Understanding the Challenges of Fetal Alcohol Spectrum Disorders: Strategies for School-Age Care Professionals

MOFAS Mission

Our **mission** is to eliminate disability caused by alcohol consumption during pregnancy and to improve the quality of life for those living with Fetal Alcohol Spectrum Disorders throughout Minnesota.

Our **vision** is a world in which women do not drink alcohol during pregnancy and people living with Fetal Alcohol Spectrum Disorders are identified, supported, and valued.

Learning Objectives

- Basic overview of Fetal Alcohol Spectrum Disorders (FASD)
- Strategies for school-age care professionals working with students on the FASD spectrum

What is FASD?

- FASD is a brain-based disorder with a variety of symptoms and affects individuals to varying degrees.
- FASD impacts individuals across all races, ethnicities, and socio-economic statuses.
- A 2014 prevalence study estimates FASD affect 1 in 50 children in the Midwest (NIAAA, May et al).
**FASD is not a Diagnosis**

FAS  Fetal Alcohol Syndrome  
PFAS Partial Fetal Alcohol Syndrome  
ARND Alcohol Related Neurodevelopmental Disorder  
ARBD Alcohol-Related Birth Defects

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**We have moved beyond “blaming” the mother:**
FASD is a complex public health issue

- Alcoholism is a highly challenging condition to overcome
- FASD can occur when a mother does not know of a pregnancy
- Society condones drinking in women of childbearing age
- FASD can occur from binge drinking, which is generally highly socially-accepted (e.g. college, e.g. bachelorette party)
- Public still misunderstands risks from drinking and does not recognize the high prevalence of FASD
- Doctors implicitly give permission by not discussing alcohol use with their patients or downplaying the risks

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**Factors that affect each pregnancy**

- Risks with Known Prenatal Alcohol Exposure:
  - Not always going to result in an FASD
  - Manifestations are unique in each individual
- Factors that affect each pregnancy:
  - Blood alcohol concentration of the mother
  - Binge drinking is especially harmful
  - Timing of the exposure
  - Resiliency of the fetus
  - Metabolism and diet of the mother

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**Facial Features of Fetal Alcohol Syndrome**


Challenges Identifying FASD

FASD is often referred to as an invisible disability. Can you identify the youth with an FASD?

FASD & the Brain

Autopsy Study

6 week old healthy brain 6 week old with FAS

Rule of Thumb

### Chronological Age Expectations

<table>
<thead>
<tr>
<th>chronological age expectations</th>
<th>Developmental Age with an FASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Typical 10 Year Old</td>
<td>10 Years Going on 6 Years...</td>
</tr>
<tr>
<td>• Reads books without pictures</td>
<td>Beginning to read, with pictures</td>
</tr>
<tr>
<td>• Answers abstract questions</td>
<td>Mirror and echo words, behaviors</td>
</tr>
<tr>
<td>• Knows right from wrong</td>
<td>Supervised play</td>
</tr>
<tr>
<td>• Gets along with the others, solves problems</td>
<td>Learn from modeled problem solving</td>
</tr>
<tr>
<td>• Learns inferentially, academic and social</td>
<td>Developing a sense of fairness</td>
</tr>
</tbody>
</table>

Common Traits Associated with FASD

- Difficulty picking up on social cues
- Impairment in short-term memory and processing speed
- Difficulty understanding and remembering stranger-safety warnings
- Poor insight and judgment (concrete, rigidity, dysmaturity)
- Attention deficits
- Difficulty with abstract concepts (including concepts of time and space)
- Difficulty identifying dangerous people and/or situations
- Easily influenced by others
- Difficulty generalizing knowledge
- Difficulty understanding cause-and-effect relationships
- Sensory processing disorder
Common Strengths of Persons with FASD

- **Friendly, likable**: May be outgoing and sociable and 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 and training.
- **Determined, resilient**: They don’t hold grudges and will come back if rejected. Every day is a new day!
- **Want to be liked**: They will do whatever they can to have friends.
- However, these strengths also may get them into difficulty.

Challenges

- FASD is often an invisible disability.
- FASD is spectrum disorder.
- It results in a consistent pattern of inconsistencies.
- Cognitive functioning (IQ) is not always correlated with adaptive functioning.
- Lack of scientifically validated an evidence based interventions for students with an FASD.

Remember!

"Could someone help me with these? I’m late for math class."

Remember: everyone in the classroom has a story that leads to misbehavior or defiance. 9 times out of 10, the story behind the misbehavior won’t make you angry. It will break your heart.

— Annette Breaux

Paradigm Shift

<table>
<thead>
<tr>
<th>Seeing individual as:</th>
<th>To understanding the individual as:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Won’t/home</td>
<td>Can’t</td>
</tr>
<tr>
<td>Bad</td>
<td>Frustrated, challenged</td>
</tr>
<tr>
<td>Refuses to sit still</td>
<td>Over-stimulated</td>
</tr>
<tr>
<td>Resisting/don’t care</td>
<td>Doesn’t get it</td>
</tr>
<tr>
<td>Trying to get attention</td>
<td>Needing support/accommodation</td>
</tr>
<tr>
<td>Doesn’t try</td>
<td>Tired of failing</td>
</tr>
</tbody>
</table>
Strategies not Solutions

- There is no magic bullet.
- Behaviors that result from the effects of FASD can be challenging and try the patience of the most experienced and dedicated education professionals.
- Strategies are not always transferable from one person to another.
- Go to the source for information.

Strategies & Interventions

The most important strategy to remember when working with students with an FASD is to be patient and understanding.

Apply the maxim, “Seek first to understand, then to be understood”.

Use Humor!

Build Relationships

The external brain concept coined by International FASD expert Sterling Clarren, MD

“The individual with a disability caused by prenatal alcohol exposure will always need an external brain”.
Change the Environment

Adapt the Environment

- Reduce visual distractions
- Reduce the brightness of the lighting in the classrooms
- Pets can help students to relax
- Free classroom of unnecessary distractions

Adapt the Environment

- Visual boundaries can help kids organize themselves
- Mark visual boundaries on the floor using tape or carpet squares

Opportunities to “Peace Out”

Adapt the Environment

- Weighted blankets or fleece blankets
- Reading a book or drawing
- Listening to music
- Manipulating hand-held toys (Fidgets)
- Normalize the space for all
Strategies & Interventions

Planning for Transition

- Proactive transition plans are important and can help avoid melt downs.
- Research supports the use of visual timers with students with an FASD.
- Timers can be effective for all students.

Research supporting Visual Timers:


Develop Rituals

Structure
- Individuals on the spectrum often function best in well controlled setting.
- Are most successful in a predictable environment with accountability.
- Prepare students in advance for changes (i.e. substitute teachers)

Daily Routines
Redirect
Consistent Rules
Keep Calm
Create Goals

The Importance of Options

- Empowerment allows kids to select from some available options.
- Highlight the options available.
- It is much easier guiding children into appropriate activities they select, then to force them to do things they don’t want to do.
Strategies not Solutions

Consequences must be directly related to the behavior and used as a means of correcting not punishing.

- May be able to repeat the rule/condition verbatim.
- May not understand how to put the rule into effect.
- May not understand why putting the rule into effect is a good idea.
- May struggle with abstract concepts like “respect”.

Cherokee Point is an example of a Trauma-Informed School. The school conforms and accommodates to kids.

http://acesstoohigh.com/2013/07/22/at-cherokee-point-elementary-kids-dont-conform-to-school-school-conforms-to-kids/

Strategies not Solutions

Communication
- Allow extra time for processing and responding
- Simple, short directives
- Non-verbal cues
- Concrete and specific
- Manageable tasks
- Importance of options
- Repeat, Repeat, Repeat
- Use the same verbiage
- Check for understanding
- Monitor for frustration

Proximity & Supervision

Supervision is Key
- Vulnerability
- Bullying
- Isolation
- Susceptible to negative influences
- Negative behavior is typically cue something is off in the environment

Strategies & Interventions

- Focus on changing the environment rather than trying to change the child.
- Create paths for accommodating neurodiversity and brain injury
- Be proactive rather than reactive.
- Expect inconsistency and celebrate when you are wrong!
- Whenever possible meet parents with successes.
Final Thoughts

Remember the person’s brain is different! Fetal Alcohol Spectrum Disorders cannot be cured, but it can be accommodated for better outcomes for the students and the school overall.

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