



# From Pregnancy to Primary Care: Advancing Awareness, Screening, and Systems of Care for Prenatal Alcohol Exposure and FASD

2026 NNEPQIN Series

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# Disclosures

- Authors have no disclosures

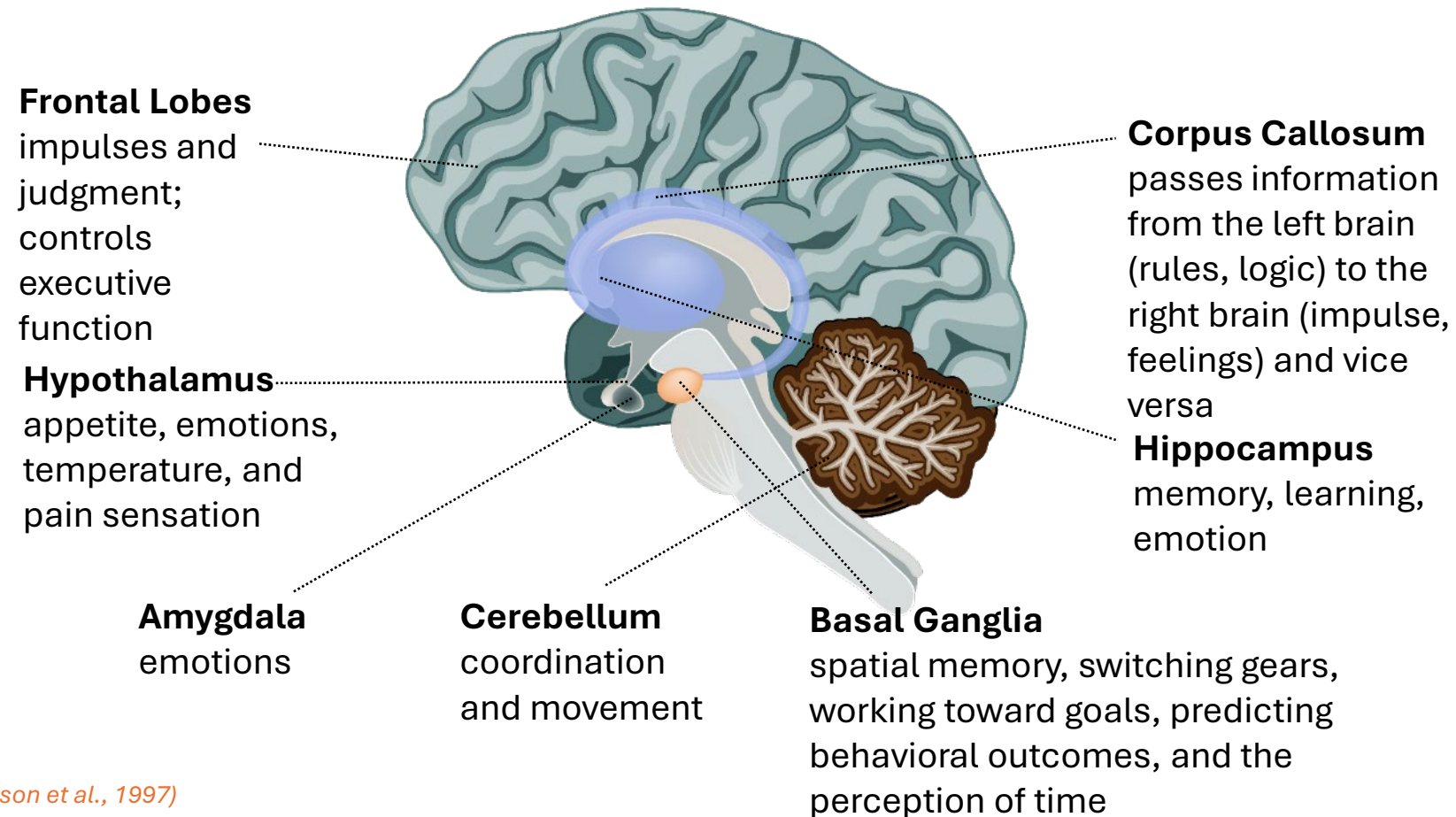
# Learning Objectives

1. **Understand** the diagnoses that can result from prenatal alcohol exposure and presentation across development
2. **Recognize** the benefits of universal screening in coordinating care for children and families
3. **Apply** team-based care coordination strategies for assessment, tracking, and monitoring care plans
4. **Understand** the policy landscape and regional and national resources
5. **Discuss** considerations for implementation in practice

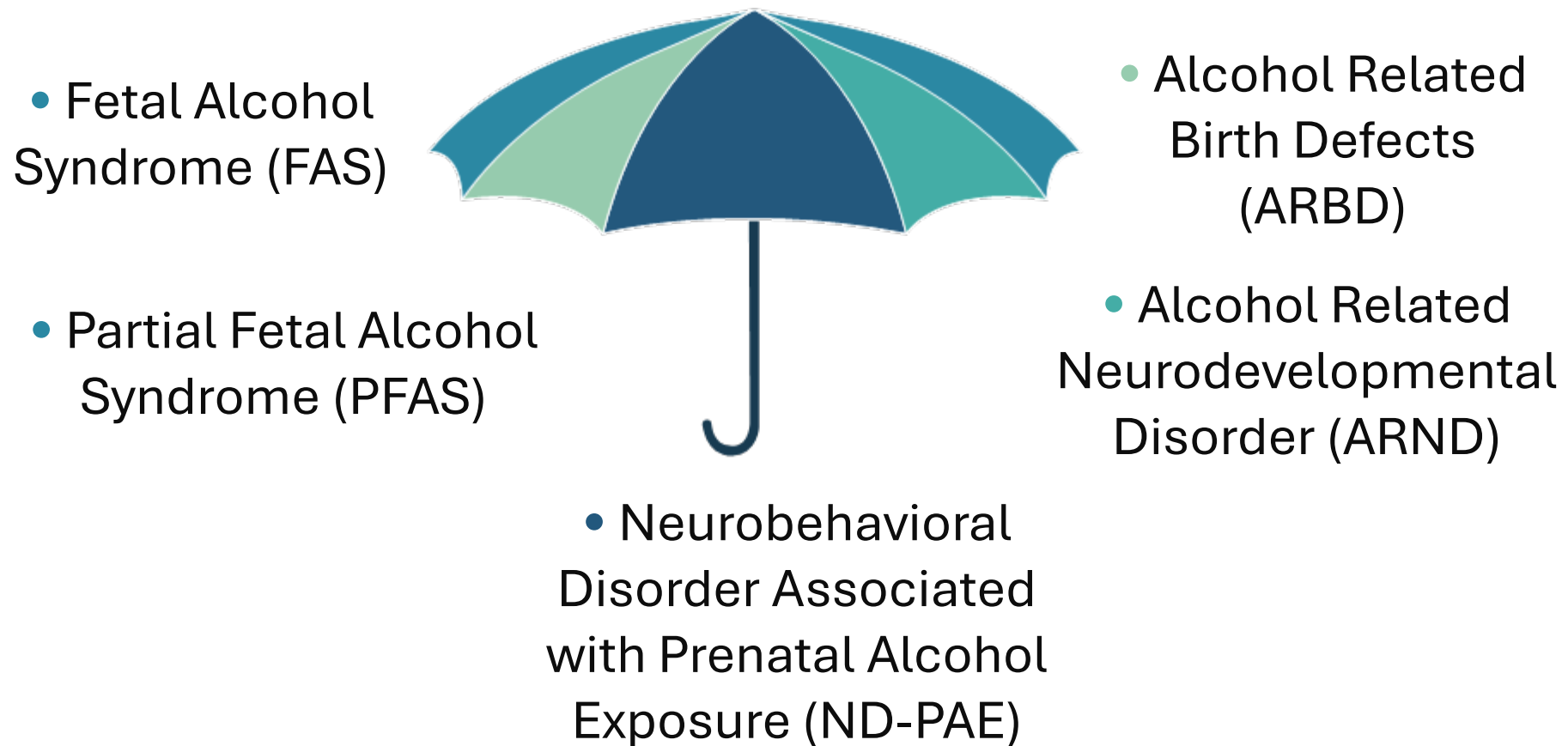
# Background and Diagnoses

# Cognitive / Behavioral Abnormalities

## *Areas of the Brain Affected By Prenatal Alcohol Exposure*



# The Umbrella of FASDs

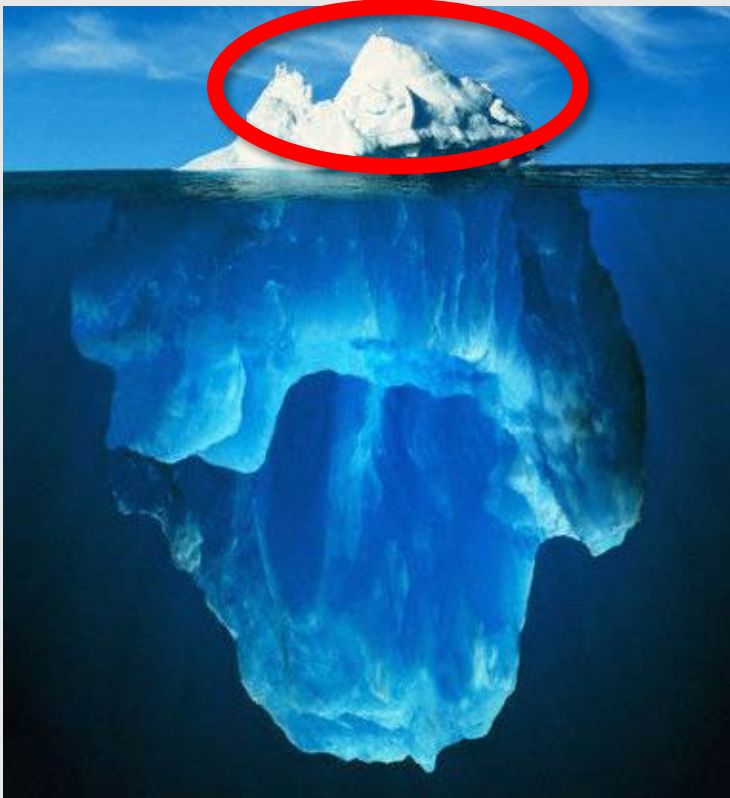




## Common Manifestations of FASDs in Children 0-5 years of age

1. Self-regulation Challenges
2. Neurocognitive Challenges
3. Adaptive Skills Delays
4. Prenatal Alcohol Exposure

## Diagnoses Resulting from Prenatal Alcohol Exposure



**Alcohol Related Birth Defects (ARBD) –**  
Congenital anomalies only (very rare)

**Fetal Alcohol Syndrome (FAS) & Partial Fetal Alcohol Syndrome (pFAS) –** Most widely known of the FASDs with physical and neurodevelopmental characteristics (rare)

**Alcohol Related Neurodevelopmental Disorder (ARND) -** Neurodevelopmental behavioral effects, no cardinal dysmorphic features (common)

**Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) –**  
Neurodevelopmental/behavioral effects with or without physical features (common)

Sources: (Hoyne, et al., 2016); (Hemingway, et.al., 2019)



# Fetal Alcohol Spectrum Disorders

Prevalence in Pediatric Practice: High



- Prevalence in a Midwestern city
  - **FAS:** 0-7.8/1000 children (0% to 0.8% 1st graders)
    - Accounts for 20% or less of all FASDs
  - **FASDs:** 11.3-50/1000 children (1 to 5% 1st graders, **weighted prevalence ~3.1-10%**)
- Increased prevalence among children in child welfare
  - **FAS:** 60/1000 children (6%)
  - **All FASDs:** 169/1000 children (16.9%)

Sources: (May, et al., 2018); (Lange et al., 2013)

## Prevalence (Continued)

Birth Defect	Prevalence
Down syndrome	1.2/1000 births
Cleft lip +/- palate	1.2/1000 births
Spina bifida	1/1000 births
Autism spectrum disorder (ASD)	23.1-44.9/1000*
Fetal alcohol syndrome (FAS)	6-9/1000*
All FASDs	24-48/1000*

\*per 1,000 school age  
children

**NOTE:** Since the method for surveillance of FASDs differs from surveillance methods for these other conditions, these prevalence data should be interpreted with caution.

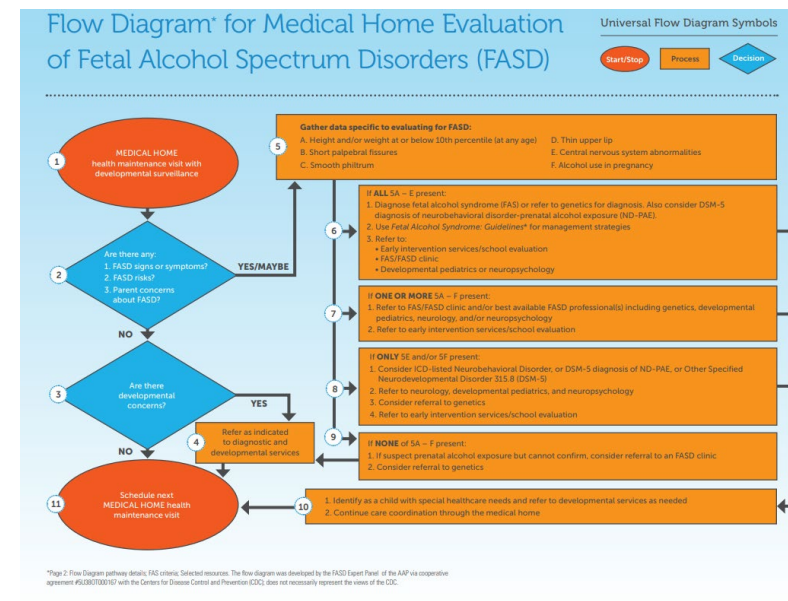
## When to Consider an FASD Diagnosis?

- Developmental, cognitive, or behavioral concerns
- Complex medical concerns (e.g. cardiac)
- Intrauterine or postnatal growth deficits (e.g. microcephaly, failure to thrive)
- History of prenatal alcohol or substance exposure
- History of a sibling diagnosed with an FASD
- Dysmorphic facial characteristics associated with FAS are present
- Children in high-risk populations
  - Children in foster care/child welfare
  - Children who are adopted internationally
  - Children in populations with high alcohol use (e.g., some American Indian or Alaska Native communities)

# AAP FASD Toolkit

(AAP.org/FASD)

- FASD Quiz, Test your Knowledge
- Policy Statements & Clinical Reports
- Flow Diagram for Evaluation of FASDs
  - [https://downloads.aap.org/AAP/PDF/FASD/fasdtoolkit\\_flow\\_diagram.pdf](https://downloads.aap.org/AAP/PDF/FASD/fasdtoolkit_flow_diagram.pdf)
- Videos, podcasts, and more!



## Resources

Prenatal alcohol exposure and  
FASDs

## Websites



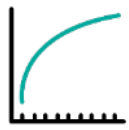



- American Academy of Pediatrics (AAP):
  - [aap.org/fasd](http://aap.org/fasd)
  - [aap.org/tic](http://aap.org/tic)
- Centers for Disease Control and Prevention (CDC): [cdc.gov/fasd](http://cdc.gov/fasd)
- FASD United: [fasdunited.org](http://fasdunited.org)
- National Institute on Alcohol Abuse and Alcoholism: [niaaa.nih.gov](http://niaaa.nih.gov)
- FASD National Partner Network Toolkit: [orau.gov/FASDChampions](http://orau.gov/FASDChampions)

## Review Records and History



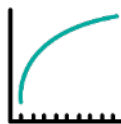



- Prenatal alcohol exposure history
- Birth records (weight, length, head circumference)
- Medical history/records (birth defects? exposures?)
- Postnatal growth records
- Developmental/behavioral history
- Psychological testing, including cognitive and behavioral assessments (e.g., school or EI testing for IEP (Individualized Education Program), 504 plan or IFSP (Individualized Family Service Plan))



# OVERVIEW: Diagnostic Criteria for FASD Categories

<b>FAS</b>	FAS with confirmed exposure	→	✓	✓	✓	✓	✓	
	FAS without confirmed exposure	→		✓	✓	✓	✓	
<b>PFAS</b>	Partial FAS with confirmed exposure	→	✓	✓			✓	
	Partial FAS without confirmed exposure	→		✓	OR		✓	
<b>ARBD</b>	Alcohol-related birth defects (ARBD)	→	✓					✓
<b>ARND</b>	Alcohol-related neurodevelopmental disorder (ARND)	→	✓				✓	
<b>ND-PAE</b>	Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)	→	✓				As Defined in DSM-	
			<b>A</b> Confirmed Exposure to Alcohol 	<b>B</b> Facial Anomalies 	<b>C</b> Growth Retardation 	<b>D</b> CNS Abnormalities 	<b>E</b> Cognitive / Behavioral Abnormalities 	<b>F</b> Birth Defects 

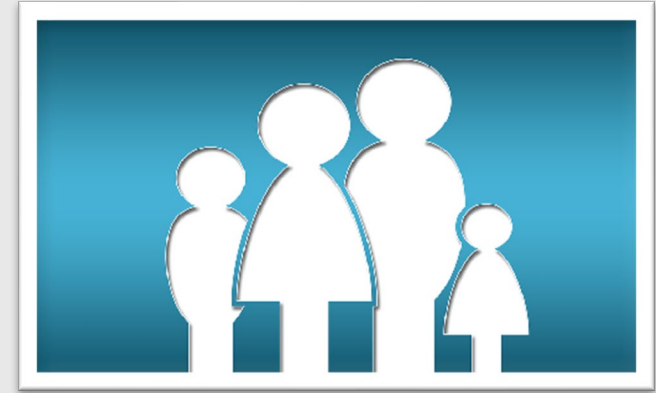
# Assessment Domains for FASD Diagnosis

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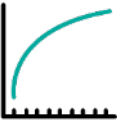



## A. Obtaining History of Prenatal Alcohol Exposure

### Routine Care



- As part of well child assessments (including review of all potential exposures)
- As part of addressing parent concerns
- Review family, social and pregnancy histories (including families new to your practice)
- Inquire when mother first learned of pregnancy
  - Late recognition of pregnancy and drinking in the 3 months prior to pregnancy are associated with a child having an FASD (May et al., 2014)
  - Inquire about drinking patterns prior to learning of pregnancy
  - Binge drinking is characterized as >4 drinks / sitting for women

# Assessment Domains for FASD Diagnosis

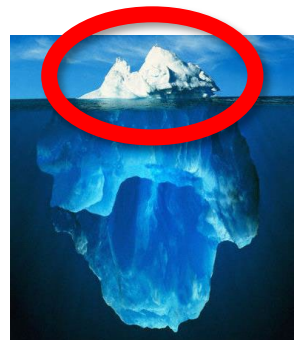
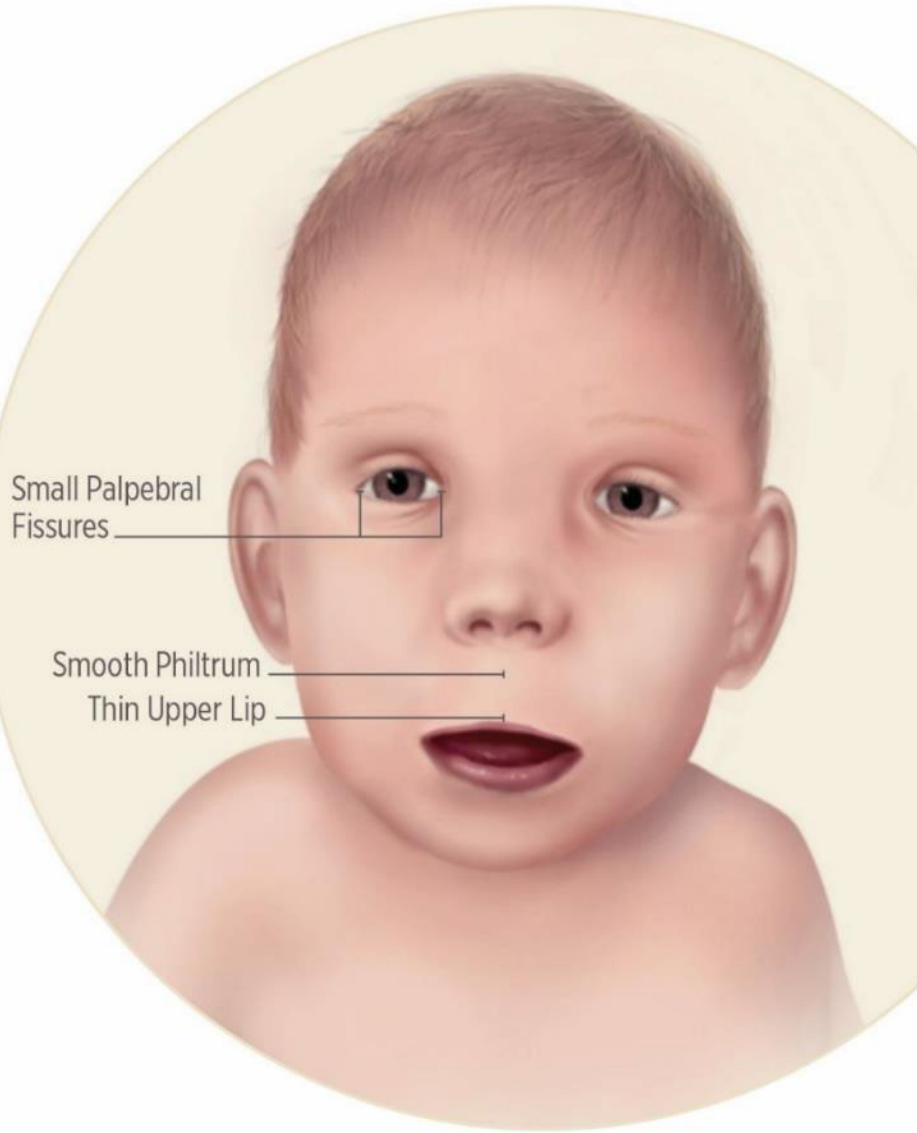
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## B. FAS Facial Features

- Sentinel/cardinal FAS Facial Features:
  - Short palpebral fissures
  - Smooth philtrum
  - Thin / flattened upper vermillion border

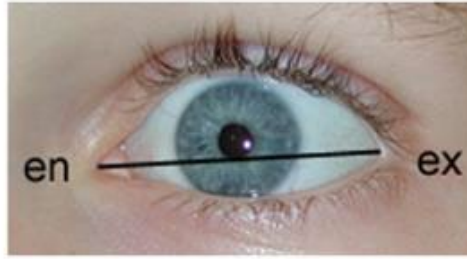
**NOTE:** There are variations in the fullness of the upper lip among different racial and ethnic groups. For example, Africans or Black persons may have fuller upper lips than Europeans.

Assess the morphology of the lip by the shape (flatness) of the upper vermillion border



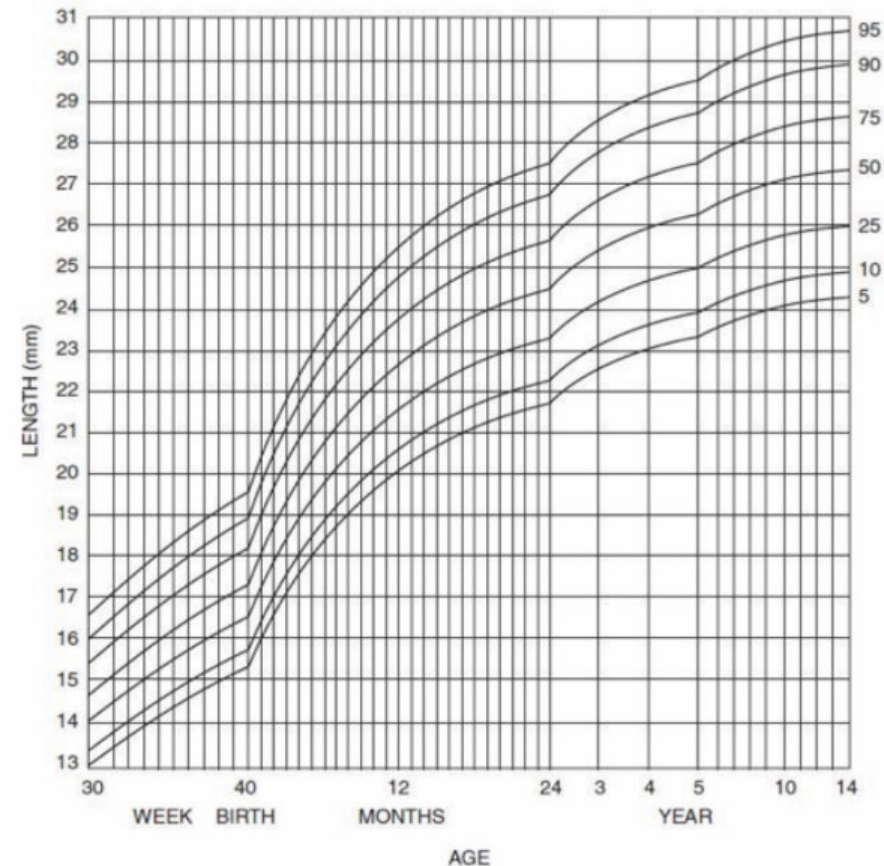
## B. FAS Facial Features

### Palpebral Fissure



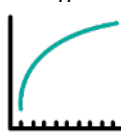

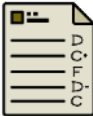



The palpebral fissure length is defined by the distance between the endocanthion (en) and exocanthion (ex) landmarks.

### Measuring Palpebral Fissure Length

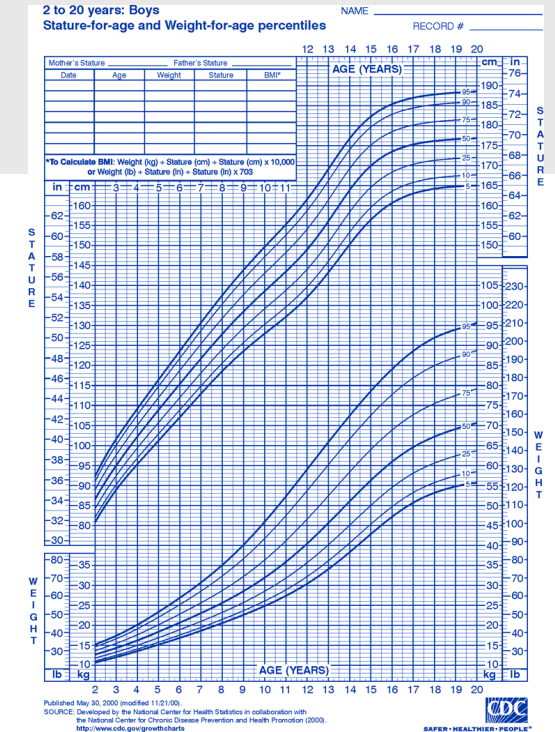
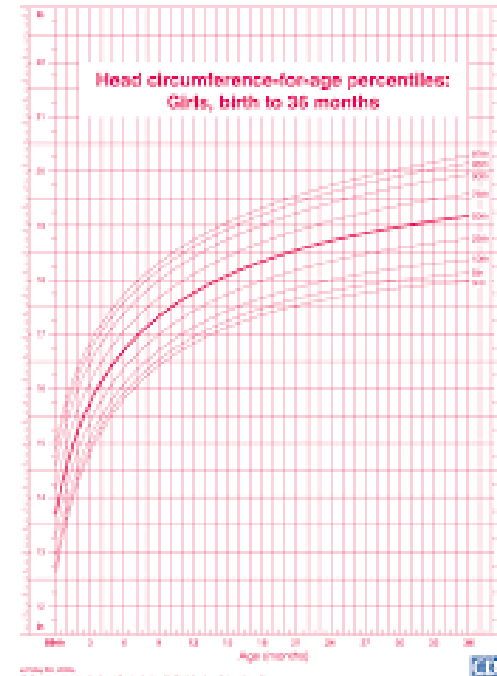


# Assessment Domains for FASD Diagnosis



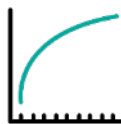



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# C. and D. Assessment of Growth and Microcephaly / Structural Brain Abnormalities

- **(C)** Weight and/or length growth deficiency (pre or post natal) at any time
- **(D)** Microcephaly or Abnormal brain structures (esp. small cranium, small corpus callosum)



# Assessment Domains for FASD Diagnosis

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## E. Cognitive/Behavioral Abnormalities

Cognitive Impairment	
<b>Global Impairment</b>	<ul style="list-style-type: none"><li>• <math>\geq 3</math> YO: IQ <math>\geq 1.5</math> SD below the mean (FSIQ/ VIQ/ PIQ)</li><li>• <math>&lt; 3</math> YO: Developmental delay <math>\geq 1.5</math> SD below the mean*</li></ul>
<b>Cognitive deficit</b>	<ul style="list-style-type: none"><li>• 1 neurobehavioral domain* <math>\geq 1.5</math> SD below the mean<ul style="list-style-type: none"><li>- Executive Function</li><li>- Specific Learning Impairment</li><li>- Memory Impairment</li><li>- Visual Spatial Impairment</li></ul></li></ul>
Behavioral impairment without cognitive impairment	
<p>Self-regulation deficits in 1 domain* <math>\geq 1.5</math> SD below the mean</p> <ul style="list-style-type: none"><li>• Mood</li><li>• Behavioral Regulation</li><li>• Attention</li><li>• Impulse Control</li></ul>	

\* ARND requires impairment in 2 domains, and cannot be diagnosed  $< 3$ YO



## E. ND-PAE: DSM-5 Criteria for Cognition and Behavioral Impairments in FASD



- DSM-5 emerging diagnosis
- Criteria describes impairment in
  - **Neurocognitive impairment,**
  - **Self-regulation impairment,**
  - **Adaptive function acquisition impairment,**
- Diagnosis is made in the context of confirmed **prenatal alcohol exposure**
- Criteria do not require the presence of physical features
- Listed as a specifier for Intellectual Disability diagnosis

## When to screen and how often?

AAP Bright Futures



### Suggested contact points:

- ✓ All prenatal visits
- ✓ The earliest well child visits
- ✓ All new patient visits
- ✓ Whenever a related concern is observed or raised

### Screening Process- 3 Screening Questions for Pediatricians

1. How often do you drink beer, wine or liquor in your household?
  2. In the 3 months before you knew you were pregnant, how many times did you have 4 or more drinks in a day?
  3. During your pregnancy, how many times did you have 4 or more drinks in a day?
- If a positive response is obtained, additional questions about amount, frequency and timing may be appropriate for diagnostic purposes.

# Conversations with Mothers

## Practicing compassion

- Be gentle, ask questions, and listen
- Stick to the facts
- Be non-judgmental, avoid stigmatizing language
- Remind her that you care about her child, her, and their family
- Use person-first language, e.g. “child with an FASD” or “child with prenatal exposure to alcohol” instead of “FASD kid”

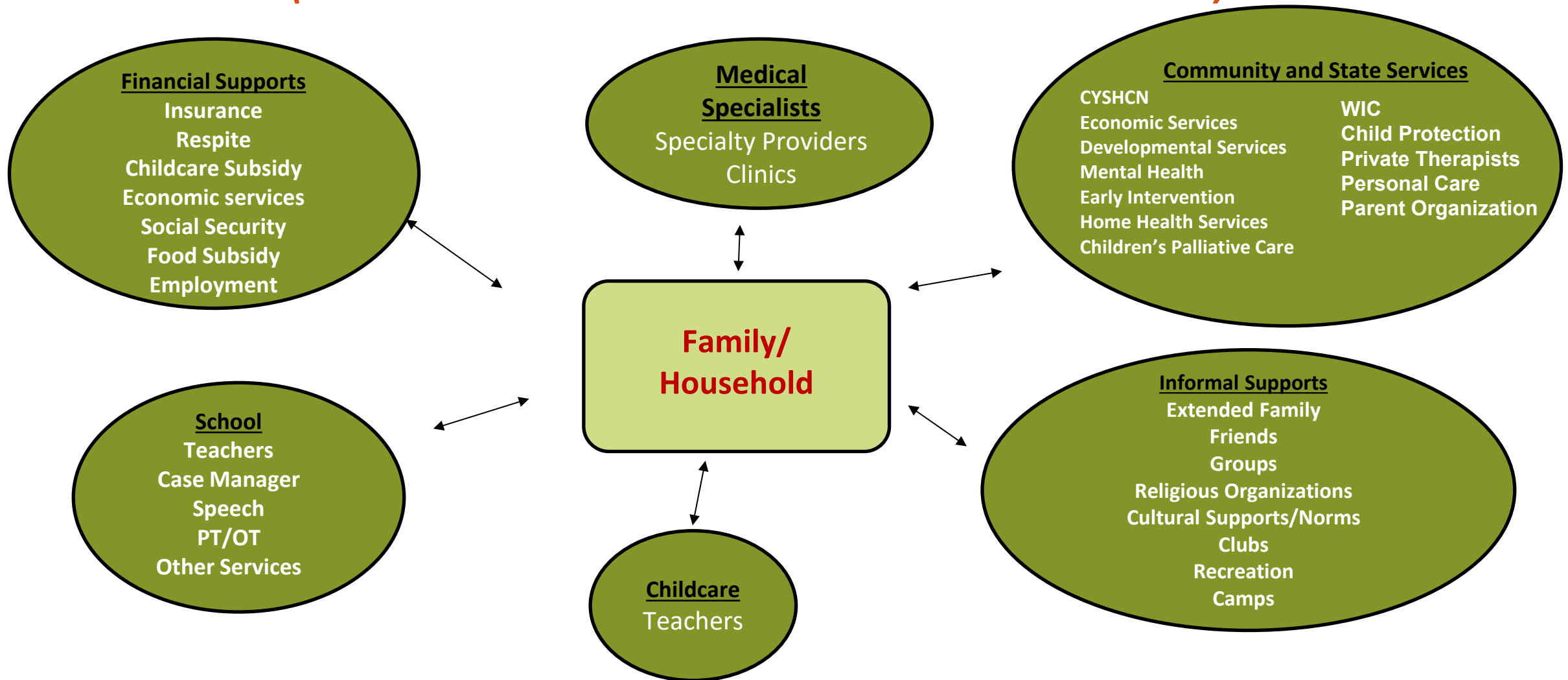
*Adapted from Practice Compassion (FASDUnited.org)*

# Care Coordination and Referral

Strategies for assessment, tracking, and monitoring care plan

# ECOMAP

**GRAPHIC REPRESENTATION OF THE FAMILY IN THEIR ENVIRONMENT  
(INCLUDES BOTH FORMAL AND INFORMAL SUPPORTS)**



# HOW TO CREATE AN ECOMAP

Always start by asking permission and explaining the purpose of doing an ecomap assessment

Example: *“I’d like to ask you more about your family and who’s helping you already so that we can plan next steps together.”*

## EXAMPLE QUESTIONS FOR ECOMAP DEVELOPMENT

### Informal Supports

- Who lives in the home?
- Are there grandparents, aunts, uncles or other relatives nearby?
- Who are your close friends you rely on?
- What does your family like to do together?

### Formal Supports

- Is your child receiving other services?
- Are other children in the family receiving any services?
- What supports your family financially?
- How is your child and family’s healthcare paid for?

# HOW TO CREATE AN ECOMAP, CONTINUED

## Tips for questions about extent of support

- Informal Supports:
  - Ask some questions in terms of how often the family talks to or spends time with the person(s) identified.
  - Ask some questions in terms of how well the family gets along with the person identified?
  - In what ways are informal supports helpful or not helpful?
- Formal Supports:
  - How is communication between service providers going? Do you feel services are coordinated?
  - Is there a primary person who helps your family the most?
  - Are the services meeting your family's needs? Are there areas of need not being addressed?
  - Who or what is missing that would be supportive?

\*BLUE- SPECIALTY PROVIDERS

\*GREEN- COMMUNITY PROVIDERS

\*ORANGE- FINANCIAL SUPPORT

\*GRAY- INFORMAL SUPPORT





# CARE CONFERENCES AND CARE COORDINATION ROUNDS

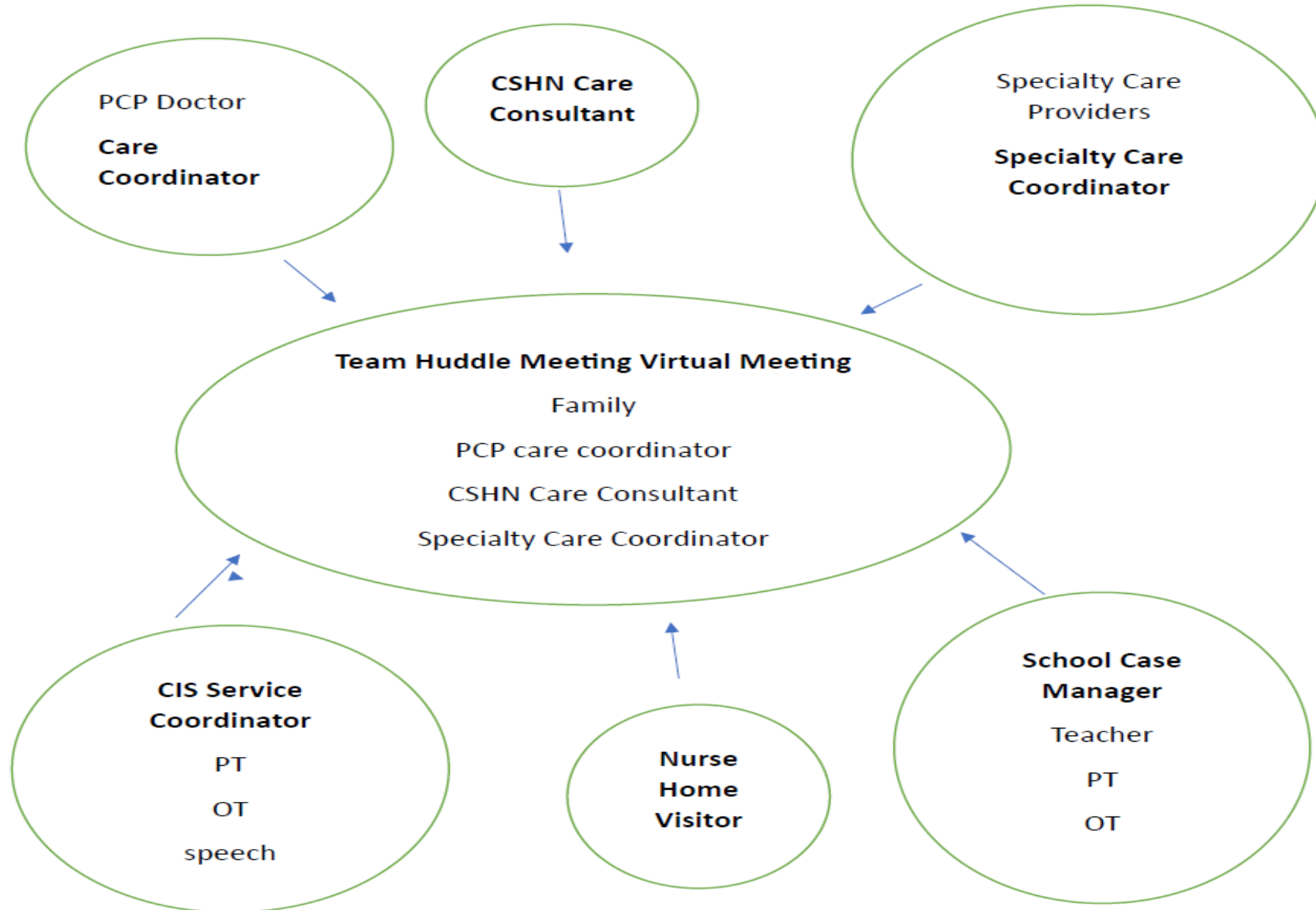
## Care Conferences

- Team meetings to coordinate and facilitate communication across providers with the youth and family.
- Focused on building on family and youth strengths, problem solving barriers, determining next steps, and updating the shared plan of care.
- Physicians can bill for care conference.

## Care Coordination Rounds

- Regular interactions with the practice care coordinator and community providers. Can be in person, phone calls, or electronically.
- Proactive strategy to address family's needs and keeps progress toward shared care plan goals moving forward.

# CARE COORDINATION ROUNDS-TEAM HUDDLE



## BENEFITS OF TEAM-BASED CARE COORDINATION

- A team approach with shared goals and shared effort makes for coordinated services and makes the work doable
- Teaming allows for more time for medical thinking for clinicians and deeper understanding of situation
- Operating more proactively and less reactively
- Improved clinical outcomes
- More time discussing the important issues and not “catching up”
- Services are less “siloed”, prevents duplication of efforts
- Prevents clinician burnout

## Policy Landscape

# FASD Respect Act: What Happens Next



Scan here for more information

## What it Does

- Authorizes programs for education, training, and awareness
- Research to develop and improve diagnostic and intervention methods
- State and Tribal Capacity Building
- Authorizes \$12.5 M/year through 2030

## What it Means for States

- Renewed dedication at federal level to address FASD and support states
- Opportunity to integrate FASD in existing systems of care
- Funding to states and tribes to build capacity for FASD identification and support

# Family Navigator Program



*Family Navigator*

The Family Navigator program is a zero-barrier national resource where individuals, families, and professionals can call to find local resources. Navigators provide personalized one-on-one peer support, referrals to vetted resources and services, and assistance with medical, educational, and disability benefits.



We answered over 1100 inquiries in 2025, offering support to more than 900 individuals.



*Resource Directory*



**Over 1200** professionally vetted resources for all 50 states. Customized referrals for each individual and family request.

# Family Navigator Program

A FASD Family Navigator can be reached **Monday through Friday between 9:00 am and 10:00 pm EST** via phone at 202-785-4585 or by completing an online form: [fasdunited.org/family-navigator/](https://fasdunited.org/family-navigator/)

There is also a new chat feature through the website.

Available for people with FASD, caregivers and family members, and professionals.

This service is free and does not require a referral.





## **FASD United**

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### *Affiliate Network*

- Monthly meetings with national updates, new resources, and opportunities.
  - Opportunities to connect to other organizations and leaders over similar goals, programs, geography, and service group.
  - Mini-grants to support involvement in FASD events.
- Free FASD Awareness Month resources and assets for social media, events, and more.
  - Access to Affiliate Hub.
  - Support navigating state advocacy.
  - Features in FASD United media and activities.
  - Ad-hoc meetings on topic deep-dives.



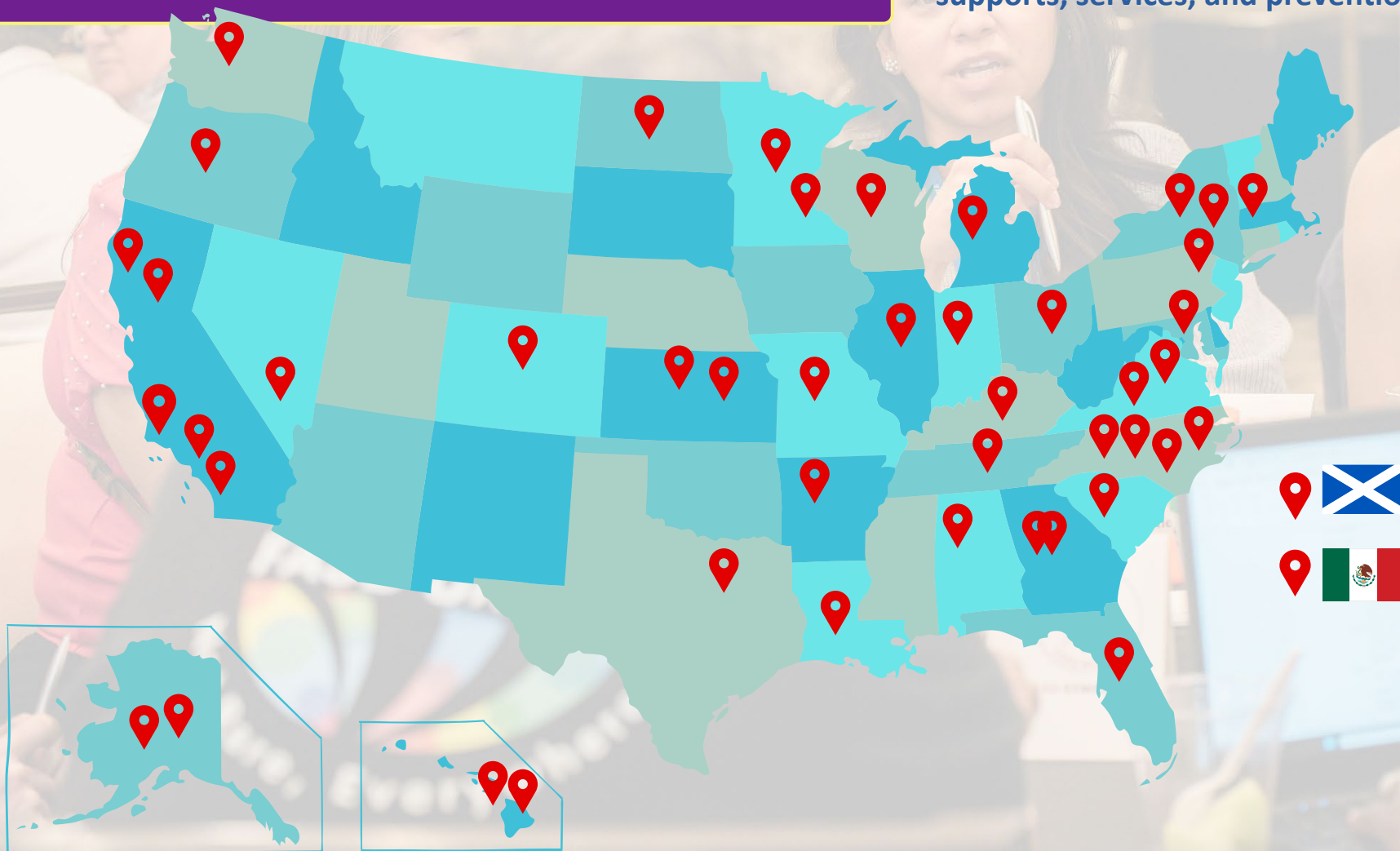
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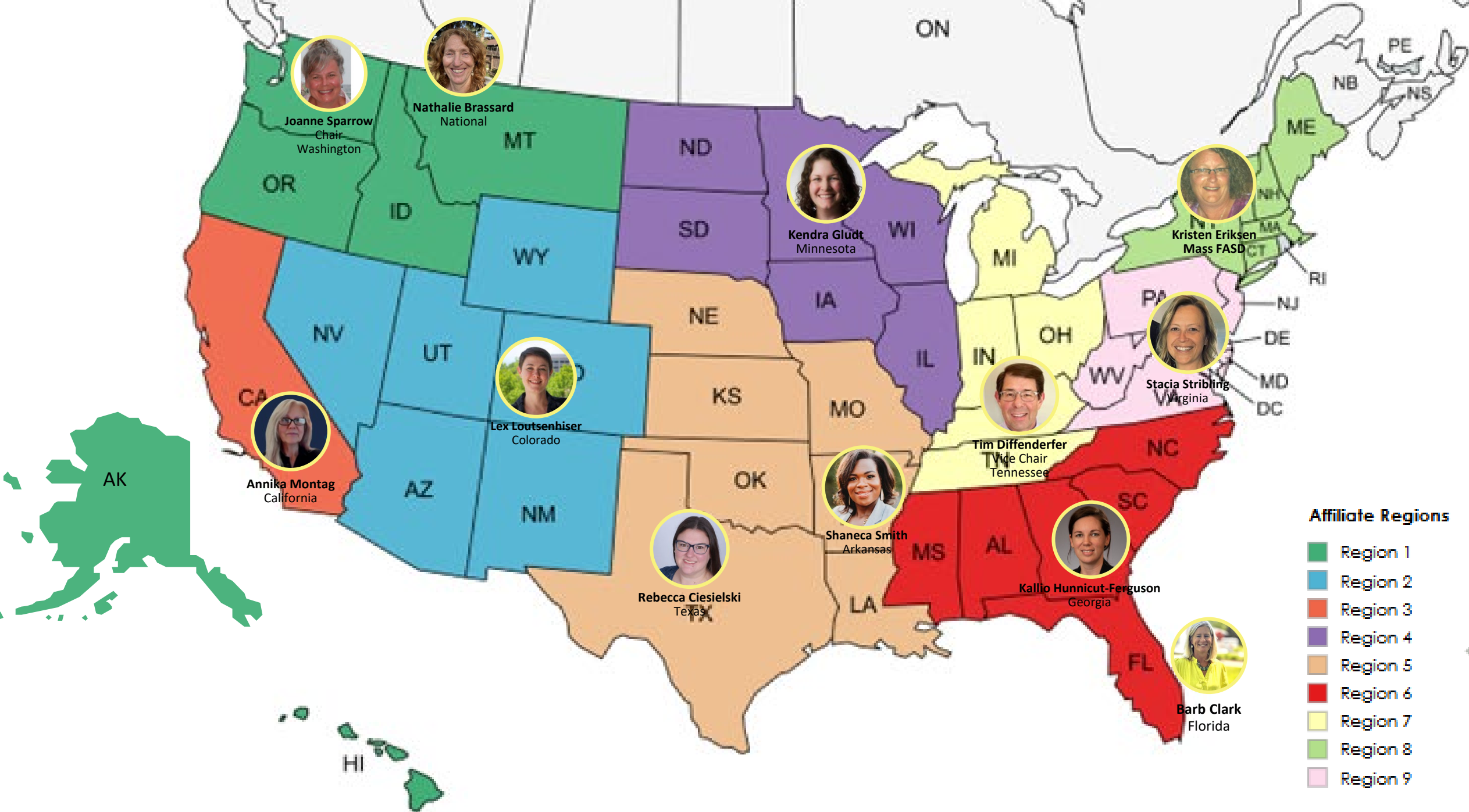


# FASD UNITED AFFILIATE NETWORK



Situated throughout the United States and beyond, FASD United Affiliates are an autonomous group of *over 50 organizations* encompassing a wide array of disciplines, focuses, and goals. They connect on the need for FASD supports, services, and prevention.





## Implications for Practice

## Regional considerations for implementation in practice

Please put thoughts in the  
chat

- Prevention
- Screening and documentation across perinatal continuum
- Adopting person-first, non-stigmatizing language
- Referral
- Interdisciplinary communication and collaboration



**Questions?**

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**Thank you!**

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