FETAL ALCOHOL SPECTRUM DISORDERS

An Ounce of Prevention

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Objectives:

- **Define and discuss** Fetal Alcohol Spectrum Disorders (FASDs)
- **Learn** how to recognize the signs & symptoms of FASDs
- **Understand** the screening and evaluation process for FASDs
- **Define and discuss** a “standard drink”, binge drinking and the impact on the developing fetus
- **Recognize** the importance of SBIRT opportunities when working with women
- **Explore** the opportunities for prevention within your community, especially when working with adolescents
FETAL ALCOHOL SPECTRUM DISORDERS

History
Terminology
Diagnostic Criteria
Range of Effects
Statistics: National and State Projections
History Worth Noting

- 1968
  Dr. Paul Lemoine of France described effects of prenatal alcohol exposure in the medical literature. He described psychomotor and language delay, as well as cognitive limitations of individuals so affected.

- 1973
  Drs. Jones and Smith (University of Washington), first used the term Fetal Alcohol Syndrome (FAS) to describe children with characteristic "craniofacial, limb, and cardiovascular defects associated with growth deficiency and developmental delay" in eight unrelated children who were exposed to alcohol in utero.
FASDs: Range of Effects

Individuals affected by prenatal alcohol exposure can have a range of serious, lifelong problems which include: delayed development, hyperactivity, learning disabilities, executive functioning challenges and behavioral problems.
Let’s Define Fetal Alcohol Spectrum Disorders (FASDs)

The umbrella term used to describe the range of effects that can occur due to prenatal alcohol exposure.

FASDs is not a diagnostic term.
Terminology

- **Fetal Alcohol Syndrome (FAS):** A medical diagnosis that meets a specified criteria; usually diagnosed by a clinical geneticist, or a developmental pediatrician. (Pediatricians can identify FAS, but usually refer to the aforementioned)

- **Partial Fetal Alcohol Syndrome (pFAS):** Individual does not meet the full diagnostic criteria for FAS but has a history of prenatal alcohol exposure, some facial abnormalities as well as a growth problems or CNS abnormalities.

- **Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE):** Neurocognitive disabilities and problems with behavior and learning [Previously referred to as Alcohol-Related Neurodevelopmental Disorder (ARND)].

- **Alcohol-Related Birth Defects (ARBD):** Structural birth defects only (e.g., kidney, heart, or brain w/o functional deficit), rarely diagnosed.
Fetal Alcohol Syndrome

A medical diagnosis that meets a specified criteria; usually diagnosed by a clinical geneticist, or developmental pediatrician.

- Evidence of Growth Retardation/Restriction
  Pre/postnatal height and/or weight at or below the 10th%
  (not due to disease, illness or malnutrition)

- Characteristic Facial Anomalies/Features*

- CNS Impairments
  - Structural
  - Neurological
  - Functional

All three of the above MUST be present to receive a diagnosis.

*Fullerton requires either physical features OR confirmed alcohol exposure.
Diagnostic Criteria

• 4 or 5 on the Lip-Philtrum Guide is suggestive of features of FAS.

• 3 or less is considered normal.
Clinic Assessment

► Comprehensive History
  ▫ Medical record review, interview with family prior to appointment
► Standardized Testing and Consultations
  ▫ Administered by Occupational Therapist, Speech Therapist and Neuropsychologist*
  ▫ Genetic Counselors
► Physical Examination
  ▫ Administered by the Geneticist/Developmental Pediatrician
► Behavioral Observations

A referral to Fullerton will not necessarily result in an appointment with the diagnostic team. This will be determined during the history intake.
FASD and Race

- An individual’s genetic/racial background, as well as history of prenatal alcohol exposure, must be considered when diagnosing an FASD.

Photo: Alcohol Health & Research World, Vol 18, No 1, 1994

Photos: “Training in the Use of Identification and Care of Fetal Alcohol-Exposed Children”, NIAAA, Fleming and Pfeifer, 2002
Diagnostic Protocol
Fullerton/Huff Center Therapies

- Fetal Alcohol Syndrome
  - Meets ALL of Criteria for FAS

- Static Encephalopathy
  - Does Not meet criteria for FAS
  - Demonstrates significant delay in 3 or more areas of development

- Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)
  - Does not meet the criteria for FAS
  - May demonstrate less significant delays in development
  - Challenges with Behavior
National Statistics

Estimated FAS

- 1–3 per 1,000 live births among the general population in the US.
- 10–15 per 1,000 in some higher-risk populations, such as children residing in foster care.

Estimated Full Spectrum of FASD

- 9.1 per 1,000 live births among the general population in the US.
- However, in-school screening and diagnostic studies suggest that the national rate could be closer to 50 per 1,000 (5%).

SAMHSA FASD Center for Excellence, 2014
North Carolina Statistics

9.1 cases per 1000 births
119,767 live births 2012<sub>NC</sub>

Estimated 1090 cases of FASD in 2012.

http://www.schs.state.nc.us/schs/vitalstats/volume1/2012/nc.html
SAMHSA FASD Center for Excellence, 2014
FETAL ALCOHOL SPECTRUM DISORDERS

It’s All Alcohol
Women and Alcohol: Scope of the Issue
Importance of SBIRT
It’s All Alcohol

Beer
Wine
Wine spritzers/coolers
Hard Lemonade
Hard Cider
Shooters
Jell-O-shots
Whipahol
Alcohol-Caffeine Drinks
Snobars
Alcopops

* Many alcopops can have 12% alcohol per 23.5 oz. can = 4-5 drinks in one container!
### Standard Drinks

<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</th>
<th>2–3 oz. of cordial, liqueur, or aperitif</th>
<th>1.5 oz. of brandy</th>
<th>1.5 oz. of spirits</th>
</tr>
</thead>
<tbody>
<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>

Red Solo Cup... Don’t fill me up!
Women and Alcohol

- Gender differences in body structure and chemistry cause women to absorb more alcohol from the stomach, and take longer to break it down and remove it from their bodies; this is due to less water in the woman’s body.

- If the woman is pregnant, this can be significant result in significant exposure to the embryo or fetus.

Note:

- The addictive disease process involves:
  - Craving and compulsion.
  - Loss of control.
  - Continued use despite consequences.
Scope of the Issue: Alcohol

Women of Childbearing Age (18 - 44 years)

Non-Pregnant
51.5% (1 in 2) reported alcohol use in the past 30 days.

Pregnant
7.6% (1 in 13) reported alcohol use in the past 30 days.

Among pregnant women, the highest estimates of reported alcohol use were among those who were:
- Aged 35-44 years
- White
- College graduates
- Employed

Scope of the Issue:
Women and Binge Drinking:

- 1 in 8 adult women.
- 1 in 5 high school girls.
- Frequent use @ 3 times a month.
- Large amounts @ 6 drinks per binge.
- Increases a woman’s chance of breast cancer, heart disease, sexually transmitted diseases, unintended pregnancy, and alcohol exposed pregnancy.

Scope of the Issue: Alcohol

North Carolina
Pregnant Women (18 - 44 years)

53.9% Drank alcohol three months prior to pregnancy.
7.5% Drank alcohol during the last three months of pregnancy.

39.5% Reported Binge drinking at least one time, three months prior pregnancy.

13.1% Did not change their alcohol consumption from before pregnancy, during pregnancy.

Source: NC PRAMS, 2011
Why Women Continue to Drink?

- Women are receiving mixed messages.
- Lack of knowledge about alcohol & binge drinking.
- Primary care physicians aren’t talking with women about alcohol consumption or about the dangers of drinking alcohol during pregnancy.
- Opportunities for Screening, Brief Intervention and Referral to Treatment (SBIRT) are being missed.
- Birth Control Methods
  - Limited access
  - Limited understanding of method/use = misuse
  - No alcohol message paired with method of choice

http://www.cdc.gov/vitalsigns/alcohol-screening-counseling/infographic.html
Opportunity for Prevention

Who should Be Screened?

- All women of childbearing age (teens, young adults)
- All pregnant women
- High-risk female drinkers
  - All women who have previously abused alcohol
- Nursing mothers

If a positive response is received on a screening instrument. The HCP should discuss the risk of drinking alcohol; especially during pregnancy.
What Does Alcohol Really Do?

Effects of Alcohol on the Developing Fetus

Activity!
Alcohol is a Teratogen?

Teratogen:
“any agent, substance or occurrence which can induce abnormalities of development in the developing embryo or fetus”

Prenatal exposure to teratogens can cause:

- Premature birth
- Pre & postnatal growth retardation
- Physical malformations
- Sudden Infant Death Syndrome
- Cognitive and behavioral problems
What Do We Know So far?

During Pregnancy there is...

- No known safe amount of alcohol
- No safe type of alcohol
- No safe time to drink

Women who are pregnant or could become pregnant should not consume alcohol!

“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
Timing is everything!

There are multiple critical periods associated with prenatal alcohol exposure.

Pregnancy Exposure Riskline
1-800-532-6302

www.mothertobabync.org
www.fasdinnc.org
The most prudent advice you can give to all women is to stop drinking before conception and to maintain abstinence throughout pregnancy and during breast feeding.
FAS Research on Timing

Kathy Sulik, (Current) UNC Research

- Narrow forehead
- Short palpebral fissures
- Small nose
- & Small midface
- Thin upper lip with flattened philtrum

Source: Kathy Sulik, (Current) UNC Research
Critical Periods in Human Development

NC PRAMS Knowledge of Pregnancy: 46% (5 to 8 weeks) 16.3% (9+ weeks)

Women <25 years of age 95.6% (5 to 8 weeks)

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\begin{array}{|c|c|c|c|c|c|c|c|}
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\hline
1 & 2 & 3 & 4 & 5 & 6 & 7 & 8 \\
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period of dividing & zygote, implantation & C.N.S. & eye & heart & eye & palate & ear \\
zygote & & & & & & & \\
implantation & & & & & & & \\
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not susceptible to & teratogens & & & & & & \\
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* Red indicates highly sensitive periods when teratogens may induce major anomalies.

Source: NC PRAMS, 2011
Much Of Embryogenesis Occurs Prior To The Time That Pregnancy Is Typically Recognized

Menses (Beginning Of Last Normal Menstrual Period; LNMP)

Day 1

Day 9

Day 17

Day 22

Day 26

Day 32

Day 42

Embryo Age = Days After Fertilization

Age Post LNMP = Embryo Age + 2 Weeks

Source: Natalie Novick Brown, PhD, FASDExperts.com Kathy Sulik, (Current) UNC Research
A Critical Point of Vulnerability in embryos only 3-4 weeks old

Source: Natalie Novick Brown, PhD, FASDExperts.com
Alcohol Crosses the Placenta

- Stomach
- Brain
- Liver
- Kidneys
- Muscles
- Nerves
- Placenta
- Breast
- Brain
- Heart
- Organs
- Fetus

Poor metabolism of alcohol /high BAC levels
Prenatal Effects of Alcohol

- Alcohol crosses the placenta.
- Causes cell death and cell migration failure.
- Brain regions don’t develop or develop incorrectly.
- Nerve formation is interrupted.
- Interferes with molecule adhesion (hampers cell-to-cell attachments).
Key Areas of the Brain

Frontal Lobes – Impulses and judgment

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

Cerebellum
Plays a role in motor coordination, behavior, and memory.

Amygdala - perform a primary role in processing and memory. Emotional reactions (fight or flight response), part of the limbic system.
Alcohol Effects on the 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

FAS and the Brain

Normal brain of baby 6 wks old

Brain of baby same age with FAS

Photo courtesy of Sterling Clarren MD
Cognitive Impairments

- May have an intellectual disability
  - IQ range from 30-140
  - FAS: IQ avg. 60
  - FASD: IQ avg. 80

- Lower level of adaptive functioning; more significantly impaired than IQ.

- Primary disabilities, such as intellectual disabilities, attention deficits, and sensory processing disorder.

Streissguth, et al. (1996)
Possible Challenges with Executive Functioning:

- Reading
- Math
- Problems with money
- Understanding abstract concepts
- Attention deficits
- Learning from experience
- Processing information

Streissguth, et al. (1996)
Activity!

Life with the Wright Family
FETAL ALCOHOL SPECTRUM DISORDERS

Presentation Across the Lifespan
Co-Occurring Disorders
Primary & Secondary Disabilities
Infancy to Preschool

Possible Issues:

- Small in height and weight
- Poor sleep patterns
- Difficult to soothe
- Poor feeding
- Bonding problems
- Stranger anxiety
- Temper tantrums
- Trouble learning rules
- Shuts down easily
- Overly sensitive or
- Under responsive to stimulation
Developmental Gaps

- Age 5 going on 2 developmentally
- Age 6 going on 3 developmentally
- Age 10 going on 6 developmentally
- Age 13 going on 8 developmentally
- Age 18 going on 10 developmentally

Malbin, 2001
School Age & Adolescents

Primary Disabilities:

- Memory problems
- Trouble processing information
- Delays in social emotional development
- Executive functioning deficits
- Impulsivity
- Difficulty with abstract concepts
- Lower IQ
- Behavioral problems

Streissguth, et al. (1996)
Adolescence in to Adulthood:

- Less obvious features
- Poor judgment and impulsivity
- Defiant and uncooperative
- Can’t predict consequences
- No “stranger danger”
- Alcohol and drug use
- Difficulty telling time, & keeping appointments
- Talk the talk, but not walk the walk

Population is at higher risk for probation violations, missed court appearances, false confessions.
Possible Behavioral Problems

- Passiveness
- Hyperactivity
- Stubbornness
- Impulsiveness
- Irritability
- Sleep difficulties
- Fearlessness
- Defiance

Streissguth, et al. (1996)
Likely Co-Occurring Disorders

- Attention-deficit/hyperactivity disorder
- Sensory processing disorder
- Schizophrenia
- Depression
- Bipolar disorder
- Substance use disorder
- Attachment challenges
- Separation disorder
- Medical disorders (e.g., seizure disorder, heart abnormalities)
Challenge of Identifying FASD Across the Lifespan

Source: Natalie Novick Brown, PhD
FASDExperts.com
Chronological Age vs. Developmental Age

This timeline depicts the developmental age for various functional areas of a hypothetical 18-year-old.

Chronological Age .................. 18 Years
Expressive Language .................. 23 Years
Social Maturity .................. 12 Years
Math Skills .................. 8 Years
Reading Decoding .................. 14 Years
Reading Comprehension .................. 9 Years

Malbin, 2001
Protective Factors to prevent against secondary disabilities

Some include:

- Early diagnosis (before age 6)
- Early intervention and Applied Strategies
- Stable and nurturing home environment
- Absence of exposure to violence
- Few changes in caretaking placements
- Eligibility for social and educational services

Interdisciplinary team of professionals is crucial
Secondary Disabilities

- Mental Health Issues  94%
- Disrupted School Experience  61%
- Trouble with the Law   60%
- Jail or Treatment Facilities  50%
- Alcohol and Drug Problems  35%
- Dependent Living  83%
- Employment Problems   79%

Streissguth, et al. (1996)
FETAL ALCOHOL SPECTRUM DISORDERS

An Ounce of Prevention

What if?
Good Fit vs. Poor Fit
Your Role as a Provider:
Identification, Interventions & Strategies
What if?

We viewed the damage done by prenatal alcohol exposure to the brain as a physical condition?

- Genetics, trauma, and a wide range of teratogens and events cause physical changes.
- Alcohol kills cells, including in the brain.
- Alcohol and other drugs affect the structure and function of the brain.
- Behaviors are usually the only symptoms.

Fetal Alcohol Spectrum Disorders is an invisible physical disability with behavioral symptoms. Malbin, 2001
What if some of the clients you work with have an FASD and were never identified?
Secondary Behavioral Characteristics

Defines as defensive behaviors that develop over time when there is a “poor fit”

Defensive behaviors are normal reactions to pain and frustration and may be prevented or resolved

Adapted from: Ann Streissguth, 1996
**Example of a Poor Fit**

<table>
<thead>
<tr>
<th>FA/NB Characteristic</th>
<th>Technique, values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual learner</td>
<td>Verbal instruction</td>
</tr>
<tr>
<td>Processes slower</td>
<td>Fast paced</td>
</tr>
<tr>
<td>Needs external support</td>
<td>Work independently</td>
</tr>
<tr>
<td>Difficulty organizing</td>
<td>Organize, prioritize</td>
</tr>
<tr>
<td>Concrete</td>
<td>Abstract</td>
</tr>
</tbody>
</table>

Malbin, 2001
Tertiary Symptoms
(Secondary Disabilities)

Are the net result of a chronic poor fit, failure, isolation and alienation:

- Trouble in school
- Social services involvement
- Involvement with the justice system
- Homelessness
- Addictions/ mental health issues, suicide, etc.

Malbin, 2001
## Examples of a Good Fit

<table>
<thead>
<tr>
<th>FA/NB Characteristic</th>
<th>Technique, values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual learner</td>
<td>Provide visual cues</td>
</tr>
<tr>
<td>Processes slower</td>
<td>Allow adequate time</td>
</tr>
<tr>
<td>Needs external support</td>
<td>Provide supports</td>
</tr>
<tr>
<td>Difficulty organizing</td>
<td>Provide structure</td>
</tr>
<tr>
<td>Concrete</td>
<td>Experiential, build on strengths</td>
</tr>
</tbody>
</table>

Malbin, 2001
The Benefits of Identification and Interventions

- Decrease anger and frustration for individuals, their families, providers and communities.

- Increases understanding that negative behavior results from the disability and *is not willful*.

- Helps people with an FASD succeed by focusing on their strengths and what will help them, not on their ‘weaknesses’ and what they’ve done ‘wrong’.

- Helps improve outcomes.

- Helps prevent future births of children with an FASD.

Source: SAMHSA FASD Center for Excellence: fasdcenter.samhsa.gov
Looking Through a Different Lens

When addressing individuals/clients across the lifespan; consider the following:

- Invisible brain based disability.
- Developmental age vs. Chronological age.
- Protective factors didn’t occur.
- Overlapping diagnosis.
- Never diagnosed or misdiagnosed.
- History of substance use/trauma.

Adapted from following source: Natalie Novick Brown, PhD FASDExperts.com
# Our Paradigm Shifts and FASD

<table>
<thead>
<tr>
<th>From:</th>
<th>To:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Won’t..........................</td>
<td>Can’t</td>
</tr>
<tr>
<td>IS the problem................</td>
<td>HAS a problem</td>
</tr>
<tr>
<td>Doesn’t work..................</td>
<td>Has trouble starting</td>
</tr>
<tr>
<td>Acts immature.................</td>
<td>Is dysmature</td>
</tr>
<tr>
<td>Doesn’t try....................</td>
<td>Tired of failing</td>
</tr>
</tbody>
</table>

Malbin, 2001
The Impact of Interventions

“We must move from viewing the individual as failing if s/he does not do well in a program; to viewing the program as not providing what the individual needs in order to succeed.”

- Dubovsky, 2000

“Our interpretation of the behavior will determine the intervention.”

- Dr. Ross Greene
When working with Individuals with an FASD

- Build on strengths

- Use strategies that focus on these strengths
Strengths of Individuals with an FASD

- Learn by doing, by being shown, and/or by relationship
- Learn through consistency, continuity, and relevance
- Able to participate in problem solving with appropriate support
- Often have a strong long-term visual memory
- Highly verbal
Key Strategies to Remember

- Concrete
- Consistent
- Repetition
- Routine
- Simplicity
- Specific
- Structure
- Supervision
FETAL ALCOHOL SPECTRUM DISORDERS

Opportunities for Prevention
Prevention Efforts

FASD AWARENESS STRATEGIES

- Universal Prevention: education and awareness for everyone.
- Selective Prevention: intervention for those at risk.
- Indicated Prevention: targeted intervention for those at greatest risk.

- Education about alcohol, contraception, and FASD for all.
- Provide alcohol screening to all women of childbearing age.
- Provide brief alcohol intervention for women at risk.
- Provide targeted alcohol treatment and promote contraception use for women at highest risk:
  - Women who have a child with an FASD.
  - Women with a history of alcohol abuse/dependence.
  - Teen girls using alcohol are vulnerable to Unintended pregnancy.
What are we up against?

Say no to drugs. That way, you'll have more time to drink.
Your Charge for Prevention

- Take the opportunity to talk about alcohol use with everyone, especially women!!
- Pair the alcohol message with any discussions related to life planning.
- Continue your awareness of alcohol trends, the impact of environmental factors and the need for policy change.
- Support local coalitions that are addressing underage drinking in our state.
- Pair the FASD Message with the PUD message.
NOW IS A GOOD TIME
TO STOP DRINKING.
Fetal Alcohol Spectrum Disorders are 100% Preventable.
Resources

www.fasdinnc.org
www.nofas.org/
www.cdc.gov/ncbddd/fasd/index.htm
http://www.womenandalcohol.org/
www.fasdcenter.samhsa.gov/
www.fascets.org/
http://www.everywomansoutheast.org/partners/north-carolina
http://www.marchofdimes.org/northcarolina/
http://www.reddit.com/
An Ounce of Prevention is Worth a Pound of Cure.

Benjamin Franklin