FETAL ALCOHOL SPECTRUM DISORDERS

Adapted from SAMSHA by Carol Cohen Weitzman, M.D.
Associate Professor of Pediatrics and Child Study Center
Yale University School of Medicine
Director – Yale Adoption Clinic
Fetal Alcohol Spectrum Disorders (FASD): The Basics

Objectives:

1. Understanding Fetal Alcohol Spectrum Disorders (FASD)
2. Effects of Alcohol on the Developing Brain
3. Individuals With An FASD – Strengths, Difficulties, and Approaches
4. Diagnosing Children with FASD
5. Prevention and Risk Reduction
1. UNDERSTANDING FETAL ALCOHOL SPECTRUM DISORDERS (FASD)
Fetal Alcohol Spectrum Disorders (FASD)

• Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.

• May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

• Not a diagnosis.

• Often under-recognized and under-diagnosed
Diagnostic Terminology

• Fetal Alcohol Syndrome (FAS)
  
  • The term FAS was first used in 1973 by Dr. David Smith and Dr. Ken Lyons Jones at the University of Washington.

  • While FASD describes a range of disorders, FAS is a specific birth defect caused by alcohol use while pregnant.

  • FAS is a diagnosis: It is medical diagnosis Q86.0 in the International Classification of Diseases (ICD-10).
Other Diagnostic Terminology

- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)
- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Static encephalopathy (an unchanging injury to the brain)
Facts About FASDs

• FASDs are the leading known cause of preventable mental retardation.¹
• FASDs effect an estimated 40,000 newborns each year in the United States.²
• FASDs are more common than autism.³
• The effects of FASDs last a lifetime.
• People with an FASD can grow, improve, and function well in life with proper support.

• **FASDs are 100% preventable.**

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3. The Autism Society of America (2009) estimates that there are 24,000 new cases of autism each year in the U.S.
Facts About FASDs

- 2005 – Surgeon General reports: No amount of alcohol consumption during pregnancy is proven to be safe.\(^1\)
- FASDs are not caused by the biological father’s alcohol use.

- **FASDs are not caused intentionally by the mother:** Many women simply may not know when they are first pregnant or may not be aware of the harm that alcohol consumption during pregnancy can cause.
Facts About Alcohol Use Among Pregnant Women

- Nearly 12 percent of pregnant women report using alcohol in the past month.

- Past-month alcohol use among pregnant women and recent mothers aged 15 to 44 did not change significantly between 2002-2003 and 2006-2007.

- Nearly 16 percent of pregnant women aged 15 to 17 used alcohol in the past month, and they consumed an average of 24 drinks in that month (i.e., they drank on an average of 6 days during the past month and had an average of about four drinks on the days that they drank).

*The NSDUH Report, 9/11/2008, published by OAS/SAMHSA.*
Cause of FASDs

• The sole cause of FASDs is the fetus being exposed to alcohol during the pregnancy.

• Alcohol is a *teratogen*: A drug or other substance capable of interfering with the development of a fetus, causing birth defects.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—*IOM Report to Congress, 1996*
Cause of FASDs

• All alcoholic beverages are harmful.

• Binge drinking is especially harmful.*

• While it’s true that not every woman who drinks during pregnancy will have a child with an FASD, that does not mean that these disorders are rare or random.

• Any time a pregnant woman consumes alcohol, it becomes possible that her baby will have an FASD.

* Binge = 4 or more standard drinks on one occasion for women

aNational Advisory Council of the National Institute on Alcohol Abuse and Alcoholism (NIAAA)
### What’s A Standard Drink?

<table>
<thead>
<tr>
<th>12 oz. of beer or cooler</th>
<th>8–9 oz. of malt liquor</th>
<th>5 oz. of table wine</th>
<th>3–4 oz. of fortified wine (such as sherry or port)</th>
<th>2–3 oz. of cordial, liqueur, or aperitif</th>
<th>1.5 oz. of brandy (a single jigger)</th>
<th>1.5 oz. of spirits (a single jigger of 80-proof gin, vodka, whiskey, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>~5% alcohol</td>
<td>~7% alcohol</td>
<td>~12% alcohol</td>
<td>~17% alcohol</td>
<td>~24% alcohol</td>
<td>~40% alcohol</td>
<td>~40% alcohol</td>
</tr>
<tr>
<td>12 oz.</td>
<td>8.5 oz.</td>
<td>5 oz.</td>
<td>3.5 oz.</td>
<td>2.5 oz.</td>
<td>1.5 oz.</td>
<td>1.5 oz.</td>
</tr>
</tbody>
</table>

*Shown straight and in a highball glass with ice to show the level before adding a mixer.*
What’s a Standard Drink?

In recent research, frequent drinkers and the majority of women reported drinking larger-than-standard drinks:

• Daily drinkers were consuming drinks that were anywhere from three to six times the size of a standard drink.

• The majority of drinkers underestimated the number of fluid ounces they were consuming by about 30%.
Economic Costs of FAS

- FAS alone is estimated to cost the United States nearly $4 billion each year.
- The average lifetime cost for each child with FAS is almost $3 million.
Economic Costs of FAS

- One prevented case of FAS saves:
  - $130,000 in the first 5 years
  - $360,000 in 10 years
  - $587,000 in 15 years
  - More than $1 million in 30 years

Increased savings through prevention
2. EFFECTS OF ALCOHOL ON THE DEVELOPING BRAIN
Areas of Brain Affected By Prenatal Alcohol Exposure

- Impulses and judgment. The prefrontal cortex, controls what are called the Executive Functions.
- Appetite, emotions, temperature, and pain sensation.
- Coordination and movement.
- Memory, learning, and emotion.
- Spatial memory and behaviors like perseveration and the inability to switch modes, work toward goals, and predict behavioral outcomes, and the perception of time.
- Memory, learning, and emotion.

Passes information from the left brain (rules, logic) to the right brain (impulse, feelings) and vice versa.
FAS and the Brain

Normal brain of baby 6 wks old

Brain of baby same age with FAS

Photo courtesy of Sterling Clarren MD
Alcohol effects on corpus callosum

A: 14 - y.o. control subject: Normal corpus callosum

B. 12 - y.o. with FAS and a thin corpus callosum

C. 14 - y.o. with FAS and agenesis of the corpus callosum

Major Effects of Alcohol by Trimester

- **1st Trimester**
  - Increased risk of spontaneous abortion
  - Major morphological abnormalities

- **2nd Trimester**
  - CNS Effects

- **3rd Trimester**
  - Decreased fetal growth
3. INDIVIDUALS WITH AN FASD – STRENGTHS, DIFFICULTIES, AND APPROACHES
Typical Strengths of Persons With an FASD

• Often Friendly and cheerful

• Likable

• Socially Motivated

• Verbal
Primary Disabilities That Can Occur in Persons With an FASD

• Lower IQ
• Usually NOT in the intellectually disabled range
• Impaired ability in reading, spelling, and arithmetic
• Lower level of adaptive functioning
Learning Profile Often Seen in FASD

• **Strengths**–
  › Decoding words
  › Oral reading
  › Spelling skills

• **Weaknesses**
  › Reading comprehension
  › Story, essay and report writing
  › Arithmetic skills
    • Math reasoning
  › Organization and study skills
  › Abstract reasoning

• **Academic achievement lower than IQ would predict**
Typical Difficulties For Persons With an FASD

Sensory: May be overly sensitive to bright lights, certain clothing, tastes and textures in food, loud sounds, etc.

Physical: Have problems with balance and motor coordination (may seem “clumsy”).
Typical Difficulties For Persons With an FASD

Information Processing:

• Do not complete tasks or chores and may appear to be oppositional

• Have trouble determining what to do in a given situation

• Do not ask questions because they want to fit in

• Have trouble with changes in tasks and routine
Typical Difficulties For Persons With an FASD

Information Processing:

• Have trouble following multiple directions
• Say they understand when they do not
• Have verbal expressive skills that often exceed their verbal receptive abilities
• Cannot operationalize what they’ve memorized (e.g., multiplication tables)
• Misinterpret others’ words, actions, or body movements
Typical Difficulties For Persons With an FASD

Executive Function and Decision-Making:

- Repeatedly break the rules
- Give in to peer pressure
- Tend not to learn from mistakes or natural consequences
- Frequently do not respond to reward systems (points, levels, stickers, etc.)
- Have difficulty entertaining themselves
- Naïve, gullible (e.g., may walk off with a stranger)
- Struggle with abstract concepts (e.g., time, space, money, etc.)
Typical Difficulties For Persons With an FASD

Self-Esteem and Personal Issues:

- Function unevenly in school, work, and development – Often feel “stupid” or like a failure
- Are seen as lazy, uncooperative, and unmotivated – Have often been told they’re not trying hard enough
- May have hygiene problems
- Are aware that they’re “different” from others
- Often grow up living in multiple homes and experience multiple losses
Sleep Disorders

• 30-50% have problems with sleep
• Rate of sleep disorders goes up with alcohol exposure
• Alcohol affects circadian rhythms
• Facial anomalies and low tone make them high risk for obstructive sleep apnea
• Often have disturbed sleep architecture, less REM sleep
• Can mimic or worsen ADHD and other daytime cognitive and behavioral issues
Diagnoses often given to persons with FASD

• Attention-Deficit/Hyperactivity Disorder (ADHD)
• Oppositional Defiant Disorder (ODD)
• Conduct Disorder (CD)
• Reactive Attachment Disorder (RAD)
• Sleep Disorders
• Schizophrenia
• Depression
• Bi-polar disorder
• Substance use disorders
• Post-Traumatic Stress Disorder (PTSD)
Risks of Not Accurately Identifying and Treating an FASD

For the individual with an FASD:
- Unemployment (79%)
- Loss of family
- Homelessness
- Juvenile Justice (60%)
- Jail and arrest (50%)
- Premature death
- Increased substance abuse (35%)
- Mental Health problems (94%)
- School dropout (43%)

For the family:
- Loss of family
- Increased substance use
- Premature death
- Financial strain
- Emotional stress

Factors Associated With Improved Outcomes

- Stable home >72% of child’s life
- Early diagnosis before age 6
- No violence against oneself
- More than 2.8 years in each living situation
- Recognized disabilities
- Diagnosis of FAS (rather than another FASD)
- Good quality home from ages 8 to 12
- Basic needs met for at least 13 percent of life
School Treatment Plan

1. Documentation of child’s strengths and weaknesses as well as risk and protective factors.
2. Appropriate classroom modifications
3. Neuropsychological testing
4. IEP with appropriate goals and objectives including social goals
5. Adequate communication with parents, health care providers if child is on medications
8 Magic Keys

1. Concrete
2. Consistency
3. Repetition
4. Routine
5. Simplicity - Keep it short and sweet
6. Specific - say exactly what you mean
7. Structure
8. Supervision/supportive environments
9th Key: Realistic Expectations

Evensen and Lutke 1997
4. DIAGNOSING CHILDREN WITH FASD
Identifying an FASD

Only trained professionals can diagnose a disorder from the FASD spectrum. Diagnosis may be done by a team that may include:

- Developmental pediatricians
- Geneticists
- Neurologists
- Dysmorphologists (physicians specializing in birth defects)
- Education consultants
- Psychologists, psychiatrists, and social workers
- Occupational therapists
- Speech and language specialists
Possible Signs of an FASD

Signs that may suggest the need for FASD assessment include:

› History of multiple placements, foster care
› Sleeping, breathing, or feeding problems
› Small head or facial or dental irregularities
› Heart defects or other organ dysfunction
› Deformities of joints, limbs, and fingers
› Slow physical growth before or after birth
› Vision or hearing problems
› Mental retardation or delayed development
› Behavior problems including symptoms of ADHD, Executive functioning deficits
› Maternal alcohol use
## 4 Digit Diagnostic Code

<table>
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<tr>
<th>Growth Deficiency</th>
<th>FAS Facial Features</th>
<th>CNS Damage</th>
<th>Growth</th>
<th>Face</th>
<th>CNS</th>
<th>Etoh</th>
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</tbody>
</table>

*Significant Signficant Significant 4 X X X 4 Definite Moderate Moderate Probable 3 X 3 Some risk Mild Mild Possible 2 2 Unknown None None Unlikely 1 1 No risk Growth Deficiency FAS Facial Features CNS Damage Growth Face CNS Etoh Prenatal Alcohol*
Faces of FASD
Growth Deficiency

- Height deficiency (birth or since)*
- Weight deficiency (birth or since)*

*Not better explained by other influences on growth (chronic illness, severe malnutrition, etc)
Facial Differences

- Short Palpebral fissures
- Shallow philtrum
- Thin Upper lip

- Most stable features over time
- Although one can see other anomalies, these are more inconsistent
Palpebral Fissure Measurement

www.fasdpn.org
Lip- Philtrum
CNS Abnormality

• Structural
  › Head circumference at or below the 10\textsuperscript{th} percentile or if with height or weight deficit, HC $\leq$ 3rd %ile
  › Clinically significant abnormalities on neuroimaging

• Neurological
  › Seizures
  › Focal deficits

• Functional-Global cognitive deficit or significant developmental delay in at least 3 of the following domains
  › Cognitive/developmental deficits or discrepancies
  › Executive functioning deficits
  › Motor functioning delays
  › Problems with attention or hyperactivity
  › Problems with social skills
  › Others: Sensory problems, pragmatic language problems, memory deficits, etc.
Relevance of FASD to Health Care Professionals

- When you encounter children with learning/behavior problems and/or with abnormalities in growth and facial features, or ADHD that is resistant to the usual management,

CONSIDER THE DIAGNOSIS OF FASD.
5. PREVENTION AND RISK REDUCTION
Research shows that brief interventions can help reduce alcohol use among women of childbearing age, whether pregnant or non-pregnant.

Typical brief interventions include outreach, screening, referral, and other activities that promote the health of the mother (and, among pregnant women, the fetus).

Brief interventions have been effectively implemented by health professionals in primary care, emergency, and substance abuse treatment settings, and also on campuses.
Now is a good time to stop drinking.

Did you know Minnesota women of childbearing age drink more frequently than women in nearly every other state? If you’re a woman who’s drinking and pregnant, you’re increasing the chance that your baby will be born with alcohol-related birth defects – such as mental retardation, delayed development or lifelong behavioral disorders. Remember, one drink is one too many. Call 1-800-728-5420 for more information.

Don’t take the risk. Don’t take the drink.

This message brought to you by the State of Minnesota.
We Can All Talk About Alcohol Use

Talk about the effects of alcohol on an individual and on a fetus:

• Begin at an early age, such as elementary school.
• Indicate that stopping drinking at any time during pregnancy will help the fetus.

The father can play an important role in preventing FASD by helping the mother avoid alcohol.
Who Needs To Know

EVERYONE!

While FASD awareness may seem like it’s just about women who are pregnant, it’s not. Anyone who can help a woman remain alcohol-free during pregnancy should know: Men, women, family, friends, health care providers, educators…

EVERYONE!
Raise Awareness in Schools

- Ask the school to put up posters about drinking and pregnancy.

- Include information about FASDs in health, science, and physical education classes.

- Hold an assembly to talk about the effects of alcohol on a person and on a baby.
Resources

- SAMHSA FASD Center for Excellence: fasdcenter.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
- National Clearinghouse for Alcohol and Drug Information (NCADI): ncadi.samhsa.gov
In Summary

- FASD is disorder secondary to differing degrees of brain damage leading to a wide range of disability.

- Disabilities often underrecognized, underappreciated.

- Early identification improves outcomes.

- Educational/ environmental modifications and a supportive school environment key interventions.

- Goal= Prevention of Secondary Disabilities