A Disability by any Other Name

Why Children with Fetal Alcohol Neurodevelopmental Disorder are not Identified and Treated (and what you can do about it)

Learning Objectives

- Describe how the history of fetal alcohol spectrum disorders has shaped hesitancy to diagnose children with this neurodevelopmental disability
- Identify signs of Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)
- Describe FASD-specific interventions and why FASD should qualify as a disability under IDEA
- Encourage pediatricians to screen each of their patients for prenatal alcohol exposure and identify children with possible ND-PAE

“Each of their mothers was an alcoholic”


Alcohol Use and Binge Drinking Among Women of Childbearing Age—United States, 2011-2013

- 11.5% of US pregnant women drank alcohol in the past 30 days
- 3.9% of pregnant women reported binge drinking in the past 30 days
- The prevalence of binge drinking among nonmarried pregnant women almost 3 times the prevalence of married pregnant women.
- Among non-pregnant women, prevalence of alcohol use and binge drinking was 53.6% and 18.2%
No woman drinks because she wants to hurt her baby

Mean ratings of difference, disdain, and blame for serious mental illness (SMI), substance use disorder (SUD), jail, and fetal alcohol spectrum disorder (FASD).


The Most Common Cause of Intellectual Disability and Birth Defects in The United States

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

FASD is Especially Prevalent in Foster Care

Of 1,400 children diagnosed with FASD:
- 70% were no longer in the care of their birth parents and had on average three out-of-home placements.
- At least 34% were physically abused and 24% sexually abused.
- 75% had one or more documented mental health disorders, the most prevalent being ADHD (53.9%).
- 93% percent had other prenatal exposures
...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 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
- 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 development across species

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

mouse fetus

alcohol-exposed normal
- Fetal alcohol syndrome occurs in about 1 in 1,000 children (facial features, growth deficits and neurocognitive disabilities)
- The greater continuum of fetal alcohol spectrum disorders occurs in 2-5% in the US general population
- Nine in ten children affected by prenatal alcohol exposure do not have facial features of FAS

**Comparison of the face (A) and interior brain (B) of a normal mouse embryo and one damaged by alcohol (C&D).** The nostrils are abnormally positioned (C), the brain is missing midline structures (D).

Alcohol kills specific cells in the developing brain depending upon the stage of development

A ten-day mouse embryo (corresponding to a 28-day human embryo)

Cells killed by alcohol have taken up dark blue stain

**Sensitive Periods of Embryological Development**
“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

A Hidden Disability

The Strange Tale of Phineas Gage

A Brain-Based Disorder with Behavioral Manifestations

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, switching gears, 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


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)
- DNA methylation and other biomarkers (work-in-progress)

Screening for Prenatal Alcohol Exposure

- How far along in your pregnancy were you when you discovered you were pregnant?
- Before you knew you were pregnant, how many drinks of alcohol (beer, wine, or liquor) did you drink?
- After you found out you were pregnant, how many drinks of alcohol did you drink?
- How often did you use other substances (marijuana, cocaine, opioids)?
- Significant prenatal exposure is 13 drinks/month or more than 2 drinks at one time

Screening for Prenatal Exposure to Alcohol: An Implementation Guide for Pediatric Primary Care Providers, American Academy of Pediatrics, 2018.
Obtaining History of Prenatal Alcohol Exposure as Routine Care

- Include within the birth history on all initial well child visits.
- In all assessments of children with developmental or behavioral challenges.
- Screen for other substances that are often used with alcohol.

Histories suggestive of possible prenatal alcohol exposure

- Early placement in foster care
- Primary guardian other than the child’s mother
- Child or sibling born with positive urine toxicology to other drugs
- Early childhood behavioral and school difficulties
- Developmental delay (speech, gross/fine motor)
- Two or more past psychiatric diagnoses
- Two of more past psychiatric hospitalizations
- Sibling with a diagnosis of an FASD

Secondary Disabilities


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

- 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 (the ability to function independently in everyday life including communication, socialization, and daily living).
- Low adaptive behavioral skills is a hallmark of FASD.
- Disability equivalence allows accommodations for services despite IQ scores above 70.

<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>Memory, Time Concept</td>
<td>6yrs</td>
</tr>
<tr>
<td>Executive Function</td>
<td>6yrs</td>
</tr>
<tr>
<td>Physical Memory</td>
<td>6yrs</td>
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<tr>
<td>Reading Ability</td>
<td>16yrs</td>
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<tr>
<td>Social Skills</td>
<td>7yrs</td>
</tr>
<tr>
<td>Living Skills</td>
<td>15yrs</td>
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</tbody>
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The Trajectory of FASD

- About 60% of individuals with FASD have a history of trouble with the law.
- 50% have a history of confinement in a jail, prison, residential drug treatment facility, or psychiatric hospital.
- Among 287 youth seen over a year’s time in a Canadian juvenile court, 23.3% had an FASD.
- Youth in juvenile facilities have 40 times the expected rate of FASD compared to the general population.
- The average age children with FASD begin having trouble with the law is 12.8 years.

FASD in adults at 20 year follow up

- 27% Living with mother or father
- 0% Living with their own family
- 0% Living with partner
- 14% Living alone independently
- 3% Institutions
- 35% Dependent-Living

(Spohr, 2007)
Protective Factors

- Diagnosis before 6 years of age
- A diagnosis of FAS (facial features) rather than FAE (no facial features), making early diagnosis feasible
- A stable home for over 70% of one’s lifetime
- Staying in each living situation for more than 2.8 years
- Receipt of therapeutic help and assistance
- Having basic needs met for at least 13% of one’s lifetime

Spohr, 2007

FASD Interventions

- Education of parents, foster parents and teachers
- Family-focused interventions, parent training, re-framing behaviors, use of antecedent strategies
- Direct child interventions with community-based services (early intervention, special education, vocational education)
- Realistic expectations guided by strengths (start where the child is)
- Put supports in place before the child fails, not based on threshold of need
- Coordination across services across systems and developmental ages
- Evidence-based interventions for children with an FASD

What difference does a diagnosis make?

Caregivers who attribute their child’s misbehavior to underlying developmental disabilities are more likely to use antecedent strategies and feel more confident in managing their child’s behavior.

Parents who attribute their child’s misbehavior to willful disobedience are more likely to rely on consequence strategies and feel more ineffective.

A Disability by any other Name

- Currently, only a fraction of children and adults with FASD meet criteria for Part B of IDEA
- Only 24% of children with FAS and 7–16% of children with fetal alcohol effects meet criteria of an IQ of below 70, despite having significant neurobehavorial 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.

A Disability, not a Disorder

- The behavioral disabilities seen in children and adults prenatally exposed to alcohol are manifestations of underlying brain damage that occurred during neurodevelopment.
- By highlighting the disability, rather than the often difficult to manage behaviors these children and their families struggle with, we imply the need for disability-specific services under the imperative of the Individuals with Disabilities Education Act.

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.


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
FASD Advocacy

- Require training for healthcare professionals, early intervention providers, educators, lawyers and judges, and foster parents on FASD
- Parent support services (including FASD education, respite and support groups)
- Screen all children entering the child welfare and juvenile justice systems
- Include FASD as a qualifying diagnosis for vocational and supportive housing
- A diagnosis of any FASD should be eligible for IDEA and OPWDD services

National Task Force on Fetal Alcohol Syndrome, 2009

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

AAP One-Page Handouts

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


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 a network of 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

Choline and FASD