

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



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 1970's

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

ESTIMATES OF ALCOHOL USE AMONG CHILD-BEARING AGE WOMEN



Children with FASDs

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

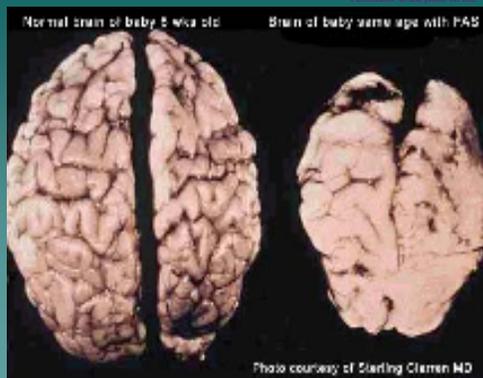
Children with FASDs: Behaviors

- ◆ Sleep and sucking disturbances
- ◆ Hyperactive behavior
- ◆ Poor reasoning and judgment
- ◆ Problems with daily living

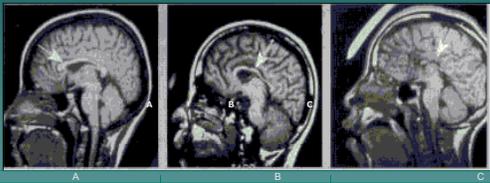
FASD and the Brain

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

FAS and the Brain



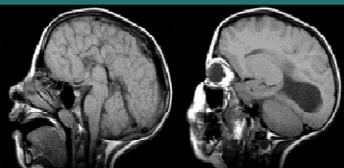
FAS and the Brain



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 psychol. studies: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49-52.

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.

Source: Mattson, S.N., Jernigan, T.L., and Riley, E.P. 1994. MRI and psychol. studies: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49-52.

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



Typical Difficulties for Persons With an FASD

Multiple Issues

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



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 Persons With an FASD

Executive Function Deficits

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



Secondary Disabilities of Persons With an FASD

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

Protective Factors for Children with FAS

- ◆ Stable, nurturing, loving home
- ◆ Involved in Special Education and Social Services
- ◆ Early diagnosis
- ◆ Diagnosis of FAS
- ◆ Absence of Violence
- ◆ Good quality home from ages 8 to 12
- ◆ More than 2.8 years in each living situation
- ◆ Basic needs met for at least 13 percent of life

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



Source: Astley, S.J. 2004. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, Third Edition*. Seattle: University of Washington Publication Services, p. 114.

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

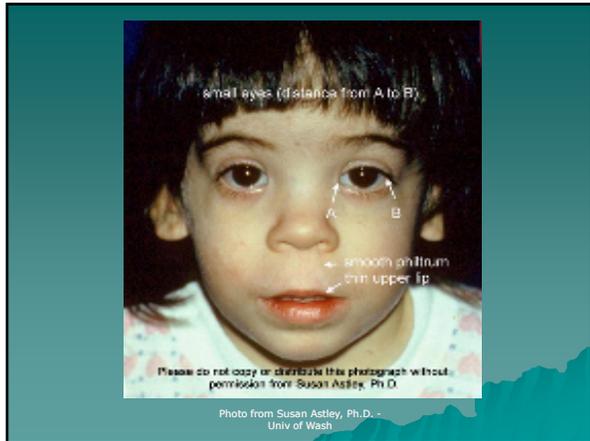
- ◆ Growth Deficiency
- ◆ FAS Facial Phenotype
- ◆ CNS Abnormalities
- ◆ Prenatal Alcohol Exposure

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





Central Nervous System

- ◆ 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

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

Diagnostic Categories

- ◆ 256 Diagnostic Codes grouped into 22 Diagnostic Categories

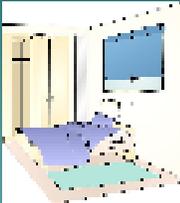
EXAMPLE: 1 (No Growth Abnormalities)
2 (Mild Facial Features)
2 (Possible CNS Damage)
3 (Some Alcohol Exposure)

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.



Photo courtesy of SAMHSA

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




Permission to use photos on file

Strengths of Persons With FASD

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




Photo courtesy of Microsoft

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.
