The Basics of Fetal Alcohol Spectrum Disorders (FASD)

Shauna Feine, Senior Training Coordinator
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.
True or False?

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

1 in 200
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?

<table>
<thead>
<tr>
<th>A group of birth defects that is the result of prenatal alcohol exposure</th>
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</thead>
<tbody>
<tr>
<td>Wide range of symptoms including physical, mental, behavioral, &amp; learning disabilities</td>
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<tr>
<td>Prenatal alcohol exposure affects each person differently</td>
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<tr>
<td>Organic brain injury causes inconsistency</td>
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<td>Permanent disability, lasts a lifetime</td>
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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

**FAE**  fetal alcohol effects (outdated term)
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 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

Community Poll
What is the Guidance?

“No amount of alcohol consumption can be considered safe during pregnancy.”

- Center for Diseases Control (CDC)
- US Department of Health and Human Services
- World Health Organization (WHO)
- Institute of Medicine
- American Academy of Pediatrics (AAP)
- SAMHSA
- NIH NIAAA
True or False?

The most effective method of diagnosing FASD is looking for the facial features.
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
- Angry or frustrated & may take longer to calm
- Extreme under or over-sensitivity to sensory input
- Difficulty following directions or connecting steps
### Developmental Skills Timeline

<table>
<thead>
<tr>
<th>Skill</th>
<th>Expected Developmental Age Equivalent</th>
</tr>
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<tbody>
<tr>
<td>Expressive language</td>
<td>→ 20 years</td>
</tr>
<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>
</tr>
<tr>
<td>Physical Maturity</td>
<td>→ 18 years</td>
</tr>
<tr>
<td>Reading Ability</td>
<td>→ 16 years</td>
</tr>
<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)

(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
- Learning difficulties (commonly but not limited to math)
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
Structure
Specific
Simplicity
Consistency
Repetition
Routine

"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
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
Proof Alliance Resources

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