Fetal Alcohol Spectrum Disorder: Diagnosis, Disability, & Strategies

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Causes & Characteristics of Fetal Alcohol Spectrum Disorders

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The #1 (preventable) cause of MR

Drink when you’re pregnant
and the hangover can last
FOREVER

When a pregnant woman drinks alcohol she risks having a baby with brain
damage and lifelong speech, learning, and behavior problems. If someone
you care about is pregnant and drinking, show her you care.

TALK TO HER. SHOW HER YOU CARE.
Because drinking during pregnancy isn’t worth the risk.

For more information, call
1-877-9 BEST 4-2 or visit www.best4-2.com
Alcohol Consumption Facts

• In 1999, > 50% of US women of childbearing age reported alcohol use in the past month
• 13% of women said they consumed 5 + drinks (binge drinking) at least once in the past month
• 13% of pregnant women continue to use alcohol
• 3% of pregnant women report binge drinking or frequent drinking (>7 drinks)
• Per CDC, 1-6000 babies born with FAS annually
  – FAS present in 1-2 per 1000 babies
  – FASD 6x that frequency
• Completely preventable!
Dosage of Alcohol

• Glass of wine, bottle of beer, shot of liquor are equal
• Approximately .5 oz absolute alcohol
• Fetal brain damage occurs at regular doses of 1-2 oz/day
Variability in FASD

- Dose of alcohol
- Pattern of exposure - binge vs chronic
- Developmental timing of exposure
- Genetic variation
- Maternal characteristics
- Synergistic reactions with other drugs
- Interaction with nutritional variables
Fetal Alcohol Syndrome

- Specific pattern of facial features
- Pre- and/or postnatal growth deficiency
- Evidence of central nervous system dysfunction

Photo courtesy of Teresa Kellerman
microcephaly
short palpebral fissures
flat midface
indistinct philtrum
thin upper lip
epicanthal folds
low nasal bridge
minor ear anomalies
short nose
micrognathia
Palpebral Fissures
Minor Anomalies
Change in brain size

Cerebrum

Cerebellum

Corpus Callosum

PEA

FAS

$p < 0.010$

$p \leq 0.001$

Mattson et al., 1994
Corpus callosum abnormalities

Mattson, et al., 1994; Mattson & Riley, 1995; Riley et al., 1995
Brain damage resulting from prenatal alcohol

photo: Clarren, 1986
Growing up with FAS

Courtesy of Ann Streissguth
Fetal Alcohol Spectrum Disorders

• Umbrella term for several diagnoses that are all related to prenatal exposure to alcohol

• Why "Spectrum?"
  – Each individual may have some or all of a spectrum of mental and physical challenges.
  – May have these challenges to a degree or "spectrum" from mild to very severe.
Prenatal Alcohol Exposure

- A continuum of fetal damage
  - 1st trimester → birth defects
  - 2nd trimester → miscarriage
  - 3rd trimester → reduced growth
  - Continuous → all
- Brain damage throughout
- FAS DX: Altered growth, appearance, brain function
- FAE a partial expression (now FASD, includes ARBD, ARND)
- Face: short palpebral fissures, long, flat philtrum, thin upper lip, ear anomalies
- Other: heart, skeletal, unusual palmar creases
FAS – Only the tip of the iceberg

- Fetal alcohol syndrome
- Fetal alcohol effects
- Clinically suspect but appear normal
- Normal, but never reach their potential
- Fetal Alcohol Spectrum Disorder – The Whole iceberg

Adapted from Streissguth
Alcohol Related Neurodevelopmental Disorder

- **Infant:**
  - Problems with sleep, feeding, milestones, muscle tone, sensory information processing

- **Child:**
  - Hyperactive, poorly coordinated, delayed, distractible, problems with learning, memory, attention, impulsive and uninhibited, social/obnoxious, school failure

- **Adolescent/Adult:**
  - Poor judgment, attention, problems with arithmetic, memory, abstraction, frustration/anger

- **Secondary Disability:**
  - School dropout, drug abuse, teen parenting, unemployment, homelessness, legal and marital difficulty, short life span--huge societal cost
There are serious disabilities associated with ARND/FASD:

- Decreases in overall intelligence
- Learning disabilities
- Secondary disabilities
- Deficits in Executive Function
- Communication disorders
General Intellectual Performance

Mental Retardation in FASD
25% of people with FAS
9% of those with FAE

Neuropsychological Performance

Mattson, et al., 1998
Learning Disabilities

• **Reading** and vocabulary skills are consistent with (or exceed) IQ
  – achievement in reading comprehension often limited to 4th-5th grade level
• **Math** disabilities – skills below that expected by their IQ
  – average around second grade level
Other than qualifying for resource in math, often they don’t fit into special education services.
Secondary Disabilities

Individuals with FAS/FAE have a range of secondary disabilities – disabilities that the individual is not born with, and which could be ameliorated with appropriate interventions.

Streissguth, et al., 1996
Mental Health Complications

• ADHD
• High rate of depression (40-50%) and suicidal attempts (25%)
• Intermittent Explosive Disorders Rage attacks (25%)
• Sleep Disturbance (50%)
Fetal alcohol exposure is associated with growing up in a poor social environment...

- 80% are not raised by their birth mothers
- 70% experience physical, sexual and domestic violence
- On average:
  - change households every 2-3 years
  - 33% of their lives are spent with a person abusing alcohol/drugs
  - only 65% of life in stable & nurturing home
Executive Function Disabilities

• Executive functions are the ability to hold information in your head, organize it, manipulate it and direct your attention and behavior accordingly.

• Executive function deficits may present as:
  – Attention deficits
  – Memory Impairment
  – Inability to predict consequences of actions
  – Difficulties with problem solving

• More info on executive function deficits at: www.chrisdendy.com/executive.htm
Executive functioning deficits

Move only one piece at a time using one hand and never place a big piece on top of a little piece

Starting position

Ending position

Rule Violations

Mattson, et al., 1999

NC
PEA
FAS

P<0.001
Communication and Social Performance Deficits

- Mixed receptive and expressive language disorder
  - talk a lot, good vocabulary, but “their brain is not connected to their speech”
- Deficits in social cognition and communication
- Social communication requires executive function
  - attending, encoding and manipulating information in memory and formulating appropriate responses
Leading to Social Isolation and Exploitation

Why don’t they like me?
Behaviors in FASD & How to Work With Them

Annie Adams, MS
Genetic Counselor
Perception of the World in FASD

- Concrete
  - Difficulty understanding abstract concepts
  - i.e. time, money, cause & effect, safety, boundaries
- Unrealistic & poor insight
- Don’t understand responsibility, repercussions, social cues
- Hypersensitivity to auditory, touch, visual stimuli
Behaviors in FASD

• Social skills:
  – Talkative
  – Very social
  – Overly friendly
  – Inappropriate touching
  – Lacks social boundaries

• Judgment:
  – Impulsive
  – Fearless
  – Risk taking
  – Poor judgment
  – Unaware of consequences

• Activity level:
  – Hyperactive
  – Poor attention span
  – Easily overstimulated

• Learning:
  – Appears functional
  – Tries hard, but often fails
  – Poor self esteem

• Comprehension:
  – Can’t generalize
  – Need simple, single, repeated instructions
Overview of Approach to FASD Child/Student

• Each child is unique
  – FASD overlaps many other conditions, especially ADHD, MR, autism

• Set long term goals for integrating into society
  – Socialization
  – Independence
  – Prevent secondary disability

• See/perceive the world differently
  – Organic brain damage with superimposed secondary problems, i.e. poor self-esteem
  – Work on positives

• Examine assumptions, observe child, include multisensory experiences
Getting Help Early

• Stability, stability, stability!
• Parent-child assistance program can help
  – Intensive home visitation model for the highest risk mothers
  – Professional advocates paired with family from birth to 3 years
  – Links clients with community services
  – Positive outcomes—reduced foster placement, welfare dependence

• Consistency is critical

Grant, T.M., 1999; Ernst, C. C., et al. 1999
Preventing Poor School Outcomes

- IEP? Not for FAS
- Must qualify under other disabilities:
  - Developmental delay
  - Speech impairment
  - Specific learning disability
  - Cognitive impairment
  - Emotionally disturbed
- Many children don’t meet these requirements
- Neuropsych evaluation is often helpful
Specific Difficulties in FASD

• Input Processing
  – Visual input
    • Try: bookstands, overlays, no copying, verbal input, touch
  – Auditory input, discrimination
    • Try: visual demos, picture story, reduce noise
  – Missing obvious social cues
    • Try: teaching cues/responses, how to play, practice

• Memory
  – Short and long term
    • Try: repetition, mnemonics, acting out, lists/notes
Specific Difficulties in FASD

• Integration
  – Sequencing, abstraction, conceptualization, generalization, organization, transitions
    • Try: recognize, assist, repeat, act out/practice, follow-up
  – Transitions
    • Try: repetition, warn

• Output
  – Language
    • Try: practice, role-play,
  – Motor
    • Try: different writing tools, dictation/typing, tracing
Disrupted School Performance

- Children with true mental retardation continue in special education
- Children with higher IQ become increasingly frustrated
  - Schoolwork more difficult than it seems it should be
  - May be labeled as lazy, troublemaker
  - Behaviors often misunderstood as willful misconduct
- 50-60% risk of disruption, e.g., suspension
  - 40% of adolescents and adults do not graduate from high school
## Misinterpreting Common Behaviors

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Misinterpretation</th>
<th>True Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noncompliance</td>
<td>Willful misconduct, attention seeking, stubborn</td>
<td>Difficulty translating verbal directions into actions, doesn’t understand</td>
</tr>
<tr>
<td>Repeating same mistakes</td>
<td>Willful misconduct, manipulative</td>
<td>Cannot link cause &amp; effect or see similarities, difficulty generalizing</td>
</tr>
<tr>
<td>Often late</td>
<td>Lazy, slow, poor parenting, willful misconduct</td>
<td>Can’t understand time, needs help organizing</td>
</tr>
<tr>
<td>Won’t sit still</td>
<td>Seeking attention, bothering others, willful misconduct</td>
<td>Neurologically based need to move while learning, sensory overload</td>
</tr>
<tr>
<td>Poor social judgment</td>
<td>Poor parenting, willful misconduct, abused child</td>
<td>Not able to interpret social cues from peers, doesn’t know what to do</td>
</tr>
<tr>
<td>Overly physical</td>
<td>Willful misconduct, deviancy</td>
<td>Hyper- or hypo-sensitive to touch, does not understand social boundaries</td>
</tr>
<tr>
<td>Doesn’t work independently</td>
<td>Willful misconduct, poor parenting</td>
<td>Chronic health problems, cannot translate verbal directions into action</td>
</tr>
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Amended from original, Debra L. Evenson, MA, 1994
FASD “Solutions”

- Assess individual situation
- May need to treat younger than chronologic age
  - May give the illusion of being higher functioning than they actually are
- Repetitive, consistent learning
  - Structure
  - Consistency
  - Brevity
  - Variety
  - Persistence
  - Multisensory experiences
- “Act out normal” as opposed to punishing abnormal
- Work to exclude external stimuli that may be creating difficulties in learning
  - Kids may “shut down” if they feel overloaded
  - “Find the hippity-hop” (Fantastic Antone Succeeds)
Appropriate Education Makes a Difference

• Using individualized “tracks” for education can help
  – FAS/E incidence roughly equal in Germany & US
  – Schooling based on abilities
  – Kids with FAS often in special education or vocational schools
  – Lower rate of adverse outcomes

• Advocate for more appropriate education
  – If they can qualify for IEP, use it!
  – Utilize vocational training to fullest extent
  – Students need strong advocates
Reality Intercedes

• School resources often limited
• Only so many people to help kids without more extreme disabilities
• Only so much disruption can be tolerated in the classroom
• How can we help these kids?
  – Vocational track started early in high school
  – Find something fun about school or after school (i.e. art, music, animals) to help self-esteem
  – Patience: remember that they aren’t purposefully being difficult
  – Persistence: don’t give up, repetition is everything!
  – Creativity: think outside the box for ways to teach
More Behavioral Advice

• Routine, clearly stated rules
• Supervision increased over the norm to maintain consistency
  – Without supervision, many kids can’t make good decisions and end up in trouble
• Limit independence
  – Encourage parents to co-sign checks or administer money directly
  – “Expected” freedoms, like driving, should be carefully considered
Getting Ready for Independent Living

• Instead of pushing the children along to independence...
  – It benefits children to treat them as younger than their chronologic age
  – Need continued supervision well past typical age of independence (to mid-late 20s)
• May mean staying in school longer than average for structure
• Often means living with parents much longer than typical
Treat Now to Prevent Later

- Typically treat children to optimizing learning and growth
- Paradigm shift to preventing secondary disabilities/adverse outcomes
Outcome in FAS vs. FAE

Adverse Life Outcomes-FAS vs FAE

- Inappropriate sexual behavior
- Disputed School Performance
- Trouble with the law
- Confinement
- Alcohol and Drug problems

The graph shows the percentage of adverse life outcomes for FAS vs FAE.
Think Outside the Box

- May need to isolate kids to reduce distractions
- Extra repetition may be very necessary!
- Teach using multiple senses

“Typical” classroom learning styles often don’t work for kids with FASD
Common Problems in FASD
Example 1

- Problem:
  - Child can’t focus in class; easily distractible
Common Problems in FASD Example 1

• Problem:
  – Child can’t focus in class; easily distractible

• Possible solutions:
  – Face desk away from classroom
  – Use a cubicle or cubbyhole
  – Use headset to silence ambient noise
  – Put desk in hallway/ outside of classroom
Common Problems in FASD
Example 2

- Problem:
  - Child is hyperactive, fidgety, distracting him/herself and other children
Common Problems in FASD Example 2

• Problem:
  – Child is hyperactive, fidgety, distracting him/herself and other children

• Possible solutions:
  – Find a “stress ball” or similar toy for child to hold onto to focus energy
  – Find a location or seat for the child that enables some movement to allow him/her to expend energy (find the “hippity hop”)
  – Adjust normal physical activity for the individual child (can be a positive or a negative)
Common Problems in FASD
Example 3

• Problem:
  – Child won’t follow directions
Common Problems in FASD
Example 3

• Problem:
  – Child won’t follow directions

• Possible solutions:
  – Consider literal interpretation of what you’re asking
  – Make sure they know definitions of words you use
  – May need to show the child basic skills to follow-through
  – Give directions in single steps
Common Problems in FASD
Example 4

• Problem:
  – Child can’t remember schedules, seems very upset in changes in routine
Common Problems in FASD
Example 4

• Problem:
  – Child can’t remember daily changing schedules, seems very upset in changes in routine

• Possible solutions:
  – Set up a picture calendar within visual range, i.e. on desk or on notebook
  – Repeatedly prepare ahead of time for changes in routine
  – Use PDA, timers, or other electronic devices as reminders
Common Problems in FASD
Example 5

• Problem:
  – Child refuses to follow directions, is oppositional
Common Problems in FASD

Example 5

• Problem:
  – Child refuses to follow directions, is oppositional

• Possible solutions:
  – Consider why child is being oppositional
    • May be “shutting down” due to overload
    • May not understand what’s being asked
  – Simplify request, break it down
Common Problems in FASD
Example 6

• Problem:
  – Child is caught red-handed doing something wrong, but denies it
Common Problems in FASD Example 6

• Problem:
  – Child is caught red-handed doing something wrong, but denies it

• Possible solutions:
  – Realize that child may not have a “conscience” & doesn’t understand right from wrong
  – Try to minimize opportunities for misbehavior (i.e. stealing) through maintaining supervision
  – Repetition may help children have a “learned conscience”
Work WITH, Not AGAINST Them

Our perception ≠ Their reality
These defects of the **brain** and the **body** exist because of prenatal exposure to alcohol. As one parent of a child with FASD states, defects of the **spirit** exist because:

"Often the neurological damage goes undiagnosed, but not unpunished. They can become the forgotten kids - the children that have nearly invisible disabilities. They have their arms and legs, can see and hear, run, play, etc., but most have never been to a birthday party or a sleepover. They are last to be chosen to play, and first to be blamed. Their illnesses aren't fatal, but a small part of their hearts and souls die with every rejection. Their behaviors may seem odd or unpredictable to themselves as much as society." - Bruce Richie FASLink