Diagnosis of Children with Fetal Alcohol Neurodevelopmental Disorder

Douglas Waite, MD
Assistant Professor of Pediatrics, Mount Sinai Hospital
Medical Director
The Keith Haring Clinic at Children’s Village
Dobbs Ferry, New York
“Each of their mothers was an alcoholic” 1973

The most preventable 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

Among binge drinkers, pregnant women reported a statistically significant higher frequency of binge drinking than non-pregnant women.

MMWR, 9/25/15
Placement 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.
Misdiagnosis and Missed Diagnoses in Foster and Adopted Children With Prenatal Alcohol Exposure

Ira J. Chasnoff, MD, Anne M. Wells, PhD, Lauren King, MA

**Objective:** The purpose of this article is to assess the rate of misdiagnosis and missed diagnoses of fetal alcohol spectrum disorders (FASD) among a population of foster and adopted youth referred to a children's mental health center.

**Methods:** Data were collected from a sample of 547 children who underwent a comprehensive multidisciplinary diagnostic evaluation. Utilizing current diagnostic criteria, children were diagnosed, as appropriate, with fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol-related neurodevelopmental disorder, or alcohol-related birth defects. Changes in rates of alcohol exposure-related diagnoses and cooccurring mental health disorders pre- and postassessment were analyzed by using McNemar's test for dependent proportions.

**Results:** Among 156 children and adolescents who met criteria for a diagnosis within the fetal alcohol spectrum, 125 had never been diagnosed as affected by prenatal alcohol exposure, a missed diagnosis rate of 80.1%. Of the 31 who had been recognized before referral as affected by prenatal alcohol exposure, 10 children's FASD diagnoses were changed within the spectrum, representing a misdiagnosis rate of 6.4%. The remaining 21 (13.5%) children's diagnoses stayed the same. There also were significant changes in the rate of mental health diagnosis, and learning disorders, communication disorders, and intellectual disability, objective signs of neurocognitive damage, were not recognized in a significant number of children with FASD.

**Conclusions:** Within this clinical sample, 86.5% of youth with FASD had never been previously diagnosed or had been misdiagnosed. These high rates of missed diagnoses and misdiagnosis have significant implications for intervention and therapeutic services.
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)
The traces of prenatal alcohol exposure can sometimes be seen in the face.
FAS Identification

Criteria:
- Growth abnormalities
- Facial abnormalities
- CNS abnormalities
- Confirmed or suspected intrauterine alcohol exposure
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.
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).

Cells killed by alcohol have taken up dark blue stain.
# Sensitive Periods of Embryological Development

<table>
<thead>
<tr>
<th>Period</th>
<th>Main Embryonic Period (in weeks)</th>
<th>Fetal Period (in weeks)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not susceptible to teratogenesis</td>
<td>Death of embryo and spontaneous abortion common</td>
</tr>
</tbody>
</table>

### Neural Tube Defects (NTDs)
- **TA, ASD, and VSD**
- **Amelia/Meromelia**
- **Cleft lip**
- **Low-set malformed ears and deafness**
- **Microphthalmia, cataracts, glaucoma**

### Mental Retardation
- **Heart**
- **Upper limb**
- **Lower limb**
- **Upper lip**
- **Ears**
- **Eyes**
- **Teeth**
- **Enamel hypoplasia and staining**
- **Cleft palate**
- **Masculinization of female genitalia**
- **External genitalia**
- **Palate**

### Common site(s) of action of teratogens
- Normal
- Less sensitive period
- Highly sensitive period
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
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

### Developmental Age and FASD

**Actual age = 18 years**

<table>
<thead>
<tr>
<th>Skill</th>
<th>Developmental Age Equivalent</th>
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<tbody>
<tr>
<td>Expressive Language</td>
<td>20yrs.</td>
</tr>
<tr>
<td>Comprehension</td>
<td>6yrs.</td>
</tr>
<tr>
<td>Money, Time Concept</td>
<td>8yrs.</td>
</tr>
<tr>
<td>Emotional Maturity</td>
<td>6yrs.</td>
</tr>
<tr>
<td>Physical Maturity</td>
<td>18yrs.</td>
</tr>
<tr>
<td>Reading Ability</td>
<td>16yrs.</td>
</tr>
<tr>
<td>Social Skills</td>
<td>7yrs.</td>
</tr>
<tr>
<td>Living Skills</td>
<td>11yrs.</td>
</tr>
</tbody>
</table>

Source: Adapted from: Research findings of Streissguth, Claren et al.  
Diane Malbin, 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 Delay 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)
Fetal Alcohol Neurodevelopmental Delay Across the Lifespan of Childhood

**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 Delay 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 Delay 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
How can prenatal alcohol-exposure be determined?

- Maternal history or disclosure
- 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
Challenges for FASD Prevention and Treatment

- 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.
- More than 50% of women who might become pregnant report drinking alcohol and 12.4% of women of childbearing age report binge drinking.
- Meconium testing is expensive and universal screening is not legally mandated.
- 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.
- There is no medical test to confirm diagnosis.
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
Structured, consistent and realistic interventions

• Realistic expectations
• Consistent routines
• Limited stimulation
• Concrete language and examples
• Multi-sensory learning (auditory, visual and tactile)
• 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)
It’s in the culture

- More than 3 million US women are at risk of exposing their developing baby to alcohol.
- 3 in 4 women who want to get pregnant as soon as possible report drinking alcohol.
- 100% Fetal alcohol spectrum disorders are completely 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
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