FETAL ALCOHOL SPECTRUM DISORDERS

The Basics
Understanding Fetal Alcohol Spectrum Disorders

This section includes:

- Fetal Alcohol Spectrum Disorders (FASD)
- Terminology
- FASD Facts
- Cause of FASD
- FASD and Alcohol
- Alcohol and Women
- FASD and the Brain
- Number of People With an 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
Terminology

• Fetal alcohol syndrome

• Term first used in 1973 by Drs. Smith and Jones at the University of Washington

• One of the diagnoses used to describe birth defects caused by alcohol use while pregnant

• A medical diagnosis (760.71) in the International Classification of Diseases (ICD)
Terminology

Pregnancy + Alcohol

May result in

• Fetal alcohol effects (FAE)
• Alcohol-related birth defects (ARBD)
• Alcohol-related neurodevelopmental disorder (ARND)
• Partial FAS (pFAS)
FASD Facts

- 100 percent preventable
- Leading known cause of preventable mental retardation
- Not caused on purpose
- Can occur anywhere and anytime pregnant women drink
- Not caused by biologic father’s alcohol use
- Not a new disorder
Cause of FASD

- The sole cause of FASD is women drinking alcoholic beverages during pregnancy.

- Alcohol is a teratogen.

“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
FASD and Alcohol

- All alcoholic beverages are harmful.
- Binge drinking is especially harmful.
- There is no proven safe amount of alcohol use during pregnancy.
FASD and Alcohol

- Binge = 4 or more drinks on one occasion
- Drink = 12 ounces of beer, 3 ounces of wine, or 1 ounce of hard liquor
Size Matters

- **Beer**: 12 oz
- **1 small glass of wine**: 3 oz
- **1 single measure of spirits**: 1 oz
- **1 small glass of sherry**: 3 oz
- **1 single measure of aperitifs**: 2 oz
Size Matters

12 oz.  vs.  16 oz.
Alcohol and Women

- If a woman is pregnant, it does not matter what form the alcohol comes in.
  - *Wine spritzers, alcohol pops*

Check labels for alcohol content.
FASD and the Brain

• Prenatal alcohol exposure causes brain damage.

• Effects of FASD last a lifetime.

• People with an FASD can grow, improve, and function well in life with proper support.
FAS and the Brain

Normal brain of baby 6 wks old

Brain of baby same age with FAS

Photo courtesy of Sterling Clarren MD
FAS and the Brain

A. Magnetic resonance imaging showing the side view of a 14-year-old control subject with a normal corpus callosum; B. 12-year-old with FAS and a thin corpus callosum; C. 14-year-old with FAS and agenesis (absence due to abnormal development) of the corpus callosum.

These two images are of the brain of a 9-year-old girl with FAS. She has agenesis of the corpus callosum, and the large dark area in the back of her brain above the cerebellum is essentially empty space.

Number of People With an FASD

• No one knows for certain how many individuals are born each year with an FASD.

• No one knows how many individuals are living with an FASD.
Prevention and Risk Reduction

This section includes:

- Prevention Is the Best Cure
- Talk About Alcohol Use
- Who Needs To Know
- Raise Awareness in Schools
- Raise Awareness in the Community
Prevention Is the Best Cure

• Ask all women of childbearing age about alcohol use:
  • Ask routinely at every medical appointment.
  • Ask at appointments in various systems.
  • Ask in a nonjudgmental manner.
  • Use effective screening tools.
  • Ask about possible prenatal exposure.
Talk About Alcohol Use

• Talk about alcohol’s effects 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.

Convey the message: If you’re pregnant, don’t drink.
If you drink, don’t get pregnant.
NOW IS A GOOD TIME
TO STOP DRINKING.

DO NOT TAKE THE RISK

DO NOT TAKE THE DRINK
Who Needs To Know

- Women of childbearing age?
- Women who have a history of alcohol or other drug use?
- Women who are at risk?
- Teenagers?
- Men?
- EVERYONE!
Raise Awareness in Schools

- Ask the school to put up posters about drinking and pregnancy.
- Include information about FASD in health, science, and physical education classes.
- Hold an assembly to talk about the effects of alcohol on a person and on a baby.
Raise Awareness in the Community

• Post FASD information in doctors’ offices, treatment centers, and community centers.


• Focus attention on FASD. You can help the entire community.
Symptoms and Difficulties of FASD

This section includes:

• Overall Difficulties in Persons With an FASD
• Primary Disabilities in Persons With an FASD
• Typical Difficulties for Persons With an FASD
• Secondary Disabilities in Persons With an FASD
• Factors That Reduce Secondary Disabilities
Overall Difficulties for Persons With an FASD

- Taking in information
- Storing information
- Recalling information when necessary
- Using information appropriately in a specific situation
Primary Disabilities in Persons With an FASD

- Lower IQ
- Impaired ability in reading, spelling, and arithmetic
- Lower level of adaptive functioning; more significantly impaired than IQ

Streissguth, et al. (1996)
Typical Difficulties for Persons With an FASD

Sensory Integration Issues

• Are overly sensitive to sensory input
  • Upset by bright lights or loud noises
  • Annoyed by tags in shirts or seams in socks
  • Bothered by certain textures of food

• Have problems sensing where their body is in space (i.e., clumsy)
Typical Difficulties for Persons With an FASD

Memory Problems

- Multiplication
- Time sequencing
Typical Difficulties for Persons With an FASD

Information Processing Problems

• 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
Typical Difficulties for Persons With an FASD

Information Processing Problems

• Say they understand when they do not

• Have verbal expressive skills that often exceed their level of understanding

• Misinterpret others’ words, actions, or body movements

• Have trouble following multiple directions

Straighten up your room and put your toys away. Do you understand?

YES! (How do you straighten up? Make sure the bed/Chair is straight?)
Typical Difficulties for Persons With an FASD

Executive Function Deficits

- Go with strangers
- Repeatedly break the rules
- Do not learn from mistakes or natural consequences
- Frequently do not respond to point, level, or sticker systems
- Have trouble with time and money
- Give in to peer pressure
Typical Difficulties for Persons With an FASD

Self-Esteem and Personal Issues

- Function unevenly in school, work, and development
- Experience multiple losses
- Are seen as lazy, uncooperative, and unmotivated
- Have hygiene problems
Typical Difficulties for Individuals With an FASD

Multiple Issues

- Cannot entertain themselves
- Have trouble changing tasks
- Do not accurately pick up social cues
Secondary Disabilities in Persons With an FASD

- Mental health issues
- Disrupted school experience
- Trouble with the law
- Inappropriate sexual behavior
- Confinement in jail or treatment facilities
- Alcohol and drug problems
- Dependent living
- Employment problems

Streissguth, et al. (1996)
Secondary Disabilities in Persons With an FASD

Percent of Persons With FAS or FAE Who Had Secondary Disabilities

- Mental health problems
- Disrupted school experience
- Trouble with the law
- Confinement
- Inappropriate sexual behavior
- Alcohol and drug problems
- Dependent living
- Problems with employment

= Age 6+
= Age 12+
= Age 21+
Factors Associated With Reduced Secondary Disabilities

- Stable home
- Early diagnosis
- No violence against oneself
- More than 2.8 years in each living situation
- Recognized disabilities
- Diagnosis of FAS
- Good quality home from ages 8 to 12
- Basic needs met for at least 13 percent of life

Streissguth, et al. (1996)
Diagnosis

This section includes:

• Diagnosing Fetal Alcohol Syndrome
• Differential Diagnosis of Features of FAS
• FASD and Mental Health
• Risks of Not Identifying and Appropriately Treating FASD
• Benefits of Identification
Diagnosing Fetal Alcohol Syndrome

- Prenatal maternal alcohol use
- Growth deficiency
- Central nervous system abnormalities
- Dysmorphic features
  - Short palpebral fissures
  - Indistinct philtrum
  - Thin upper lip

Differential Diagnosis of Features of FAS

- Differential diagnosis is very important because:
  
  - Many syndromes can cause features that look like FAS.
  
  - Facial features alone cannot be used to diagnose FAS.
• Prenatal alcohol exposure may lead to severe behavioral, cognitive, and psychiatric problems but is not a psychiatric disorder.

• An FASD may co-occur with mental illness or substance use disorders.
Risks of Not Identifying and Appropriately Treating FASD

• Unemployment
• Loss of family
• Homelessness

• Jail
• Premature death
• Increased substance use
Benefits of Identification

• Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful

• Helps people with an FASD succeed by focusing on why they have trouble in certain programs

• Helps improve outcomes

• Helps prevent future births of children with an FASD
Treatment

This section includes:

• General Issues in FASD
• Intervention Issues
• Systems of Care Serving Persons With an FASD
• Economic Costs of FAS
General Issues in FASD

• Often undiagnosed, especially in adolescents, adults, and persons without FAS facial features

• More difficulties seen in those without FAS facial features and with higher IQs

• Adaptive functioning more impaired than intelligence
Intervention Issues

• Failure in traditional mental health treatment programs
  
  • People with an FASD may know what they need to do but cannot follow through
  
  • Caregivers with unrecognized FASD often labeled neglectful, uncooperative, or sabotaging treatment because they do not follow instructions
  
• Limited FASD-specific services
Systems of Care Serving Persons With an FASD

- Health
- Education
- Social and community services
- Legal and financial services
# Systems of Care

**Many Doors, No Master Key: Resources Needed for Brandan, Age 1-2 Years**

<table>
<thead>
<tr>
<th>Health</th>
<th>Education</th>
<th>Social and Community Services</th>
<th>Legal and Financial Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric</td>
<td>Feeding Specialist</td>
<td>Local Indian Child Welfare Advisory Committee</td>
<td>Daycare</td>
</tr>
<tr>
<td>Neurologists (2)</td>
<td>Nutritionist</td>
<td>Tribal Social Worker</td>
<td>Div. of Dev., Disabilities/Case Worker and Family Resource Coordinator</td>
</tr>
<tr>
<td>Pediatric Ophthalmologist</td>
<td>High-Risk Infant Clinic</td>
<td>Child Welfare/Case Worker</td>
<td>Medicaid</td>
</tr>
<tr>
<td>Audiologist</td>
<td>FAS Diagnostic Clinic</td>
<td>Cultural Recreational Therapy (e.g., drumming)</td>
<td>Guardian Ad Litem</td>
</tr>
<tr>
<td>Otolaryngologist</td>
<td>Lab and X-Ray Services</td>
<td>Infant Educator</td>
<td>Substance Abuse Treatment (birth mother)</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Surgeons</td>
<td>Tribal Council</td>
<td>Mental Health Counseling (birth mother)</td>
</tr>
<tr>
<td>Medical Supply Providers</td>
<td>Pulmonologist</td>
<td>Birth-3 Program: Occupational Therapist, Speech/Language Pathologist, Teacher, Aide, Play Therapist</td>
<td>Judge-Foster Care Issues</td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>Respiratory Therapist</td>
<td>Foster Care System</td>
<td>Attorneys for Birth Parents</td>
</tr>
</tbody>
</table>

~ About 40 service providers
Economic Costs of FAS

- Fetal alcohol syndrome alone cost the United States more than $4 billion in 1998.
- The average lifetime cost for each child with FAS is $2 million.
  - $1.6 million for medical care services
  - $0.4 million for loss of productivity

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

Outcomes

This section includes:

• Strategies To Improve Outcomes for Persons With an FASD
  • Strategies for Sensory Integration Issues
  • Strategies for Memory Problems
  • Strategies for Information Processing Problems
  • Strategies for Executive Function Deficits
  • Strategies for Self-Esteem and Personal Issues

• Strengths of Persons With an FASD

• Paradigm Shift
Strategies To Improve Outcomes for Individuals With an FASD

• Ask about possible prenatal alcohol exposure at intake.

• Ask about substance use during medical appointments.

• Educate families and providers about FASD.

• Have a thorough diagnostic workup.

Dubovsky, Drexel University College of Medicine (1999)
Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Sensory Integration Issues

• Simplify the individual’s environment.

• Provide a lot of one-to-one physical presence.

• Take steps to avoid sensory triggers.
Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Memory Problems

• Provide one direction or rule at a time and review rules regularly.

• Use a lot of repetition.
Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Information Processing Problems

• Check for understanding.

• Use literal language.

• Teach the use of calculators and computers.

• Look for misinterpretations of words or actions and discuss them when they occur.
Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Executive Function Deficits

• Use short-term consequences specifically related to the behavior.

• Establish achievable goals.

• Provide skills training and use a lot of role playing.
Self-Esteem and Personal Issues

• Use person-first language (e.g., “child with FAS,” not “FAS kid”).

• Do not isolate the person.

• Address issues of loss and grief.

• Do not blame people for what they cannot do.

• Set the person up to succeed.
Strengths of Persons With an FASD

- Friendly
- Likable
- Desire to be liked
- Helpful
- Determined
- Have points of insight
- Not malicious

*Dubovsky, Drexel University College of Medicine (1999)*
Strengths of Persons With an FASD

- Cuddly and cheerful
- Happy in an accepting and supportive environment
- Loving, caring, kind, sensitive, loyal, and compassionate
- Energetic and hard working
- Fair and cooperative
- Spontaneous, curious, and involved

Photos courtesy of Teresa Kellerman
Strengths of Persons With an FASD

• Highly verbal

• Highly moral—deep sense of fairness

• Kind with younger children and animals

• Able to participate in problem solving with appropriate support

Photo courtesy of Teresa Kellerman
Strengths of Persons With an FASD

• Build on strengths of persons with an FASD, such as giving them opportunities to help in the classroom.

• Use teaching strategies that focus on strengths.

• Find jobs that use the person’s strengths.
Paradigm Shift

“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
Resources

• SAMHSA FASD Center for Excellence: fascenter.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
• These sites link to many other Web sites.