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)

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Douglas Waite, MD
Assistant Professor of Pediatrics, Mount Sinai Hospital
Division Chief, Developmental Pediatrics
BronxCare Health System

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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

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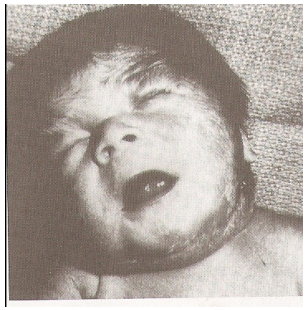
"Each of their mothers was an alcoholic"



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

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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%

MMWR, 4/26/19

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No woman drinks because she wants to hurt her baby

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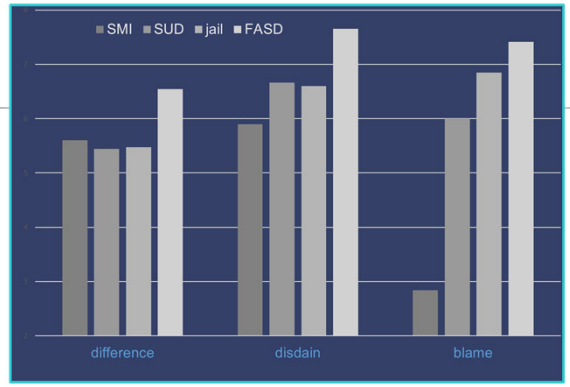

Mean ratings of difference, disdain, and blame for serious mental illness (SMI), substance use disorder (SUD), jail, and fetal alcohol spectrum disorder (FASD).

Corrigan, Patrick W., et al. "The public stigma of birth mothers of children with fetal alcohol spectrum disorders." *Alcoholism: Clinical and Experimental Research* 41.6 (2017): 1166-1173.

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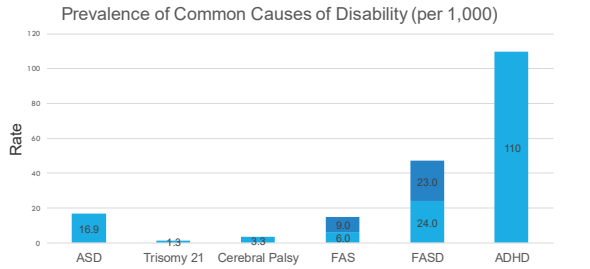
The Most Common Cause of Intellectual Disability and Birth Defects in The United States



Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. MMWR Surveill Summ 2018;67.
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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

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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

Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. Can J Clin Pharmacol, 17(1), e132-e164.

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…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

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.

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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)

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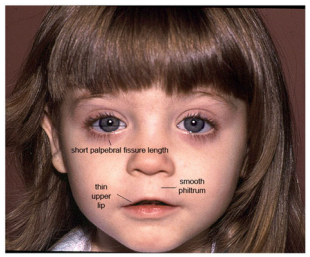
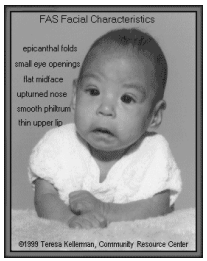
Traces of Fetal Alcohol Exposure can Sometimes be Seen in the Face





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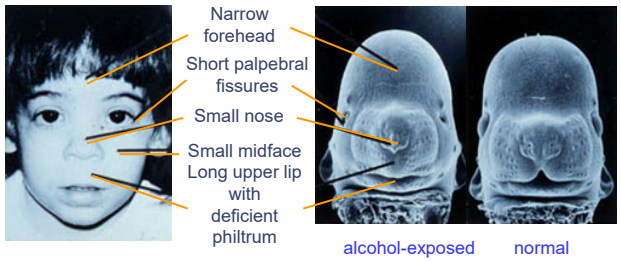
Prenatal alcohol-exposure affects development across species



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- *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

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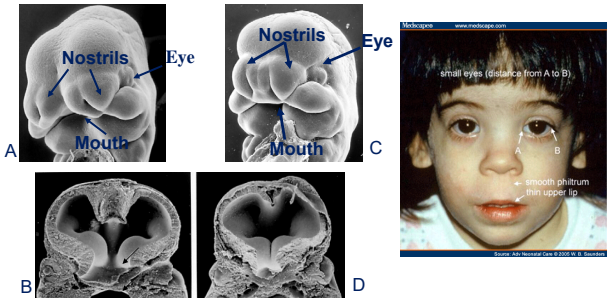
Midline structures of the face and brain in an alcohol-exposed mouse embryo and a child with FAS



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)

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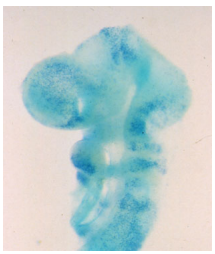
Alcohol kills specific cells in the developing brain depending upon the stage of development

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



Cells killed by alcohol have taken up dark blue stain

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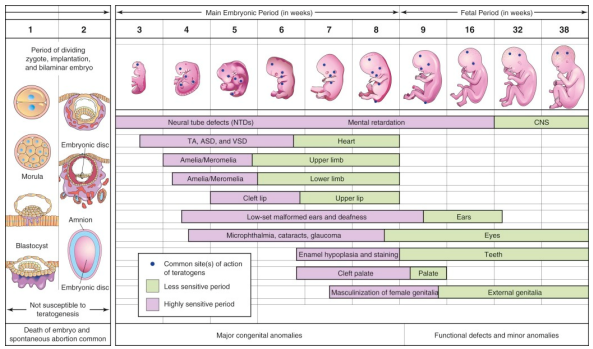
Sensitive Periods of Embryological Development



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A Hidden Disability

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The Strange Tale of Phineas Gage

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"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

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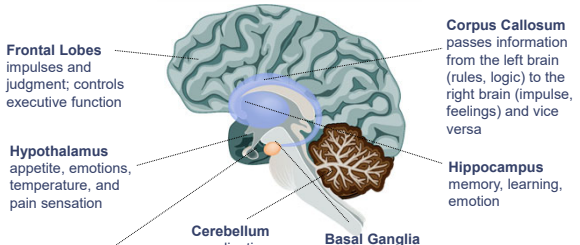
A Brain-Based Disorder with Behavioral Manifestations



Source: Dr. Sarah Mattson, University of San Diego

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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.

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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

American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). American Psychiatric Pub, 2013.

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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)

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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

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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

Implementation guide available at www.aap.org/pae

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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

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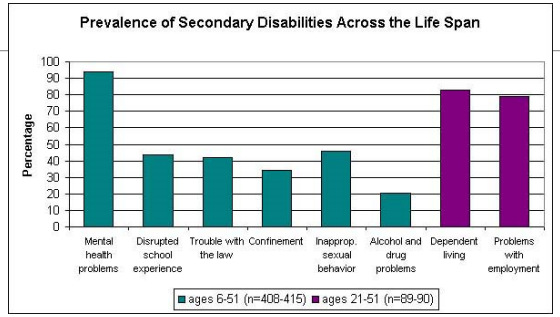
Secondary Disabilities



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.

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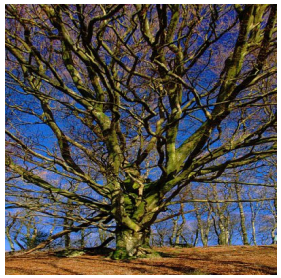
95% of children with FASD suffer from at least one psychiatric diagnosis that in contrast to physical features of FAS, are long-lasting, pervasive and devastating to development



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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

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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 (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

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.

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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

American Bar Association, 2012; **Resolution 112B**

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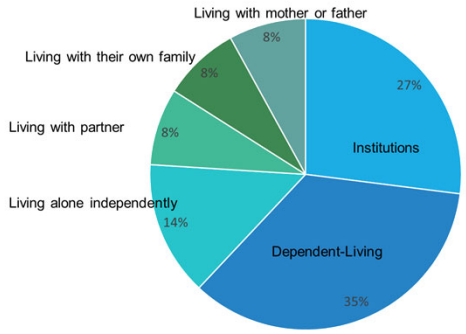
FASD in adults at 20 year follow up



(Spohr, 2007)

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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

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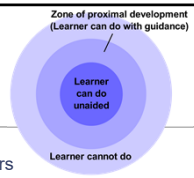
FASD Interventions



- 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

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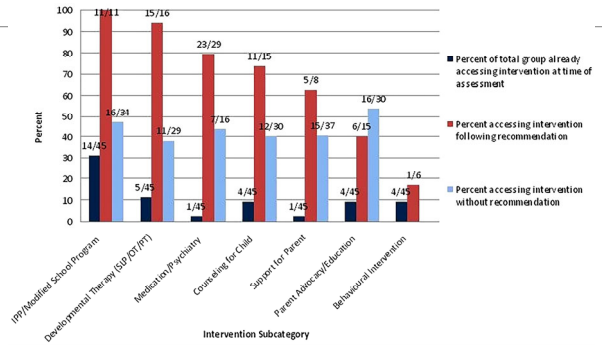
What difference does a diagnosis make?



Petrenko, Christie LM, Mary E. Pandolfino, and Rachael Roddenbery. "The association between parental attributions of misbehavior and parenting practices in caregivers raising children with prenatal alcohol exposure: A mixed-methods study." *Research in developmental disabilities* 59 (2016): 255-267.

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What Difference does a Diagnosis Make?

- Caregivers who attribute their child's misbehavior to underlying developmental disabilities are more likely to use antecedent strategies ands 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.

Petrenko, Christie, et al. "The association between parental attributions of misbehavior and parenting practices in caregivers raising children with prenatal alcohol exposure: A mixed-methods study." *Research in developmental disabilities* 59 (2016): 255-267.

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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 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.

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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.

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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.*

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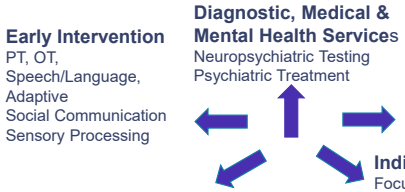
Building Community-Based FASD-Specific Intervention Services



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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

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AAP One-Page Handouts

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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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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* .

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Doyle, Lauren R., et al. "Relation between adaptive function and IQ among youth with histories of heavy prenatal alcohol exposure." *Birth defects research* (2019).

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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

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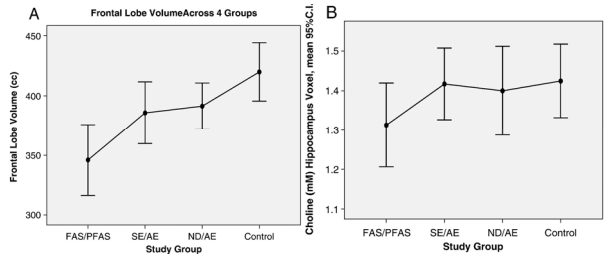
Choline and FASD



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