendations on honoring people with FASD throughout the research process.



What research have you found helpful?

On the leaf shapes, write examples of research or data that you have found useful or impactful.



What steps would be needed to move scientific answers from theory to real-life practice?

On the star shapes, write recommendations on moving scientific answers/research into real life practice.

Session 2: Data Collection

Task Force recommendation: Intensify research initiatives and interagency coordination.

What is a major takeaway from your discussion? Tell us on Slido.

Now is the time to make your voice heard!

Slido submissions and written notes are our main "data buckets."

E-mail notes to brown@fasdunited.org.



Slido #3982061

Lunch Break

12:45–2:00

Session 3

National Forum



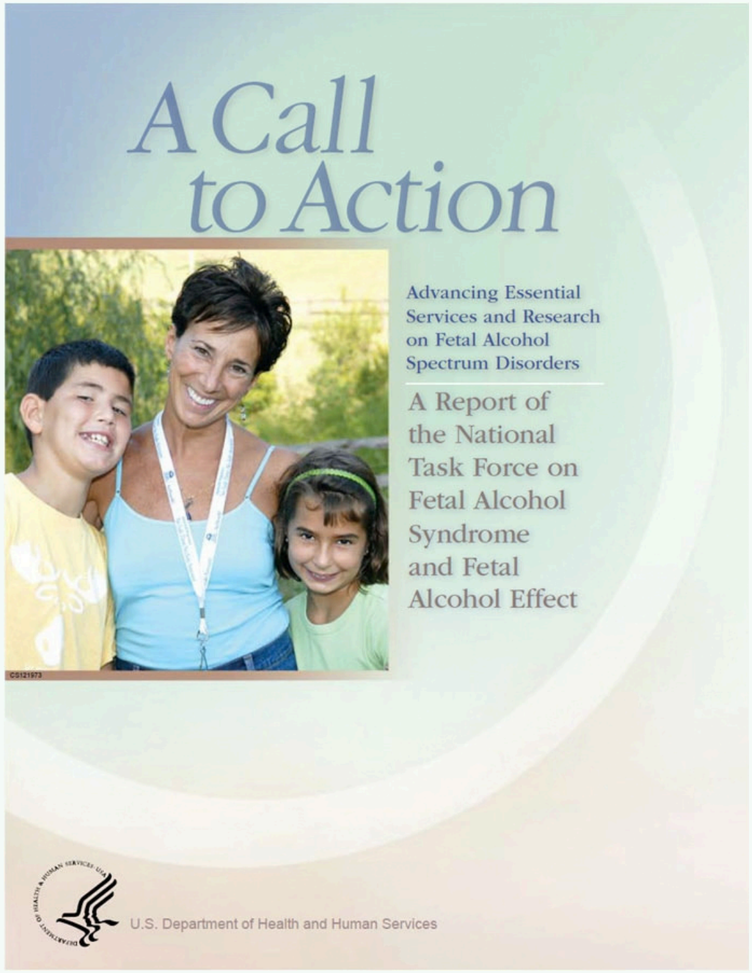
Task Force recommendation: Maintain a national forum in which parents, advocates, professional organizations, and experts in the field of FASDs can work to advance essential services and research for individuals with FASDs and their families.

ONE EXAMPLE OF A NATIONAL FORUM:

THE INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SPECTRUM DISORDERS (ICCFASD)

Tatiana Balachova, PhD
ICCFASD Scientific Coordinator and Executive Secretary
National Institute on Alcohol Abuse and Alcoholism, NIH

September 28, 2026, Arlington, Virginia



National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. A Call to Action. U.S. DHHS (2009). Olson et al.

2009 NATIONAL TASK FORCE CALL TO ACTION

"Collaboration between government agencies, professional organizations, researchers, and families is needed to adequately address FASDs."

RECOMMENDATION #10

"Maintain a national forum in which parents, advocates, 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."

The question before us:

Where are we now—and what could turn broad participation into a sustained, coordinated national effort?

ONE EXAMPLE OF A NATIONAL FORUM

Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD)

1996	FEDERAL	COORDINATION	NIAAA / NIH
	Interagency forum	Across research, policy, programs, and services	Sponsor and chair

Created in 1996, following the 1996 Institute of Medicine recommendation made in response to a mandate from the U.S. Congress to conduct a study of FAS.

Includes representatives from federal research, public health, education, disability, health care, and service agencies.

Sponsored and chaired by NIAAA, NIH.
Chair: Patricia Powell, PhD, NIAAA Deputy Director

Not a direct-service program, regulator, or separate funding agency

ICCFASD

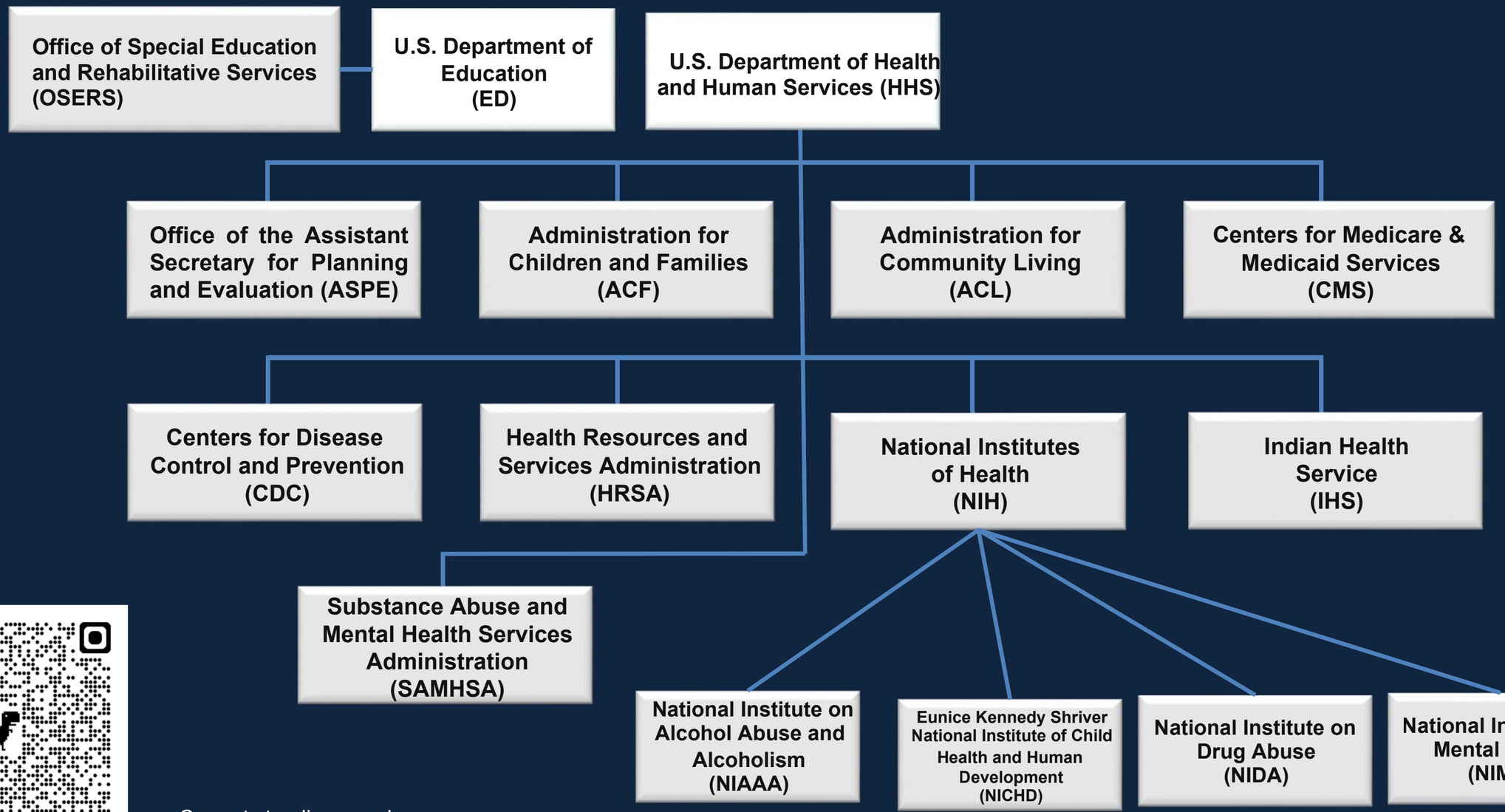
Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders



Mission: enhance and increase communication, cooperation, collaboration, and partnerships among disciplines and federal agencies to address issues that are relevant to disorders caused by prenatal alcohol exposure.

Vision: collaborative partnerships, using the resources of government and other organizations, will reduce the prevalence of individuals affected by prenatal exposure to alcohol and provide appropriate interventions and support to persons affected by Fetal Alcohol Spectrum Disorders (FASD) and their families.

ICCFASD Structure and Collaboration



Current standing member agencies • September 2026

FASD-Related Work Across ICCFASD Agencies

- Federal agencies work on different areas related to FASD.
- FASD crosses agency missions, authorities, budgets, data systems, and service systems.
- ICCFASD helps agencies connect complementary work and identify gaps.



How does the ICCFASD work?

AGENCY UPDATES & CONSULTATION

Members share agency updates, identify overlap, and consult on opportunities.

PUBLIC MEETINGS

Members report on federal activities and invite scientific, clinical, community, and lived-experience perspectives.

SPECIAL FOCUS WORKING GROUPS

Time-limited, issue-specific groups led by participating agencies; some include outside experts and stakeholders.

CONNECTIONS & FOLLOW-THROUGH

Members carry information back to their agencies and identify complementary opportunities.

Distributed leadership: ICCFASD's impact comes from coordination and connection—not a separate command structure.

Public Meetings: Open and Transparent

• Federal members report and discuss agency FASD activities.

• Invited panels add scientific, clinical, community, and lived-experience perspectives.





- Public meetings are open to the public
- Meetings are available in person and through live and archived NIH VideoCastaccess.

https://videocast.nih.gov

Agency Report Example: Health Resources and Services Administration (HRSA)

Representative: Martha Fermin, MSW, LICSW, Maternal and Child Health Bureau

Supporting FASD Screening and Interventionprogram (SFASDSI) – primary-care education and practice improvement

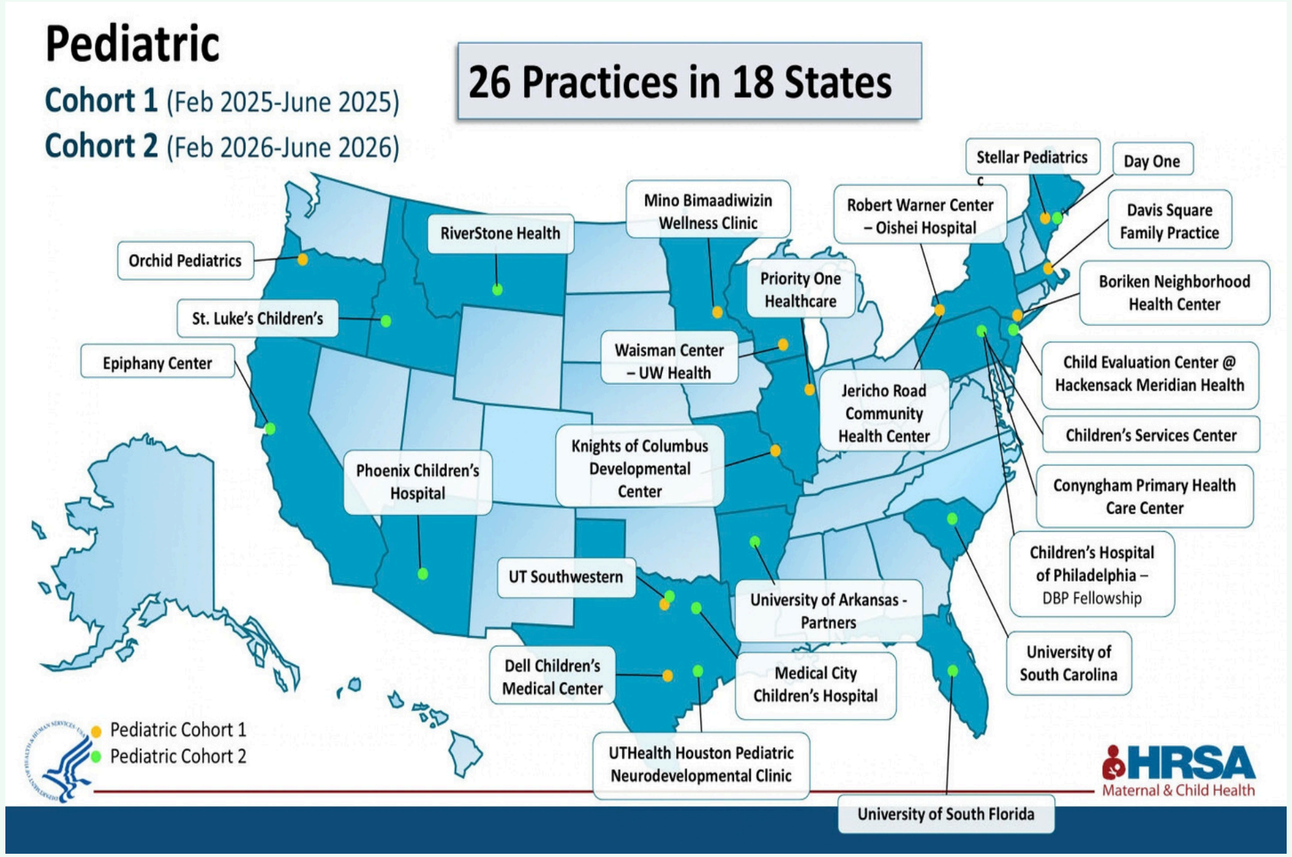
2024–2029 cooperative agreement

Boston Medical Center, in partnership with Proof Alliance

PURPOSE To support reducing alcohol use during pregnancy and improving developmental outcomes for children and adolescents with a suspected or diagnosed FASD

REACH Pediatric and prenatal care practices in states, territories, communities with high rates of binge drinking among pregnant women, including rural areas.

AWARD Appr.$950,000 annually/five years



Example of agency work reported through ICCFASD; not a program administered by ICCFASD.

Invited Panels Bring Multiple Perspectives

Federal work, science, clinical services, community, and lived experience in one public forum

2026 | FASD Across the Lifespan: Understanding Comorbidities and Their Impact

- FASD as a Whole-Body Disorder: From Research to Clinical Care Across the Lifespan –Claire Coles, PhD, Emory University
- Comorbidities in FASD: Evidence from U.S. Hospital Data –Brandon Attell, PhD, Georgia State University
- Comorbidities in FASD: Discovering Mechanisms –Olivia Weeks, PhD, Boston Children's Hospital
- Seeing Through the Lens of Lived Experience –Laura Bousquet, The Texas FASD Network

2024 | Fetal Alcohol Spectrum Disorders: 50 Years—Looking Back and Moving Forward

- Research, clinical, families, women's health research, and federal agency perspectives



"Nothing About Us Without Us"

2023 | What Is Working in Your Community

- Lessons Learned from Lived Experiences

2022 | FASD Changemakers' "Lay of the Land" Survey

- Equality vs. Equity—What 468 Adults with FASD Want You to Know

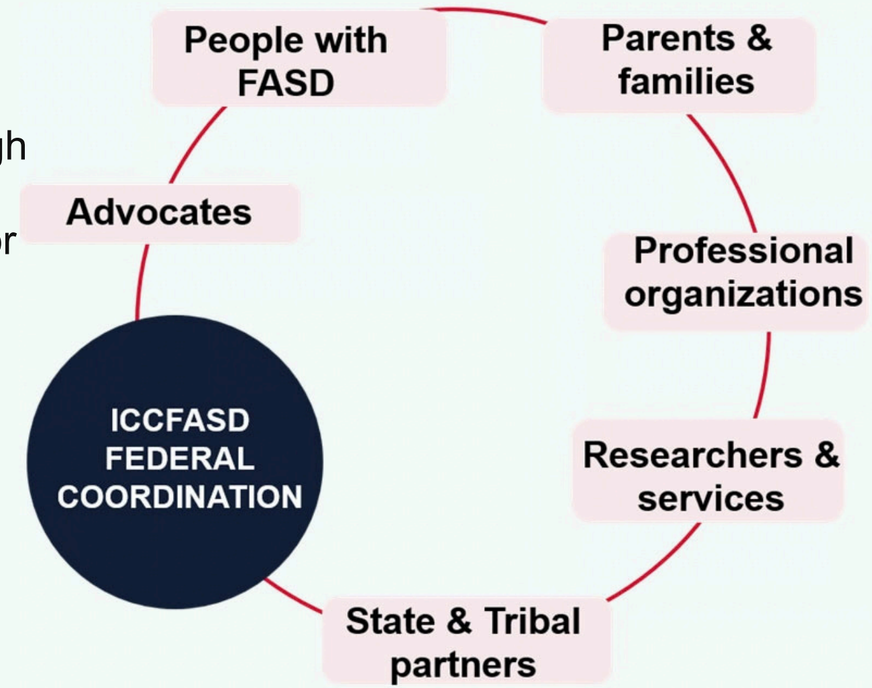
How can the public participate?

BEFORE A MEETING

- Review the agenda and meeting materials
- Submit questions or commentsthrough announced channels
- Coordinate through an organization or network
- Respond to requests for information

DURING A MEETING

- Attend in person or watch NIH VideoCast
- Contribute when invited as a speaker
- Useannounced Q&A orcomment opportunities



BETWEEN MEETINGS

- Contact ICCFASD
- Share evidence and emerging priorities
- Respond to requests for input or working-group invitations

Representation has limits

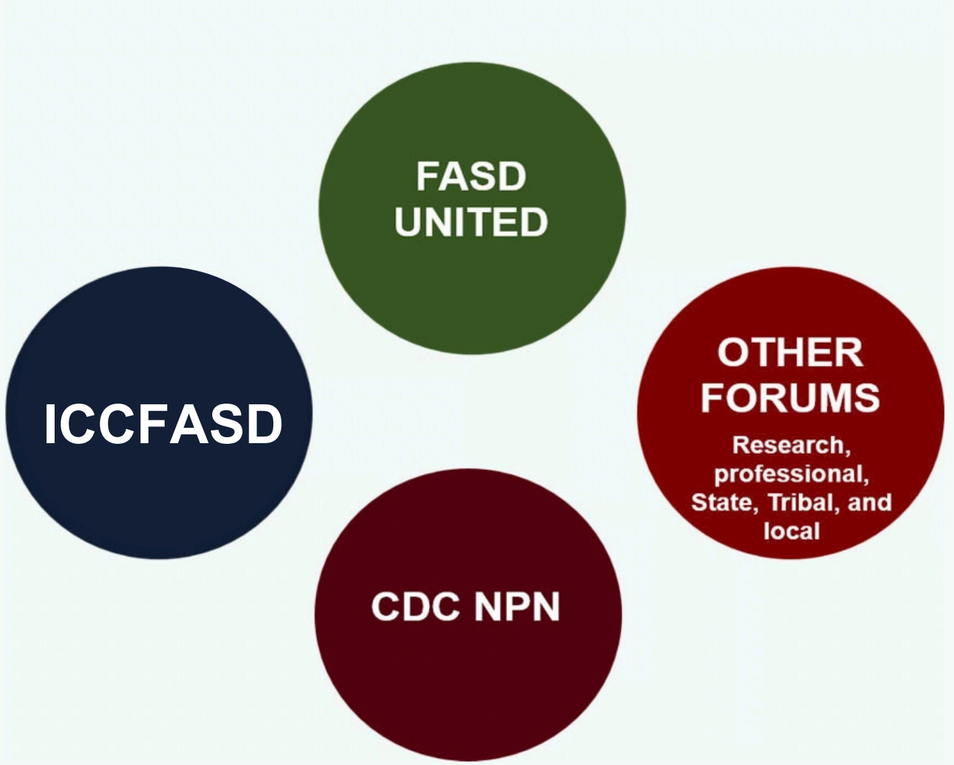
- Standing membershipisfederal
- External voices are invited—not standing shared governance
- Representation is not systematic across all States, Tribal Nations, professions, systems, and communities

A valuable federal forum—not the full national forum envisioned in Recommendation #10

Recommendation #10: partially achieved

What has been achieved

- Sustained federal coordination through ICCFASD
- Progress in public and lived-experience participation
- Several national forums -complementary community, advocacy, professional, research, and partner structures
    - ICCFASD -federal agency coordinating forum
    - FASD United -community and advocacy forum that convenes families, advocates, affiliates, and professionals
    - The Centers for Disease Control and Prevention (CDC) National Partner Network (NPN) -professional cross-sector partnership
- Public Law 119-44 strengthens FASD program authority and capacity-building



One ecosystem—multiple complementary forums; no single integrated structure

What remains

- Limited integration across forums

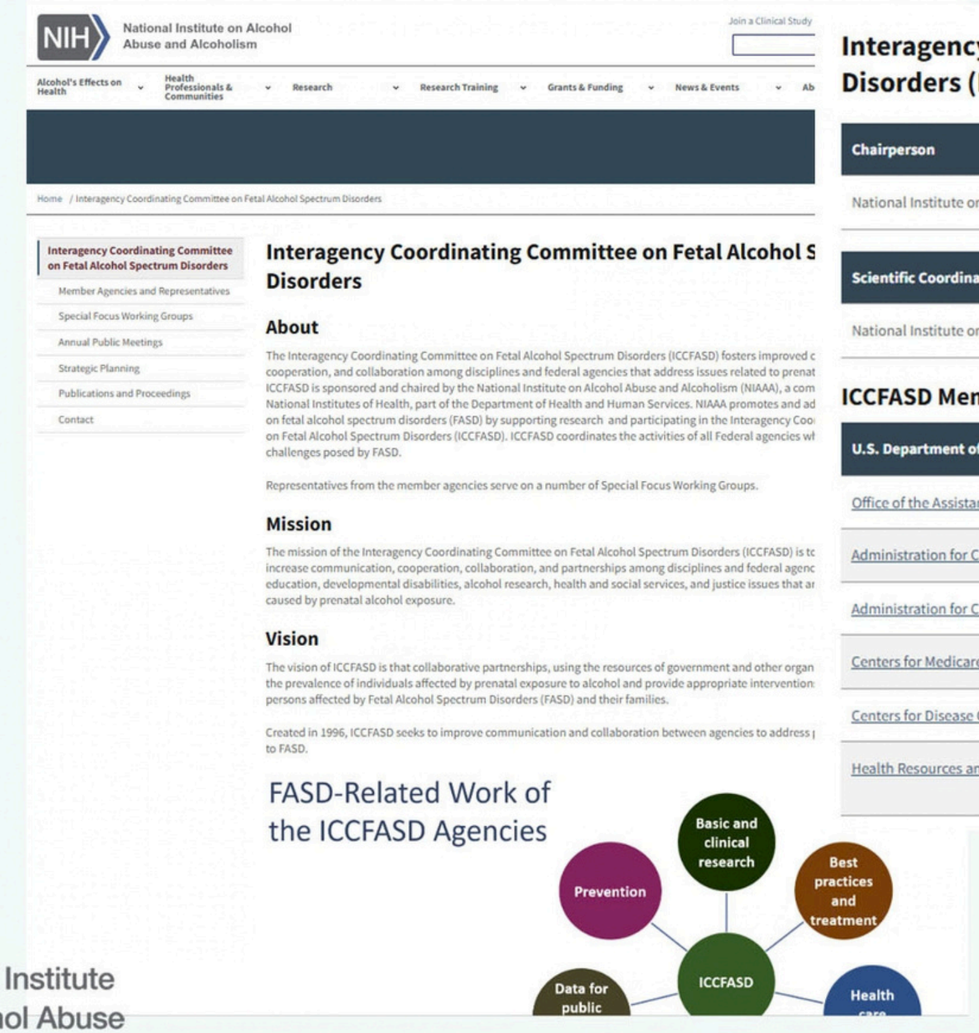
ICCFASD is an essential federal coordinating forum and one example of a national forum, but it is not the complete national forum described in the 2009 recommendation.

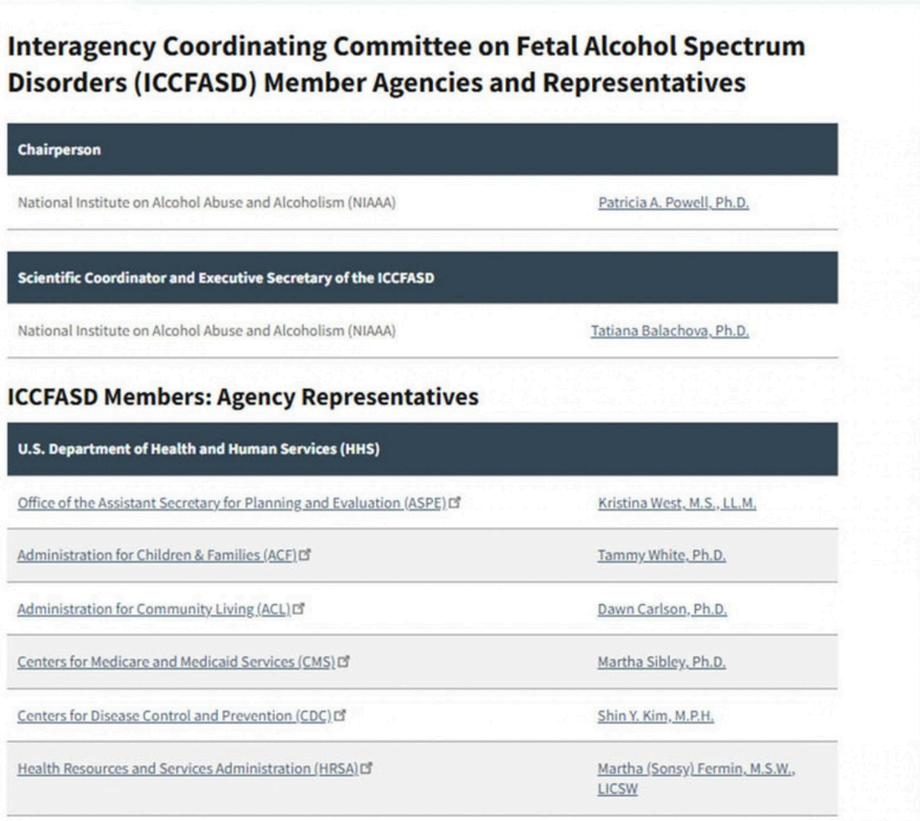
Discussion framing; not an official NIH or HHS recommendation

ICCFASD

Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders

Thank you—and over to the discussion





For information about ICCFASD:

NIH National Institute on Alcohol Abuse and Alcoholism

Session 3: Introductions

Please share your name and a space where you feel you get to use your voice for good.

Session 3: Leading Question

Task Force recommendation: 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.

What would an accessible and effective national forum look like?

Session 3: Activity



NATIONAL FORUM PLANNING

WHAT WOULD AN ACCESSIBLE AND EFFECTIVE NATIONAL FORUM ON FASD LOOK LIKE?

CONSIDERATIONS

- What focus areas/topics/themes should be discussed?
- What would the goals be?
- How do we ensure there are meaningful outcomes?
- How do we ensure all voices are included? What groups or people should we intentionally invite to get more involved?

MORE QUESTIONS ON BACK

- How often should the forum take place?
- Would the forum be in-person, virtual, or hybrid & why?
- How could this work be funded?

RATING YOUR FORUM

On a scale of 1-5 (with 5 stars being the best), how would you rate the forum you have planned based on...

- ***Cost*** ☆☆☆☆☆
- ***Accessibility*** ☆☆☆☆☆
- ***Feasibility**** ☆☆☆☆☆

**Feasibility means: how possible is this forum with current resources?*

- How did the rankings above influence your planning? Who would you need to invite to your table to make this event happen?

How did you complete this form?

☐ Filled out with my table ☐ Filled out individually

Session 3: Data Collection

Task Force recommendation: 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.

What is a major takeaway from your discussion? Tell us on Slido.

Now is the time to make your voice heard!

Slido submissions and written notes are our main "data buckets."

E-mail notes to brown@fasdunited.org.

Slido #1671174

Sharing Out

We want to hear from you about today's discussions!

- What were some themes in your discussions?
- What was a major takeaway?
- What are concrete next steps for us to consider?

What's Next?

FASD Symposium, Part 2

On Wednesday, there will be an extended session on federal programs; we hope you can join us!

White Paper 1.3

- Compile & review data from today's discussions
- Organize data thematically
- Draft White Paper 1.3
- Review of White Paper 1.3 with FASD United staff and partners, including:
  - People with living experience
  - Researchers and subject matter experts
  - FASD Affiliate Network



Anticipated release: Summer 2027

Timeline

01

September 2024



First FASD Symposium

02

2025



White Paper 1.1 published

03

September 2025



2nd FASD Symposium

04

2026



White Paper 1.2 published

05

September 2026



3rd FASD Symposium

06

2027



White Paper 1.3 published



What’s Next?

Let’s keep working together to uplift, empower, and support people with FASD, their families, and communities as a whole.

Thank you for being a part of the 2026 FASD Symposium!

