

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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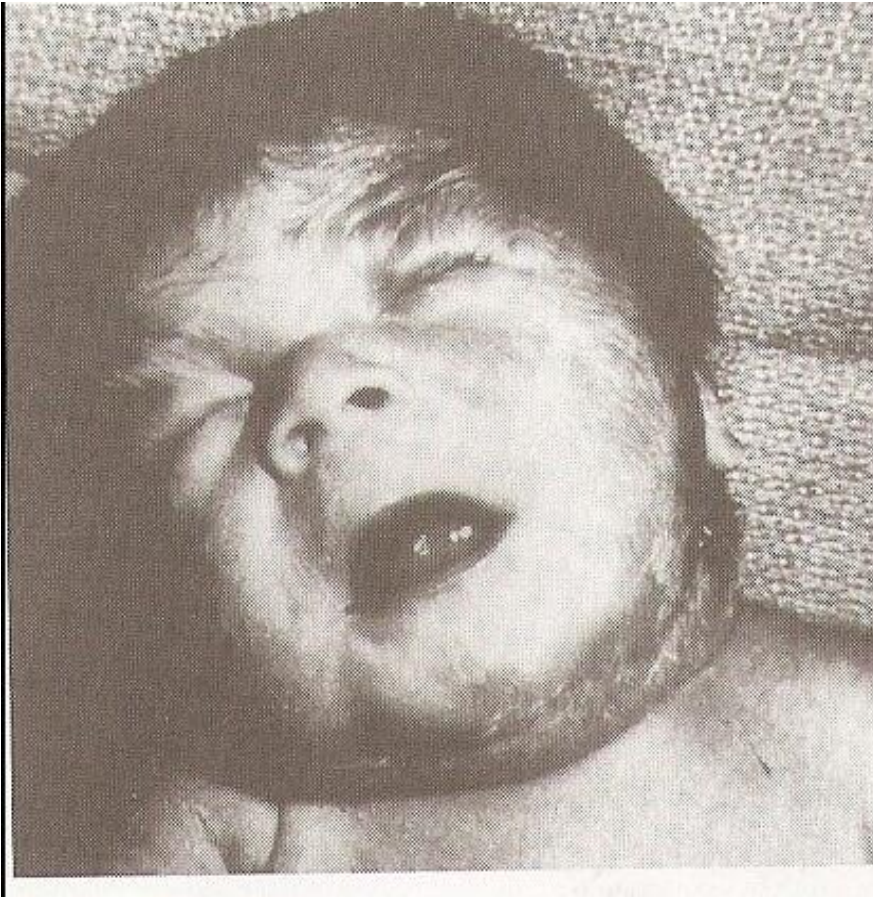
Dobbs Ferry, New York



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

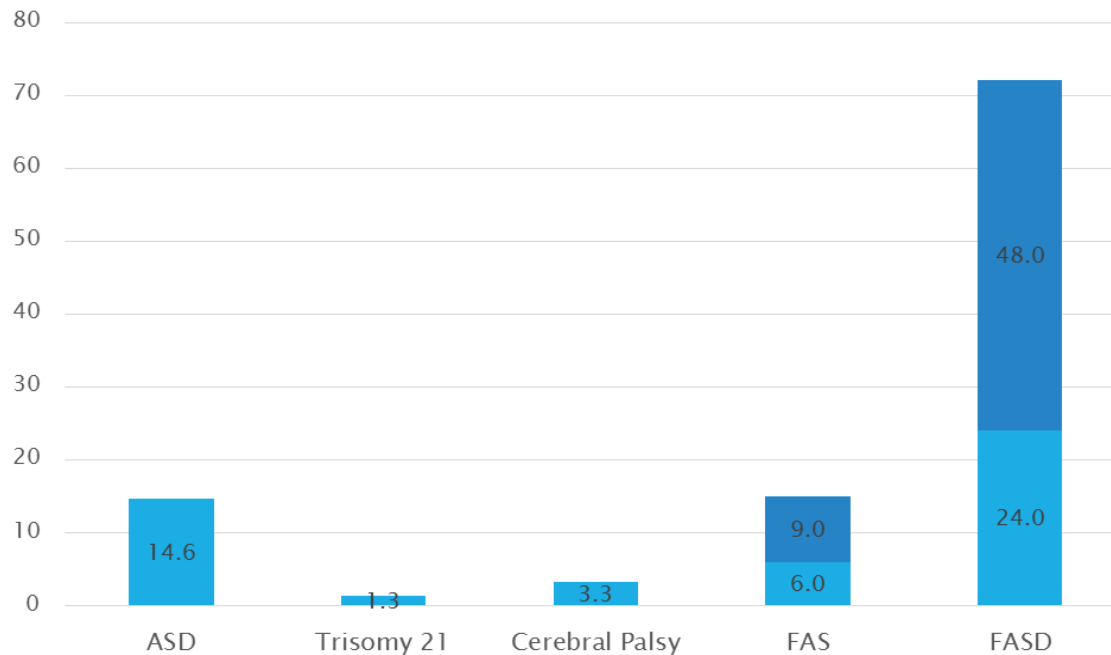
“Each of their mothers was an alcoholic”



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

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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

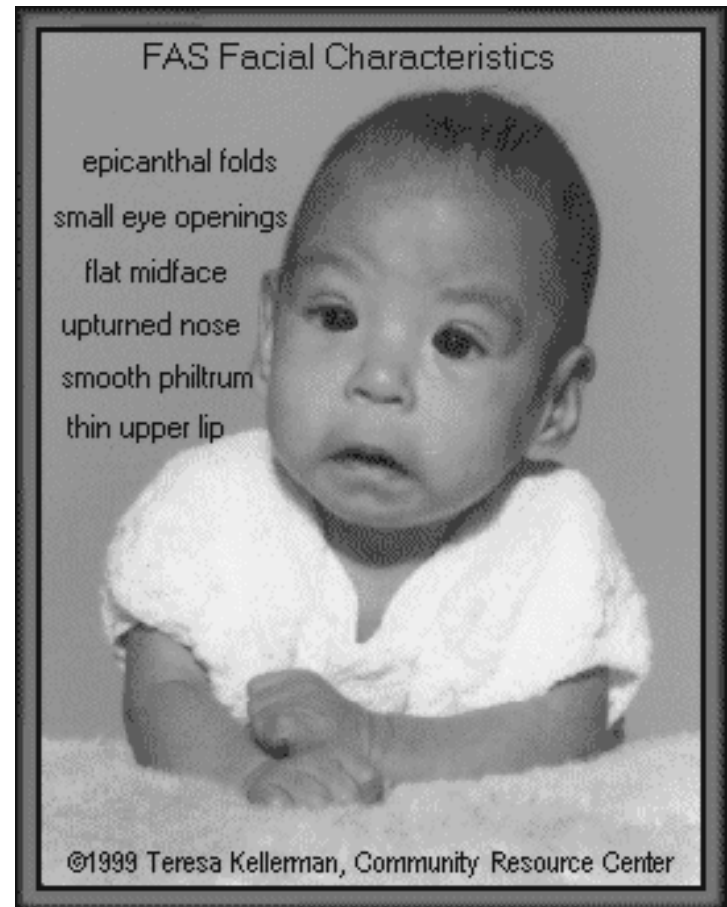
Chasnoff, Ira J., Anne M. Wells, and Lauren King.
"Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure." *Pediatrics* 135.2 (2015): 264-270.

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

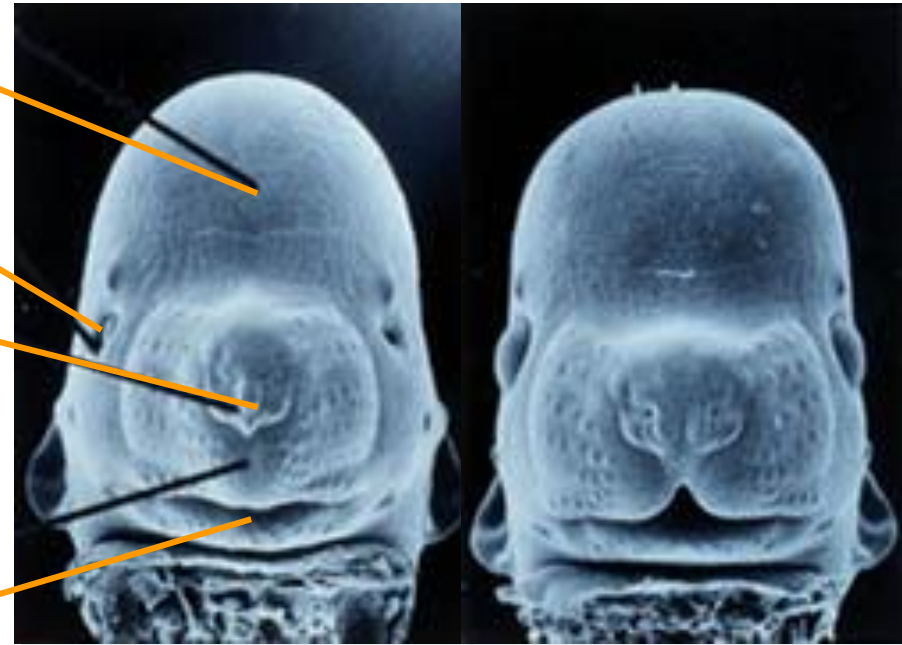


Prenatal alcohol-exposure affects the most basic processes of development

mouse fetus



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



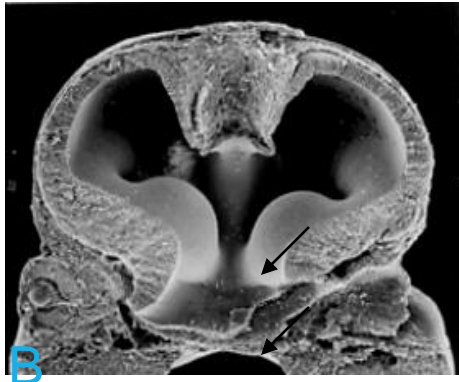
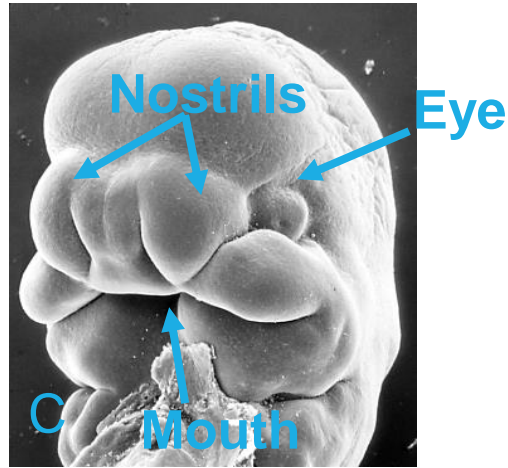
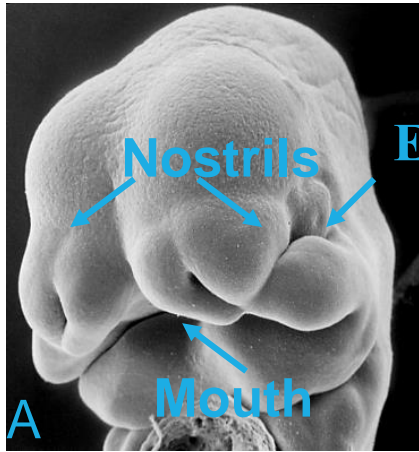
alcohol-exposed

normal



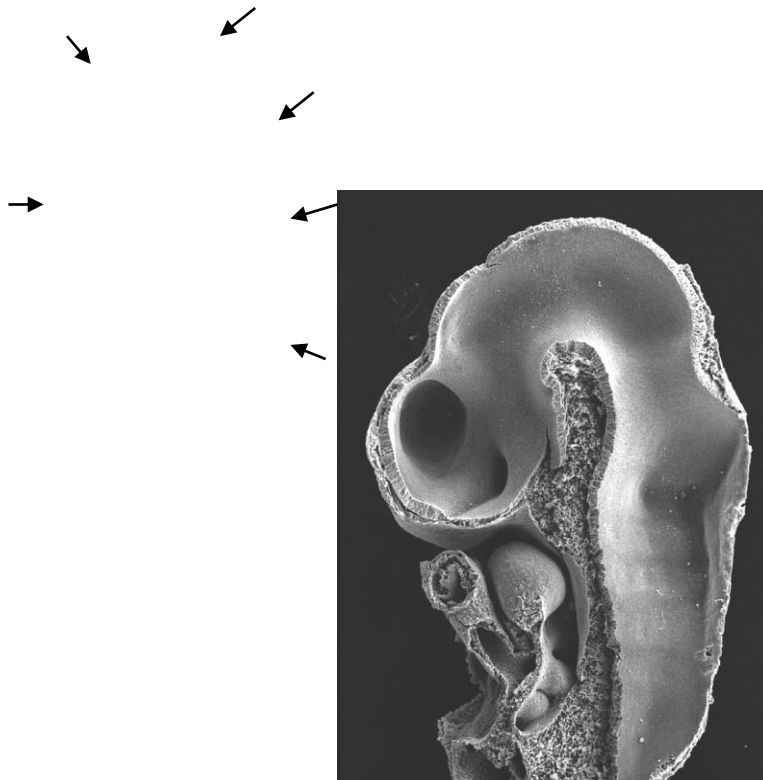
- Fetal alcohol related-neurodevelopmental disability occurs in at least 1:100 children
- More recent estimates are 2-5% in the US general population
- It is estimated that as many as 70% of children in foster care have had fetal alcohol exposure

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



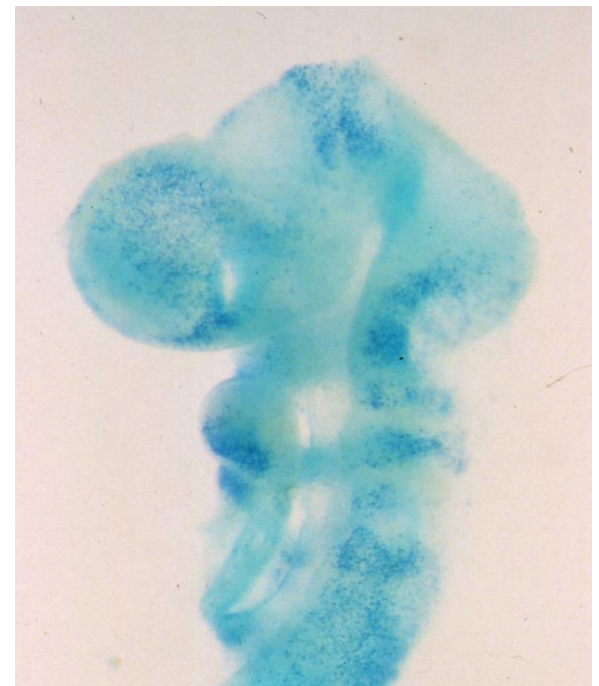
Comparison of the face (A) and interior brain (B) of a normal mouse embryo and one damaged by alcohol (C&D) shows that the nostrils are abnormally positioned (C) and the brain is missing midline structures (D)

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

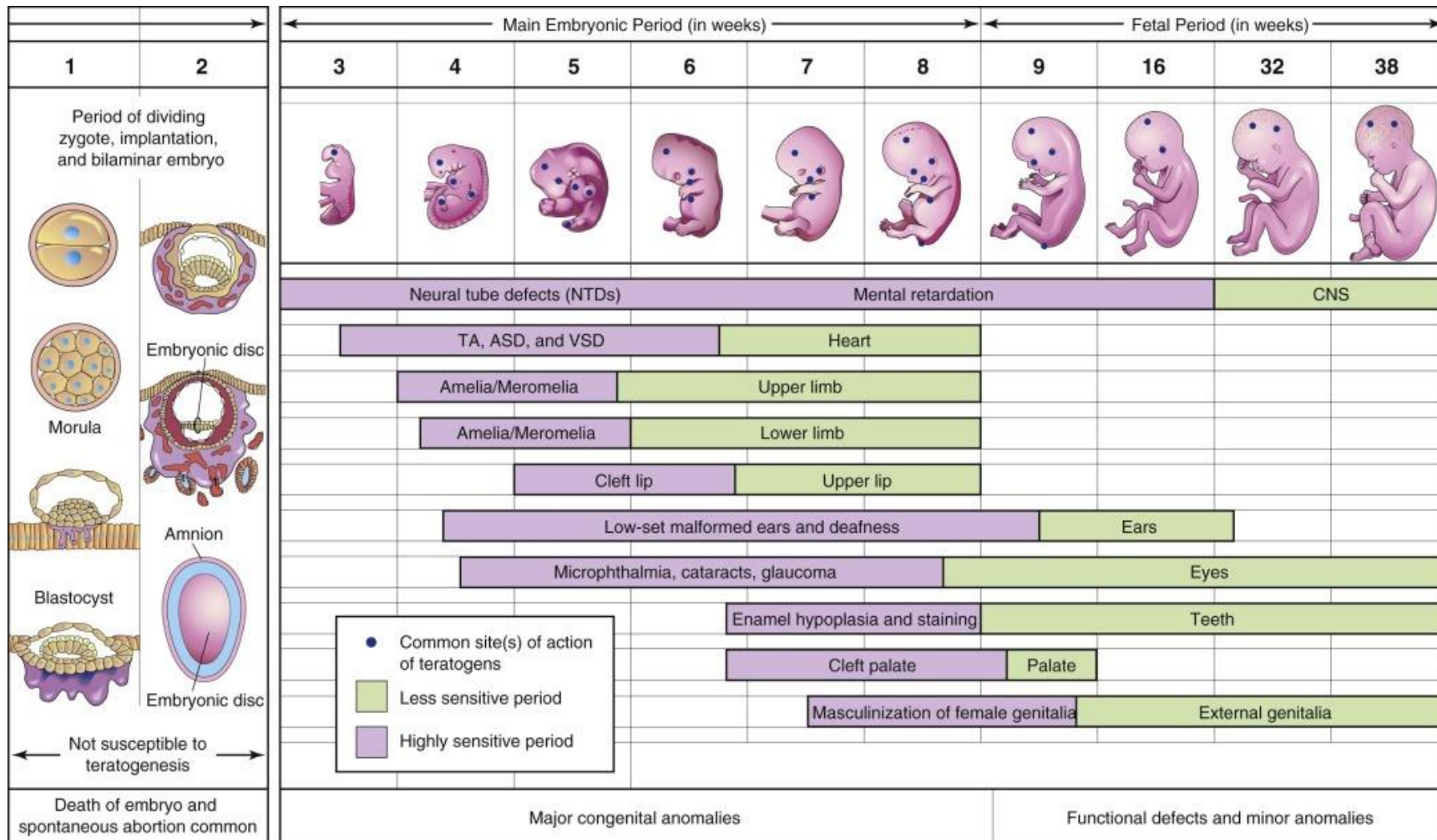


The inside of a 10 day mouse embryo
(corresponding to a 28 day human)

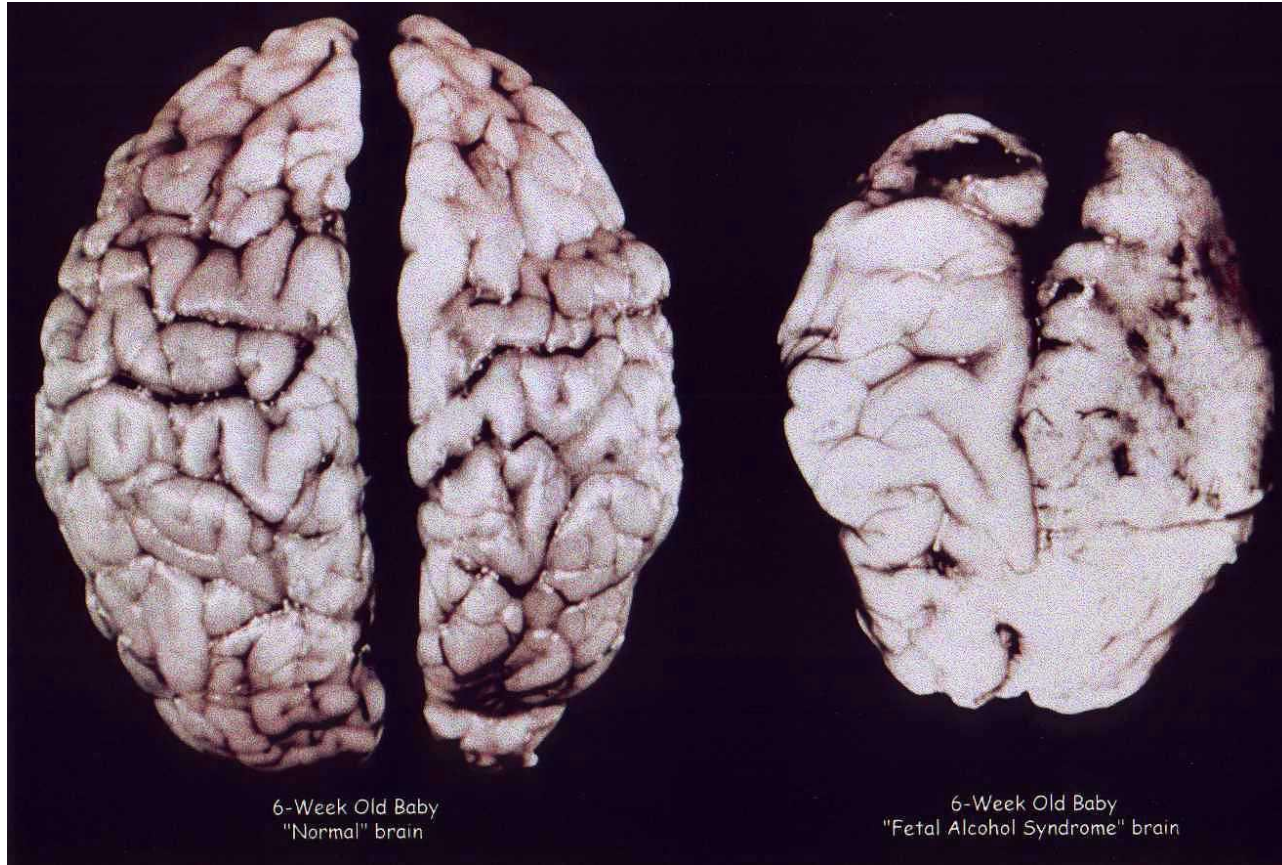
Cells killed by alcohol have
taken up dark blue stain



Sensitive Periods of Embryological Development



The hidden devastation of prenatal alcohol exposure



The Strange, Sad Tale of Phineas Gage



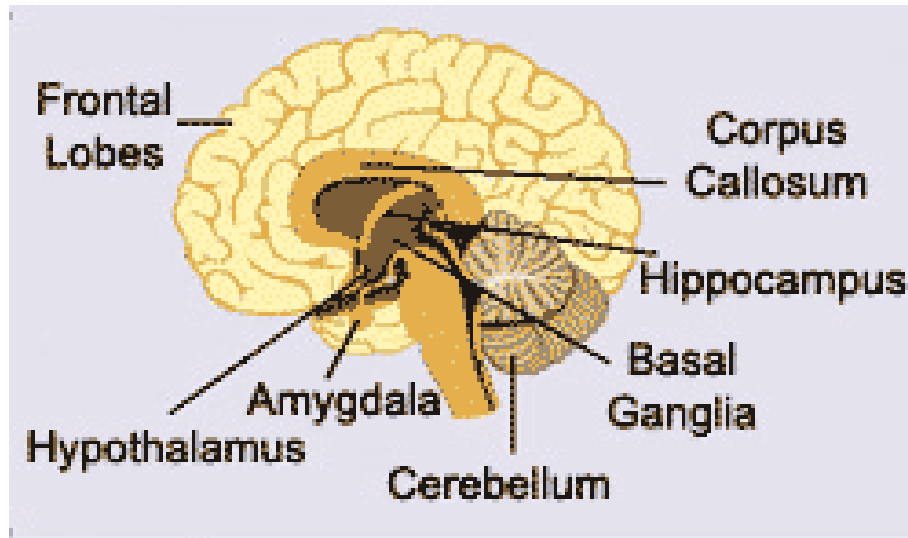
“The equilibrium or balance, so to speak, between his intellectual faculties and animal propensities, seems to have been destroyed. He is fitful, irreverent, indulging at times in the grossest profanity (which was not previously his custom), manifesting but little deference for his fellows, impatient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

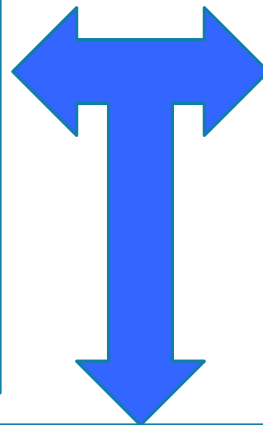
Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

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.

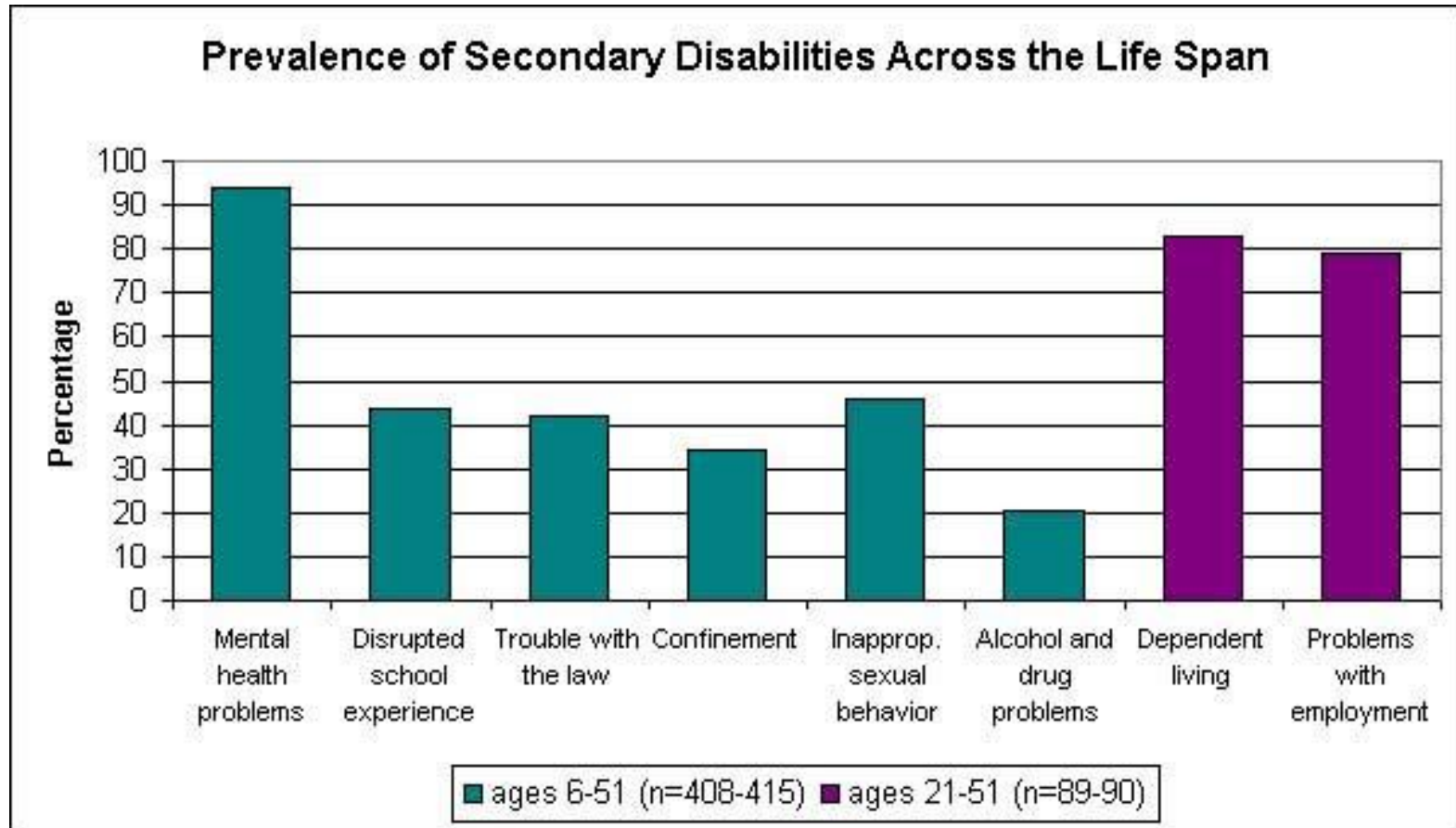
Developmental Age and FASD

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 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.

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

- 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

Support & Advocacy Networks

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

Diagnostic, Medical & Mental Health Services

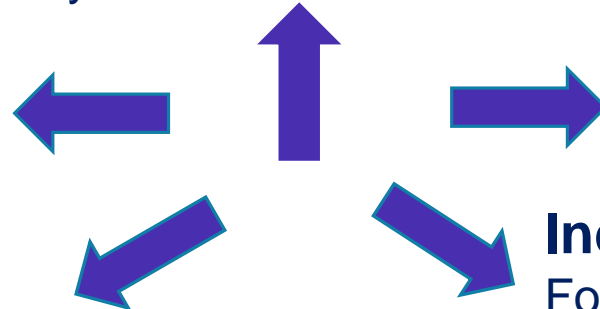
Neuropsychiatric Testing
Psychiatric Treatment

CSE Services

Least Restrictive Environment
PT, OT,
Speech/Language
Vocational

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

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

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

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Fast, D. and Conry, J. (2004), The challenge of fetal alcohol syndrome in the criminal legal system. *Addiction Biology*, 9: 161–166.

Debra S Harris, E.Thomas Everhart, John Mendelson, Reese T Jones. The pharmacology of cocaethylene in humans following cocaine and ethanol administration *Drug and Alcohol Dependence*, Volume 72, Issue 2, 24 November 2003, Pages 169–182.

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., et al. "Identifying the behavioural phenotype in fetal alcohol spectrum disorder: sensitivity, specificity and screening potential." *Archives of women's mental health* 9.4 (2006): 181-186.

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.

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

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.

Steinhausen, Hans-Christoph, and Hans-Ludwig Spohr. "Long-term outcome of children with fetal alcohol syndrome: Psychopathology, behavior, and intelligence." *Alcoholism: Clinical and Experimental Research* 22.2 (1998): 334-338.

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