FASD: Support for Individuals, Families and Communities

National Organization on Fetal Alcohol Syndrome

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National Organization on Fetal Alcohol Syndrome (NOFAS)
Fetal Alcohol Spectrum Disorders (FASD)

- Caused by drinking alcohol during pregnancy
- Alcohol is a toxic substance – if a pregnant mother drinks, it can affect the baby in many ways:
  - Birth defects
  - Intellectual abilities
    - Brain damage, behavioral problems, low IQ
  - Characteristic facial features
- These are life-long effects – the baby does not “outgrow” them
FASD FACTS

• FASD annual births are higher than Down Syndrome, Cerebral Palsy, Cystic Fibrosis, Spina Bifida and Sudden Infant Death Syndrome—COMBINED.

• Some believe that cocaine is the primary substance abused by pregnant women, although this is untrue. The % of pregnant women that use alcohol is more than double of those that use cocaine while pregnant.

• In 1996, the Institute of Medicine reported “Of all substances of abuse (including heroin, cocaine, marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”
Alcohol & SIDS

“Alcohol use while pregnant is a leading causal factor in both fetal and infant death.”

- Ken Warren, PhD, Acting Director, NIAAA
  NOFAS interview, www.nofas.org

Kathy Mitchell, NOFAS 2014
Fetal Alcohol Spectrum Disorders

- FAS
- pFAS
- ARBD
- ND-PAE
- ARND

Fetal alcohol effects

Kathy Mitchell, NOFAS 2014
Families raising a child with an FASD face many challenges

- Most cases of FASD are never diagnosed. Symptoms of FASD are identified and addressed. But rarely is alcohol identified as the causal factor.

- Few physicians, healthcare professionals, disability professionals, psychologists, therapists, etc. are trained in how to identify FASD.
The vision of the National Organization on Fetal Alcohol Syndrome (NOFAS) is a global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with Fetal Alcohol Spectrum Disorders (FASD).
NOFAS www.nofas.org

- **Clearinghouse**
  - Resource Directory
  - Materials Dissemination
  - NOFAS Information Clearinghouse

- **Affiliate and Stakeholder Networks**
  - Capacity Building
  - Friends of NOFAS

- **Media Outreach**
  - Social Media

- **Training and Curriculum**
  - Students and professionals

- **Policy and Advocacy**

- **Prevention**
  - Circle of Hope Birth Mothers Network
  - Public Awareness campaigns

Kathy Mitchell, NOFAS 2014
The Weekly Roundup is published to provide a spotlight on media, industry research, and events pertinent to FASD and alcohol exposed pregnancies.

- NOFAS Facebook Page, COH Facebook, & Twitter account.

- AlcoholFreePregnancy YouTube Channel
  - 175 new interviews
  - NOFAS-NOW

Kathy Mitchell, NOFAS 2014
“Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks”

- JUDGES 13:7
Use of Ethanol in Threatened Premature Labor

- View on the absolute safety of alcohol in pregnancy continued into the 1960’s when the alcohol drip was introduced in obstetrics.
- One of few medical uses of ethanol.
- Involved I.V. ethanol infusion for 6–10 hours, reaching BAC as high as 160 mg/dl
Alcohol is a teratogen (*def.* an agent that can cause malformations of an embryo or fetus). Alcohol can cross the placenta and enter fetal circulation, damaging cells and the DNA they contain.
Impact of Alcohol Use on the Developing Fetus

Adapted from Moore and Persaud, 1993.
What happens in the womb can effect our health through the lifespan. Riley

- Increased insulin/diabetes (Chen)
- Greater risk of cancers (Sakar)

But, we still know little about long term health effects......
FASD is a Systemic Disability

Animal Studies (Joanne Weinberg, 2008)

- Study examines how alcohol exposure affect neurological systems in an animal model and implications for intervention.
  - Altered hormonal, immune, and behavioral function
  - Special emphasis on stress
Initial Findings:

- Maternal alcohol consumption increases HPA (hypothalamic pituitary adrenal) activity and alters HPA regulation to the mother and the offspring.
- HPA is the stress axis and may be a common pathway for early adverse life experiences.
Dosing Matters in Animal Models

- Effects of Moderate Blood Alcohol Prenatally:
  - Poor sensory motor development, poor suckling, increased hyperactivity, learning and behavioral problems

- Effects 1-2 binge episodes:
  - FAS, physical anomalies, neurochemical alterations in brain

Kathy Mitchell, NOFAS 2014
Easier to diagnose patients with a measurable bio-marker
3 D Facial Imaging and Computerized Facial Recognition may Improve Diagnosis
Growth (CDC Diagnostic Guidelines):

- Confirmed prenatal or postnatal height or weight, or both, at or below the 10th percentile, documented at any one point in time

(adjusted for age, sex, and race or ethnicity)
The face is a window into the brain: Not all children with FASDs have the face, but the brain is still affected by prenatal alcohol exposure.

Most severe face

Adapted from Roussotte et al., 2011, CIFASD
Visualization of the brain of a typical (A) and two children exposed to alcohol (B,C) shows permanent loss of the tissue indicated by the arrows (portions of the corpus callosum).

Normal  FAS/PEA  FAS

Images courtesy of Dr. S. Mattson.
Prenatal exposure to alcohol can cause permanent changes in the brain

- These changes in brain are not due to poor postnatal environments, being in foster care, or a host of other possibilities.
- Heavy prenatal alcohol exposure is associated with a wide range of neurobehavioral deficits including visuospatial functioning, verbal and nonverbal learning, attention, and executive functioning.
- Children with and without physical features of the fetal alcohol syndrome display qualitatively similar deficits.

Riley 2004
Prenatal alcohol exposure and the brain

1. Neurocognitive impairments
   - abnormalities in executive function, visual-spatial learning, attention, information processing speed, memory, higher order language tasks
2. Problems with self regulation
3. Impairments in adaptive functioning including deficits in social skills

Learning Theory assumes that the student/adult is capable of:

- Learning a rule or principle
- Understanding the underlying concepts of that principle
- Remembering these concepts
- Generalizing this learning to many different situations
Even with a diagnosis, systems of care aren’t educated on FASD

- School systems do not want to provide resources for students that look “just fine”
- Educators are unaware of teaching strategies
- Children with an FASD often don’t fit in with their peers—nor do they fit in with children with other
What currently happens to most students with FASD?

- *Early childhood* - when they do the best they’re going to do in our system
- *Elementary grades* - we start to see problems
- *Middle/Junior High* - they start to fall through the cracks
- *High School* - we lose most of them

D. Evensen 2013
Students with Information Processing Deficits have difficulty with:

- Abstract reasoning
- Generalization skills
- Memory
- Time
- Anxiety and frustration
- Socialization and skills of independence

D. Evensen 2013
Other Concepts that may be problematic:

- Decision Making - easily led
- Understanding and handling money
- Impulsiveness
- Seeing another perspective - point of view
- Adaptive behavior - Has no idea what to do, when he does not know what to do
- Can’t see the big picture - only the little immediate picture
- Distinguishing between public and private behaviors
- Difficulty expressing themselves

Kathy Mitchell, NOFAS 2014
Common disorders identified with FASD

- Autism/Aspergers’ Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Borderline Personality Disorder
- Attachment-Bonding Disorder
- Depression
- Learning disability
- Oppositional-Defiant Disorder
- Post Traumatic Stress Disorder (PTSD)
- Receptive-Expressive Language Disorder
- Conduct Disorder

Kathy Mitchell, NOFAS 2014
Chronological Age Expectations: Typical 18-year Old ...

- On the verge of independence
- Maintain a job and graduate from school
- Have a plan for their life
- Budget their own money
- Organize
- Accomplish tasks independently at home, school, and job

D. Evensen 2013
Developmental Age With FASD: 18-years Going on 9-years ...

- Needs structure and guidance
- Limited choices of activities
- In the “here and now,” very little future projection
- Giggles, curiosity, frustration
- Vulnerable to bullying
- Gets an allowance
- Gets organized with help of adults
- Boundary issues. Just learning...

D. Evensen 2013
# FAS TIMELINE

**Actual age of individual:** 18

<table>
<thead>
<tr>
<th>Skill</th>
<th>Developmental age equivalent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Expressive Language</strong></td>
<td>&gt;= 20</td>
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<tr>
<td><strong>Comprehension</strong></td>
<td>=&gt; 6</td>
</tr>
<tr>
<td><strong>Money, time concepts</strong></td>
<td>=&gt; 8</td>
</tr>
<tr>
<td><strong>Emotional maturity</strong></td>
<td>=&gt; 6</td>
</tr>
<tr>
<td><strong>Physical maturity</strong></td>
<td>=&gt; 18</td>
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<tr>
<td><strong>Reading ability</strong></td>
<td>=&gt; 16</td>
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<tr>
<td><strong>Social skills</strong></td>
<td>=&gt; 7</td>
</tr>
<tr>
<td><strong>Living skills</strong></td>
<td>=&gt; 11</td>
</tr>
</tbody>
</table>

Adapted from: Research findings of Streissguth, Clarren et al. Diane Malbin 1994
Screening for FASD: Lifelong Problems Appear Across a Continuum of Severity

Cognition
- Mild: Reduced IQ, Learning Disabilities, poor insight and judgment, executive functioning, attention, short term memory and processing speed
- Severe: Aggression, temper outbursts, impulsivity

Behavior
- Mild: Poor boundaries, difficulty reading facial expressions or body language
- Severe: Pragmatic speech, receptive and expressive language

Social Skills
- Mild: Pragmatic speech, receptive and expressive language
- Severe: Anxietiy, depression, mood disorders

Speech and Language
- Mild: Fine, gross motor skills impairment
- Severe: Anxietiy, depression, mood disorders

Emotion
- Mild: Fine, gross motor skills impairment
- Severe: Anxietiy, depression, mood disorders

Motor Skills
- Mild: Fine, gross motor skills impairment
- Severe: Severe

Lockhart, P. 2006
Individuals with FASD are at risk for victimization....

- Functioning at a lower developmental age, BUT may have appearance of being higher functioning
- Understanding & remembering stranger-safety
- Difficulty with abstract thinking (predicting future behaviors)
- Retrieving information, ST memory
- Difficulty translating from brain to behaviors (thinking-speaking, hearing-writing)
- Difficulty comparing & contrasting
- Understanding cause-effect relationships

Kathy Mitchell, NOFAS 2014
Brain Differences in individuals with FASD: RETHINKING EXPECTATIONS

Kathy Mitchell, NOFAS 2014
Behavior is not purposeful
Paradigm Shift:

- Person with a developmental disability
- Can’t not Won’t
- Need support (External Brain)
Structure & Support

Foundation for success

D. Evensen 2010
Be Innovative and Creative

- Follow your intuition
- Watch the child and learn from the messages he sends

Re-Think the System

How can we adapt to better serve my client?

Kathy Mitchell, NOFAS 2014
Appropriate Behavior

POSITIVE ATTENTION
catch the good behaviors

increases + behaviors

Inappropriate Behavior

CRITISM
Increases -- behaviors

IGNORE
Decreases -- behaviors

NO ATTENTION
Decreases + behaviors

D. Evensen 2010
Focus on Strengths

- STRUCTURE
- REPETITION
- CONSISTENCY
- BREVITY
- PERSISTENCE
- GO SLOW, SLOW, SLOW
Specific

Be direct. Say exactly what you mean.
Simplicity

- Remember the KISS rule: Keep it short and simple. Over-stimulation in the environment means that a person with FASD will feel anxious and be unable to think clearly.

D. Evensen 2014
STRUCTURE

... a few examples

- Needs an “external brain”
- Consistency with time and schedules
- Smooth transitions
- Allows time for longer thought processing
- Offer lists and written instructions
- Reminding without blaming

D. Evensen 2014
WINNING STRATEGIES

- Communication
- Communication (what is working and not working)
- Humor
- Creativity
Celebrate Successes!
Point of Light Awardee

Karli Schrider receiving a Point of Light Award
Kathy Mitchell, NOFAS 2014
It’s not the end of the world to have issues related to FASD.

- Help the individual recognize their disability in reasoning, judgment and memory
- Help them to understand that everyone has strengths and weaknesses
- Accept them accept who they are “today”
- Ignore some of their “issues/difficulties”
- Recognize their effort to improve

They are right where they are supposed to be, and are perfect just the way they are today.

Kathy Mitchell, NOFAS 2014
8 Magic Keys

- 1. Concrete
- 2. Consistency
- 3. Repetition
- 4. Routine
- 5. Simplicity
- 6. Specific
- 7. Structure
- 8. Supervision

D. Evensen 2010
Interventions for Children with FASDs

- **MILE**
  - Emory University
  - www.psychiatry.emory.edu/PROGRAMS/GADrug

- **PACT**
  - Children’s Research Triangle
  - www.childstudy.org

- **Good Buddies**
  - U. of California, Los Angeles
  - www.semel.ucla.edu/fas/

- **Families Moving Forward**
  - Children’s Hospital, Seattle
  - http://depts.washington.edu/fmffasd
CDC FASD APP


- [ACOG Webpage on alcohol and women](http://www.womenandalcohol.org)
American Academy of Pediatrics

- CDC is working with AAP on a variety of activities:
  - Professional education materials to inform pediatricians about prevention, identification, and treatment of children with FASDs
  - PediaLink online training course
  - AAP FASD Toolkit – www.aap.org/fasd
Resources

- National Organization on Fetal Alcohol Syndrome (NOFAS): [www.nofas.org](http://www.nofas.org)
- SAMHSA FASD Center for Excellence: [fasdcenter.samhsa.gov](http://fasdcenter.samhsa.gov)
- Centers for Disease Control and Prevention FAS Prevention Team: [www.cdc.gov/ncbddd/fas](http://www.cdc.gov/ncbddd/fas)
Contact me ANYTIME!
Thank You!

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