



PRoF Alliance

What You Need to Know
about Fetal Alcohol
Spectrum Disorders (FASD)



PROF Alliance

Our mission is to prevent fetal alcohol spectrum disorders and to support all impacted throughout Minnesota and beyond.

Our vision is a world in which alcohol is not consumed during pregnancy and people living with fetal alcohol spectrum disorders are identified, supported and valued.

* Disclosure *

Proof Alliance acknowledges that not every person who can become pregnant identifies as a woman. We try to use gender-neutral language as often as possible, much of the current research available currently refers only to “women” when discussing the ability to become pregnant. When citing this research, we refer to the language used in the study. In these cases, “woman” refers to someone who was assigned female at birth.

Learning Objectives

- Discover what are fetal alcohol spectrum disorders (FASD)
- Explore common myths & discuss risk factors
- Learn the impacts prenatal exposure to alcohol may have on brain
- Discuss strategies to support children with an FASD effectively

Why Care?

It's about the kids!

Understanding the complexities of FASD will help caregivers be better equipped to meet children's needs.



Prevalence Study



Research shows as many as 1 in 20 children in the U.S. have an FASD.

What is FASD?

Fetal Alcohol Spectrum Disorder

- A group of birth defects that is the result of prenatal alcohol exposure
 - Wide range of symptoms including physical, mental, behavioral, & learning disabilities
 - Prenatal alcohol exposure affects each person differently & organic brain injury causes inconsistency
 - Permanent disability, lasts a lifetime
 - All people with FASD can be successful
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FASD is Not a Diagnosis

FAS fetal alcohol syndrome

PFAS partial fetal alcohol syndrome

ARND alcohol related neurodevelopmental disorder

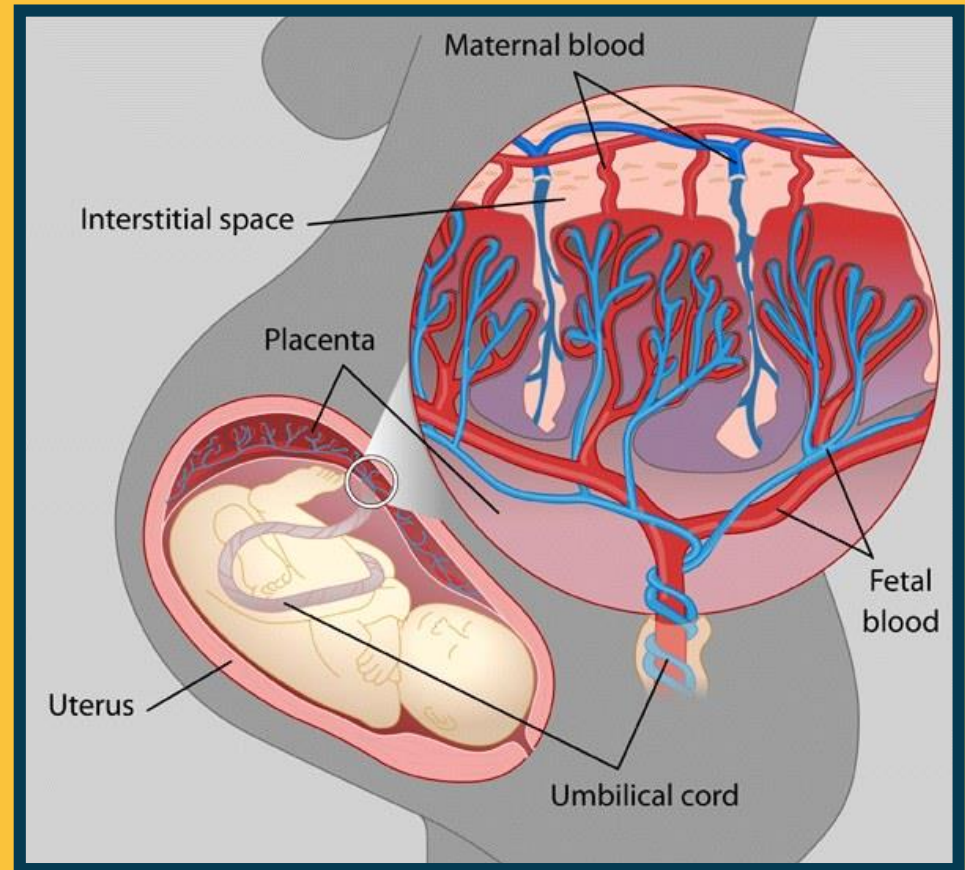
ARBD alcohol related birth defects

ND-PAE neurobehavioral disorder associated with prenatal alcohol exposure (mental health diagnosis)

FAE fetal alcohol effects (outdated term)

Effects of Alcohol during Pregnancy

- Pregnant person drinks alcohol
- Alcohol enters the placenta & passes from maternal blood supply to fetal blood supply
- Fetus excretes alcohol into the amniotic fluid
- Fetus then swallows amniotic fluid
- Alcohol is perpetually reabsorbed by the fetus





Factors of Severity

Factors that impact fetal vulnerability:

- Dosage/BAC
- Resiliency of the fetus
- Mother's health, age, etc.
- Genetics
- Other substance exposure
- Timing of the exposure

Remember:

- PAE does not always result in an FASD
- FASD is not generational

True or False?

Most people with an FASD have distinct facial impairments caused by prenatal alcohol exposure.

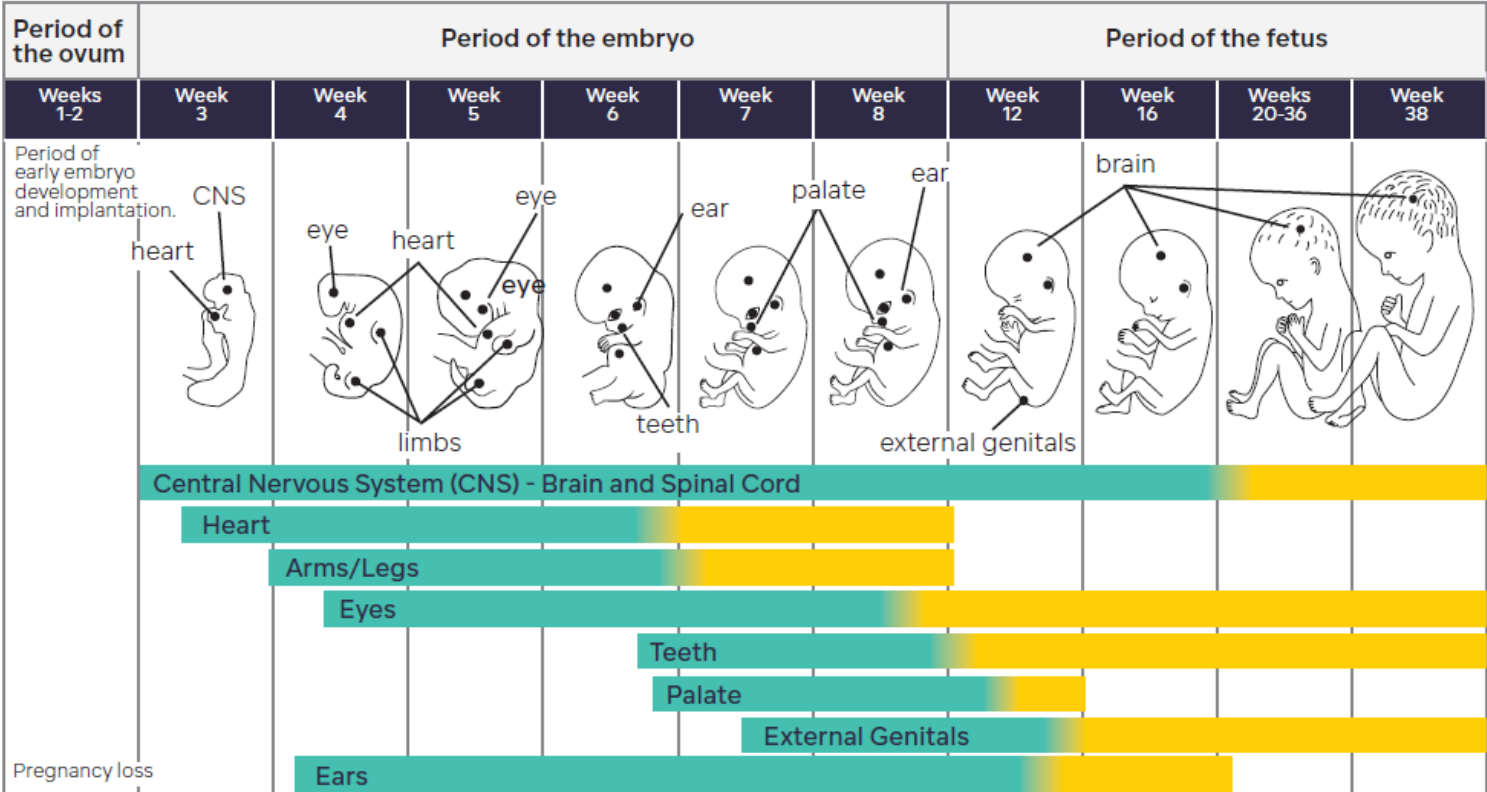
FALSE!



Fetus Developmental Timeline

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, the National Organization on Fetal Alcohol Syndrome (NOFAS), 2009, and the Centers for Disease Control (CDC), 2018.¹
 *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 their last menstrual cycle.

Ending the Stigma








Why do people drink alcohol during pregnancy?



FASD is a Complex Public Health Issue

- Unplanned pregnancy may lead to drinking without the knowledge they are pregnant
- Substance use disorders
- Form of self-medicating or coping mechanism due to external stressors or mental illness
- Binge drinking is generally socially-accepted
- Mixed messages from family, friends, media, etc.
- Doctors implicitly give permission by not discussing alcohol use with their patients or downplaying the risks
- Public still misunderstands risks from drinking and does not recognize the high prevalence of FASD

Developmental Skills: Case Example

Physical maturity		18 years old
Comprehension		6 years
Emotional maturity		6 years
Social Skills		7 years
Concept of money, time		8 years
Reading level		16 years
Expressive language		20 years

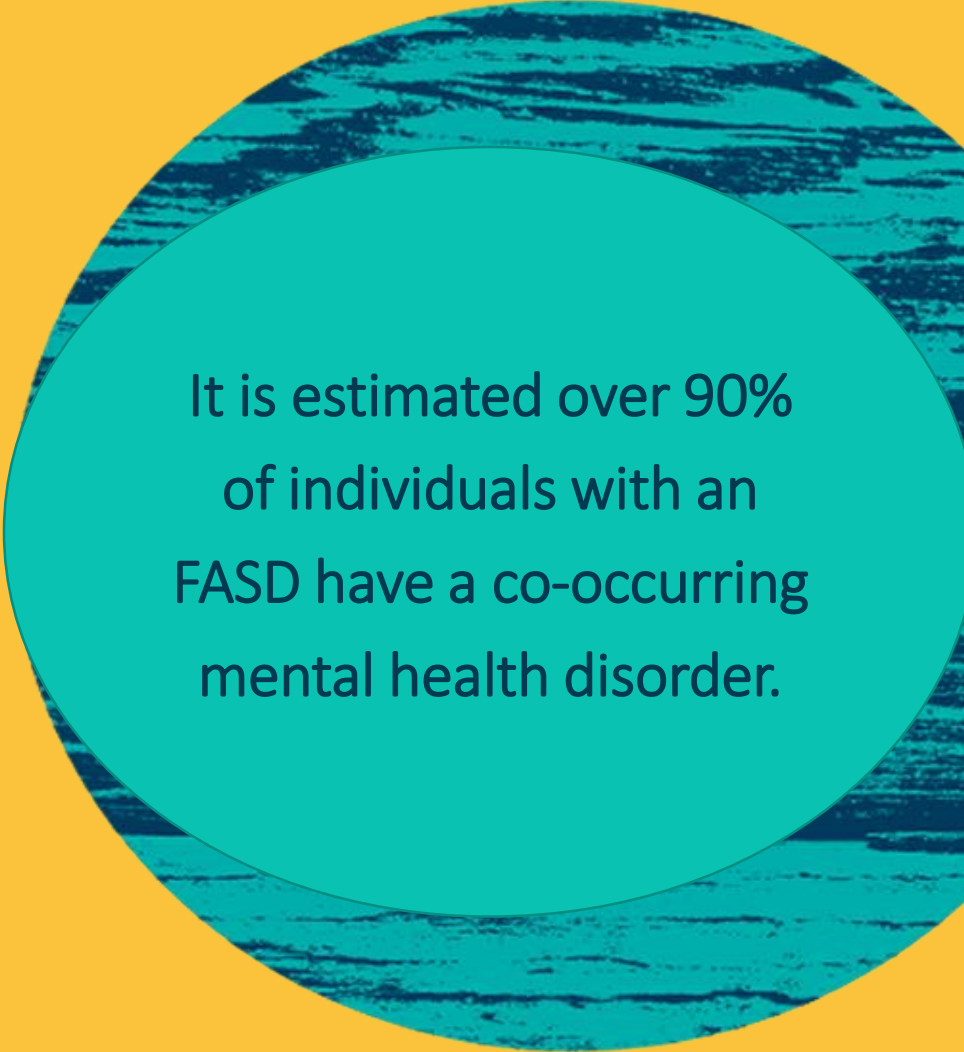
Common Neurobehavioral Symptoms

It's important to remember that FASD is a spectrum disorder. This is only a small sampling of the characteristics that are common with FASD.

- Difficulty with abstract concepts
- Poor social skills/lack of boundaries
- Slower information processing
- Learning difficulties (commonly but not limited to math)
- Anger or frustration often & may take longer to self regulate
- Extreme under or over-sensitivity to sensory input
- Difficulty following directions or connecting steps
- Poor impulse control, problem solving skills, memory and/or attention

What Else Can FASD Look Like?

- Attention deficit disorder
- Autism
- Reactive attachment disorder
- Sensory processing disorder
- Bipolar disorder
- Depression
- Trauma
- and more...



It is estimated over 90%
of individuals with an
FASD have a co-occurring
mental health disorder.

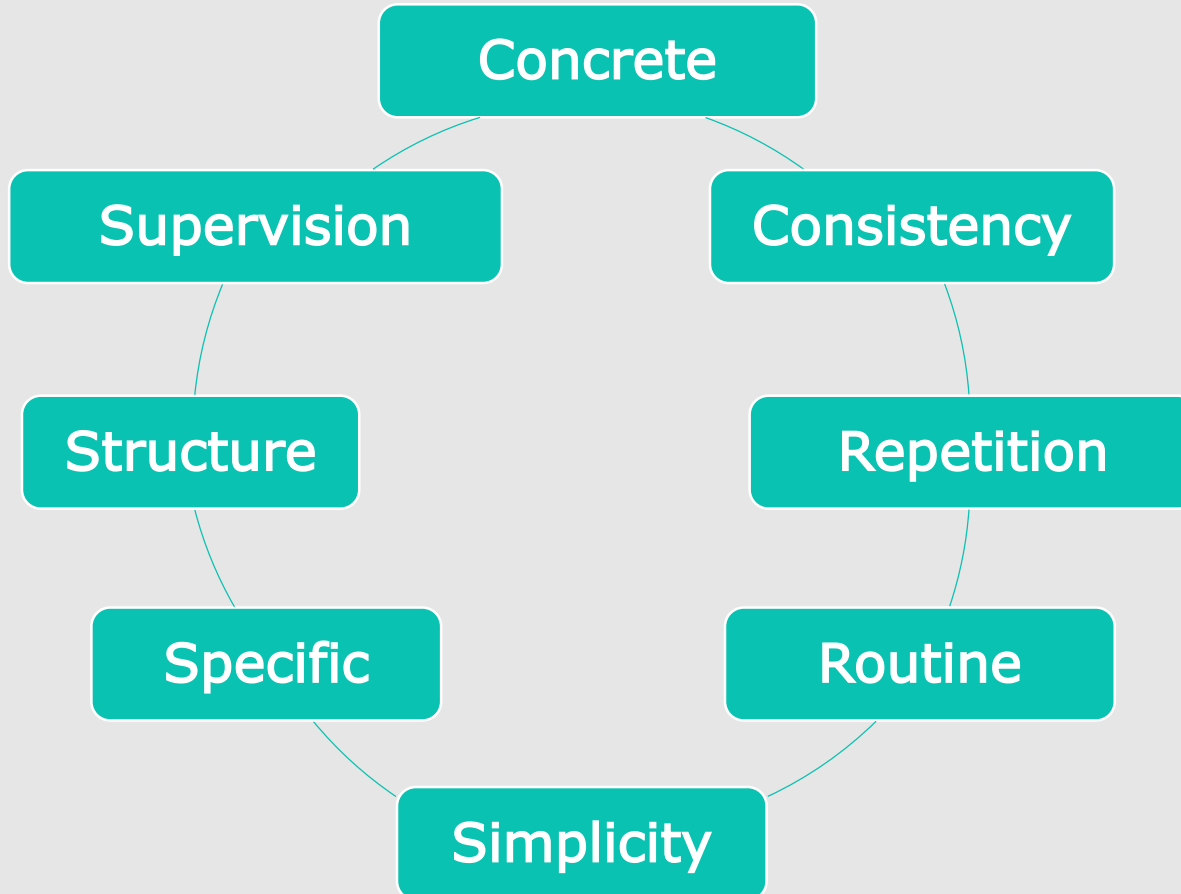
Recognize Strengths

- **Friendly, likable:** May be outgoing & sociable & have little anxiety about strangers
 - **Verbal, chatty:** May be very socially interested (but not necessarily socially skilled)
 - **Helpful, hard-working:** If you ask, they will do it. They can be very good workers with the right job & training
 - **Determined, resilient:** They don't hold grudges & will come back if rejected. Every day is a new day!
 - **Want to be liked:** They will do whatever they can to have friends
-

Paradigm Shift

Instead of:	To understanding as:
Having behaviors	Experiencing symptoms
Won't/defiant	Can't
Refuses to sit still	Under/Over-stimulated
Resisting/doesn't care	Doesn't get it
Lying	Memory deficits, confabulation
Doesn't try	Tired of failing

The Eight Essentials for Success



"Our children living with an FASD may need an "external brain". Someone in their life who can help them in the areas they struggle with."

- Dr. Sterling Clarren

From 8 Magic Keys - developed by Deb Evensen & Jan Lutke 1997



Strategies: Environment

- Adapt the environment & ensure that the physical environment is welcoming
 - Set them up to succeed
 - Decrease distractions (sight, sound, smells)
 - Create calming space
 - Use concrete approaches to help organize and concentrate
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Strategies: Communication

- Simple, short directives
- Manageable tasks
- Concrete & specific
- Give alternative options to what is not allowed
- Be consistent with rules & try to limit number
- Use visual reminders

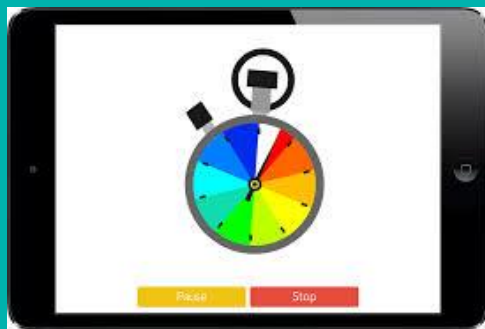
Strategies: Communication

- Check for understanding
- Role playing
- Demonstrate instructions multiple times
- Allow extra time for processing & responding
- Use positive language
- Repeat, repeat, repeat
- Consistency in language

Strategies: Transition

- Proactive transition plans are important & can help avoid meltdowns
- Changes to routine should be communicated as soon as possible (if applicable)
- Visual timers may be helpful
- Redirect when person is having difficulty
 - Give them a task
 - Teach specific non-verbal cues
 - Create natural break in routine & have a discussion
 - Ask simple questions that prompt self-correction. Instead of “sit down for dinner” say, “Can you pick out where you want to sit for dinner?”

Strategies: Transition



CHANGE ALERT

Instead of	We Will Have
	

AUTISM CLASSROOM
Tools & Resources

Strategies: Regulation

- Be proactive versus reactive
- Co-regulate until they can self-regulate
- Sensory breaks & fidgets
- Actively listen
- Planned breaks
- Structure can provide a sense of calm



Strategies: Structure



Sun	Mon	Tues	Wed	Thurs	Fri	Sat
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

Test Today
 Ride Bus Home
 Track Meet



Proof Alliance Resources

- Family engagement & support
- Youth & young adult program
- Diagnostic clinic
- Public awareness & prevention
- Public policy work
- Professional education
- Proof Alliance website resources





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