

Understanding the Diagnosis of Fetal Alcohol Spectrum Disorders (FASD)

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Disclosures

- FASD Affiliate
- Sources include peer reviewed Journals, American Academy of Pediatrics, Proof Alliance
- Lived experience
- No financial disclosures

Who we are influences how we are. That is just as important as what we do.



What is FASD?

- ▶ Fetal Alcohol Spectrum Disorders (FASD) are lifelong, brain-based conditions
- ▶ Caused by prenatal alcohol exposure.
- ▶ It affects how the brain processes information, regulates emotions, and manages daily life.

- ▶ A diagnosis is not about blame or judgment. It is about **understanding how a child's brain works** so that expectations, supports, and interventions can be better matched to their needs.

Red flags for an FASD



- Prenatal & Early History
- Growth & Physical Features (*may be subtle or absent*)
- Developmental Delays
- Cognitive & Learning Red Flags

Red flags continued



- Behavioral & Emotional dysregulation
- Executive Function Challenges
- Social & Adaptive Functioning
- Sensory & Neurological Concerns
- Mismatch Between Appearance and Ability
- Family & Systems Red Flags
 - Sibling with an FASD
 - Multiple prior diagnoses without a unifying explanation (e.g., ADHD, ODD, anxiety, learning disability)

Feel free to add your own red flag in the chat!

Important Notes for Families

- There is no single test for FASD
- Diagnosis is based on patterns across multiple areas of functioning
- Some children receive a formal FASD diagnosis, while others receive a description of neurodevelopmental differences consistent with prenatal alcohol exposure
- Supports can and should begin even without a confirmed diagnosis



Complicating considerations

- ▶ Foster care/adoption, undocumented alcohol exposure
- ▶ Lack of birth records or limited PCP well child care prior to visit
- ▶ Limited awareness in medical community about FASD red flags

Documentation of Alcohol Exposure

- Can be difficult to get accurate history
- Birth mothers may be hesitant to disclose drinking while pregnant
- Providers can be hesitant to ask
- Adoptive/foster parents may not have full prenatal history
- When FAS criteria are met, documented alcohol exposure is helpful but not necessary for diagnosis

Multidisciplinary approach

Diagnosing is a team sport, ideally*

- ▶ Primary Care Provider (Pediatrician or Family Physician)
- ▶ Developmental-Behavioral Pediatrician
 - ▶ Helps differentiate FASD from ADHD, autism, trauma-related disorders, or learning disabilities
- ▶ Clinical Psychologist or Pediatric Neuropsychologist
 - ▶ Identifies patterns consistent with brain-based differences
- ▶ Child Neurologist
- ▶ Genetics
- ▶ Therapists: Speech & Language, Occupational, Physical (as needed)
- ▶ Social workers or care coordinators

Prepping for the evaluation:



Medical work up:

- ▶ Robust pregnancy, birth, and family history taken
- ▶ Head circumference and assessment of growth charts
- ▶ Physical exam- better to do after 1 year of age
 - ▶ Facial features
 - ▶ Neurologic exam
 - ▶ Skin
 - ▶ Subtle differences (ex. Fingers, elbows)
- ▶ Observing behaviors and social engagement in the clinic
- ▶ Qualitative evaluation:
 - ▶ Processing delay present?

Additional interventions:

- ▶ Brain MRI- recommended 'at some point' in childhood, presence of 'soft neurologic signs' on physical exam
 - ▶ What this tells us: is there structural differences present?
 - ▶ Reasons for needing more emergently:
 - ▶ Suspected brain injury
 - ▶ Seizures
 - ▶ Cerebral palsy
 - ▶ Without clear concern/suspected TBI, radiology and neurology do not recommend elective brain MRI before age 3
- ▶ Genetic testing
 - ▶ Whole exome sequencing

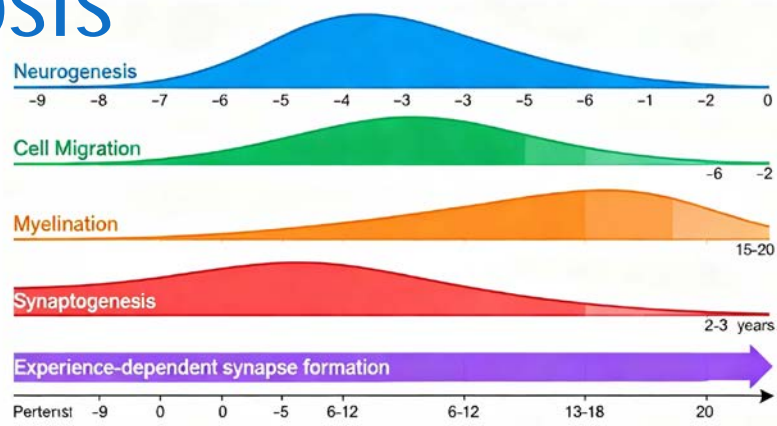
Assessing behavior, development, social skills

- ▶ Screenings:
 - ▶ Behavior inventory (CBCL, Vanderbilt)
 - ▶ Adaptive skill abilities (Vineland, clinical interview)
 - ▶ Social engagement
- ▶ Educational evaluation (review IEP if available)
 - ▶ Developmental assessment in younger kids- looking for delay vs disorder, inconsistency
- ▶ *May be completed:*
 - ▶ Sensory profile
 - ▶ Speech and language evaluation
 - ▶ Fine motor/ visual-perceptual evaluation

FASD Across the Lifespan: common signs



Why age matters at time of diagnosis



- Neuroplasticity! It's never too late but the earlier the better.
- Symptoms change over time.

Diagnosis considers:

- Developmental expectations for age
- Daily functioning
- Supports already in place

Infancy

Common signs:

- Sleep and state regulation challenges (hard to settle, hard to stay asleep)
- Feeding difficulties; sensory sensitivities (sound, touch, light)
- Differences in muscle tone and/or quality of movement
- Signs of delayed integration of sensory processing
- Delays or differences in early motor and social engagement may show up



Toddler

Common signs:

- Delayed speech or language development
 - Language may be uneven: words present but understanding/processing lags
- Poor sleep or feeding difficulties
- Sensory sensitivities (noise, touch, textures)
- Difficulty calming or self-soothing
 - Big emotions, rapid escalation, difficulty with transitions
 - Safety awareness may be low; impulsivity becomes clearer
- Delayed motor skills

Often mistaken for temperament or parenting challenges.

Preschool age

Common signs:

- Difficulty learning from experience and repeating multi-step routines
- Challenges with pretend play/social problem-solving
 - May seem younger than peers
- Fine motor and sensory needs can affect school readiness



School age (6-11 years)

Common signs:

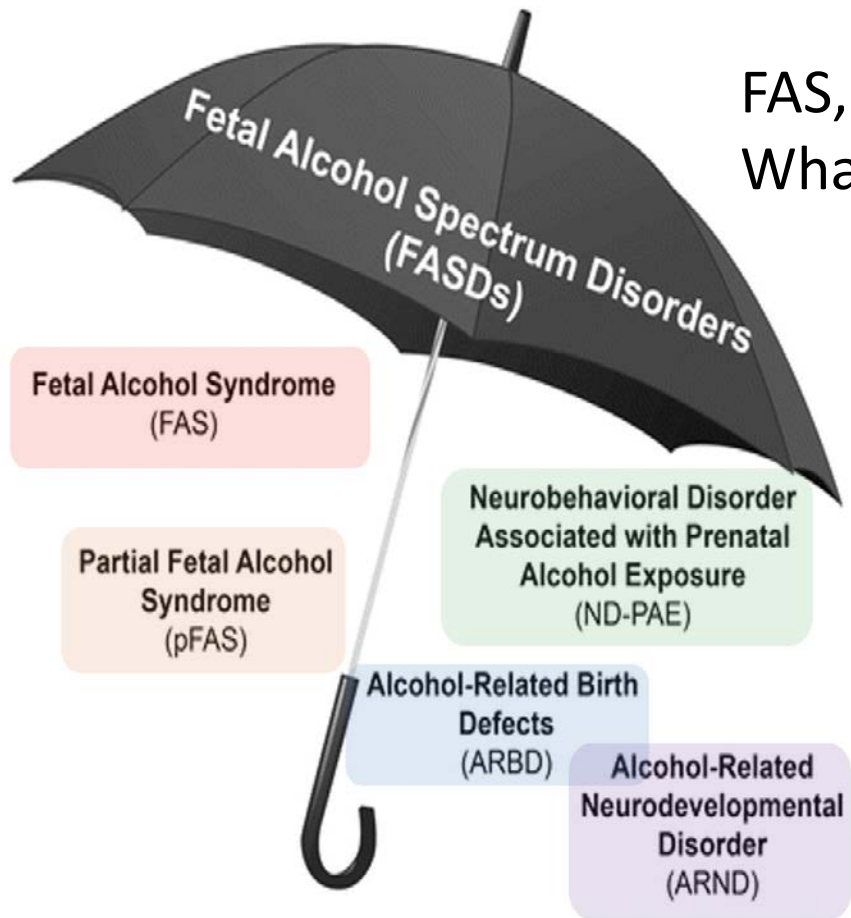
- Memory, attention, and executive function needs become more obvious
- Math, reading comprehension, and written expression can be hard (especially multi-step tasks)
- Social vulnerability: gullibility, misreading peers, trouble with cause-and-effect

Adolescence (12-18 years)

Common signs:

- Poor impulse control and decision-making
- Difficulty understanding consequences
- Emotional intensity or shutdowns
 - Behavior may be misinterpreted as defiance.
- Mental health concerns (anxiety, depression)
- Trouble with friendships and peer pressure
- Social vulnerability

Why all the letters?



FAS, pFAS, ARND, ND-PAE...
What Do They Mean?

The Two Main Diagnostic Frameworks

- ▶ In the U.S., two main diagnostic approaches are most commonly used:
 - The **Washington State (4-Digit Diagnostic Code)**
 - The **IOM / Hoyme-based criteria**, which informs many clinical programs

Washington State / 4-Digit Diagnostic Code



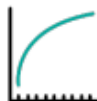



- Developed to increase **objectivity and consistency**.
- Uses four ranked domains:
 - **Growth deficiency**
 - **Facial features**
 - **Brain structure or function**
 - **Prenatal alcohol exposure**
- Each domain is rated on a **4-point scale**, resulting in a numeric code.
- Outcomes may include terms like:
 - FAS
 - Partial FAS
 - Static encephalopathy (alcohol-exposed)
 - Neurobehavioral disorder (alcohol-exposed)
- ▶ **Key features:**
 - Very **structured and conservative**
 - Requires **clear evidence of brain impairment**
 - Often used in **specialty clinics and research settings**

IOM / Hoyme-Based Framework

- Based on Institute of Medicine criteria, updated by Hoyme and colleagues.
- Focuses on **clinical pattern recognition** across:
 - Facial features
 - Growth
 - Neurodevelopmental functioning
 - Prenatal alcohol exposure (confirmed when possible)
- Produces diagnoses such as:
 - FAS
 - Partial FAS
 - ARND (Alcohol-Related Neurodevelopmental Disorder)
- ▶ **Key features:**
 - More **clinically flexible**
 - Allows diagnosis when real-world impairment is evident, even if testing is uneven
 - Commonly used in **pediatric and developmental clinics**

How Do the Evaluations and Outcomes Differ?

Spectrum of FASD

		A	B	C	D	E	F
FAS	FAS with confirmed exposure	✓	✓	✓	✓		
	FAS without confirmed exposure		✓	✓	✓		
PFAS	Partial FAS with confirmed exposure	✓	✓		OR		
	Partial FAS without confirmed exposure		✓	✓	OR		
ARBD	Alcohol-related birth defects (ARBD)	✓					✓
ARND	Alcohol-related neurodevelopmental disorder (ARND)	✓			OR		
ND-PAE	Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)	✓			As Defined in DSM-5		
		A Confirmed Exposure to Alcohol	B Facial Anomalies	C Growth Retardation	D CNS Abnormalities	E Cognitive Abnormalities	F Birth Defects
							

Adapted from *Neuroscience and Biobehavioral Reviews* (2007); 31:230-238
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Talking about a diagnosis

- Use simple, kind language; start early and revisit over time
- Reframe: “Your brain learns differently—so we use different tools.”
- Validate feelings; emphasize strengths; avoid blaming birth parents
- Give hope: with supports, kids can thrive



After Diagnosis: Age-Specific Supports

- Young children:
 - Early intervention, speech/OT
- Teens:
 - School accommodations, mental health care
- Young adults:
 - Life skills coaching, vocational support

What to do if diagnosis is not made...

- ▶ Even without a formal FASD diagnosis, **documented neurodevelopmental impairment related to prenatal alcohol exposure is meaningful.**

Common contributors to delayed diagnosis:

- ▶ Sometimes more information is needed following diagnostic visit and multiple visits are indicated
- ▶ A 'preliminary diagnosis' may be made during the larger evaluation timeline
- ▶ Recommend operating as if *this is FASD*- in terms of parenting, transition planning, advocacy in school

Strengths Across All Ages

- Creativity and problem-solving
- Strong visual or hands-on learning
- Kindness and empathy
- Persistence when supported

Diagnosis helps match supports to strengths.

Questions and Discussion

- ▶ Thank you for being here! Your advocacy makes a difference.



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