FAS 101 Disabilities of Discovery: Insights Into Brain-Based Disorders: For Teachers by Teachers (WB9 WC1)

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FAS 101 Disabilities of Discovery: Insights Into Brain-Based Disorders WB10 WC2)

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Abstract

One of the original goals established for Alaska’s Comprehensive Fetal Alcohol Syndrome (FAS) Project was to improve lifelong outcomes for individuals with FASD through improved services. To accomplish this goal, training of all appropriate service providers was critical.

During the past 3 years, 42 dedicated individuals have become FASD 101 Certified Trainers, through the Office of FAS. These trainers are certified to use the developed curriculum FASD 101, Disabilities of Discovery: Insights into Brain-Based Disorders.

Through this training, we can begin to change the paradigm related to this disability (brain damage vs. behavior problem), and it can begin the process of systems changes within our existing service delivery systems- education, developmental disabilities, juvenile justice, child protection, health care, public assistance, vocational rehabilitation, substance abuse treatment, mental health and corrections to name a few. If we expect to improve how services are provided to this population of
individuals and their families, change needs to occur within these existing service systems. We are very excited about this program and believe that by developing local community-based expertise, we can more effectively train service providers across the state and across disciplines, which will begin the process of changing the paradigm of thinking about this disability. This, in turn, will change how our systems approach their work with individuals affected by prenatal exposure to alcohol. For additional information contact Jennifer Pendergraft at the DHSS Office of FAS, 877-393-2287, fas@health.state.ak.us., or visit our website www.hss.state.ak.us/fas/ to find a trainer near you.

Notes:
FASD 101
Disabilities of Discovery:
Insights into Brain-Based Disorders

Objectives
- *Learn* about FASD including terminology; facts; and effects on the body and brain
- *Understand* primary and secondary disabilities resulting from FASD
- *Understand* the purpose of a diagnosis
- *Discuss* Alaska’s resources and approach

FASD Information
- Terminology
- Key Facts about FASD
- Latest FASD data in Alaska
- FASD and the Brain
What is FAS?

- Medical diagnosis for a permanent condition caused by prenatal alcohol exposure
  - Growth deficiency
    - Head, height, weight
  - Special pattern facial features
  - Signs of central nervous system damage

Terminology

<table>
<thead>
<tr>
<th>FASD</th>
<th>FAS</th>
<th>FAE</th>
<th>ARND</th>
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<tbody>
<tr>
<td>Fetal Alcohol Spectrum Disorders is an umbrella term used to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.</td>
<td>Medical diagnosis that is a subset of FASD.</td>
<td>Outdated term used to describe individuals who had problems associated with prenatal alcohol exposure, but did not have enough of the outward signs to be eligible for the medical diagnosis of FAS.</td>
<td>Has been widely used to describe the specific damage that prenatal alcohol exposure can have on the central nervous system.</td>
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FASD 101

What other terms have you heard?

False Beliefs About FASD

- FAS is a childhood disorder, people outgrow it.
- People with FAS have a “more severe” condition than others with prenatal exposure to alcohol.
- Behavior problems associated with FAS and FAE are the result of poor parenting.
- Mothers of children with FASD are young, careless and are not concerned about their substance abuse and its effects on their developing baby.
False Beliefs About FASD

- Nothing works for people with FASD.
- FASD can be passed on genetically.
- Children are negatively affected by alcohol only if a mother drinks early in her pregnancy.
- FASD is specific to certain races or communities.

Current Research in Alaska

- 16 teams conducting ongoing diagnoses in the State of Alaska since 1999
- 614 diagnoses submitted to date

FASD Risk in Alaska

For every 1,000 births in Alaska, 16.3 children are at risk for problems associated with FASD.

Of those 16.3, 1.5 will meet the full case definition of FAS. That means more than 163 children are born each year in Alaska at risk.
Further Research Findings

- Of all the diagnoses with evidence of organic brain damage, 90% do not have accompanying facial features.

“*It is not the face that needs the services.*”

(Streissguth & O’Malley, 2000, p. 178)

Why Know About FASD?

- Alcohol abuse in Alaska cost more than $249 million per year.
- Over 20,000 Alaskan women of childbearing age have acknowledged that they are heavy drinkers.
- Alaska has the highest KNOWN incidence of FAS in the US.
FASD Around the World

- FAS was first identified in France in 1968.
- Current surveillance efforts are underway in Russia, as well as prevention efforts all over the world.
- South Africa's wine region has the highest documented rate of FAS (40.6 per 1,000) in the world.

Alcohol Is Accepted

- Alcohol is a traditional part of cultures everywhere.
- Alcohol is used to celebrate, relax, and socialize.
- Many people have strong feelings about alcohol.

How does drinking alcohol during pregnancy affect a developing fetus?
Alcohol Is a Teratogen

- A teratogen is a substance that causes developmental malformations.
- Alcohol has a direct toxic effect on cells and can produce cell death, thereby causing certain areas of the brain to actually contain fewer cells than normal.

(Streissguth, 1997, p. 58)

Factors That Impact a Fetus

- When and how much a mother drinks while pregnant
- Mother’s genetic make-up
- Baby’s genetic make-up

Fetal Brain Development Begins Very Early

[Diagram showing fetal brain development at various stages]
Different organs are more vulnerable during different phases of pregnancy

Genetics Plays a Role

Animal Research
Alcohol and the Brain

“Children with FASD have a whole brain disorder that compounds their ability to communicate their understanding of the world.”
(Kapp, O’Malley, 2001, p. 7)

Subtle to Severe Problems

- Alcohol can cause physical conditions and birth defects
- More likely cause or first cause - Central Nervous System (CNS) problems.

Key Areas of The Brain

- Cerebellum plays a role in motor coordination, behavior, and memory.
Key Areas of The Brain

Basal Ganglia
Involved in monitoring the progress of movement and affects spatial memory. It may also be related to the ability to perceive time.

Key Areas of The Brain

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

The Corpus Callosum in an individual with FASD might be smaller than normal, thicker, and in some cases nonexistent.

Corpus Callosum Damage

14-year old control subject with a normal corpus callosum
12-year old with FAS and a thin corpus callosum
14-year with FAS and agenesis (absence due to abnormal development) of the corpus callosum

(Abnormal Health and Research World 18, #1, 1994)
Key Areas of The Brain

Hippocampus
Part of the limbic system, which is involved in emotional aspects of survival and plays a role in memory.

Range of Possible Damage

Missing Brain Matter
Review: FASD “Top Five”

1. There is no proven safe amount of alcohol use during pregnancy.
2. Alcohol can damage the fetus at all stages.
3. People with FASD are everywhere and in all systems of care (diagnosed or not).
4. FASD can occur in all communities.
5. People with the greatest difficulty are often the ones least recognizable.

FASD Disabilities

- Primary Disabilities
- Secondary Disabilities

Primary Disabilities

- Processing deficits:
  - Managing incoming sensory information
  - Sleeping and eating
- Cognition and learning:
  - Visual spatial skills, learning, memory
  - Speed of central processing of information
  - Executive functioning
- Speech and language
Processing Differences

- Input
- Integration
- Memory
- Output

Processing Deficits

- Abstract reasoning
- Generalizing information and rules
- Memory deficits
- Time management
- Judgment skills
- Socialization and independence

Abstract Reasoning

- Missing meaning, humor, and insight in conversations
Abstract Reasoning

- Thinking about the cause and effect of consequences
- Predicting an outcome
Generalizing Information and Rules
- Difficulty forming links
- Inferential thinking

Generalizing Information and Rules

Memory Deficits
- Poor short term auditory memory
- Slow auditory pace
- Difficulty getting information out of long term memory
Memory Deficits

Time Management

- Sleeping / eating cycles
- Problems with transition
- Monthly budgeting
- Making and keeping appointments
- Employment

Time Management
Judgment Skills

- Act before they think
- May seem noncompliant and willful when in fact they are simply unable

Socialization and Independence

- Not be able to rely on their own skills
- May have life-long needs for support and supervision
Socialization and Independence

Ages and Stages

- Dysmaturity — socially and developmentally younger than their chronological age.
- People with FAS often can talk the talk but can’t walk the walk.

Secondary Disabilities

- Disabilities that a person is not born with and are preventable with the right support, interventions, and accommodations.
Secondary Disabilities

- Mental health issues – 90%
- Disrupted school experience – 60%
- Trouble with the law – 60%
- Confinement - 50%
- Inappropriate sexual behavior – 49%
- Alcohol and drug problems – 35%

(Streissguth, Barr, Kogan and Bookstein, 1996)

Disrupted School Experience

Secondary Disabilities

- Other Concerns
  ✓ Secondary disabilities are more prevalent for individuals diagnosed FAE/ARBD than for individuals with FAS.
  ✓ Secondary disabilities are more common for affected individuals with higher IQs.
Secondary Characteristics

- Fatigue, frustration
- Anxiety, fearfulness
- Rigid, resistant, argumentative
- Flat affect, appear to not care, shutdown, lie
- Poor self concept, feelings of failure and low self esteem
- Isolation — fewer and fewer friends
- Aggressive

Protective Factors

- Living in a stable nurturing home for most of one’s life - i.e. over 72% of the time
- FAS diagnosis before the age of 6
- Not a victim of violence
- Being found eligible for DD services
- FAS diagnosis

FASD: So what do we do?

The first step to individual success is:
Quality Diagnosis

A diagnosis is a road map.
Diagnosing FAS

Diagnostic Features:
- Small eye opening
- Indistinct philtrum (groove between nose and upper lip)
- Small head circumference
- Thin upper lip

Diagnosing FAS

Associated Features:
- Epicanthal folds
- Minor ear anomalies
- Flat midface
- Short nose
- Low nasal bridge

Diagnosing FAS in Alaska

- Alaska follows a diagnostic model developed at the University of Washington called “The Four Digit Code”
- The four digit code is a comprehensive assessment involving the following professionals:
  - Physician
  - Parent navigator
  - Occupational and/or physical therapist
  - Clinical and/or school psychologist
  - Speech and language pathologist
The Value of a Diagnosis; Reduced Secondary Disabilities

Prenatal alcohol exposure causes brain damage. While this brain damage can’t be undone, people can grow, improve, and be successful.

Dan Dubovsky, 2004
Common Misinterpretations

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Misreading</th>
<th>Correct Interpretation</th>
</tr>
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<tbody>
<tr>
<td>Non-compliance</td>
<td>Willful misconduct</td>
<td>Difficulty translating verbal directions</td>
</tr>
<tr>
<td></td>
<td>Stubborn</td>
<td>Doesn’t understand</td>
</tr>
<tr>
<td></td>
<td>Attention Seeking</td>
<td></td>
</tr>
<tr>
<td>Makes same</td>
<td>Manipulative</td>
<td>Cannot link cause and effect</td>
</tr>
<tr>
<td>mistakes</td>
<td>Willful</td>
<td></td>
</tr>
<tr>
<td>Often late</td>
<td>Lazy</td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td>Poor parenting</td>
<td>Organization</td>
</tr>
<tr>
<td>Out of seat behavior</td>
<td>Willful Pest</td>
<td>Sensory integration</td>
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Reframe Behavior Interventions

If behaviors are believed to be willful, intentional, or the result of emotional problems

Then interventions focus on changing behaviors.

If behaviors are understood as reflecting brain differences

Then interventions focus on changing environments to prevent frustration and provide support.
Assessments Help Interventions

Try Changing How You Do Things

- Give people with FASD longer to answer, develop, and achieve.
- Reteach skills in every environment they will be used — don’t assume.
- Think differently — use a bouncing chair.
- Move from what’s wrong with them to what is going on for them.

Keys To Working With People With FASD

- Modify the environment.
- Modify expectations.
- Think younger or think “stage not age.”
- Think perpetual innocence.
- Make the world make sense.
- Rethink, reteach, respect.
Keys To Working With People With FASD

- Be concrete and specific.
- Keep things simple.
- Repeat directions, rules, etc.
- Have a routine and be consistent.
- Use structure.

Keys to Working With People With FASD

- Adjust expectations to reflect the reality of the child’s needs and capabilities.
- Think “cognitive wheelchair”.
- Be an interpreter, not an interrogator.
- Be an investigator, not a judge.

Burnout on Both Sides of the Relationship

<table>
<thead>
<tr>
<th>People with FASD</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel it is better to be bad than look stupid</td>
<td>Consistent inconsistency in their child</td>
</tr>
<tr>
<td>Tired and anxious all the time</td>
<td>Negative feedback from others</td>
</tr>
<tr>
<td>Chronically fail</td>
<td>Have the wrong expectations for their child</td>
</tr>
<tr>
<td>Experienced a life-long “poor fit”</td>
<td></td>
</tr>
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</table>
Avoiding Burnout

- Remember people with FASD are not “being bad.” They have brain damage.
- Look for resources, ask questions, ask for help.
- Remember your strengths and the strengths of the individual with FASD.
- Admit your limits and theirs.
- Plan for when you both need breaks.

Stick to your plan!

See People As Mysteries

- Not problems—or people with problems.
- Remember that expectations have to be realistic and appropriate to each person with FASD and not a generalization about FASD.

Think of What It Feels Like to Be A Little Out Of Step

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