What are the Long-Term Effects and Impacts of Fetal Alcohol Spectrum Disorders (FASD) on Individuals and their Families

National Organization on Fetal Alcohol Syndrome

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National Organization on Fetal Alcohol Syndrome
1. Describe some of the possible lifelong developmental, behavioral, and physical effects of fetal alcohol spectrum disorders (FASD).

2. Discuss strategies to reduce the stigma associated with FASD.

3. Describe challenges and resiliency factors within families living with FASD.
What recreational drug causes the most long term damage to the developing fetus?

a) Heroin
b) Cocaine
c) Alcohol
d) Prescription Opioids
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.”
Fetal Alcohol Spectrum Disorders

- FAS (Fetal Alcohol Syndrome)
- PFAS (Partial FAS)
- ARND (Alcohol-Related Neurodevelopmental Disorder)
- ND-PAE (Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure)

Fetal and Infant Death
NOFAS Clearinghouse

nofas.org

Materials, Resources and FASD Facts

• National Resource/Referral Directory
• Weekly NOFAS Roundup
• K-12 FASD Prevention Curriculum
• Fact Sheets, Books, Posters, DVDs
• Educational webinars/trainings
• Conference presentations
• Facebook
• Twitter @NOFAS_USA
• YouTube: Alcohol-Free Pregnancy
no woman drinks because she wants to hurt her baby.
Old Medical Model: the act of drinking caused the alcoholism

- They don’t care about their health
- Must be shown the destruction so they’ll be scared to drink
- Withdrawal ends in 3 days, if they drink after that it’s because they have mental issues
- Slow suicide (MH)
- If you’re young or drink less than your doctor, you can’t be an alcoholic
Most alcoholics don’t need psychiatry/AA more effective
Physiological not psychological
Not crazy, immoral, weak-willed, or disgusting
Differences from male alcoholics:

* Women more frequently report a positive family history (denial/fear)
* Progression of disease is quicker than men
* Woman's partner is more likely to be addicted than a male’s partner
* Victims of domestic violence
* More likely to combine alcohol with RX drugs
* More barriers in seeking help
  * Financial problems
  * Child care responsibilities
  * Family pressures
  * Social stigma
1977
Karli, Danny and Erin
A Happy Little Hippie Family
Karli age 10 (diagnosed with cerebral palsy)
Alcohol is a teratogen \((\text{def. an agent that can cause malformations of an embryo or fetus})\). Alcohol can cross the placenta and enter fetal circulation, damaging cells and the DNA they contain.
every single baby reacts differently to alcohol.

no one can predict how each baby will be affected.
The Doctors Bag: Prescription Pad

- 90% of women use some form of prescription medication throughout their pregnancy.
- Over the last 30 years, first trimester use of prescription medications has increased more than 60% (CDC).
- About 3.4 of every 1,000 infants born suffer from withdrawal symptoms related to misuse of narcotic prescription medications; that is one newborn every hour.
- According to the Journal of the American Medical Association, infants suffering from Neonatal Withdrawal Syndrome has more than tripled within the past decade.
“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
Impact of Alcohol Use on the Developing Fetus

Adapted from Moore and Persaud, 1993.
“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
The facial features of Fetal Alcohol Syndrome can be seen in both a child and a mouse fetus that were exposed to alcohol during development.

- Narrow forehead
- Short palpebral fissures
- Small nose
- Small midface
- Long upper lip with deficient philtrum

Child with FAS

Mouse fetuses

Alcohol-exposed

Normal
The facial features of FAS are not always obvious.
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)
Preventing FASD may prevent many other health consequences

Patients Health Chart at (35 years old)

- Systemic lupus
- Idiopathic thrombocytopenia purpura
- Chronic migraine
- Antiphospholipid syndrome
- Fibromyalgia
- Hiatal hernia
- Pituitary microadenoma

- Hysterectomy
- Prolapsed bladder
- Depression
- Anxiety
- Learning disabilities
- Poor executive functioning
A severely affected prenatally-exposed brain

- from Sterling Clarren
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).

Kathy Mitchell, NOFAS 2014

Images courtesy of Dr. S. Mattson
Prenatal exposure to alcohol causes the brain to actually be “built” differently ...
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
Alcohol during pregnancy can result in a brain that:

- ...can’t read the emotions or body language of other people
- ...thinks like the brain of someone much younger
- ...forgets information
- ...has difficulty with time and money
- ...responds slowly
- ...can’t link cause and effect
- ...thinks in a disorganized way
- ...has trouble moving information from one situation to another
- ...uses poor judgment
Common disorders identified with FASD

* Autism/Aspergers’s 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
FAS TIMELINE

Actual age of individual: 18

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

Adapted from: Research findings of Streissguth, Clarren et al. Diane Malbin 1994
1. Developmental or behavioral concerns
2. Dysmorphic facial features associated with prenatal alcohol exposure (PAE)
3. Growth deficiency at or below 10th percentile for head circumference, height, weight at any time, including prenatally
4. History of confirmed or suspected PAE
5. Self-reported or family concern about possible FASD

Kathy Mitchell, NOFAS 2017
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.
  - Birth mothers can face incarceration in some states.
  - Birth families can live with painful judgements and stigma.

Kathy Mitchell, NOFAS 2014
Helping Families to COPE

Change Perception: linear to circular

Acceptance is a process, not an event

One day at a time
Traits of Healthy & Resilient Families

* Commitment
* Time Together
* Respect
* Spirituality

- Connectedness
- Adaptability
- Communication
- Cohesion
Family in Recovery

* Learns that addiction is a disease-not self-inflicted.
* Discovers hope for self & user.
* Has peace of mind/serenity.
* Helps others.
* Can discuss and work out problems.
* Has support network and can identify and discuss feelings.
* May assume prior family roles.
* Learns not to personalize behaviors of FASD
My Child has FAS: The Scarlet Letter

A lifetime of public shaming, judgment and blaming:
(individuals living with FASD, mother, father, sisters, brothers, grandmother, grandfather, granddaughters, grandsons, nieces, nephews, aunts, cousins, son-in-laws, daughter-in-laws, their in-laws, etc.)

Mitchell, K. 2009
Peer Mentoring Support:

- Improve and strengthen the lives of birth families
- Provide peer support for birth families
- Decrease the stigma, blame and shame that birth families may experience

Kathy Mitchell, NOFAS 2004
Words Can Perpetuate Stigma:

* Avoid blaming language
  - FASD occurs when a fetus is exposed to alcohol NOT FASD occurs when a pregnant woman drinks
  - A child who has an FASD versus an FASD child (person first language)
Conversations with mothers:

* Be gentle, non-judgmental, ask, then listen to their story.
* Stick to the facts by providing information and education on alcohol/drug use, dependency or addiction in a matter of fact manner.
* You may be the only person that CAN help move them to change.
* To provide the best care possible it’s important to know all of the facts about the pregnancy including any exposures.
* Remind her that you care about her child and HER and want the best health possible for the entire family.

Mitchell, 2016
Join the campaign!
www.nofas.org/stigma

Join NOFAS and the NOFAS Circle of Hope to stop the stigma of birth mothers of children with FASD and the stigma of all individuals and families living with the disorders.
Take Away Message:

- Identify women with SUD and get them the support they need
- Addiction and FASD affects the entire family; all family members need support and counseling
- Treatment and support can come in many ways for women and their families
- Consider the possibility of FASD or other developmental disabilities in clients and their children
Nofas.org

- ACOG Webpage on alcohol and women: www.womenandalcohol.org

- AAP FASD Toolkit – www.aap.org/fas
Contact me ANYTIME!
Thank You!

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