

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)

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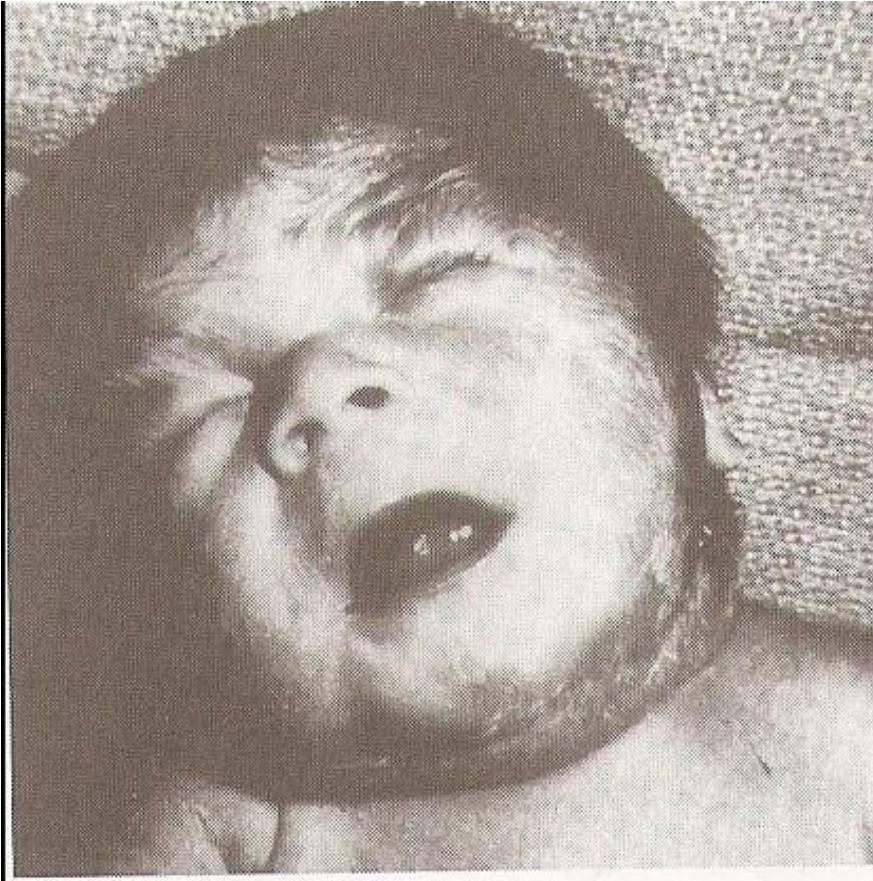
Dobbs Ferry, New York



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

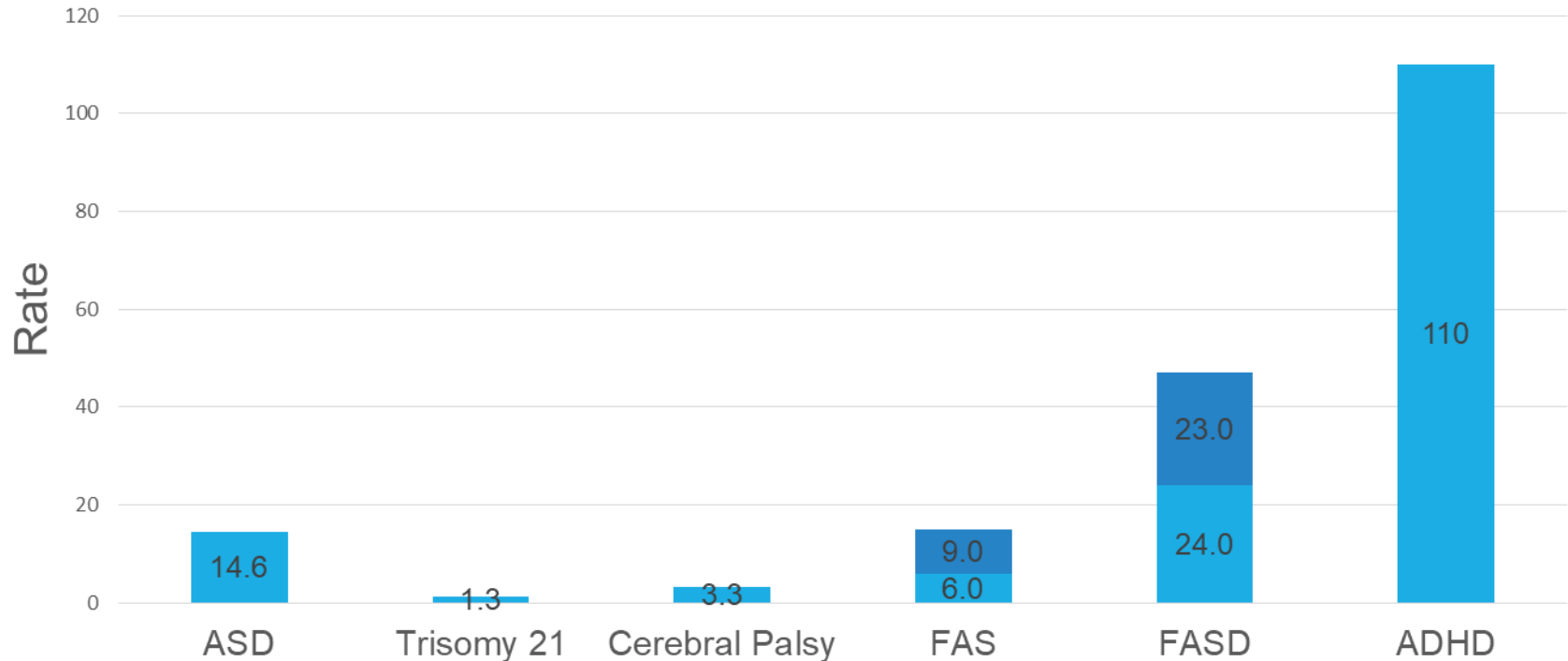
“Each of their mothers was an alcoholic”



Jones, Kenneth L, and David W Smith. "Recognition of the fetal alcohol syndrome in early infancy." *The Lancet* 302.7836 (1973): 999-1001.

The most common cause of intellectual disability and birth defects in the United States

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



Christensen, Deborah L. "Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012." MMWR. Surveillance Summaries 65 (2016).

Parker SE, Mai CT, Canfield MA, et al. Updated national birth prevalence estimates for selected birth defects in the United States, 2004-2006. Birth Defects Res A Clin Mol Teratol. 2010;88:1008-16.

Prevalence of cerebral palsy: Autism and Developmental Disabilities Monitoring Network, three sites, United States, 2004

May PA, Baete A, Russo J, Elliott AJ, Blankenship J, Kalberg WO, Buckley D, Brooks M, Hasken J, Abdul-Rahman O, Adam MP, Robinson LK, Manning M, Hoyme HE. Prevalence and characteristics of fetal alcohol spectrum disorders. Pediatrics. 2014;134:855-66

<https://www.cdc.gov/ncbddd/adhd/data.html>

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

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

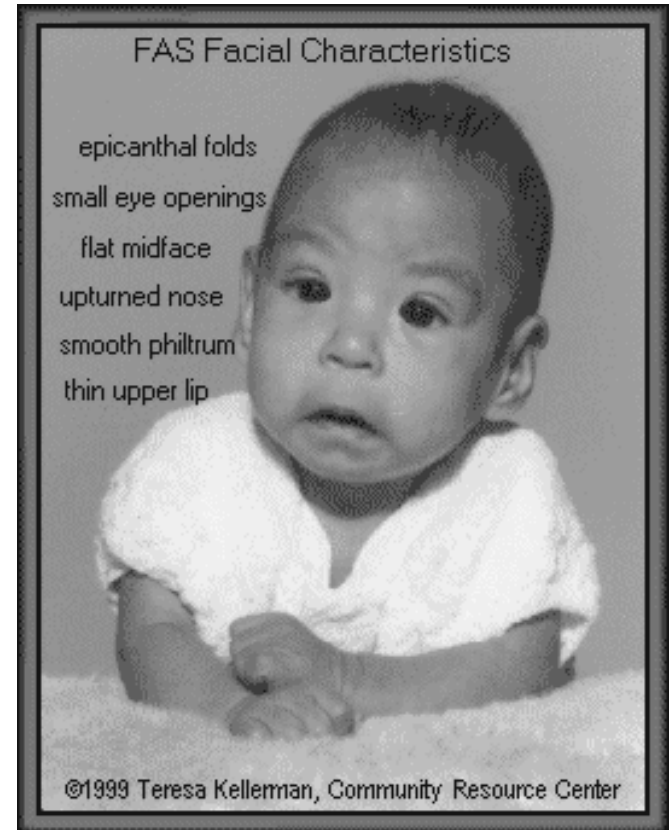
Chasnoff, Ira J., Anne M. Wells, and Lauren King.
"Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure." *Pediatrics* 135.2 (2015): 264-270.

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

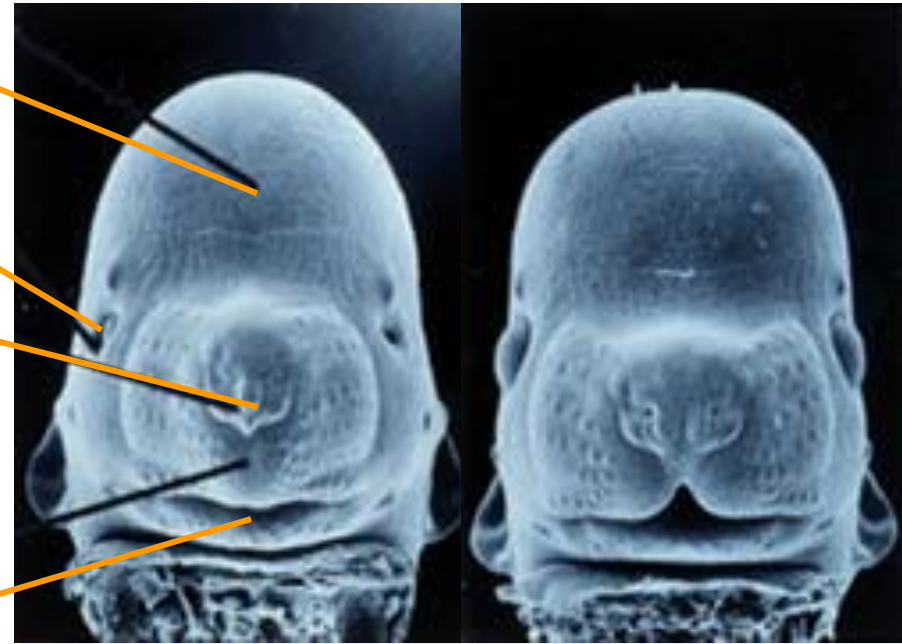


Prenatal alcohol-exposure affects the most basic processes of development

mouse fetus



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



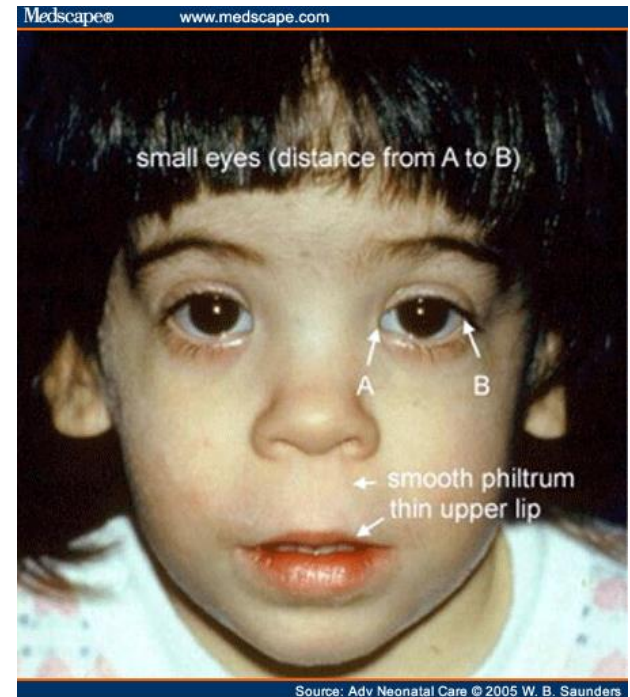
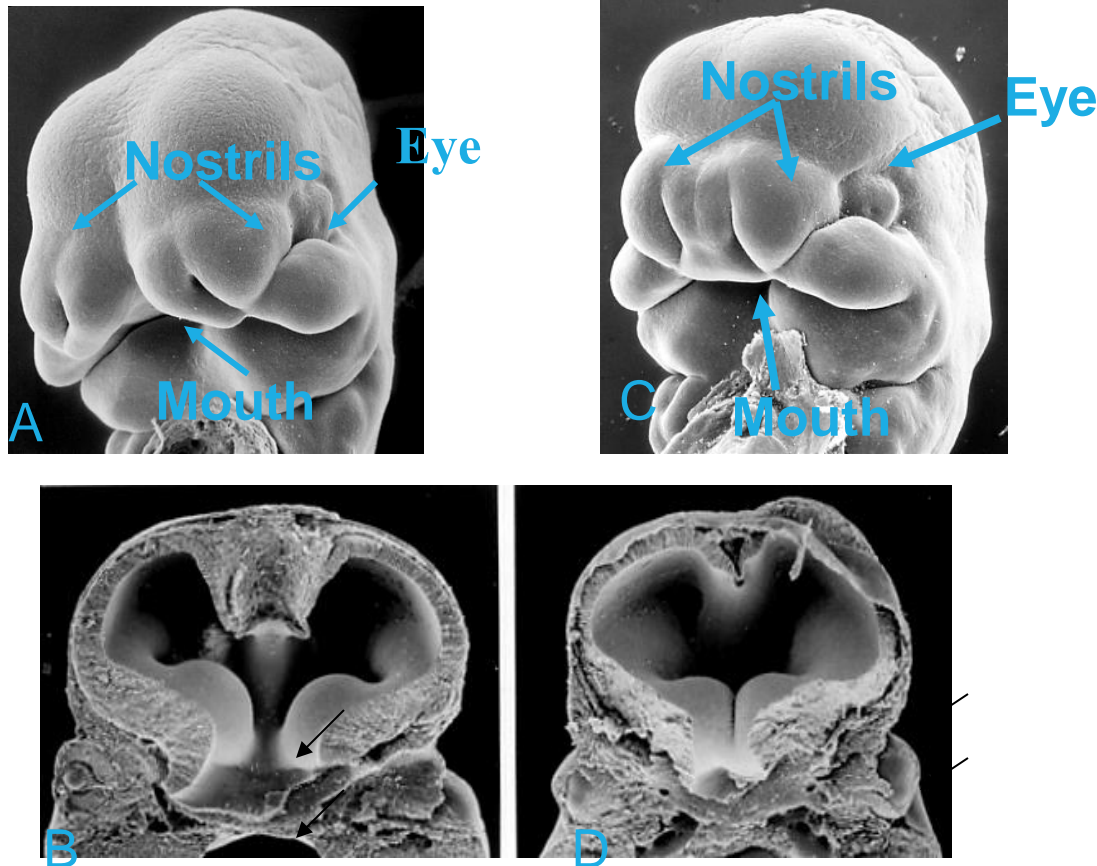
alcohol-exposed

normal



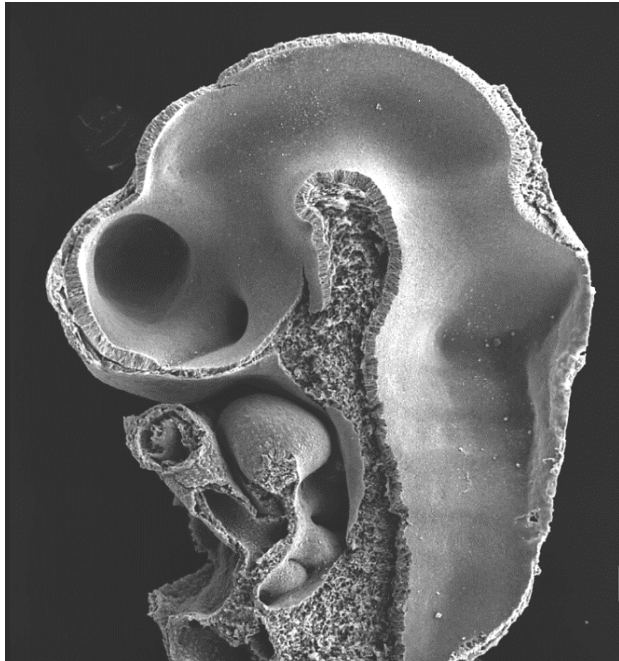
- Fetal alcohol syndrome occurs in about 1 in 1,000 children
- Fetal alcohol related-neurodevelopmental disability occurs in at least 1:100 children
- More recent estimates are 2-5% in the US general population
- The prevalence of FASD in foster care is as high as 67 times greater than in the general population

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



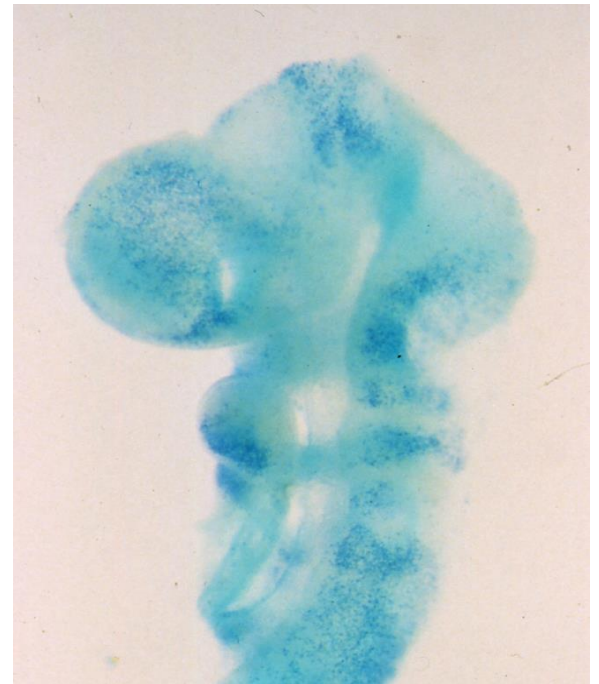
Comparison of the face (A) and interior brain (B) of a normal mouse embryo and one damaged by alcohol (C&D). The nostrils are abnormally positioned (C), the brain is missing midline structures (D)

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

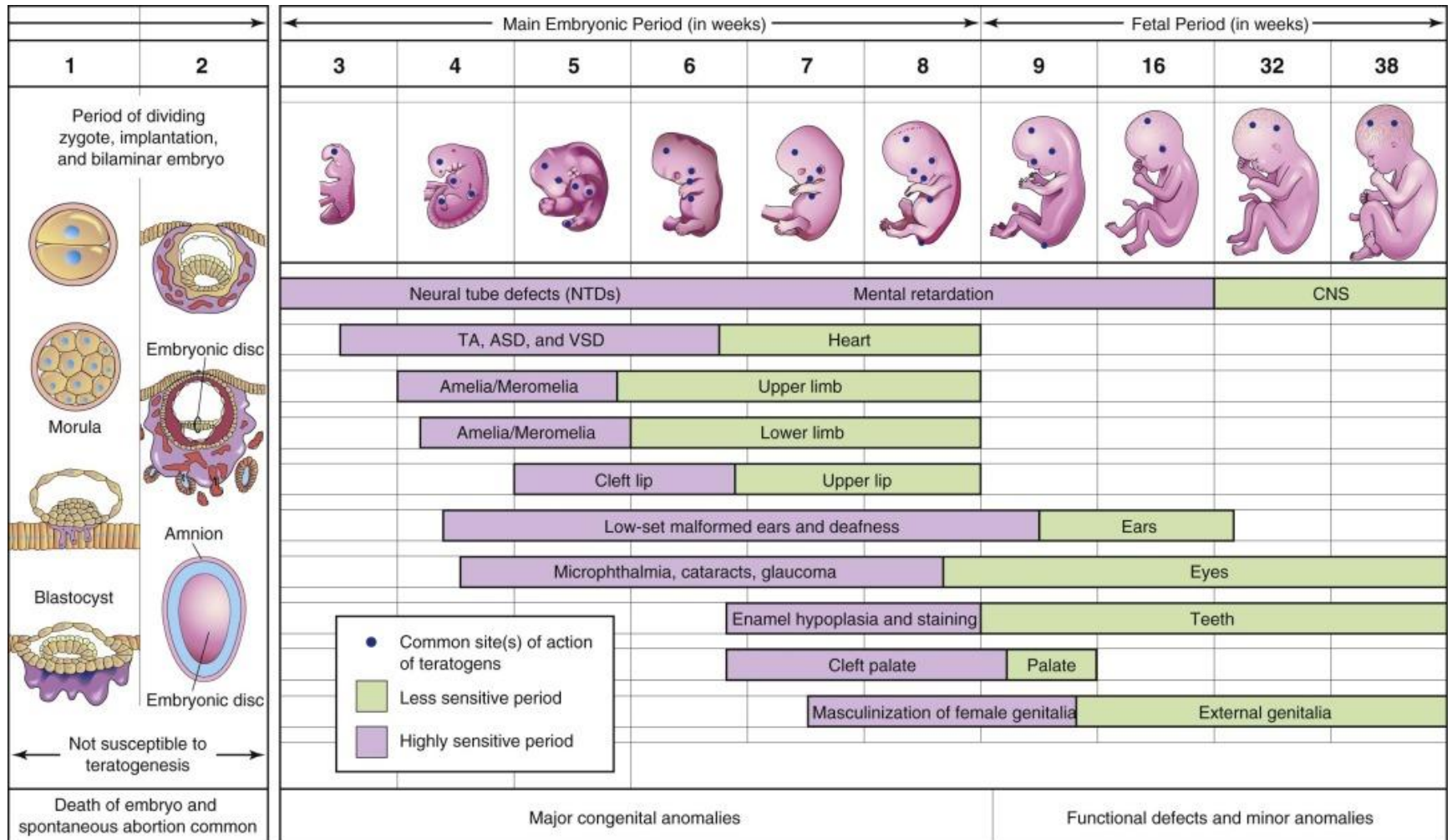


The inside of a 10 day mouse embryo
(corresponding to a 28 day human)

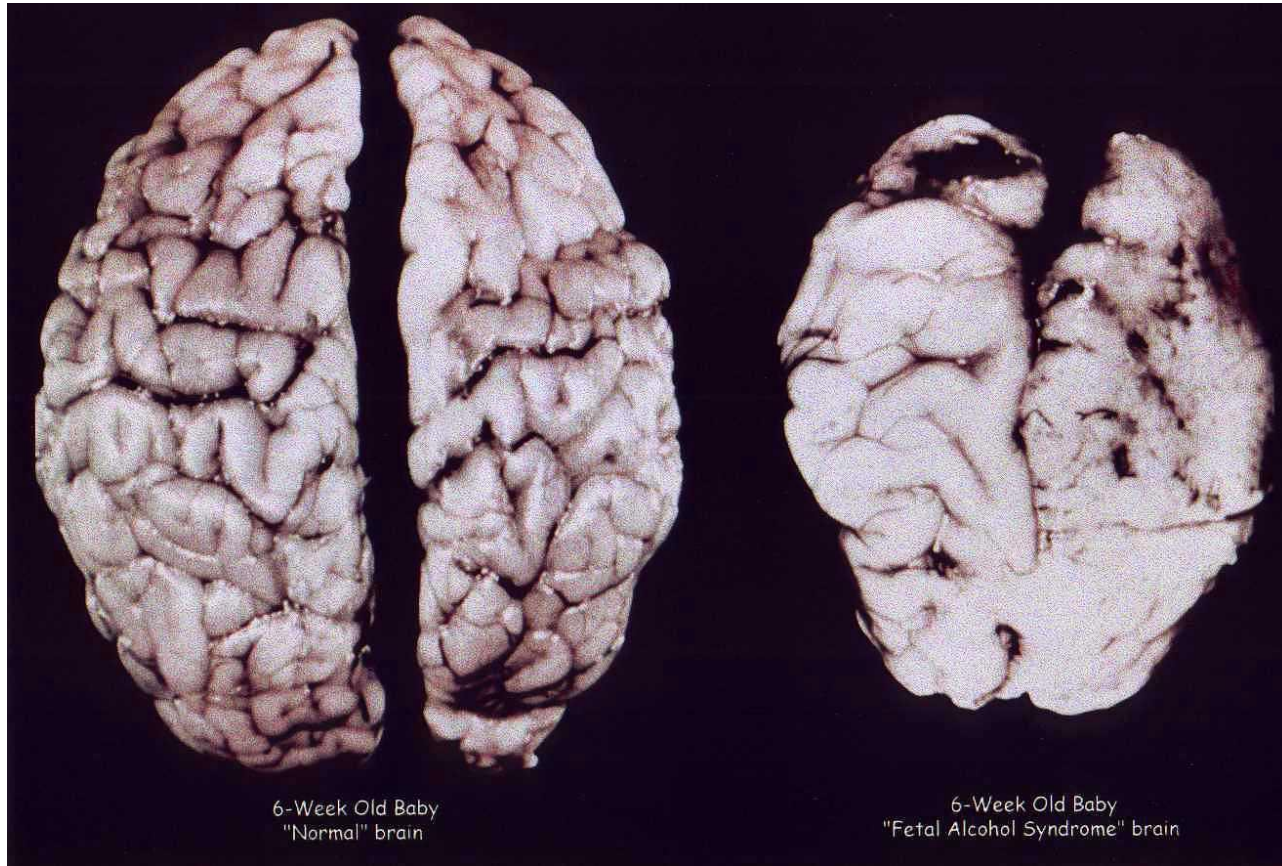
Cells killed by alcohol have
taken up dark blue stain



Sensitive Periods of Embryological Development



The hidden devastation of prenatal alcohol exposure



The Strange, Sad Tale of Phineas Gage



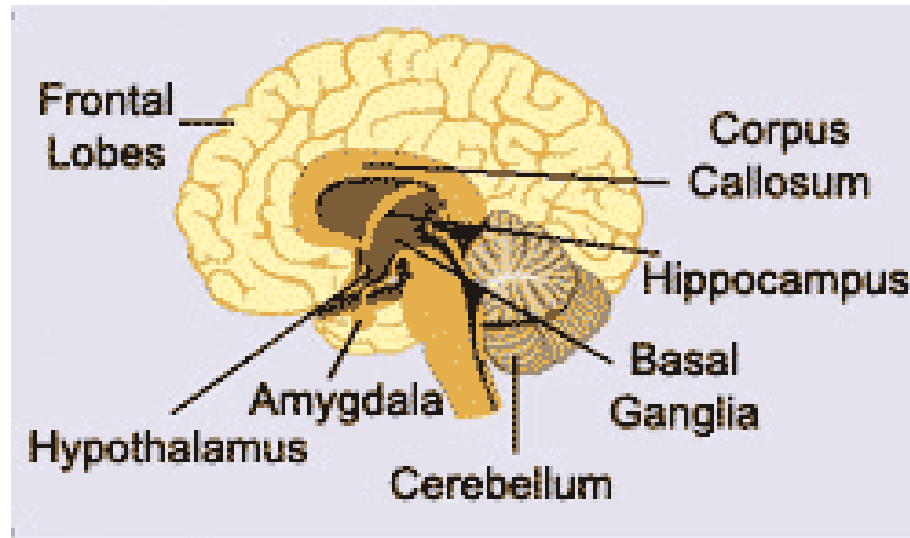
“The equilibrium or balance, so to speak, between his intellectual faculties and animal propensities, seems to have been destroyed. He is fitful, irreverent, indulging at times in the grossest profanity (which was not previously his custom), manifesting but little deference for his fellows, impatient 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



Corpus Callosum- passes information from the left brain (rules, logic) to the right brain (impulse, feelings) and vice versa.

Hippocampus – memory, learning, emotion

Amygdala - emotions

Cerebellum - coordination and movement

Basal Ganglia - spatial memory, transitions, working toward goals, predicting behavioral outcomes, and the perception of time

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

Kodituwakku , P.W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: a review. *Neurosci. Biobehav. Rev.* 31, 192-201.

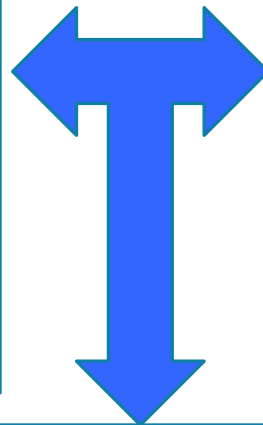
Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

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

FASD and the Concept of Intellectual Disability Equivalence.
Edwards and Greenspan, *Adaptive Behavior and FASD*,
Journal of Psychiatry and Law, (2011), 39 (4): 419-447.

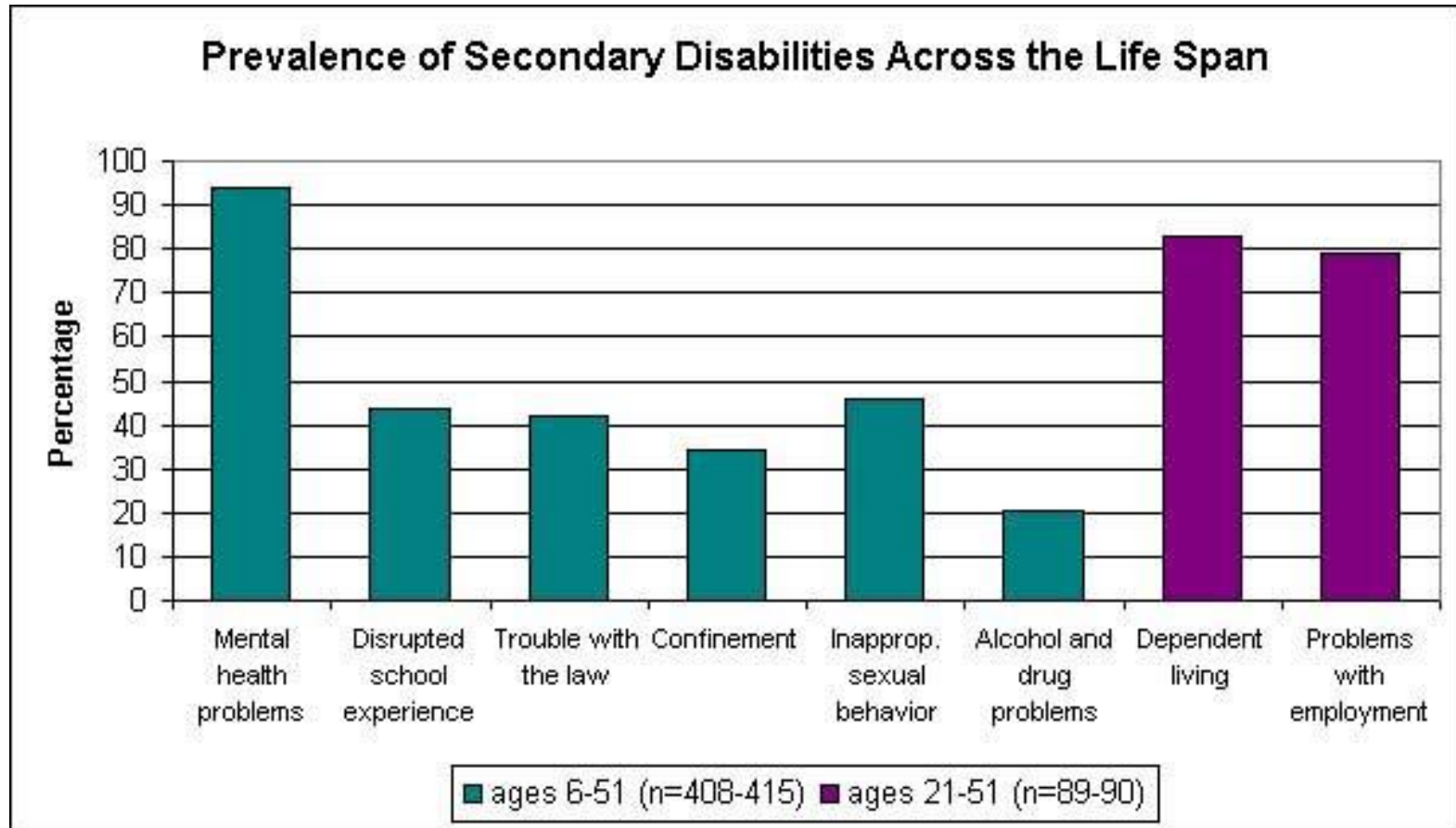
Developmental Age and FASD

Actual age = 18 years

Skill	Developmental Age Equivalent
Expressive Language=====	20yrs.
Comprehension=====	6yrs.
Money, Time Concept=====	8yrs.
Emotional Maturity=====	6yrs.
Physical Maturity=====	18yrs.
Reading Ability=====	16yrs.
Social Skills=====	7yrs.
Living Skills=====	11yrs.

Source: Adapted from: Research findings of Streissguth, Clarren et al.
Diane Malbin, 1994

Secondary Disabilities



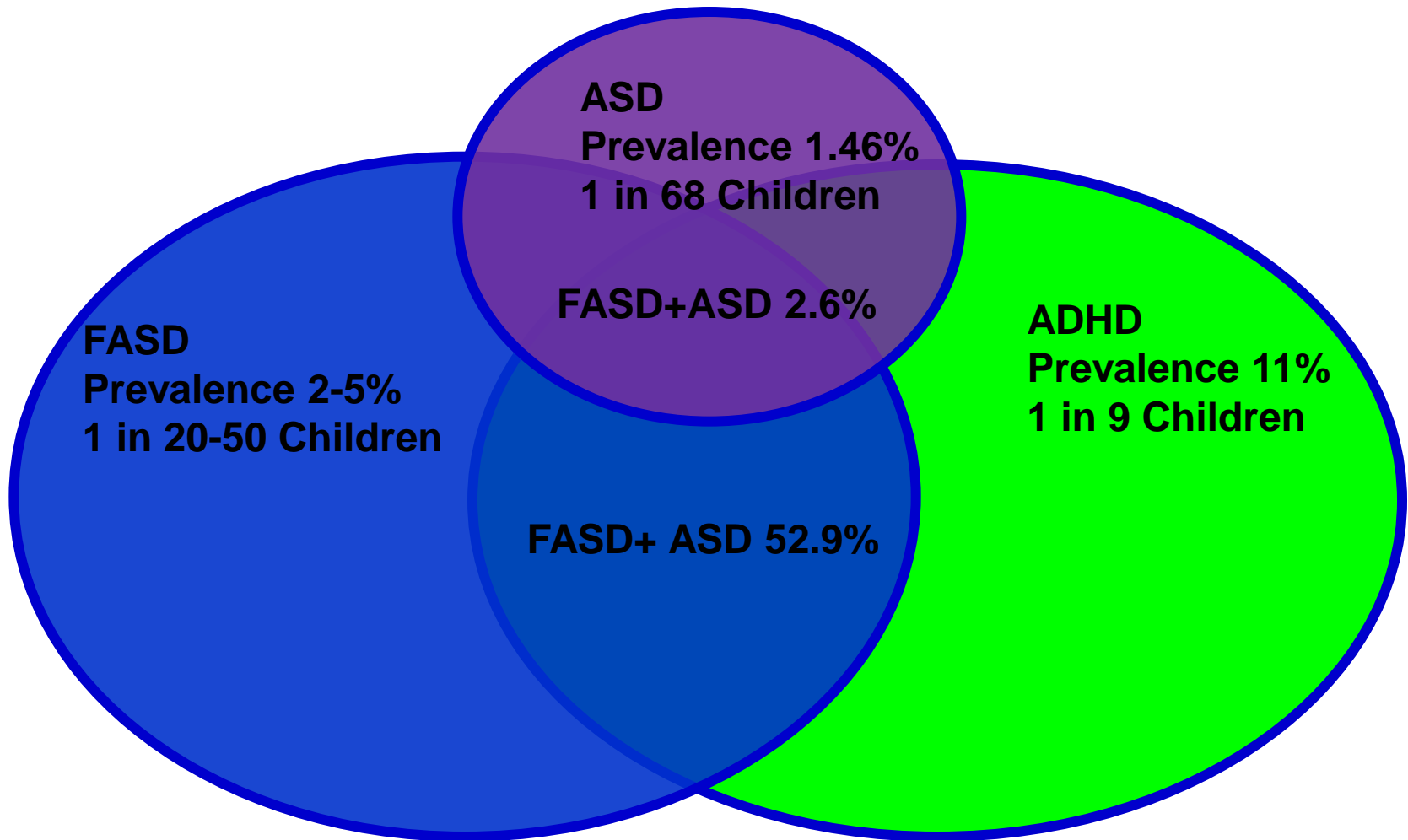
Streissguth, A.P.; Barr, H.M.; Kogan, J.; et al. 1996. *Final Report: Understanding the Occurrence of Secondary Disabilities in Clients With Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*. Seattle: University of Washington Publication Services.

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



Streissguth, A.P.; Barr, H.M.; Kogan, J.; et al. 1996. *Final Report: Understanding the Occurrence of Secondary Disabilities in Clients With Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*. Seattle: University of Washington Publication Services.

The Neurodevelopmental Disorders



Lange S, Rehm J, Anagnostou E, Popova S. Prevalence of Externalizing Disorders and Autism Spectrum Disorder among Children with Fetal Alcohol Spectrum Disorder: Systematic Review and Meta-analysis. *Biochem Cell Biol.* 2017 May 18. <http://www.cdc.gov>

The Neurodevelopmental Disorders

ASD

- Difficulties in relating to others & initiating social interaction
- Restricted patterns of behavior, interests, and activities
- Difficulty sharing feelings and using verbal & nonverbal communication
- Inflexibility to routines and rituals

FASD

- Delayed verbal and non-verbal skills with acquisition of expressive language but persistent difficulties in receptive language
- Acts young for age, indiscriminate friendliness and interpersonal boundaries
- Oppositional and at times aggressive behavior
- Difficulty with transitions and change
- Impulsive, acts without thinking of consequences
- Lying or cheating, steals from inside and outside home
- Difficulty remembering new material and thinking about multiple or abstract concepts
- Deficits in visual-spatial skills, encoding of information, and flexibility in problem solving

ADHD

- Can't concentrate with poor focus and sustained attention
- Can't sit still, restless, hyperactive
- Impulsive or acts without thinking.
- Adaptive behavior improves with age

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
- 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)
- History of domestic violence

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

- 5.4% of pregnant women have illicit drug use during pregnancy (SAMHSA)
- 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
- Drugs such as cocaine, opiates, amphetamines, marijuana and tobacco also affect fetal neurodevelopment
- 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
- Fetal alcohol spectrum disorders are a paradigm for exposure to other environmental 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.

SNAP Screen for Fetal Alcohol Spectrum Disorders

S	Self-regulation
<input type="checkbox"/>	Impairment in mood or behavioral regulation (hyperactive; difficulties with sleep; overly sensitive to sounds, light or touch)
<input type="checkbox"/>	Attention deficit (difficulty shifting attention; difficulty sustaining mental effort; past diagnosis of ADHD)
<input type="checkbox"/>	Impairment in impulse control (impulsive, does not think before acting; difficulty waiting turn or with rules; aggressive, risky behavior; needs constant supervision; lies; steals; school suspensions; inappropriate sexual behavior)
N	Neurocognitive Function
<input type="checkbox"/>	Impairment in global intellectual performance (IQ of 75 or below)
<input type="checkbox"/>	Impairment in executive functioning (poor planning/organization; difficulty following directions; inflexible, difficulty with transitions; difficulty learning from experience, repeatedly makes the same mistakes)
<input type="checkbox"/>	Impairment in learning (requires repeated exposure to learn new concepts; lower academic achievement than expected for intellectual level; specific learning disability; placement in special education; grade retention)
<input type="checkbox"/>	Memory impairment (can't remember one day or one minute to the next; difficulty carrying out multiple step commands)
<input type="checkbox"/>	Impairment in visual-spatial reasoning (disorganized drawing; difficulty copying simple visual patterns, aligning numbers in columns, differentiating left from right, up from down)
A	Adaptive Function
<input type="checkbox"/>	Communication deficit (speech delay; auditory comprehension disorder; difficulty following conversation or understanding directions)
<input type="checkbox"/>	Impairment in social communication and interaction (acts young for age; overly friendly with strangers, poor interpersonal boundaries; difficulty reading social cues; easily led by others, gullible or naive; difficulty interacting with friends/peers)
<input type="checkbox"/>	Impairment in daily living skills (difficulty with activities of daily living, daily schedule, time, money, appointments, employment)
<input type="checkbox"/>	Impairment in motor skills (fine or gross motor delay; difficulties in coordination, accident prone; discoordination)
P	Prenatal Exposure to Alcohol
<input type="checkbox"/>	Confirmed prenatal exposure (list source of confirmation)
<input type="checkbox"/>	Unconfirmed but with risk factors for prenatal alcohol exposure <ul style="list-style-type: none"> Placement in foster care or primary guardian other than the child's mother Early childhood behavioral and school difficulties Low birth weight, poor growth in weight or stature Child/sibling born with positive urine toxicology to illegal drugs History of homelessness, domestic violence, parental psychiatric illness Late, inconsistent or no prenatal care
<input type="checkbox"/>	Indeterminate (no available records or prenatal information available)
<input type="checkbox"/>	No known prenatal alcohol or other drug exposure (list source of information)

“Several months ago he jumped in the gap between the train and the platform on 125th street. He was not upset or obviously dysregulated. I was holding his hand and able to pull him back up to the platform. He requires constant supervision outside because he frequently wanders into the street or will bolt from the play ground into oncoming traffic seemingly unaware of danger.”

“There's no more head-banging, fecal smearing, night terrors, vomiting, episodes of inconsolable sobbing etc. However, he gets up 4-6x per night, very calmly but cannot sleep through out the night..”

“He is extremely empathetic, sometimes to the point where I think it becomes a negative and he takes on other people's emotions. He's always asking people if they are ok, brings his artwork home as gifts for his siblings etc. He's also excellent at imitating people's mannerisms. He is very imaginative and enjoys drawing, loves swimming, very affectionate, loves to be read to, remembers parts of the book and asks questions.”

“He continues to have episodes of inconsolable sobbing at home where the cause is not clear. He can get stuck on an idea, repeating a phrase over and over again even if it doesn't fully make sense. For example, I want to go home when we are home.”

“He's very interested in friends, but has no sense of personal space which is often interpreted as aggression on the playground but he's definitely gentle just has no boundaries. ”

“He seems to know colors or counting on Monday but not remember on Tuesday.”

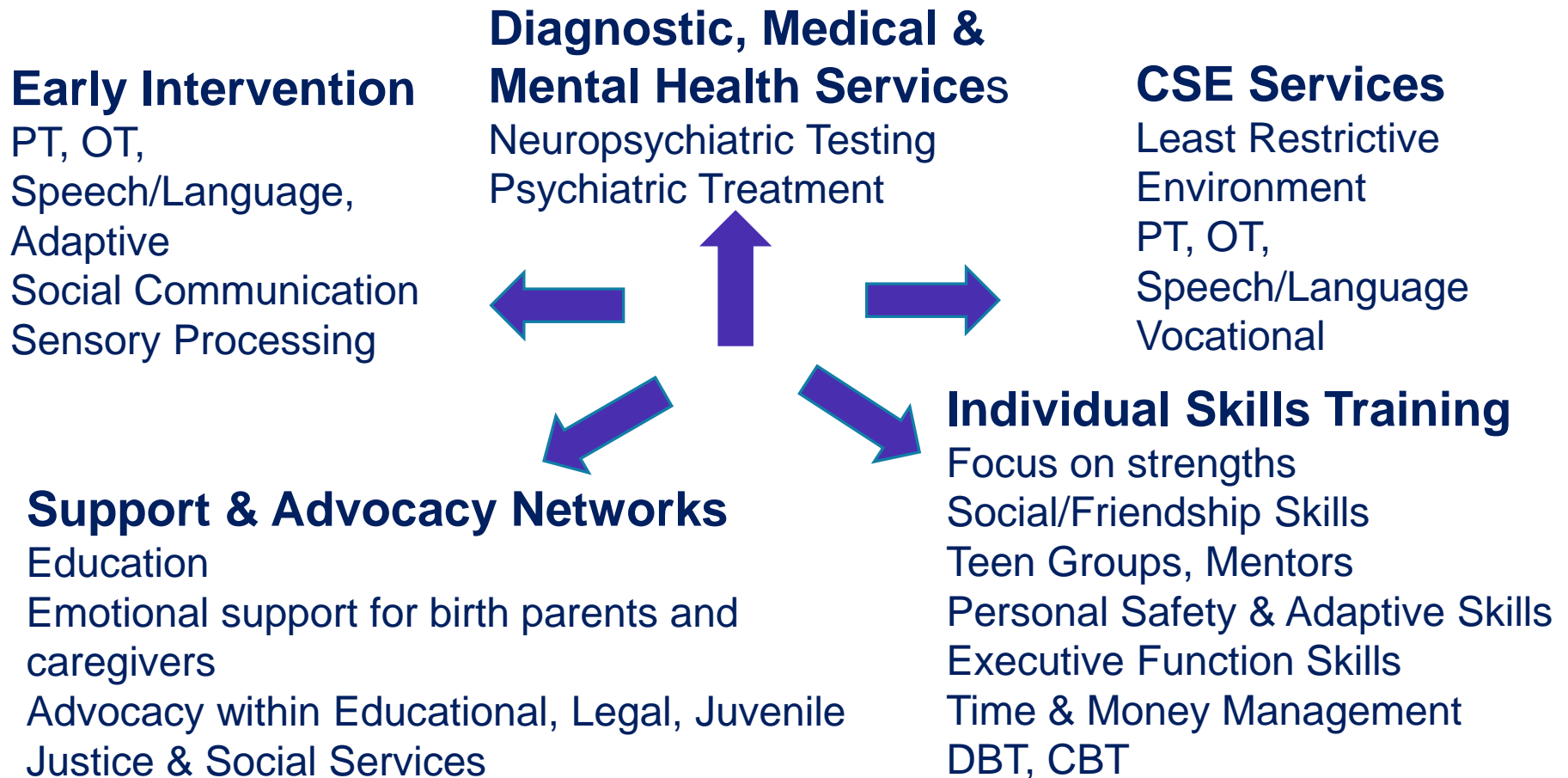
Because of the persistent nature of the impairments associated with prenatal alcohol exposure, there is need for interventions that address the manifestations of these impairments across the entire life-span.

Paley, Blair, and Mary J. O'Connor. "Intervention for individuals with fetal alcohol spectrum disorders: treatment approaches and case management." *Developmental disabilities research reviews* 15.3 (2009): 258-267.

Interventions

- Education of parents and foster parents
- Highly structured, consistent routines
- Limited stimulation
- Simplicity with concrete language and examples
- Repetition
- Realistic expectations
- Supportive environments
- Supervision

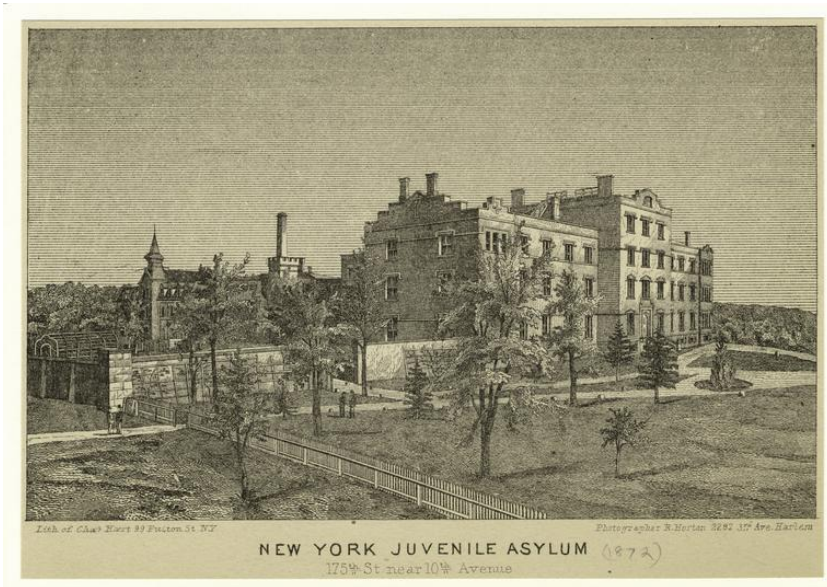
Building Community-Based FASD-Specific Intervention Services



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

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

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McCance-Katz, Elinore F., Thomas R. Kosten, and Peter Jatlow. "Concurrent use of cocaine and alcohol is more potent and potentially more toxic than use of either alone—a multiple-dose study." *Biological psychiatry* 44.4 (1998): 250-259.

Prenatal Alcohol Exposure and Educational Achievement in Children Aged 8–9 Years
Colleen M. O'Leary, Cate Taylor, Stephen R. Zubrick, Jennifer J. Kurinczuk, and Carol Bower. *Pediatrics* 2013; 132:2 e468-e475; published ahead of print July 8, 2013, doi:10.1542/peds.2012-3002 .

Stephen, J. M., Kodituwakku, P. W., Kodituwakku, E. L., Romero, L., Peters, A. M., Sharadamma, N. M., Caprihan, A. and Coffman, B. A. (2012), Delays in Auditory Processing Identified in Preschool Children with FASD. *Alcoholism: Clinical and Experimental Research*, 36: 1720–1727.

Kodituwakku , P. W. Kodituwakku , E. L. (2011). From research to practice: An integrative framework for the development of interventions for children with fetal alcohol spectrum disorders. *Neuropsychology Review*, 21, 204-223.

Nash K, Rovet J, Greenbaum R, Fantus E, Nulman I, Koren G. Identifying the behaviora phenotype in Fetal Alcohol Spectrum Disorder: sensitivity, specificity and screening potential. *Arch Womens Ment Health*. 2006 Jul;9(4):181-6. Epub 2006 May 3. PubMed PMID: 16673042

Paley, Blair, and Mary J. O'Connor. "Intervention for individuals with fetal alcohol spectrum disorders: treatment approaches and case management." *Developmental disabilities research reviews* 15.3 (2009): 258-267.

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O'Leary, C., Leonard, H., Bourke, J., D'Antoine, H., Bartu, A. and Bower, C. (2013), Intellectual disability: population-based estimates of the proportion attributable to maternal alcohol use disorder during pregnancy. *Developmental Medicine & Child Neurology*, 55: 271–277.

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Bishop S, Gahagan S, Lord C. Re-examining the core features of autism: a comparison of autism spectrum disorder and fetal alcohol spectrum disorder. *J Child Psychol Psychiatry*. 2007 Nov;48(11):1111-21. PubMed PMID: 17995487.

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