



PR%F Alliance

What You Need to Know About
Fetal Alcohol Spectrum Disorders:
Foster Care Providers &
Professionals



PR%F Alliance

Our mission is to eliminate disability caused by alcohol consumption during pregnancy & to improve the quality of life for those living with fetal alcohol spectrum disorders.

Our vision is a world in which women do not drink alcohol during pregnancy & people living with fetal alcohol spectrum disorders are identified, supported, & valued.

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 general strategies to support children with an FASD effectively
- Learn about Proof Alliance resources

Why Care?

- Children who are available for adoption are 10 – 15 times more likely to have an FASD than general population.
- It's about the kids!
 - Understanding the complexities of FASD will help caregivers be better equipped to meet children's needs



True or False?

FASD is the leading cause of intellectual disabilities in the US.



Prevalence Study



© Proof Alliance 2018

True or False?

FASD is commonly under and misdiagnosed.



What Else Can FASD Look Like?

- Attention deficit disorder
- Autism
- Reactive attachment disorder
- Sensory processing disorder
- Bipolar disorder
- Depression
- Trauma
- Institutionalization
- Poverty
- & more...

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



What is FASD?

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

FASD is Not a Diagnosis

FAS	fetal alcohol syndrome
PFAS	partial fetal alcohol syndrome
ARND	alcohol related neurodevelopmental disorder
ARBD	alcohol-related birth defects
FAE	fetal alcohol effects (outdated term)




Factors of Severity

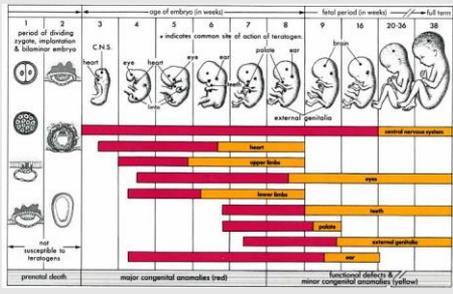
Factors that affect each pregnancy:

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

Prenatal alcohol exposure:

- Not always going to result in an FASD
- FASD is not generational
- Manifestations are unique in each individual

Fetus Developmental Timeline



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FASD Impacts Us All

What demographic of women are most likely to drink alcohol during pregnancy?

- A. College Educated
- B. High School Graduate
- C. High School Drop Outs



FASD is a Complex Public Health Issue

- FASD can occur when a mother does not know of a pregnancy
- Substance use disorders can be highly challenging conditions to overcome
- FASD can occur from binge drinking, which is generally highly socially-accepted
- Doctors implicitly give permission by not discussing alcohol use with their patients or downplaying the risks
- Public still misunderstands risks from drinking & does not recognize the high prevalence of FASD



Alcohol vs. Other Substances

According to IOM, which of the following substances cause the most serious neurobehavioral effects on a developing fetus?

- A. Opioids/Heroin
- B. Crack/Cocaine
- C. Methamphetamines
- D. Marijuana
- E. Alcohol



Impact of Prenatal Alcohol Exposure

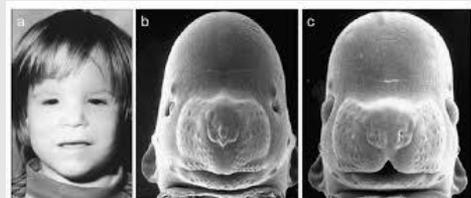
	Alcohol	Tobacco	Opioids	Meth	Cocaine	Marijuana	PCP
Growth Deficiency	X	X	X	X	X	X	X
Behavioral Problems	X	X	X	X	X	X	X
Cognitive Problems	X	X	X	X		X	X
Motor Deficits	X	X		X			X
Developmental Delays	X	X			X		
Facial Anomalies	X	X					X
Physical Defects	X	X		X	X		X

True or False?

The most effective method of diagnosing FASD is looking for the facial features.



Facial & Other Physical Features of FAS



European Journal of Medical Genetics; Volume 60, Issue 1, January 2017, Pages 55-64

The most serious characteristics of FASD are most commonly invisible symptoms due to brain injury.

Impact of Prenatal Alcohol Exposure

Behaviors that result from the effects of FASD can be challenging & try the patience of the most experienced, dedicated professionals & caregivers.

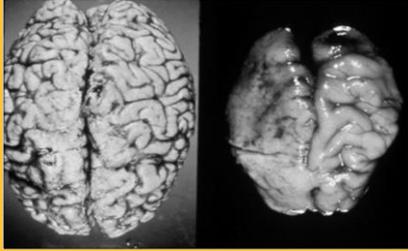


Photo courtesy of Sterling Clarren, MD

Common Symptoms

- Low birth weight, failure to thrive, feeding difficulties
- Sleeping difficulties
- Poor social skills/lack of boundaries
- Slower information processing
- Learning difficulties (commonly but not limited to math)
- Angry or frustrated often & may take longer to calm
- Extreme under or over-sensitivity to sensory input
- Difficulty following directions or connecting steps

Developmental Skills Timeline

Skill	Expected Developmental Age Equivalent
Expressive language	-----→ 20 years.
Comprehension	-----→ 6 years.
Money, Time Concepts	-----→ 8 years
Emotional Maturity	-----→ 6 years
Physical Maturity	-----→ 18 years
Reading Ability	-----→ 16 years
Social Skills	-----→ 7 years
Living Skills	-----→ 11 years

(D. Malbin) Research of Streissguth, Clarren et al.

Common Symptoms

- Poor judgment & impulsive
- Easily influenced by others
- Difficulty generalizing knowledge
- Difficulty understanding abstract concepts
- Difficulty understanding cause-&-effect relationships
- May struggle with transitions
- May be prone to confabulation



Colton Harris-Moore AKA the Barefoot Bandit smiles after his 7-year sentencing

Screening

- Facial features & growth changes in adolescence make it harder to recognize FAS
- Early diagnosis with proper intervention may decrease the appearance of & diminish secondary disabilities
- The best time to identify characteristics begins at around ages 3 to 4 (until about ages 12 to 13)

PAE Confirmation?

- Look for the characteristics and risk factors
- The amount of information available varies from placement to placement
- May have information directly from birth mother about alcohol use during pregnancy
 - Healthy skepticism can be appropriate
 - In open adoption, more information may be provided over time
- Court records, treatment records, case notes, credible source, reference to ETOH in medical history, etc.

Look for Risk Factors

- Biological family history of substance abuse
- Known drug exposure
- Children in foster &/or adoptive care system
- School difficulties starting at a very young age
- Maternal mental illness
- Siblings with an FASD or a related diagnosis
- Multiple diagnoses & meds don't work
- Regions with exceptional high rates of alcohol consumption or known cases of FASD
- Involvement in criminal justice system &/or substance use at a young age

Screening Saves Lives

Average Life Expectancy With FAS

34

Average Life Expectancy

82

A RECENT RESEARCH STUDY ESTIMATED THAT THE AVERAGE LIFE EXPECTANCY FOR SOMEONE WITH FETAL ALCOHOL SYNDROME IS 34.

J Popul Ther Clin Pharmacol. 2016;23(1):e53-9. Epub 2016 Mar 9.

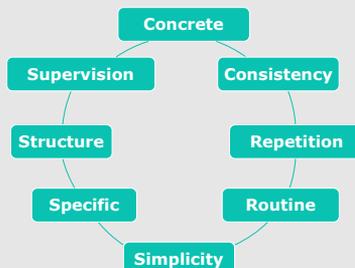
What Can You Do?

- Screening & assessment
- Get informed & trained
- Identify community resources which offer appropriate services for a child with an FASD
- Identify local advocacy groups that can assist with accessing support services
- Read books written by & for parents
- Verify insurance coverage for specialized services such as sensory integration therapy or neuropsychological testing
- **Self-care/respite**

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

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

- "Tough love" approach is not affective
- FASD is consistently inconsistent! A strategy may work one day & not the next
- Meet the child where they're at. Ask yourself: Are they developmentally at a younger age? Actively listen
- Be aware and proactive vs. reactive: communication, environment, regulation abilities, needed accommodations, etc.
- Understand the whole profile; FASD is just one piece

First-Person Perspective

Meet Morgan Fawcett

<https://bit.ly/1gZ47JK>

Proof Alliance Resources

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



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