



FASD United

THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NOFAS

**Supporting Families
& Individuals
Impacted by FASD
"Guerrilla Support"**

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Today's Conversation

- Describe FASD and the effects of PAE
- Discuss approaches to supporting people with FASD
- Identify ways of supporting families impacted by PAE

FASD United
the National Hub for FASD



Vision

An FASD-informed world where people living with FASD and prenatal substance exposure are recognized and supported.

Mission

FASD United empowers people living with FASD and prenatal substance exposure to educate systems of care and the public, enact policies, and unite communities everywhere.





Programs Offered



Justice Center



Affiliate Network



Policy & Training Center



Family Navigator



Recovering Mothers Anonymous



Media and Communications Hub



Resource Directory

What is FASD?

Fetal Alcohol Spectrum Disorders (FASDs)

- Group of conditions that can occur in a person who was exposed to alcohol before birth

A person with an FASD might have:

Behavioral issues

- Hyperactive behavior, impulsivity, dysmaturity, difficulty with attention, poor reasoning and judgment skills

Learning challenges

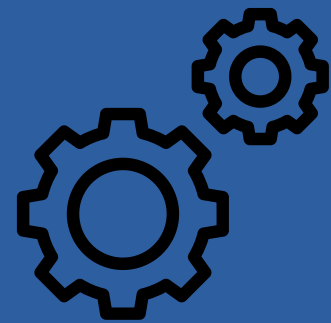
- Poor memory, learning disabilities, speech and language delays, intellectual disability

Physical problems

- Low body weight, problems with the heart, kidneys, or bones, poor coordination, vision or hearing problems

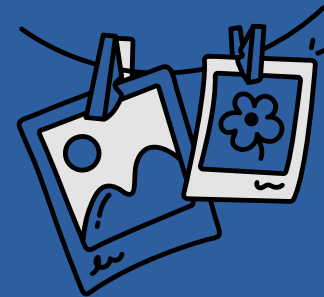


Impact on Cognitive Abilities



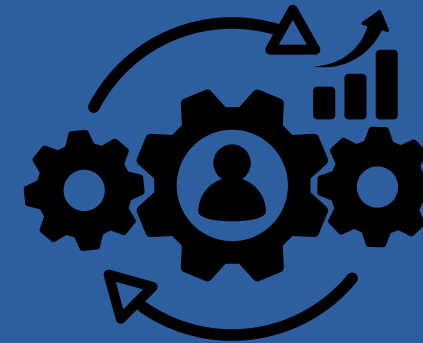
Executive Function Deficits

Individuals with PAE often struggle with planning, organizing, and problem-solving due to deficits in executive functioning (Mattson et al., 2019).



Memory Impairments

Memory, particularly short-term memory, is often affected, making it difficult to retain and recall information (Mattson et al., 2019).



Slower Processing Speed

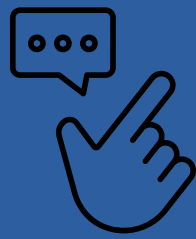
Affected individuals may need more time to process information and respond, which can be challenging in fast-paced environments like school (Kodituwakku, 2007).



Learning Disabilities

Many individuals face specific learning disabilities, especially in areas like math and language, which can further impact academic success (Kodituwakku, 2007).

Impact on Social Abilities



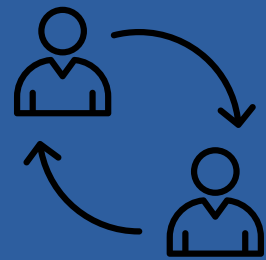
Difficulty with Social Cues

Individuals with PAE often struggle to interpret social cues like body language and facial expressions, which can lead to misunderstandings in social interactions (Mattson et al., 2019).



Immature Social Behavior

They may exhibit behaviors that are more typical of younger children, such as being overly trusting or having difficulty maintaining appropriate boundaries with others (Wartnik et al., 2022).



Challenges with Peer Relationships

These social deficits can lead to isolation, peer rejection, or even bullying, which further compounds their social challenges (Mattson et al., 2019).



Example

"A child with PAE might be overly friendly with strangers, not understanding the risks involved, or they might struggle to make and keep friends due to social misunderstandings."

Impact on Emotional Abilities

Emotional Dysregulation

Many individuals with PAE experience mood swings, irritability, and difficulty managing frustration or anger (Pei et al., 2011).

Higher Risk for Anxiety and Depression

Emotional struggles, combined with social difficulties, often lead to anxiety and depression. These mental health issues are more prevalent in individuals affected by PAE (Streissguth & O'Malley, 2000).

Poor Impulse Control

These social deficits can lead to isolation, peer rejection, or even bullying, which further compounds their social challenges (Mattson et al., 2019).

Example

"Imagine trying to control intense emotions but not having the tools to do so, resulting in meltdowns that seem out of proportion to the triggering event. This is common in individuals with PAE."





**What do we mean
by "spectrum"
disorder?**

Using labels to be more inclusive



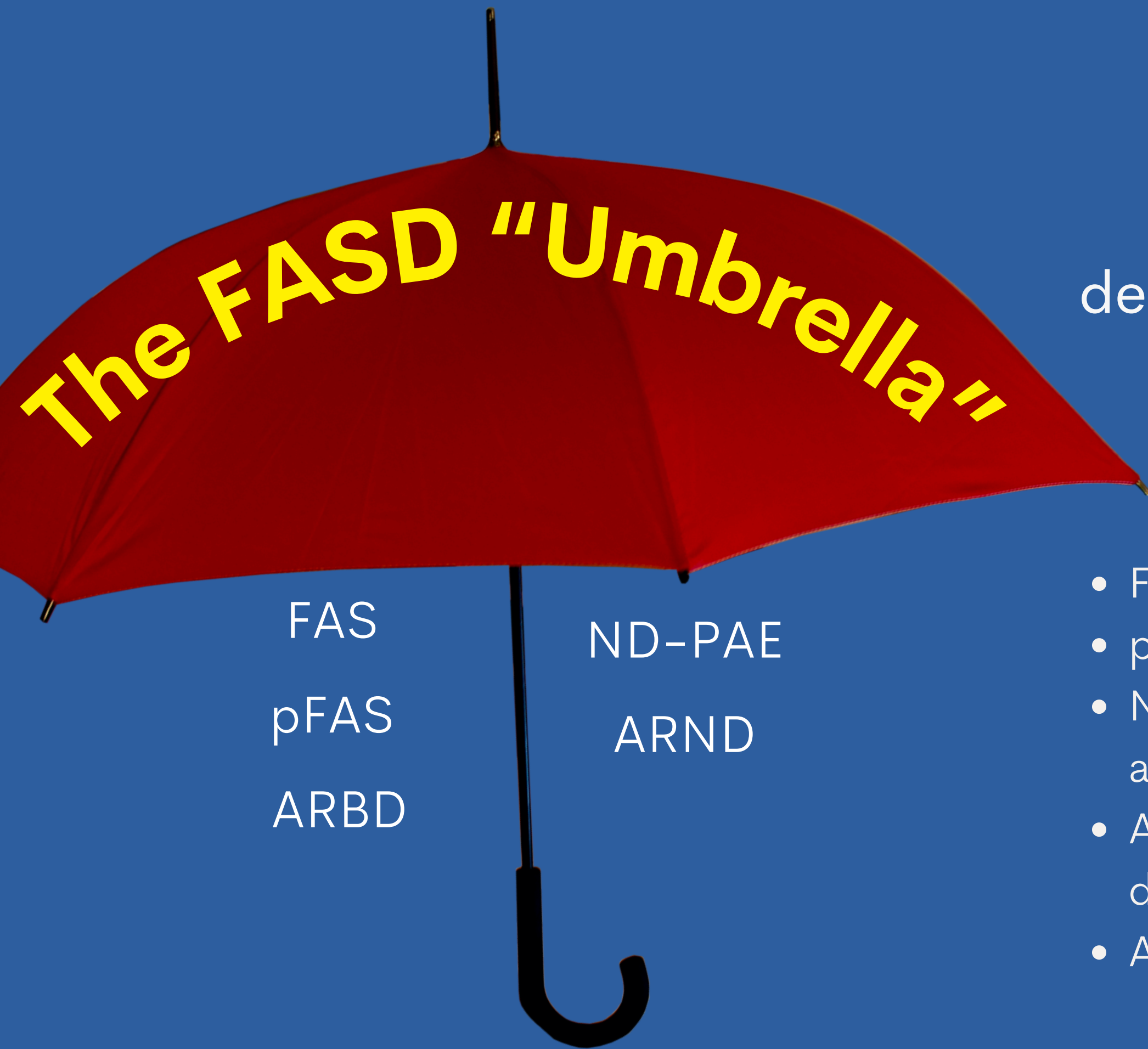
FASD – the “Umbrella Term” to describe the category of diagnoses that result from prenatal alcohol exposure (PAE)



PAE – Useful in order to include people who do not have access to FASD assessment or diagnosis.



PSE – prenatal substance exposure is important to include in conversations about FASD because co-exposure is so common.

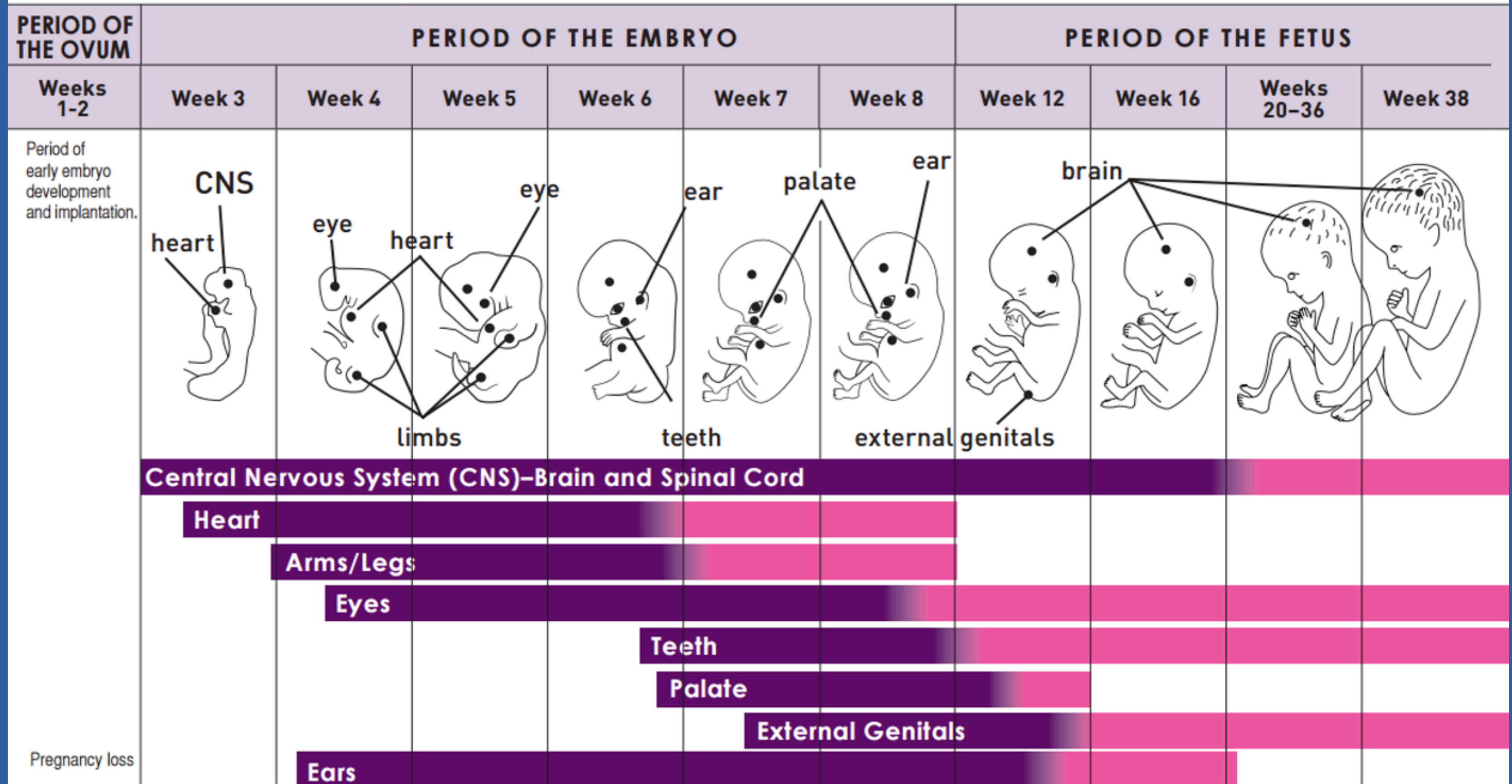


The most common way people describe the different diagnoses on the FASD spectrum.

- FAS – Fetal alcohol syndrome
- pFAS – Partial fetal alcohol syndrome
- ND-PAE – Neurobehavioral disorders associated with prenatal alcohol exposure
- ARND – Alcohol-related neurodevelopmental disorders
- ARBD – Alcohol-related birth defects

FETAL DEVELOPMENT CHART

This chart shows vulnerability of the fetus to defects throughout 38 weeks of pregnancy.*
 • = Most common site of birth defects



Period of development when major defects in bodily structure can occur.
 Period of development when major functional defects and minor structural defects can occur.

Adapted from Moore, 1993 and the National Organization on Fetal Alcohol Syndrome (NOFAS) 2009
 *This fetal chart shows the 38 weeks of pregnancy. Since it is difficult to know exactly when conception occurs, health care providers calculate a woman's due date 40 weeks from the start of her last menstrual cycle.



Factors Related to PAE

Pregnancy Health Factors:

- **Genetics**
- **Nutrition & Metabolism**
- **Overall health**
- **Maternal Age**
- **Quantity/Frequency/Timing of exposure**

Social Drivers of Health:

- **Access to/quality of healthcare & education**
- **Access to nutritious foods**
- **Social and community context**
- **Economic stability**
- **Neighborhood & built environment**

FASD awareness doesn't match its prevalence.

Rate of alcohol use during pregnancy



1 in 7

Rate of co-exposure of other substances with alcohol use during pregnancy.



40%

Rate of drug use during pregnancy



1 in 10

Rate of FASD in US school-aged children



1 in 20



FASD is Underdiagnosed and Misdiagnosed

Although FASD is common, it remains under-diagnosed, in part due to:

- Social stigma
- Complexity of diagnosis
- Reliance on facial features
- Overlap with alternative diagnoses, such as ADHD and autism

Many individuals with FASD have subtle neurodevelopmental effects that do not prompt clinical attention.



Co-occurring Behavioral and Mental Health Conditions

- Anxiety
- Depression
- Attention-Deficit/Hyperactivity Disorder (ADHD)
- Bipolar Disorders
- Substance Use Disorders
- Oppositional Defiance Disorder
- Autism Spectrum Disorder

94% of individuals with FASD have a co-occurring mental health condition

Source: Center for Disease Control and Prevention

Source: Weyrauch, D., Schwartz, M., Hart, B., Klug, M. G., & Burd, L. (2017). Comorbid Mental Disorders in Fetal Alcohol Spectrum Disorders: A Systematic Review. Journal of developmental and behavioral pediatrics : JDBP, 38(4), 283–291. <https://doi.org/10.1097/DBP.0000000000000440>



Adverse Life Experiences

People with FASD experience more adverse life experiences than those without. This includes:

- Disrupted School Experience
- Trouble with the Law
- Inappropriate Sexual Behavior
- Alcohol or Drug Dependence
- Dependent Living and Problems with Employment

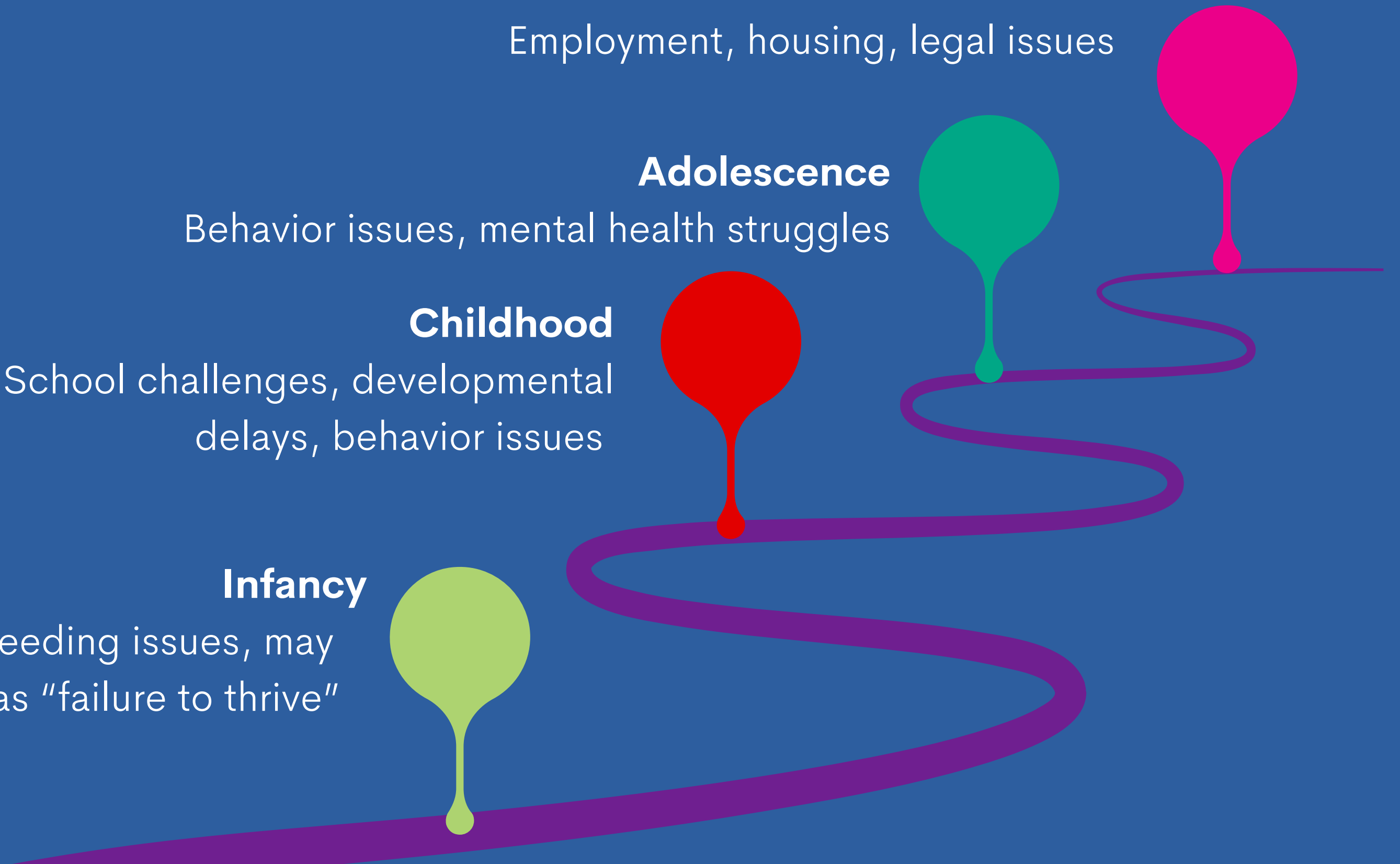
FASD Through the Lifespan

Infancy
Birth defects, feeding issues, may be diagnosed as "failure to thrive"

Childhood
School challenges, developmental delays, behavior issues

Adolescence
Behavior issues, mental health struggles

Adulthood
Employment, housing, legal issues





Early Identification sets people up for success

Identifying FASD, especially before the age of 6 years of age, helps to reduce risks later on by:

- Empowering parents with a sense of understanding
- Reducing the risk of maltreatment toward the child if behaviors are misunderstood
- Increasing opportunities for counseling
- Identifying appropriate specialty care
- Finding peer and community programs
- Making it easier to discuss accommodations or considerations in education

Supporting People with FASD

People with FASD can thrive and succeed when systems are FASD-informed and FASD is given a seat at the table.

Recognition and accommodation of people with FASD and PAE is crucial. Modifications and shifts in practices and policies will support the complex needs of people with FASD.

Key systems:

- Child Welfare
- Education
- Justice System
- Health



Strengths-Based Approach

Research shows that parents and caregivers of children with FASD report wide-ranging strengths and positive influence.

A person-centered, strengths-based approach is effective for people with FASD.

Important elements include:

- Reduction of stigma
- Improved measurement of strengths and thriving
- Utilization of strengths-based frameworks
- Increased efforts to reach underserved populations

Strengths-Based Approach



A strength-based approach focuses on abilities and capacities and the value of an individual's experiences and perspectives, rather than deficits, or things that are lacking.

Common strengths

- Loving, form close family bonds
- Social, want to be liked by others
- Trusting
- Warm, full of positive energy
- Creative thinkers

General Strategies

- Use concrete language; avoid idioms and metaphors
- Allow extra time to process information
- Check for understanding
- Create a calming environment
- Practice regulating techniques
- Build a network of support
- Model healthy boundaries



Talking about education? Give FASD a seat at the table.

A prevalence of 1 in 20 means that there is likely at least **1 student with FASD in every classroom.**

- Learning and behavioral problems
- Developmental disabilities
- Speech-language deficits
- Co-occurring conditions

Source: Centers for Disease Control and Prevention. (2023, October 5). FASDs: Information for educators.

Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/fasd/educators.html>

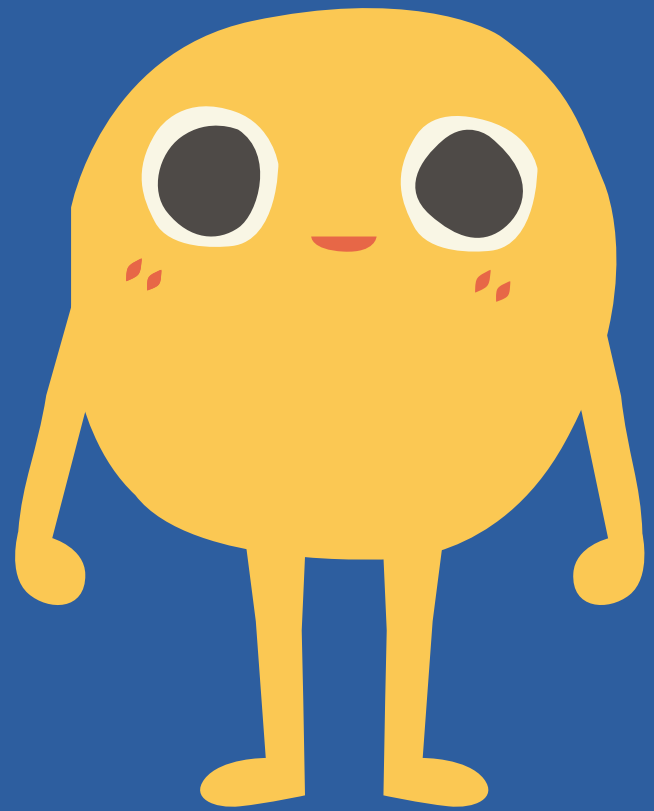
Popova S, Lange S, Burd L, Nam S, Rehm J. Special Education of Children with Fetal Alcohol Spectrum Disorder. Exceptionality. 2016 Jul 2; 24(3):165-175. doi: 10.1080/09362835.2015.1064415. Epub 2016 Mar 23. PMID: 27695197; PMCID: PMC5009761.

Checking for **Comprehension**

The florgle ramooted through the gralley as Lorp bahooed. "There's no time for bahooing," the florgle memered. So, they ramooted until lore eepen.

1. What was the florgle doing?
2. What did they did they not have time for?
3. When did they ramoot until?

Checking for **Comprehension**



The florgle ramooted through the gralley as Lorp bahooed. "There's no time for bahooing," the florgle memered. So, they ramooted until lore eepen.

FASD is often misunderstood in the classroom

Students with FASD can be seen as being oppositional and resistant, when they may not understand what they were asked, or have been reprimanded for trying to understand in the past.



Good to Know:

Students with FASD may process language slower and need time after being asked a question before they can respond. This is misunderstood as "ignoring" or defiance.



Helpful Tip:

Students with FASD require flexible strategies rather than strict or zero-tolerance policies and procedures.



Reducing stress and **encouraging** comfortable conversation

- **Do not enforce eye contact.** If it is safe to do so, be in sitting position when talking to someone with FASD. Try to stand parallel rather than face-to-face, which can feel confrontational.
- **Do not repeat their name in conversation.** Bodies respond urgently when it hears it's name, which can heighten someone's stress response.
- **Repeat, repeat, repeat.**
- **Reword, reword, reword.**
- **Make an effort to understand and/or establish the person's support network.** People with FASD may need outside help remembering appointments or following up on tasks.
- **Check for comprehension...**

IEP

- Must fit an IDEA disability
- Provides specially-designed instruction, not just accommodations
- Provides progress monitoring and goals & annual review/revision
- Procedures or parent involvement and accountability
- Departmental overseeing (IDEA & Dept of Education)
- ALL public schools must comply

504 Plan

- Any disability
- Focus on how the child learns
- Accountability & parents involvement limited
- No goals, progress monitoring,
- Not a SPED program
- Overseen by OCR and HSS
- School does not need to involve parent in in development or revisions
- Applies to any school receiving public funds

- Free/no cost
- Should meet child's needs
- Requires confirmation of disability with evaluations (though requirements differ)



What can I do?

- Keep learning about FASD
- Advocate for FASD-informed systems
 - Encourage organizations, schools, and agencies to get trained on FASD.
 - Educate people in your community on FASD.
- Connect with FASD United and use our Family Navigators!



Resources at FASD United



Family Navigator



Resource Directory

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 1000 inquiries in 2024, offering support to more than **800** individuals.



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



Family Navigators

- A FASD Family Navigator can be reached from 9am–10pm Eastern Time, Monday through Friday via phone at 202-785-4585 or by completing an online form: fasdunited.org/family-navigator/
- Available for people with FASD, caregivers and family members, professionals, pregnant people
- **This service is free and does not require a referral.**



Reach Out to FASD United

1054 31st Street NW #204 Washington, DC 20007

[FASDunited.org](https://fasdunited.org)

[202-785-4585](tel:202-785-4585)

<https://fasdunited.org/family-navigator/>

