A Hidden Diagnosis

Prenatal Alcohol Exposure & Its Many Implications for Children in Foster Care

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Learning Objectives

• Highlight the history of fetal alcohol spectrum disorders and how this has shaped hesitancy to diagnose children with this neurodevelopmental disability.
• Identify the signs and symptoms that may indicate the presence of Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)
• Describe the emerging paradigm of Neurodevelopmental Disability of the Prenatal Environment
• How we can work toward establishing community-based FASD-specific interventions
“Each of their mothers was an alcoholic”


The most common cause of intellectual disability and birth defects in the United States
Alcohol Use and Binge Drinking Among Women of Childbearing Age—United States, 2011-2013

- 10.2% of US pregnant women, ages 18 to 44, said they drank alcohol in the past 30 days
- 3.1% of pregnant women reported binge drinking in the previous 30 days
- About one third of pregnant women who consume alcohol, binge drink
  • *White, college-educated women are the women most likely to drink during pregnancy*

MMWR, 9/25/15

Prevalent in foster care

- It is estimated that up to 70% of children in foster care have histories of fetal alcohol exposure
- 80% of children with FASD do not stay with their birth parents
- Children with fetal alcohol exposure spend more time in care and suffer more placements during their childhood

…and yet these children are not being diagnosed

- 80% of foster children referred for FASD evaluation had never been diagnosed as affected by prenatal alcohol exposure.
- Mental health diagnosis, learning and communication disorders, intellectual disability and objective signs of neurocognitive damage, were not recognized in a significant number of children with FASD.
- Objective signs of neurocognitive damage were not recognized in a significant number of children with FASD


The Effects of Prenatal Alcohol Exposure

- Specific facial characteristics
- Growth deficits
- Intellectual and Learning Disabilities (especially in math and social skills)
- Attention and memory problems
- Poor coordination and motor delays
- Difficulty with judgment and reasoning
- Speech delay and auditory processing disorder

“Of all the substances of abuse (including cocaine, heroin and marijuana) alcohol produces by far the most serious neurobehavioral effects in the fetus” (Institute of Medicine, 1990)
FAS Identification: the traces of fetal alcohol exposure can sometimes be seen in the face

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

The features of Fetal Alcohol Syndrome seen in both a child and a mouse fetus exposed to alcohol during development

- alcohol-exposed mouse fetus
- normal mouse fetus
Fetal alcohol related-neurodevelopmental delay occurs three times more often than Fetal Alcohol Syndrome (about 1:100 children) – NIAAA, 1990
More recent estimates are 2-5% in the US population.

Midline structures of the face and brain in an alcohol-exposed mouse embryo and a child with FAS

Comparison of the face (A) and interior brain (B) of a normal mouse embryo and one damaged by alcohol (C&D) shows that the nostrils are abnormally positioned (C) and the brain is missing midline structures (D)
Alcohol kills specific cells in the developing brain depending upon the stage of development.

The inside of a 10 day mouse embryo (corresponding to a 28 day human).

Sensitive Periods of Embryological Development
The hidden devastation of prenatal alcohol exposure

The Strange, Sad Tale of Phineas Gage
“The equilibrium or balance, so to speak, between his intellectual faculties and animal propensities, seems to have been destroyed. He is fitful, irreverent, indulging at times in the grossest profanity (which was not previously his custom), manifesting but little deference for his fellows, impatient of restraint or advice when it conflicts with his desires, at times pertinaciously obstinate, yet capricious and vacillating, devising many plans of future operations, which are no sooner arranged than they are abandoned in turn for others appearing more feasible. A child in his intellectual capacity and manifestations, he has the animal passions of a strong man...in this regard his mind was radically changed, so decidedly that his friends and acquaintances said he was "no longer Gage."

—John Martin Harlow, MD, 1848

Areas of the Brain Affected By Prenatal Alcohol Exposure

- **Frontal Lobes** – impulses and judgment; controls executive function
- **Hypothalamus** – appetite, emotions, temperature, and pain sensation
- **Amygdala** – emotions
- **Cerebellum** – coordination and movement
- **Basal Ganglia** – spatial memory, transitions, working toward goals, predicting behavioral outcomes, and the perception of time
- **Corpus Callosum** – passes information from the left brain (rules, logic) to the right brain (impulse, feelings) and vice versa.
- **Hippocampus** – memory, learning, emotion

Source: Dr. Sarah Mattson, University of San Diego
Defining Neurobehavioral Characteristics of Children with FASD

- Impaired Executive function (conscious, goal-oriented behavior such as planning, execution, working memory, and inhibition of impulses in pursuit of goals)
- Behavioral dysfunction manifested by deficits in social functioning (aggressive and impulsive behavior)
- Attention and distractibility
- Language (auditory processing disorder, mixed receptive-expressive language disorder)
- Most children have borderline to low average cognitive ability


Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

- Neurocognitive deficits (one):
  - Global intellectual performance
  - Executive functioning
  - Learning
  - Memory
  - Visual-spatial reasoning

- Problems with self-regulation (one):
  - Mood or behavioral regulation
  - Attention deficit
  - Impulse control

- Delayed adaptive skills (two, one of which must be *)
  - Communication deficit
  - Impairment in social communication and interaction
  - Impairment in daily living skills
  - Impairment in motor skills
Intellectual Disability Equivalence

- Children with FASD have IQ scores that may fail to reflect the full range of their intellectual deficits.
- Most children with FASD have normal to borderline intelligence (above 70) but have low adaptive behavior skills.
- Low adaptive behavioral skills is a hallmark of FASD.
- Disability equivalence allows accommodations for services despite IQ scores above 70.


Developmental Age and FASD

Actual age = 10 years

<table>
<thead>
<tr>
<th>Skill</th>
<th>Developmental Age Equivalent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expressive Language</td>
<td>20 yrs.</td>
</tr>
<tr>
<td>Comprehension</td>
<td>6 yrs.</td>
</tr>
<tr>
<td>Money, Time Concept</td>
<td>8 yrs.</td>
</tr>
<tr>
<td>Emotional Maturity</td>
<td>6 yrs.</td>
</tr>
<tr>
<td>Physical Maturity</td>
<td>16 yrs.</td>
</tr>
<tr>
<td>Reading Ability</td>
<td>16 yrs.</td>
</tr>
<tr>
<td>Social Skills</td>
<td>7 yrs.</td>
</tr>
<tr>
<td>Living Skills</td>
<td>11 yrs.</td>
</tr>
</tbody>
</table>

Source: Adapted from Research findings of Strooburg, Claren et al. Diane Milbank. 1994.
Secondary Disabilities

95% of children with FASD suffer from at least one psychiatric syndrome that in contrast to physical features of FAS, are long-lasting, pervasive and devastating to development.

Fetal Alcohol Neurodevelopmental Disability Across the Lifespan of Childhood

**Infants:**
- Low birth weight
- Irritability with sensitivity to light, noises and touch
- Failure to thrive with poor weight gain, slowed growth in head circumference, length
- Slow development (fine and gross motor, language, social, adaptive)

**Toddlers:**
- Hyperactivity
- Lack of fear
- Poor sense of interpersonal boundaries with need for excessive physical contact
- Slowed speech development (auditory processing disorder)
- Early aggressive behavior
- Clumsiness and slow gross/fine motor development
Fetal Alcohol Neurodevelopmental Disability Across the Lifespan of Childhood

Grade-school years:
- Aggressive, oppositional behavior
- Short attention span
- Early academic and behavioral school failure (especially in math, social skills and behavior (referred for psychiatric evaluation by ages 5-7 years with diagnosis of ADHD, ODD)
- Poor coordination, difficulty with both fine and gross motor skills

Fetal Alcohol Neurodevelopmental Disorder Across the Lifespan of Childhood

Older Children and Teenagers
- Chronic academic school failure with suspensions for aggressive behavior
- Onset of chronic truancy
- Low self-esteem from recognizing they are different from their peers and recurrent school failure
- Poor impulse control and judgment
- Criminal behavior, gangs, substance abuse, sexual offenses
- Recurrent psychiatric hospitalization
The Trajectory of FASD

- 61% have disrupted school experiences
- 60% become involved with the criminal justice system
- 50% are incarcerated
- 49% have inappropriate sexual behaviors
- 35% have drug and alcohol problems

What’s in a Name

- The difficulty of reliable confirmation of the quantity, frequency, and timing of alcohol exposure.
- Meconium testing demonstrates 4.26 times greater identification of alcohol use during pregnancy compared to maternal self-report.
- This discrepancy highlights the fear and shame lying at the heart of alcoholism and drug addiction that has perhaps been the greatest barrier to identifying children with fetal alcohol and drug exposure.
- Indictment of a mother’s illness as the primary cause of her child’s disability.
- Fear of losing custody of children, denial of the extent of alcohol/substance use and shame associated with addiction
- Confrontation and defensive withdrawal
How can prenatal alcohol-exposure be determined?

- Maternal history or disclosure
- History obtained from relatives
- Documentation in prenatal medical records
- Previous or subsequent siblings with history of alcohol or substance exposure
- Biomarkers (hair, meconium, blood, urine)

Histories suggestive of possible prenatal alcohol exposure

- Early placement in foster care (secondary to abuse or neglect, abandonment, termination of parental rights or early death of mother or father)
- Primary guardian other than the child’s mother
- Early childhood behavioral and school difficulties
- Successively poorer pregnancy outcomes, low birth weight, miscarriage, developmental delay or sibling born with positive urine toxicology (cocaine)
- Family history of alcoholism or substance abuse (grandparent, father, mother)
- History of domestic violence
Just Alcohol?

- Results of the 2013 National Survey on Drug Use and Health showed that 5.4% of pregnant women had current illicit drug use.
- Of children diagnosed with an FASD, 83% of the mothers reportedly smoked during pregnancy, up to 67% reportedly used illicit drugs during pregnancy, and over 75% of the children were in foster or adoptive care.
- Children born to mothers who used a higher number of different drugs during pregnancy had greater neurocognitive deficits that became more apparent over the course of childhood.

Concurrent use of drugs and alcohol is common, not the exception

- Given the co-morbidity of alcohol and use of other substances, human studies struggle to adequately control for these additional neurodevelopmental exposures during pregnancy, as drugs such as cocaine, opiates, amphetamines, marijuana and tobacco also affect fetal neurodevelopment.
- Attribution of neurodevelopmental disability to prenatal alcohol exposure alone is misleading and restricts diagnosis despite prevailing evidence that exposure to other neurotoxins cause similar neurobehavioral disabilities.
A Disability, _not_ a Disorder

- The federal Individuals with Disabilities Education Act (IDEA) of 2007 _does not_ list FASD as a qualifying diagnosis.
- Only 24% of children with FAS and 7–16% of children with fetal alcohol effects meet the basic criteria of an IQ of below 70, despite having significant neurobehavioral and adaptive function deficits that place as many as 60% of children with FASD at risk for school failure.
- These hidden deficits, often not seen on traditional IQ testing, have been well described as an intellectual disability equivalence that severely impairs the trajectory of their lives.
- The term _neurobehavioral disorder_ should be changed to _neurodevelopmental disability_, as the behavioral disabilities seen in children prenatally exposed to neurotoxins are but manifestations of an underlying dysgenesis of the central nervous system during neurodevelopment.
- This nomenclature highlights the disability, rather than the often difficult to manage behaviors these children and their families struggle with, while implying the need for disability-specific services under the imperative of the Individuals with Disabilities Education Act.

A Disability by any other Name

The facial features, so important to bringing recognition of the effects of alcohol exposure on neurodevelopment, have now become secondary to the greater, more hidden cognitive and behavioral challenges children with prenatal neurotoxic exposure face each day. Although the physical exam findings remain important sentinel signs of underlying brain abnormalities, the disabilities found in these children with special needs point to where our real work must begin.
Because of the persistent nature of the impairments associated with prenatal alcohol exposure, there is need for interventions that address the manifestations of these impairments across the entire life-span.


Interventions

• Highly structured, consistent routines
• Limited stimulation
• Simplicity with concrete language and examples
• Repetition
• Realistic expectations
• Supportive environments
• Supervision
Specific Interventions

- Parent-focused interventions (education, support, strategies for behavioral management, parent-parent)
- Environmental Modification (creating external nervous system support)
- Developmental Interventions (EI, Speech, PT/OT, adaptive/social)
- Educational Interventions (teacher education, realistic educational and behavioral expectations (IEP), PBIS, ABA, CBT, vocational training)
- Psychiatric Interventions
- Juvenile Court Diversion Programs
- Transition to Adulthood (relationships, job support, money management, housing support)

Building Community-Based FASD-Specific Intervention Services

**Diagnostic, Medical & Mental Health Services**
- Neuropsychiatric Testing
- Psychiatric Treatment and Medication Management

**Early Intervention**
- PT, OT,
- Speech/Language,
- Adaptive
- Social Communication
- Sensory Processing

**Parent Support & Advocacy Networks**
- Education
- Emotional Support for Birth Parents and Caregivers
- Respite
- Advocacy within Educational, Legal, Juvenile Justice & Social Services

**CSE Services**
- Least Restrictive Environment
- PT, OT,
- Speech/Language

**Individual Skills Training**
- Encouragement with focus on strengths
- Social/Friendship Skills
- Teen Groups, Mentors
- Personal Safety & Adaptive Skills
- Executive Function Skills
- Time & Money Management
- DBT, CBT

Adapted from Carmichael Olson
Challenges for FASD Prevention and Treatment

- The name: stigma against persons with substance use disorder
- Difficulty confirming maternal alcohol use during pregnancy (alcoholism and denial, lack of communication between prenatal and post-natal care providers)
- There is no medical test to confirm diagnosis
- Nearly half of all pregnancies are unplanned and many women do not know they are pregnant at the most crucial time of early brain development
- Professionals who provide services to women of childbearing age lack knowledge or training in FASD and those who provide care to children with FASD lack training in diagnosis
- No FASD specific treatment referral sources exist

It’s in the culture

- Alcohol is legal and advertising targets people of child-bearing age
- 3 in 4 women who want to get pregnant report drinking alcohol.
- Fetal alcohol spectrum disorders are 100% preventable.
The Treatment for Alcoholism is Alcoholics Anonymous

- A.A. World Services, Inc.,
  Box 459, Grand Central Station,
  New York, NY 10163
  Tel. (212) 870-3400.
  www.aa.org

The New York Juvenile Asylum 1851

Tell the boys of the New York Juvenile Asylum that they must follow Truth, Justice and Humanity if they wish to become useful and honorable men."
Abraham Lincoln, 1860
Brief Bibliography and References


Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. Streissguth A P; Bookstein F.; Barr HM; Sampson PD; O'Malley K; Young JK. Journal of Developmental & Behavioral Pediatrics. 25(4):228-238, August 2004