Minnesota Organization On Fetal Alcohol Syndrome

Seeing the Hidden Disability & Improving Outcomes for Students Affected by FASD

Presented by, Barb Clark MOFAS Family Resource Coordinator

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.
Objectives

• Describe basic brain functioning in relation to FASD brain damage
• Identify ‘red flags’ for diagnosis
• Discover strategies for success
• Identify accommodations for IEP or 504 plans
• Learn about new treatment options and techniques that can be used in the classroom

What is FASD?

A group of birth defects that can result from prenatal exposure to alcohol
May include physical, mental, behavioral, and learning disabilities
Prenatal alcohol exposure affects each person differently
Permanent damage, 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FAE  Fetal Alcohol Effects (Outdated Term)
Facts about FASD

- FASD affects 1 in 100 live births
- In Minnesota, more than 8,500 babies are born each year with prenatal exposure to alcohol
- Nationally 1 in 13 pregnant women report alcohol use
- FASD occurs in all racial, ethnic and socioeconomic groups

FASD in Comparison

Three major known causes of intellectual disability
- Down Syndrome
- Fetal Alcohol Spectrum Disorders (FASD)
- Fragile X Syndrome

Source: National Institute on Alcohol Abuse and Alcoholism

Alcohol use during pregnancy is the leading known preventable cause of intellectual disabilities and birth defects in the United States.

Alcohol is Alcohol

12 oz = 1½ oz = 5 oz

Alcohol is Alcohol – Image courtesy of FASD Competency Based Curriculum Development Guide, CDC website, June 2008.
Alcohol is a teratogen—a substance that the fetus is exposed to that impedes growth and disrupts normal development.

“No amount of alcohol consumption can be considered safe during 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

Source: Davies & Bledsoe, 2005
Damage by Trimester

• 1st trimester – alcohol kills cells and interferes with cell replication
• 2nd trimester – cells must separate and specialize, alcohol kills cells & interferes with migration = fewer specialized cells
• 3rd trimester – Alcohol interferes with myelin formation, cuts connections between cells and causes slower information processing

Areas of the brain most affected
Video Case Studies

- Jerry
- Randy
- Brittany
- Sebastian

FAS Facial Features

- Thin upper lip
- Palpebral fissures
- Smooth, long philtrum

CDC 2004
Might also have: Low set ears, flat mid-face, up-turned nose, small chin, and epicanthal folds.

Ethnicities and Characteristic FAS Facial Features
FASD is an invisible disability

• Attention deficits
• Hyperactivity
• Memory deficits
• Difficulty with abstract concepts
• Inability to manage money

An invisible disability

• Difficulty with the passage of time
• Difficulty learning from consequences
• Immature social behavior
• Inappropriately friendly to strangers
• Lack of control over emotions
• Poor impulse control
• Poor judgment

"People who don't have the facial features are truly discriminated against in terms of services. When they don't have a classic FAS face, the tendency is to act as though there's nothing wrong. They are expected to perform normally, but they're goofing up all the time. They get blamed for being lazy or careless, yet these people have functional brain impairments.”

~Ann Streissguth
Red Flags

- In foster care or raised in adoptive home
- History of chemical dependency/child protection
- Immature & poor social behavior
- Adaptive behaviors lower than IQ indicates
- Easily distracted, hyperactive, inattentive, impulsive

Red Flags

- Involvement with justice system
- May give inconsistent answers to questions
- Unable to connect actions with consequences
- Does not seem affected by past punishments
- Truancy and school difficulties

Sensory Challenges

Sensory Processing Disorders
- Brain “misreads” information from senses, affects behavior and learning

Other challenges
- Sensory seeking
- Sensory avoiding
Behavior Challenges

- Hyperactivity/Impulsiveness - ADHD common
- Stubbornness - Perseveration
- Passivity
- Fearlessness – high-risk behaviors
- Sleep difficulties
- Hypersensitivity – Sensory integration issues
- Poor self-image
- Depression
- Irritability

Behavior Misinterpretation Reframed

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Misinterpretation</th>
<th>Reframed</th>
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<tbody>
<tr>
<td>Non compliance</td>
<td>Willful misconduct</td>
<td>Difficulty translating verbal</td>
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<tr>
<td></td>
<td>Attention seeking</td>
<td>directions into action</td>
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<tr>
<td>Often Late</td>
<td>Lazy, slow</td>
<td></td>
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<tr>
<td></td>
<td>Poor parenting</td>
<td></td>
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<tr>
<td>Stealing</td>
<td>Deliberate dishonesty</td>
<td>Doesn’t understand ownership</td>
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<tr>
<td></td>
<td>Lack of conscience</td>
<td>(abstract) immature thinking</td>
</tr>
<tr>
<td>Lying (confabulation)</td>
<td>Deliberate sociopathic</td>
<td>Memory/sequence problems</td>
</tr>
<tr>
<td></td>
<td>behavior</td>
<td>Trying to please</td>
</tr>
<tr>
<td></td>
<td>Lack of conscience</td>
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SKILL DEVELOPMENTAL AGE EQUIVALENT

- Actual age --------------- 18 yrs.
- Expressive language ------ 20 yrs.
- Comprehension ------- 6 yrs.
- Money and time concepts --- 8 yrs.
- Emotional maturity ---- 6 yrs.
- Physical maturity ---------- 18 yrs.
- Reading ability ----------- 16 yrs.
- Social Skills -------- 7 yrs.
- Living skills ------------ 11 yrs.
Modify Expectations

- Individuals with FASD may break rules repeatedly because they forget them or cannot apply them.
- Accept that the individual may have unique learning challenges.
- The emotional and social age of adults with FASD is often lower than their chronological age.

Strategies for Success

- Adapt environment to minimize frustration.
- Build in sensory time - use weighted blankets, vests, fidgets.
- Social Reminders.
- Teach self awareness & advocacy.
- Co-regulate behavior – think Mr. Rogers!
- Proactive, not reactive.

Strategies for Transition

- Timers.
- Songs.
- Picture schedules.
- Establish routines.
- Child with transition difficulty becomes the helper.
- May need to avoid waiting in lines.
Adapt the Environment

Eight essentials for success

- Concrete
- Supervision
- Consistency
- Structure
- Repetition
- Specific
- Routine
- Simplicity

From 8 Magic Keys – developed by Deb Evensen and Jan Lutke 1997

Possible Accommodations for IEP or 504 plan

- Student has assigned seat next to teacher
- Lessons will be presented in shorter segments
- Lessons will be presented with visual, tactile or auditory supports
- Reading level or homework will be adjusted to individual level
- Student is allowed extra time to complete tasks in school
Possible Accommodations for IEP or 504 plan

- Student receives assistance with organization at school
- How often and how progress will be communicated with parent
- More time for tests
- Modified school day, class schedule or passing time
- Alternative or modified disciplinary consequences

There are promising new treatment options on the horizon!

Nutrition Interventions

- Nutritional supplementation to treat effects of prenatal alcohol exposure
- Enhance development of brain cells and connections for memory
Physical Activity Interventions

Voluntary exercise may have therapeutic benefits for memory for individuals that were exposed to alcohol prenatally.

Research-based interventions

<table>
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<tr>
<th>Brun Buddies</th>
<th>Children who had friendship training showed improved social functioning &amp; decreased problem behaviors.</th>
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<tbody>
<tr>
<td>Neurocognitive Habilitation</td>
<td>Foster children 6-11 years old showed significantly improved executive functioning after 12 weekly sessions.</td>
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<td>Parent-Child Interactive Therapy</td>
<td>14 weeks of coaching &amp; education improved parental stress &amp; behavior in children with FASD.</td>
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<td>Math Interactive Learning Experience (MILE)</td>
<td>Children ages 5-11 years improved math knowledge &amp; improved behavior through interactive math workshops.</td>
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<tr>
<td>Families Moving Forward</td>
<td>Consultation improved parenting attitudes &amp; decreased child disruptive behaviors.</td>
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“We must move from viewing the individual as failing if he or she does not do well in an program as not providing what the individual needs in order to succeed”

Dan Dubovsky, FASD Center for Excellence
Recognize strengths

- Highly verbal
- Artistic, musical
- Athletic
- Long term visual memory
- Willing
- Helpful
- Loyal
- Curious
- Generous
- Energetic and hard working
- Want to succeed
- Forgiving
- Spontaneous
- Good with young kids
- Friendly and outgoing

Don’t try harder…try differently

If you’ve told a child a thousand times and he still does not understand, then it is not the child who is the slow learner.

- Walter Barbee

Booklets: Intervention

- “Reach to Teach”
- “Fetal Alcohol Spectrum Disorders: Educational Strategies”
- “Working with Students who have Fetal Alcohol Spectrum Disorders”
Resources

E-Groups & List Serves

– MOFAS Virtual Family Center

– FASLINK
  • [http://www.acbr.com/fas](http://www.acbr.com/fas)

Additional online resources

General Information on FASD & community resources

– MOFAS Resource Directory
  • [http://www.mofas.org](http://www.mofas.org)

– Center for Disease Control and Prevention, FAS site
  • [http://www.cdc.gov/ncbddd/fas](http://www.cdc.gov/ncbddd/fas)

– SAMHSA FASD Center for Excellence
  • [www.fasdcen.of.samhsa.gov](http://www.fasdcen.of.samhsa.gov)

– FASD Unit @ the Univ of Washington School of Medicine

Questions?