**Impact on Children: Fetal Alcohol Syndrome**

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**What is a Fetal Alcohol Spectrum Disorder (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.

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**Range of Disorders**

- **Fetal Alcohol Syndrome (FAS)**  
  - most severe effect of drinking during pregnancy  
  - leading preventable cause of mental retardation and birth defects  
  - characterized by abnormal facial features, growth deficiencies, and central nervous system (CNS) problems

*First described in the 1970s*
Other Disorders

- Fetal alcohol effects (FAE)
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related birth defects (ARBD)

*These conditions have some, but not all clinical signs of FAS*

Multiple Factors Contribute to Presence of FASD

- Timing of exposure
- Duration of alcohol consumption
- Amount of alcohol consumed
- Physical health and age of mother
- Prenatal care
- Polysubstance use or abuse
- Combination of one or more factors

FASD and Alcohol

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

- 0.3 – 1.5 per 1,000 live births across U.S. (4.8 per 1,000 for Alaska Natives)
- Three times higher rates of ARND and ARBD

CDC 2003: FAS Surveillance Network

Children with FASDs

- Small size in relation to peers
- Facial abnormalities
- Poor coordination
- Learning disabilities
- Developmental disabilities

ESTIMATES OF ALCOHOL USE AMONG CHILD-BEARING AGE WOMEN
Children with FASDs: Behaviors
- Sleep and sucking disturbances
- Hyperactive behavior
- Poor reasoning and judgment
- Problems with daily living

FASD and the Brain
- Prenatal alcohol exposure affects multiple systems, but targets the brain (both structural and function)
- Effects of FASD are permanent

FAS and the Brain

Permission to use photo on file.
**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.

**Source:** Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS and the Brain FAS and the Brain

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.


**Overall Difficulties for Persons With FASD**

- Taking in information
- Storing information
- Recalling information when necessary
- Using information appropriately in a specific situation
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

Multiple Issues

- Cannot entertain themselves
- Have trouble changing tasks
- Do not accurately pick up social cues

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 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

Secondary Disabilities of 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

Protective Factors for Children with FAS
- Stable, nurturing, loving home
- Early diagnosis
- Absence of Violence
- More than 2.8 years in each living situation
- Involved in Special Education and Social Services
- 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)
Benefits of Identification and Treatment
- Helps decrease anger and frustration for children, families, and communities
- Helps children with FASD succeed
- Helps improve outcomes
- Helps prevent future births of children with an FASD

Why Identify? (cont)
- Can lead to improved access to services
- More appropriate foster / adoptive placements
- Prevention of “secondary disabilities”

Profile for Older Children
- “Secondary disabilities” – emerge from experiences of frustration, failures and lack of acceptance from peers and adults
- “Easy target” - negative community influences
Factors Influencing Child’s Behavior: Prenatal
- Genetic: Fragile X, Down Syndrome
- Exposure to drugs: dilantin, valporic acid
- Exposure to illegal drugs: meth, cocaine
- Poor prenatal care
- Children whose parents have mild mental retardation, learning disabilities, ADHD

Factors Influencing Child’s Behavior: Postnatal
- Physical or sexual abuse
- Neglect resulting in FTT
- Serious head injury
- Medical conditions leading to brain damage

(Growth deficiency and behavioral problems are not specific to FAS)

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.

FASD and Mental Health Disorders

- Prenatal alcohol exposure may lead to severe behavioral, cognitive, and psychiatric problems.
- FASD is not a psychiatric disorder.
- FASD can co-occur with a mental health or substance abuse disorder.

FASD Diagnostic Teams in Alaska

- Modeled after: University of Washington FAS Diagnostic & Prevention Network
- Team Approach: medicine, psychology, speech-language, occupational therapy, social work, public health nursing, family advocacy
The 4-Digit Diagnostic Code
- Growth Deficiency
- FAS Facial Phenotype
- CNS Abnormalities
- Prenatal Alcohol Exposure

Growth Deficiency
- Exclude parental height and postnatal influences
- Consistent over time
- Review Weight and Height (at birth, current and in between)

The “Face of FAS”
- Small palpebral fissure lengths (width of eyes)
- Smooth Philtrum (area between nose and upper lip)
- Thin upper lip
Alcohol can affect the developing brain in 2 ways:
1. Can alter the brain structure
2. Can alter the brain chemistry

Both lead to altered brain function
### Ranking Alcohol Exposure

- Information is not always available or may not be accurate, and
- There is no clear consensus on the amount of alcohol that is toxic to each individual fetus

### 4-Digit Diagnostic Code Grid

<table>
<thead>
<tr>
<th>Growth Features</th>
<th>Facial Features</th>
<th>CNS Damage</th>
<th>Alcohol</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe (4)</td>
<td>Severe (4)</td>
<td>Definite (4)</td>
<td>High Risk (4)</td>
</tr>
<tr>
<td>Moderate (3)</td>
<td>Moderate (3)</td>
<td>Probable (3)</td>
<td>Some Risk (3)</td>
</tr>
<tr>
<td>Mild (2)</td>
<td>Mild (2)</td>
<td>Possible (2)</td>
<td>Unknown (2)</td>
</tr>
<tr>
<td>None (1)</td>
<td>None (1)</td>
<td>Unlikely (1)</td>
<td>No Risk (1)</td>
</tr>
</tbody>
</table>

### Diagnostic Categories

- 256 Diagnostic Codes grouped into 22 Diagnostic Categories
EXAMPLE:  
1. (No Growth Abnormalities)  
2. (Mild Facial Features)  
2. (Possible CNS Damage)  
3. (Some Alcohol Exposure)  

Diagnosis:  
Neurobehavioral Disorder  
Alcohol Exposed  

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 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.

Strategies To Improve Outcomes for Individuals With an FASD

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.

Integration of Traditional Native Beliefs, Values and Practices

- Traditional healers
- Ceremonies with extended family and community (sense of worth for person with FAS)
- Chemical Dependency Programs based on traditions
INTERVENTIONS: Helping Parents/Caregivers

◆ Start with child acquiring good communication skills
◆ Ensure speech therapy if needed
◆ Identify child’s strengths and use them as a means of intervention
◆ Redirect child ASAP into positive behavior

Helping Parents/Caregivers

◆ Rename child’s behavior from negative to challenging
◆ Allow parents and caregivers to not always be “perfect”
◆ Develop networks for support
◆ Help family in acquiring a case manager

Specific Interventions

◆ List of daily chores with increasing responsibility
◆ Structured leisure time
◆ Provide simple, concrete directions and give them one at a time
◆ Establish low to moderate levels of stimulation
◆ Use a lot of repetition
**Strengths of Persons With FASD**

- Friendly 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

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**Strengths of Persons With FASD**

- Highly verbal
- Highly moral—deep sense of fairness
- Kind with younger children and animals
- Able to participate in problem solving with appropriate support

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**Most Important Intervention:**

PREVENTION
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

Credits

♦ “A Practical Native American Guide for Professionals Working with Children, Adolescents, and Adults with FAS and FASD.” by Robin LaDue
♦ SAMSHA Power Point: FASD – The Basics
♦ University of Washington – FAS Diagnostic and Prevention Network

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.samhsa.gov
♦ Journey Through The Healing Circle: http://www.dshs/wa.gov/fosterparents/journey
♦ These sites link to many other Web sites.