

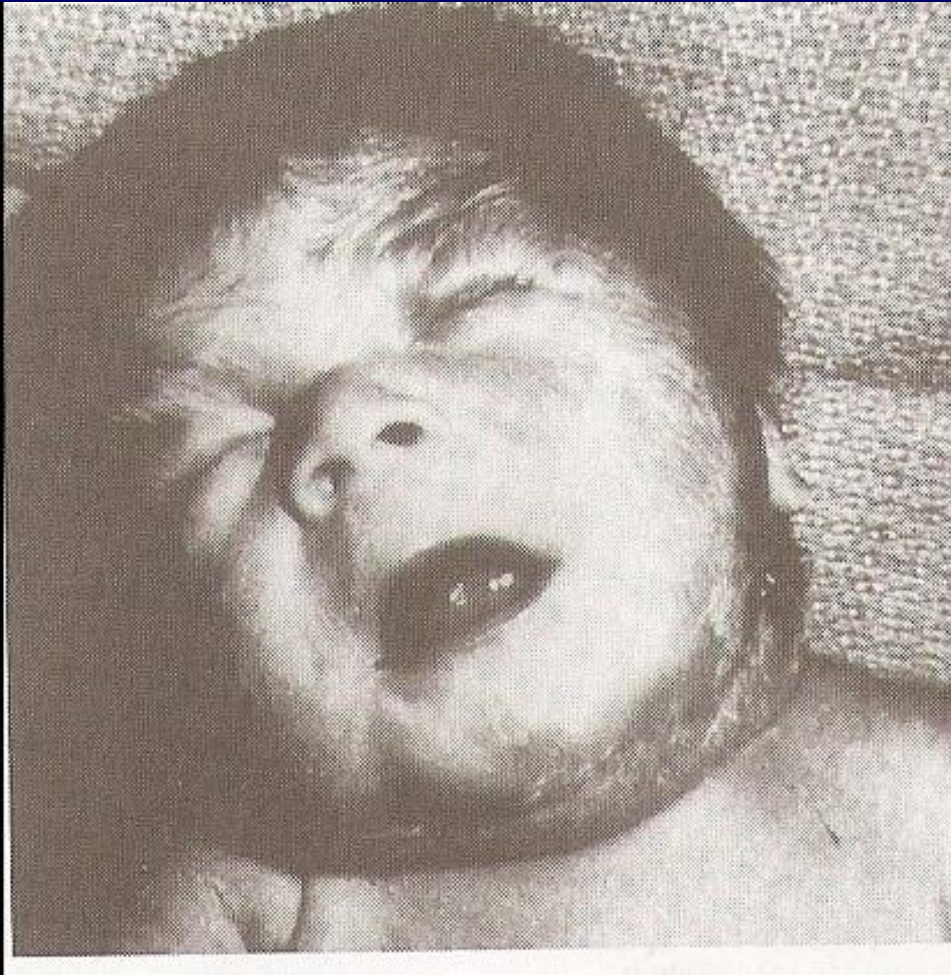
Diagnosis of Children with Fetal Alcohol Neurodevelopmental Disorder



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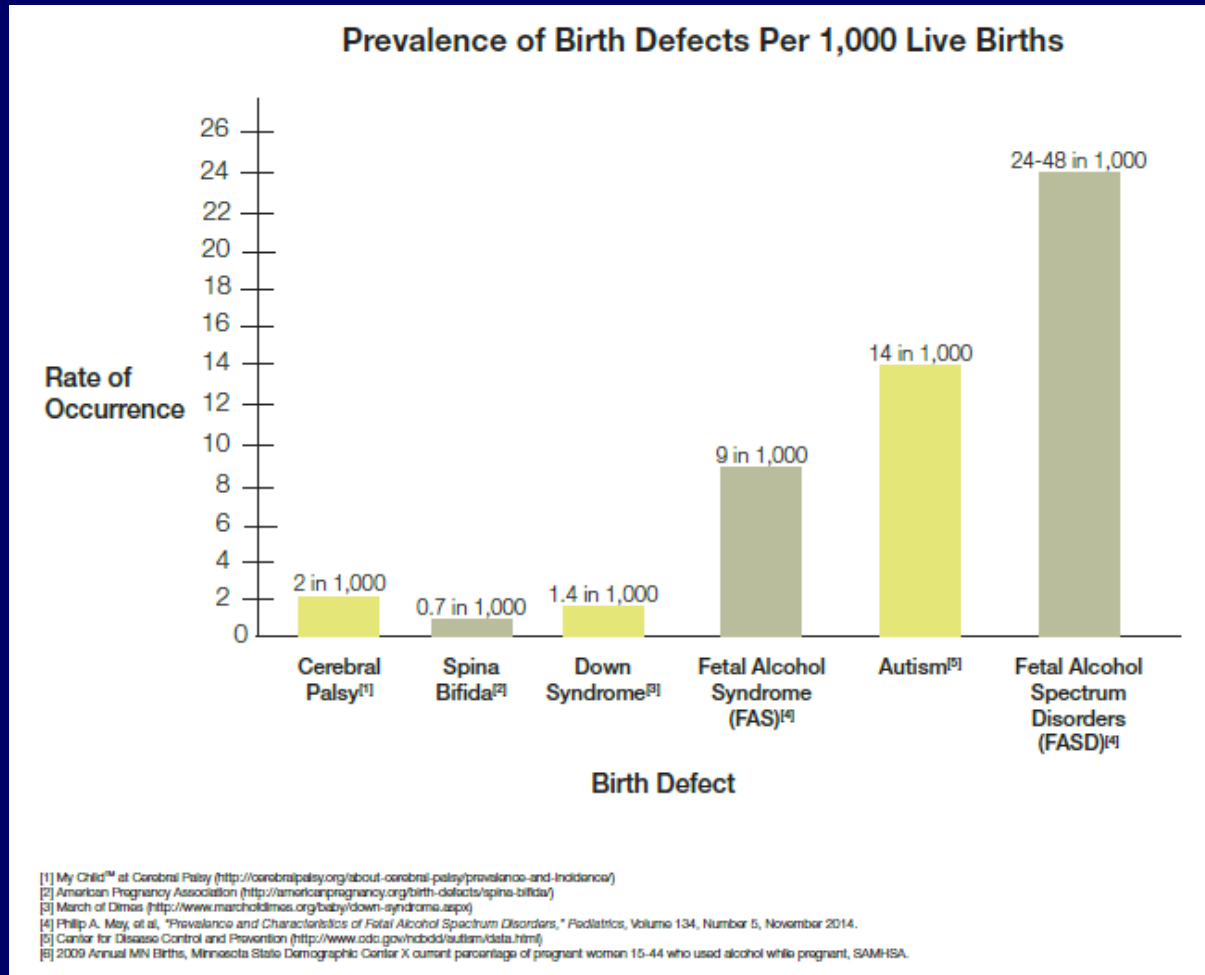


“Each of their mothers was an alcoholic” 1973



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 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.

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

...Especially in Foster Care

Misdiagnosis and Missed Diagnoses in Foster and Adopted Children With Prenatal Alcohol Exposure

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

abstract

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

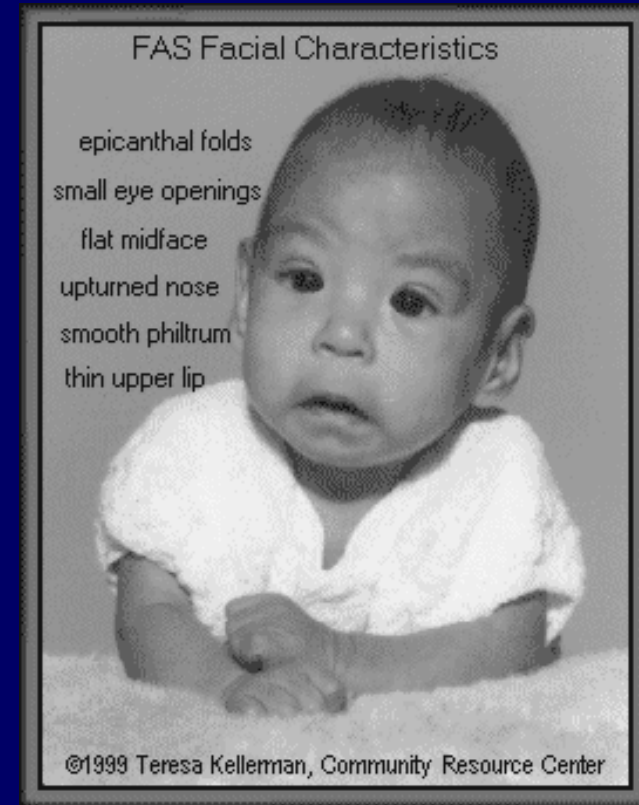
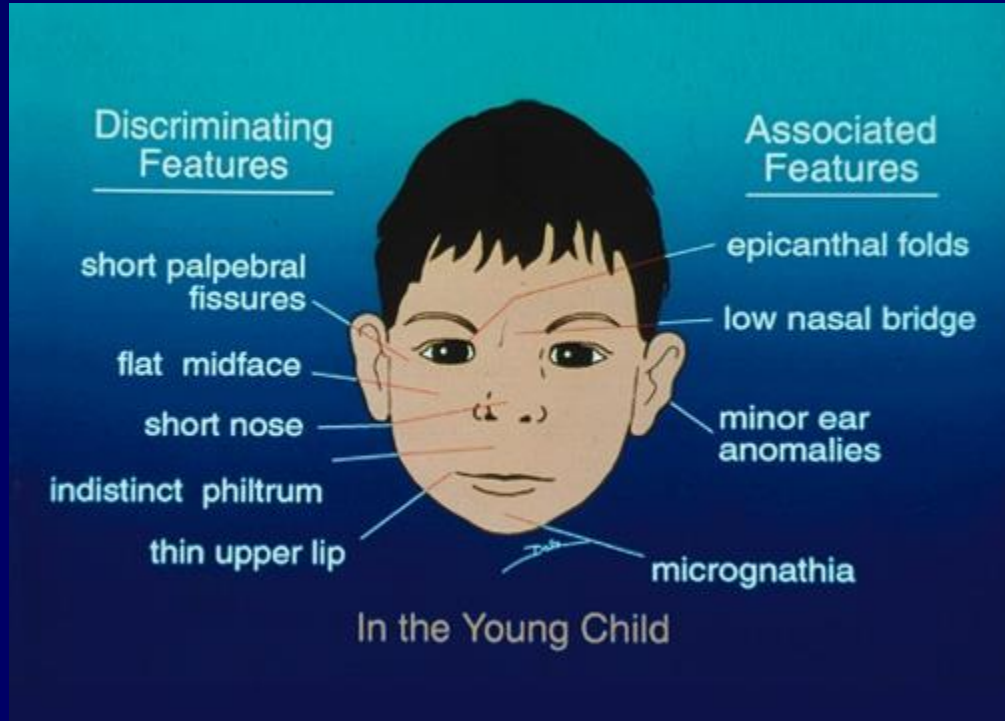
- Specific facial characteristics
- Growth deficits
- Intellectual and Learning Disabilities (especially in math and social skills)
- Attention and memory problems
- Poor coordination and motor delays
- Difficulty with judgment and reasoning
- Speech delay and auditory processing disorder

“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

mouse fetus



Narrow forehead

Short palpebral fissures

Small nose

Small midface

Long upper lip
with
deficient
philtrum



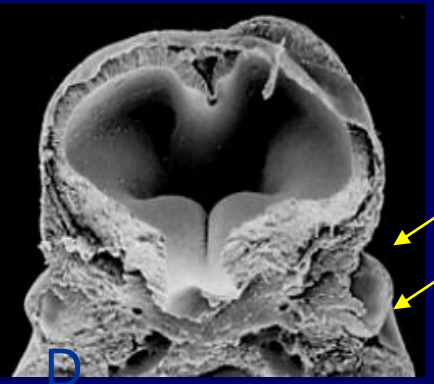
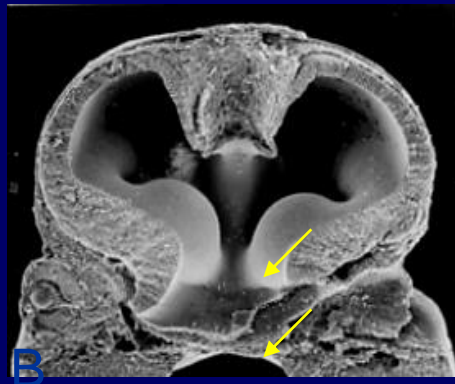
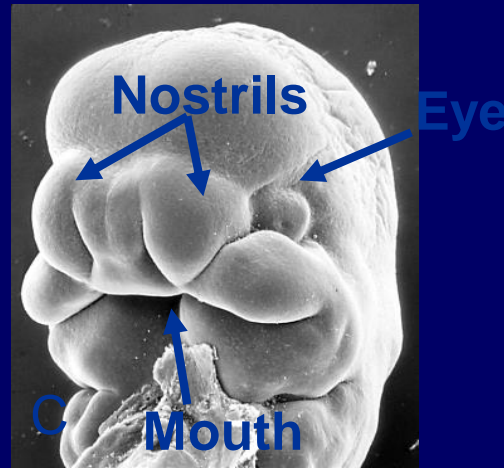
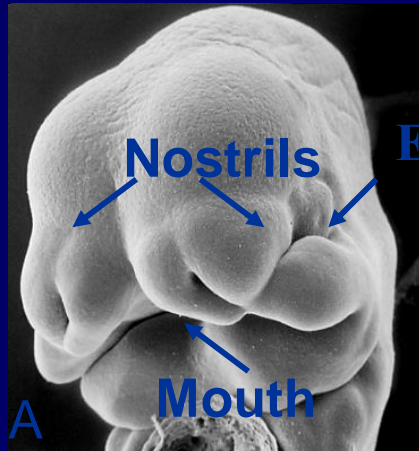
alcohol-exposed

normal



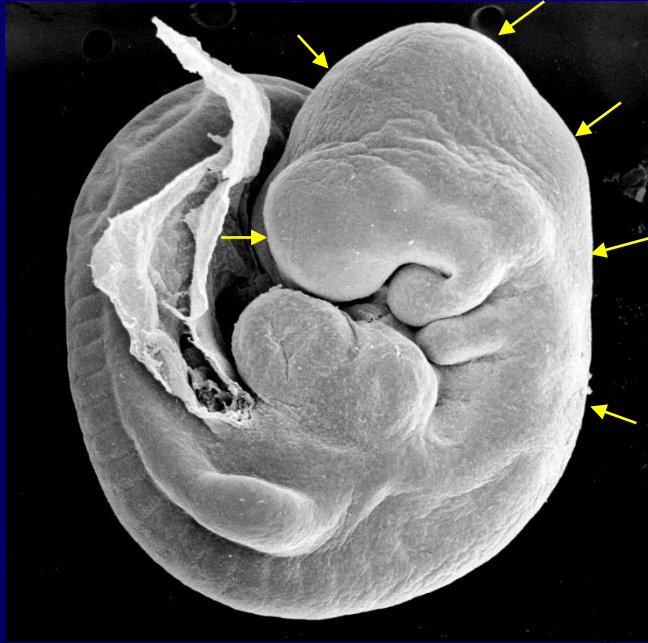
Fetal alcohol related-neurodevelopmental delay occurs three times more often than Fetal Alcohol Syndrome (about 1:100 children) –NIAAA, 1990
More recent estimates are 2-5% in the US population.

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

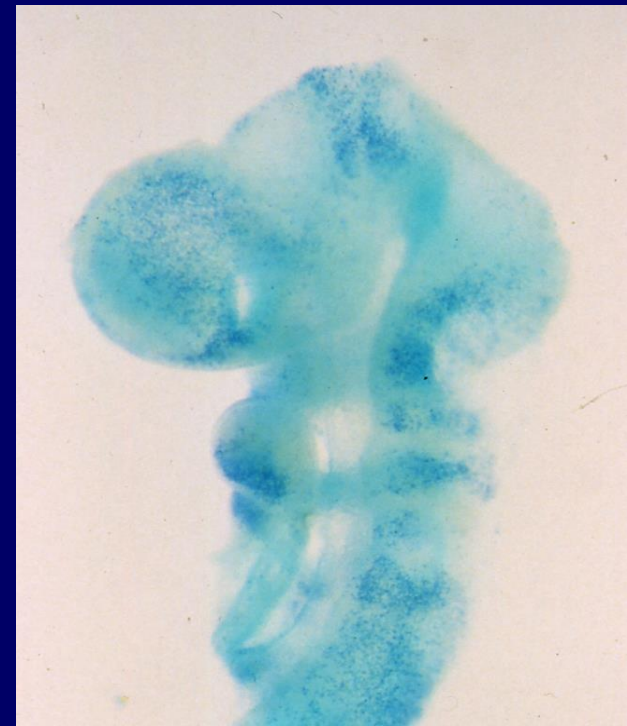


Comparison of the face (A) and interior brain (B) of a normal mouse embryo and one damaged by alcohol (C&D) shows that the nostrils are abnormally positioned (C) and the brain is missing midline structures (D)

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

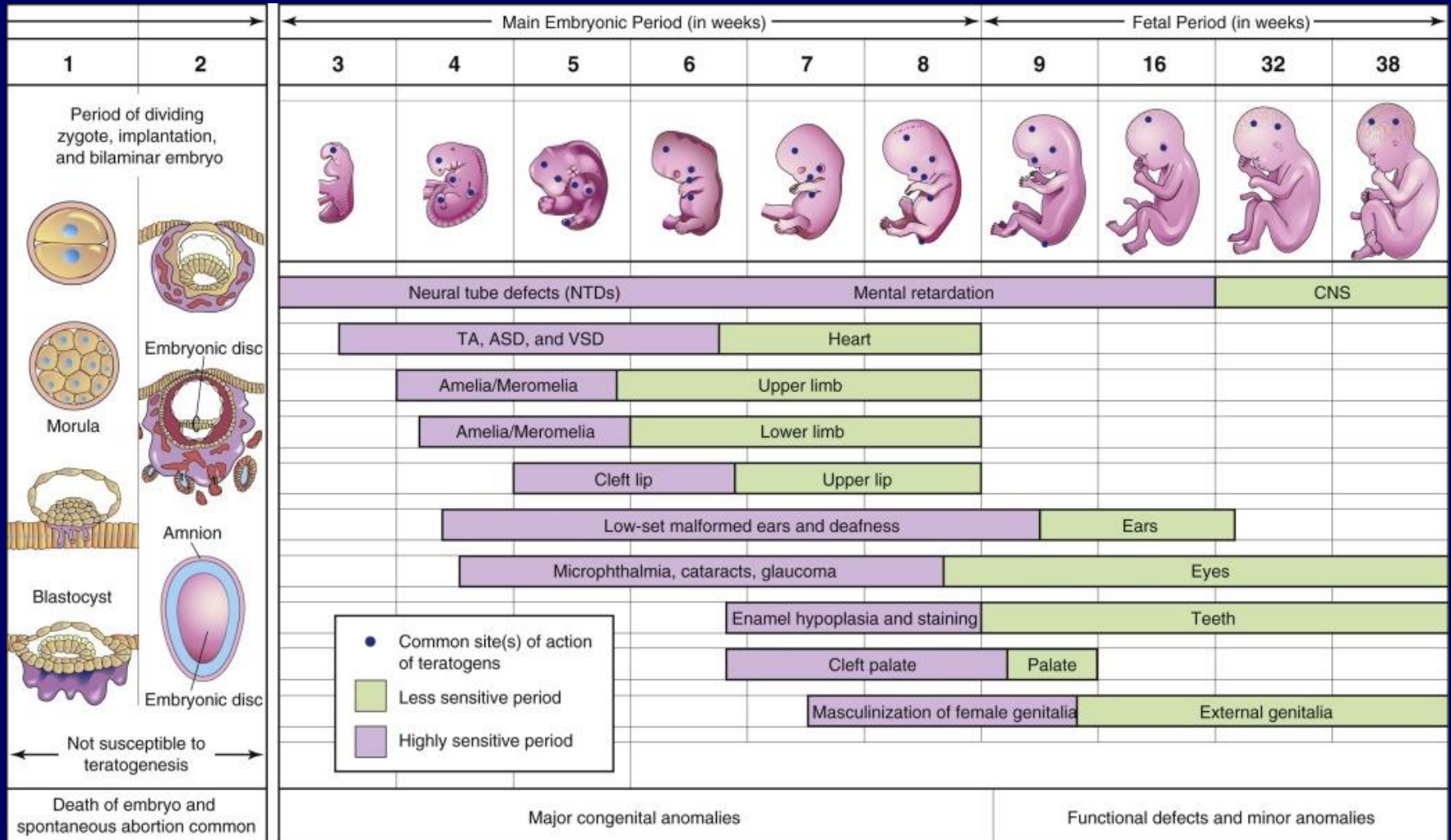


Cells killed by alcohol have taken up dark blue stain

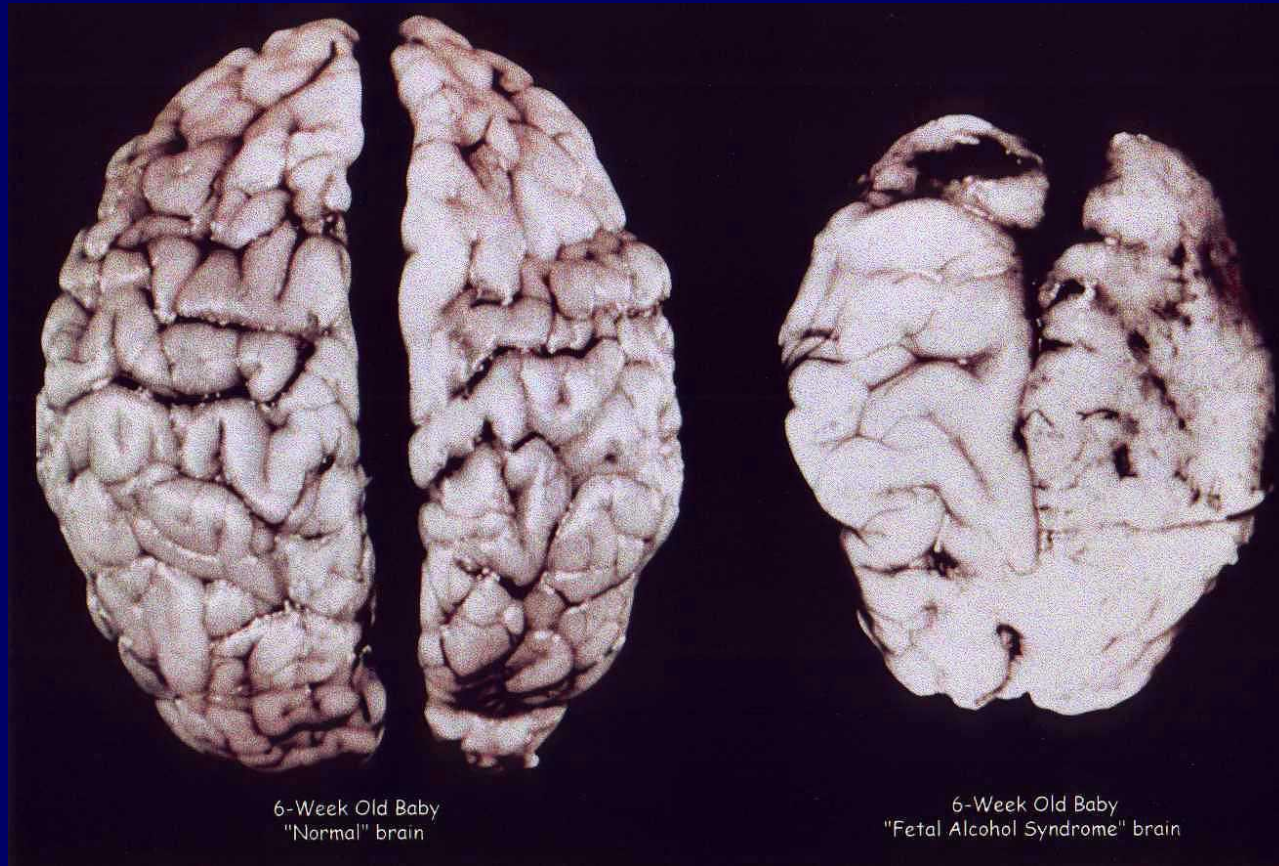


The inside of a 10 day mouse embryo (corresponding to a 28 day human)

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

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

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

Developmental Age and FASD

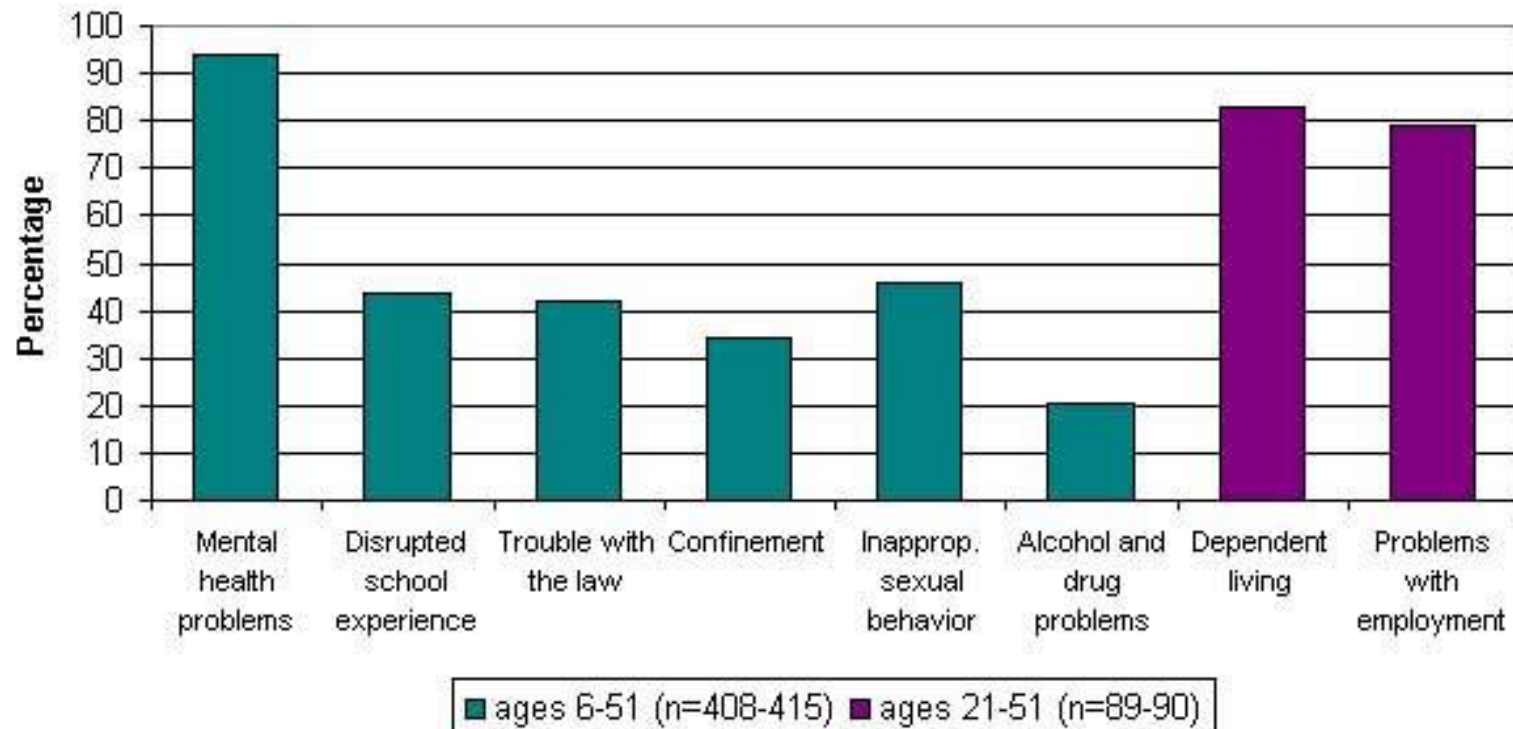
Actual age = 18 years

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

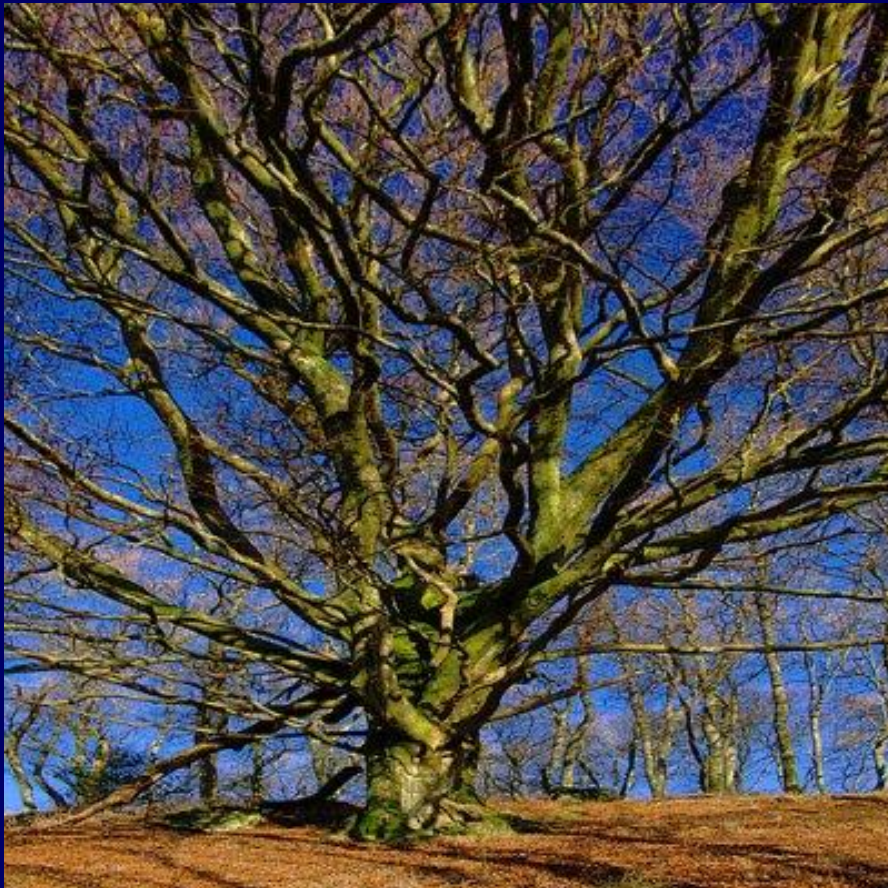
Secondary Disabilities

Prevalence of Secondary Disabilities Across the Life Span



Source: 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



Source: 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.

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.

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

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

WELCOME TO
ALCOHOLICS ANONYMOUS



- **A.A. World Services, Inc.,**
Box 459, Grand Central Station,
New York, NY 10163
Tel. (212) 870-3400.
www.aa.org

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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