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

1 in 20
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 co-occurring mental health disorders.

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- FAE  fetal alcohol effects (outdated term)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
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. Methamphetamine  
D. Marijuana  
E. Alcohol

Impact of Prenatal Alcohol Exposure

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<tr>
<th></th>
<th>Alcohol</th>
<th>Tobacco</th>
<th>Opioids</th>
<th>Meth</th>
<th>Cocaine</th>
<th>Marijuana</th>
<th>PCP</th>
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<tr>
<td>Growth Deficiency</td>
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<td>X</td>
<td>X</td>
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<tr>
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</table>

True or False?

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

Facial & Other Physical Features of FASD

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

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<tr>
<th>Skill</th>
<th>Expected Developmental Age Equivalent</th>
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<td>Expressive language</td>
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<tr>
<td>Comprehension</td>
<td>6 years</td>
</tr>
<tr>
<td>Money, Time Concepts</td>
<td>8 years</td>
</tr>
<tr>
<td>Emotional Maturity</td>
<td>6 years</td>
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<tr>
<td>Physical Maturity</td>
<td>18 years</td>
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<tr>
<td>Reading Ability</td>
<td>16 years</td>
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<tr>
<td>Social Skills</td>
<td>7 years</td>
</tr>
<tr>
<td>Living Skills</td>
<td>11 years</td>
</tr>
</tbody>
</table>

D. Malbin (1994)

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

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.

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

Concrete
Supervision
Consistency
Repetition
Structure
Routine
Specific
Simplicity

"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

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
Meet Morgan Fawcett

https://bit.ly/1gZ47JK

First-Person Perspective

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

Proof Alliance

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