A Disability by any Other Name

Why Children with Fetal Alcohol Neurodevelopmental Disorder Have Not Been Diagnosed and Treated (and what you can do about it)

Douglas Waite, MD
Assistant Professor of Pediatrics, Mount Sinai Hospital
Medical Director
The Keith Haring Clinic, Children’s Village
Dobbs Ferry, New York
Learning Objectives

- Highlight the history of fetal alcohol spectrum disorders and how this has shaped hesitancy to diagnose children and adults with this neurodevelopmental disability
- Identify the signs and symptoms that may indicate the presence of Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)
- Why FASD should qualify as a disability under IDEA
- 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

Prevalence of Common Causes of Disability (per 1,000)

- ASD: 14.6
- Trisomy 21: 1.3
- Cerebral Palsy: 3.0
- FAS: 6.0
- FASD: 48.0


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 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.

www.nofas.org
...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)
Traces of fetal alcohol exposure can sometimes be seen in the face
Prenatal alcohol-exposure affects the most basic processes of development.
- Fetal alcohol related-neurodevelopmental disability occurs in at least 1:100 children
- More recent estimates are 2-5% in the US general population
- It is estimated that as many as 70% of children in foster care have had fetal alcohol exposure
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) shows that cells killed by alcohol have taken up dark blue stain.
# Sensitive Periods of Embryological Development

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period of dividing zygote, implantation, and bilaminar embryo</td>
<td></td>
</tr>
<tr>
<td>Embryonic disc</td>
<td></td>
</tr>
<tr>
<td>Morula</td>
<td></td>
</tr>
<tr>
<td>Amnion</td>
<td></td>
</tr>
<tr>
<td>Blastocyst</td>
<td></td>
</tr>
<tr>
<td>Not susceptible to teratogenesis</td>
<td></td>
</tr>
<tr>
<td>Death of embryo and spontaneous abortion common</td>
<td></td>
</tr>
</tbody>
</table>

## Main Embryonic Period (in weeks)

<table>
<thead>
<tr>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>16</th>
<th>32</th>
<th>38</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neural tube defects (NTDs)</td>
<td>Mental retardation</td>
<td>CNS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TA, ASD, and VSD</td>
<td>Heart</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amelia/Meromelia</td>
<td>Upper limb</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amelia/Meromelia</td>
<td>Lower limb</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleft lip</td>
<td>Upper lip</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low-set malformed ears and deafness</td>
<td>Ears</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Microphthalmia, cataracts, glaucoma</td>
<td>Eyes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enamel hypoplasia and staining</td>
<td>Teeth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleft palate</td>
<td>Palate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Masculinization of female genitalia</td>
<td>External genitalia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Major congenital anomalies

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

## Functional defects and minor anomalies
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 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 and adults have borderline to low average cognitive ability

Neurodevelopmental 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 and adults with FASD have IQ scores that may fail to reflect the full range of their intellectual deficits
- Most people 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 = 18 years

<table>
<thead>
<tr>
<th>Skill</th>
<th>Developmental Age Equivalent</th>
</tr>
</thead>
<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, Clarren 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

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

- 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.
- Drugs such as cocaine, opiates, amphetamines, marijuana and tobacco also affect fetal neurodevelopment.
- Fetal alcohol spectrum disorders are a paradigm for exposure to other neurotoxins that cause similar neurobehavioral disabilities.
A Disability, *not* a Disorder

- The term *neurodevelopmental disorder* should be changed to *neurodevelopmental disability*, as the behavioral disabilities seen in adults and 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

- Only a fraction of children and adults with FASD meet criteria for Part B of IDEA, often only qualifying in the category of learning disabled, behavior disorder, or other health impairments.
- 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, severely impair the trajectory of their lives.
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
Building Community-Based FASD-Specific Intervention Services

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

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

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

**Support & Advocacy Networks**
- Education
- Emotional support for birth parents and caregivers
- Advocacy within Educational, Legal, Juvenile Justice & Social Services

**Individual Skills Training**
- Focus on strengths
- Social/Friendship Skills
- Teen Groups, Mentors
- Personal Safety & Adaptive Skills
- Executive Function Skills
- Time & Money Management
- DBT, CBT
Where do We Go From Here?

- Expand focus beyond national education to developing local on-the-ground services
- Funding (local non-profit organizations, individuals, state and local government grants)—donors like to give local
- Regional conferences on FASD to local build coalitions
- Advocate and develop community-based services for families of children with prenatal alcohol and drug exposure
- National partners already in place include NOFAS, AAP, CDC, Administration for Children & Families, CWLA
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