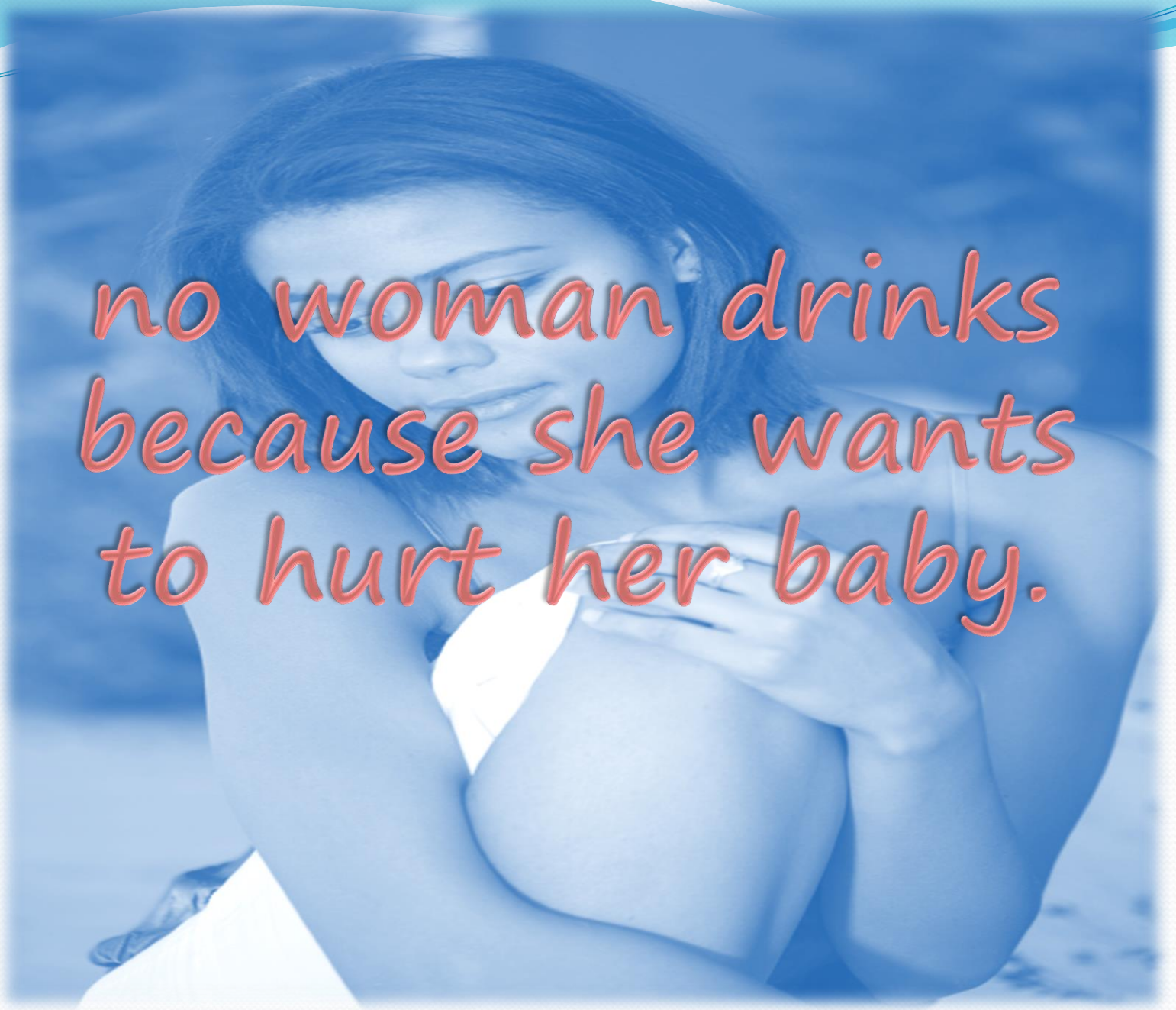
Fetal Alcohol Spectrum Disorders (FASD): An Invisible Lifelong Disability

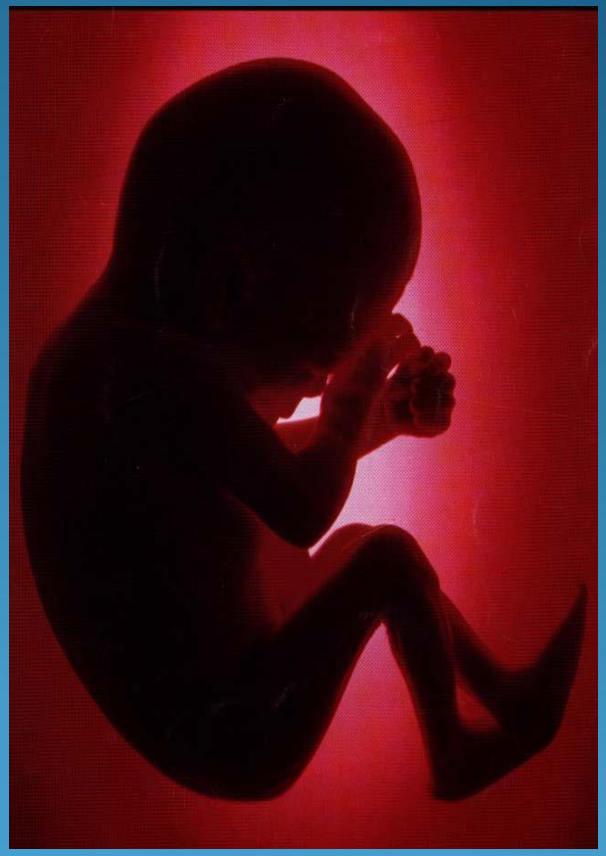
Kathleen Mitchell, MHS, LCADC

Vice President & International Spokesperson
National Organization on Fetal Alcohol Syndrome


no woman drinks
because she wants
to hurt her baby.

Prenatal Alcohol Exposure can cause Lifelong Brain Damage

FASD: the leading cause of preventable fetal brain damage that may result in intellectual disability, learning and/or emotional or behavioral disorders and the leading known cause of birth defects.



ABA Resolution

- RESOLVED, That the American Bar Association urges attorneys and judges, state, local, and specialty bar associations, and law school clinical programs to help identify and respond effectively to Fetal Alcohol Spectrum Disorders (FASD) in children and adults, through training to enhance awareness of FASD and its impact on individuals in the child welfare, juvenile justice, and adult criminal justice systems and the value of collaboration with medical, mental health, and disability experts.

- FURTHER RESOLVED, That the American Bar Association urges the passage of laws, and adoption of policies at all levels of government, that acknowledge and treat the effects of prenatal alcohol exposure and better assist individuals with FASD.

Fetal Alcohol Spectrum Disorders

FAS

Fetal Alcohol Syndrome

PFAS

Partial FAS

ND-PAE

Neurobehavioral Disorder associated with Prenatal Alcohol Exposure

Fetal and Infant Death

Other Neurodevelopmental Disorders

- 315.8 Other Specified Neurodevelopmental Disorder

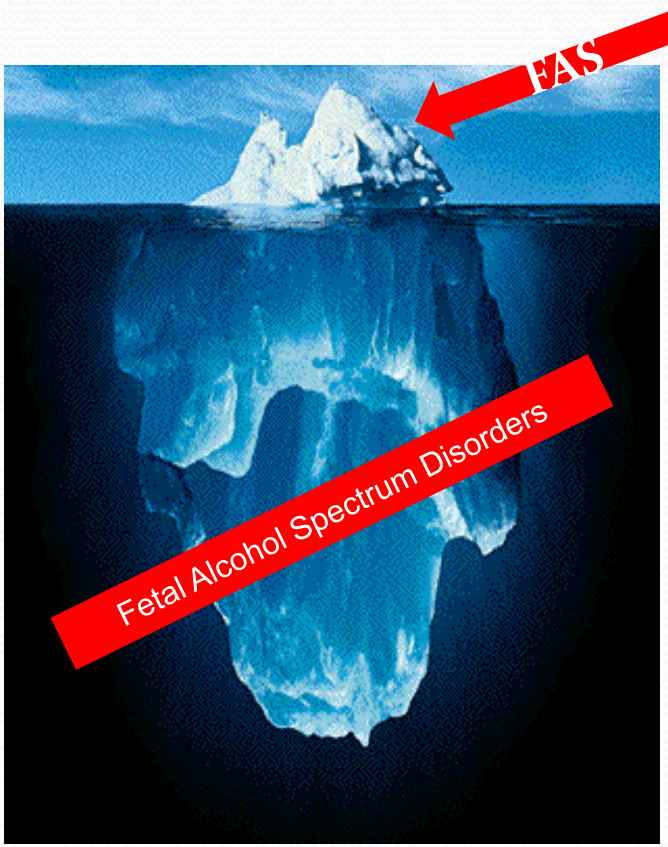
Impairment in social, occupational, or other areas of functioning, predominate but do not meet the full criteria for any other of the neurodevelopmental disorders diagnostic class

(ex. Neurodevelopmental disorder associated with prenatal alcohol disorder)

- **315.9 Unspecified Neurodevelopmental Disorder**

Impairment in social, occupational, or other areas of functioning, predominate but do not meet the full criteria for any other of the neurodevelopmental disorders diagnostic class. Used in situations in which the clinician chooses NOT to specify the reason that the criteria are not met for a specific ND, and includes presentations where there is insufficient information to make a specific diagnosis. (ex. ER settings)

Prevalence



- The CDC FAS Surveillance Network 0.3 per 1000 ages 7-9 in medical and other records in 2010 (AZ, CO, and NY) (Fox et al., MMWR, 2015)

FAS estimated (active case ascertainment approach)

- 2 to 7 per 1,000 (May et al., 2009)
- 6-9 per 1,000 children in a Midwest community (May et al., 2014)

Higher prevalence in children adopted and in foster care- 1/100 children (Astley et al., 2002)

FASD

- 2 - 5% in school children (May et al., 2009; 2014)
- 24 - 48/1,000 or 2.4% to 4.8% in Midwest

About NOFAS

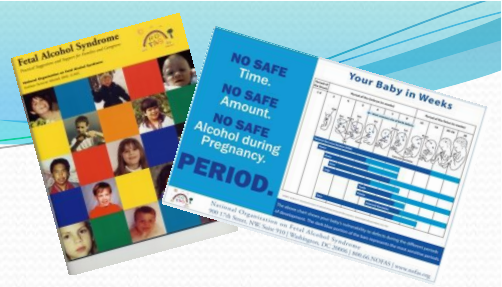
Mission:

NOFAS prevents FASD, raises awareness about the risk of prenatal alcohol exposure, and supports individuals, families, and communities living with FASD.

Vision:

The vision of NOFAS is a global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with FASD.

NOFAS Clearinghouse



Materials, Publications and Media Outreach

- Books
- Posters
- DVDs
- Weekly NOFAS Roundup Emails
- K-12 FASD Prevention Curriculum
- Educational webinars
- Facebook, Pinterest
- Twitter @NOFAS_USA
- YouTube: Alcohol-Free Pregnancy

N·O· FAS Weekly Roundup

Pinterest

twitter

YouTube

101 Things to Know

- In 1996, the Institute of Medicine reported "Of all substances of abuse (including heroin, cocaine, marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."
- One study estimated that 70% of children in foster care have prenatal alcohol exposure
- Sixty percent of individuals with FASD will require institutional support (incarceration or mental health facility)

2002 Foster Care Study on Full FAS

Astley, Stachowiak, Clarren, & Clausen

- **Studied the pictures of foster care children in Washington State to determine if the children had facial morphologies characteristic of FAS.**
- **Positive using a pictorial screening tool = a multidisciplinary diagnosis**
- **The study concluded that the rate of FAS in this population of foster children was 10 to 15 times the incidence in the general population.**
- **Child welfare workers should consider the possibility that a child may have FASD, and seek appropriate follow-up assessment.**
- **Child welfare workers and foster parents need education on FASD.**

How is FASD an Invisible Disorder?

- Most cases of FASD are never diagnosed. Symptoms of FASD are identified and addressed. But rarely is alcohol identified as the causal factor.
- Few physicians, healthcare professionals, disability professionals, psychologists, therapists, etc. are trained in how to identify FASD.

The Doctors Bag: Prescription Pad

- 90% of women use some form of prescription medication throughout their pregnancy
- Over the last 30 years, first trimester use of prescription medications has increased more than 60% (CDC).
- About 3.4 of every 1,000 infants born suffer from withdrawal symptoms related to misuse of narcotic prescription medications; that is one newborn every hour.
- According to the Journal of the American Medical Association, infants suffering from Neonatal Withdrawal Syndrome has more than tripled within the past decade.

Opioid Abuse Skyrockets

- Addiction from opioid prescriptions is the fastest rising public health problem in the United States.
- Over 2,000 deaths per week have been attributed to opioid abuse.
- Most of the fatalities are due to Oxycontin
- Over 100 people die every day in US from drug overdose
- Americans consume 99% of the world's supply of hydrocodone.

Alcohol use among US women, 2011-2013

Behavioral Risk Factor Surveillance System (BRFSS)

State-based, random-digit–dialed telephone survey of 206,481 women aged 18–44 years, 8,383 were pregnant

Tan CH, Denny CH, Cheal NE, Sniezek JE, Kanny D. Alcohol Use and Binge Drinking Among Women of Childbearing Age — United States, 2011–2013. MMWR 2015;64:1042-1046.

A multi-stage nationally representative sample of households In-person interviews 5,601 women aged 15–44 years, including 4,303 nonpregnant, nonsterile women

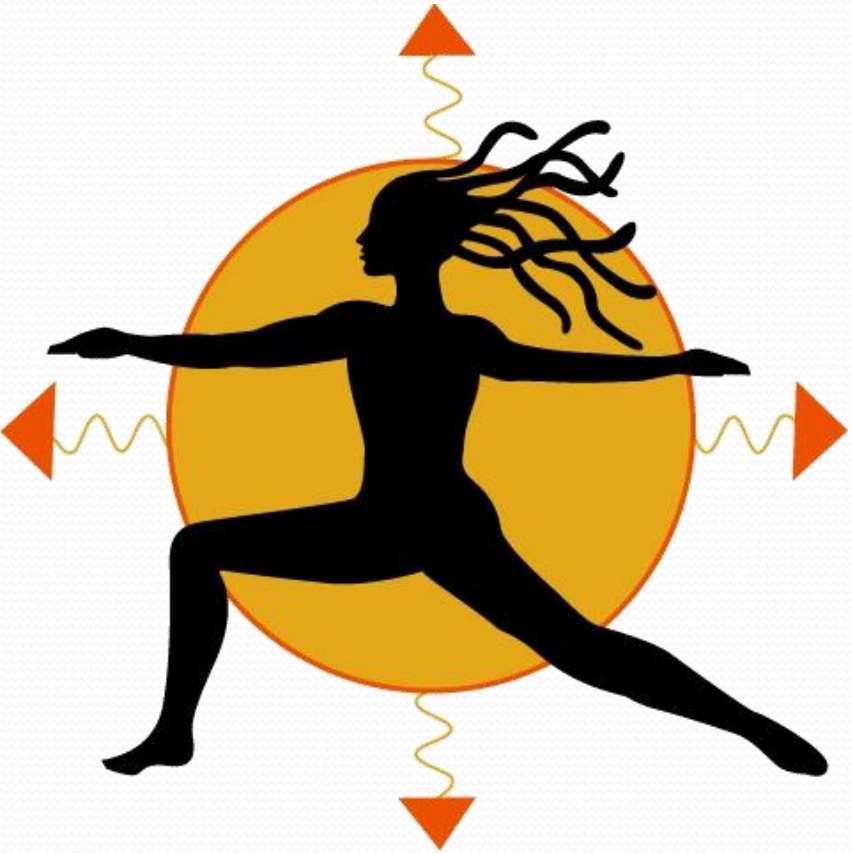
3 in 4
women who want to get pregnant as soon as possible report drinking alcohol

Green PP, McKnight-Eily LR, Tan CH, Mejia R, Denny CH. Vital Signs: Alcohol-Exposed Pregnancies — United States, 2011–2013. MMWR, 2016;65:91–97.

NOFAS Circle of Hope
Birth Mothers Network

www.nofas.org/coh

Mitchell@nofas.org



- Peer mentoring Support
- Speakers Bureau
- Newsletter
- Annual Meetings
- Private Facebook site for birthmoms

"Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks"

- JUDGES 13:7

Use of Ethanol in Threatened Premature Labor

- View on the absolute safety of alcohol in pregnancy continued into the 1960's when the alcohol drip was introduced in obstetrics.
- One of few medical uses of ethanol.
- Involved I.V. ethanol infusion for 6–10 hours, reaching BAC as high as 160 mg/dl
  - First report — Fuchs, F., et al., *Am. J. Obstet. Gynecol.,* 99:627 (1967)

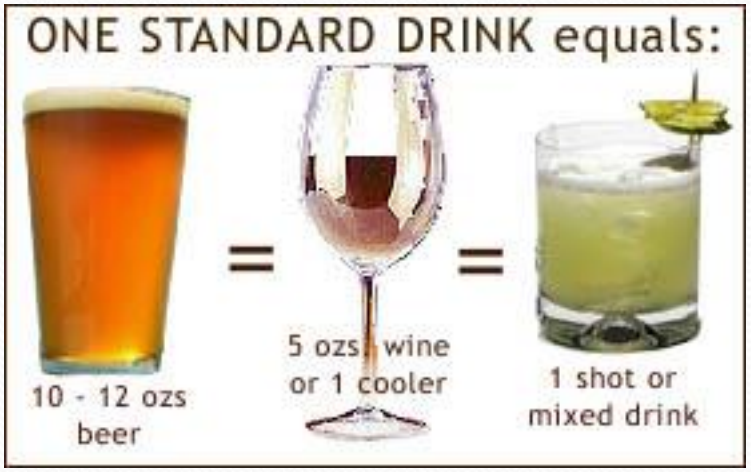
The developing embryo is vulnerable to alcohol even when it is small enough to fit inside the zero on a penny

Alcohol & SIDS

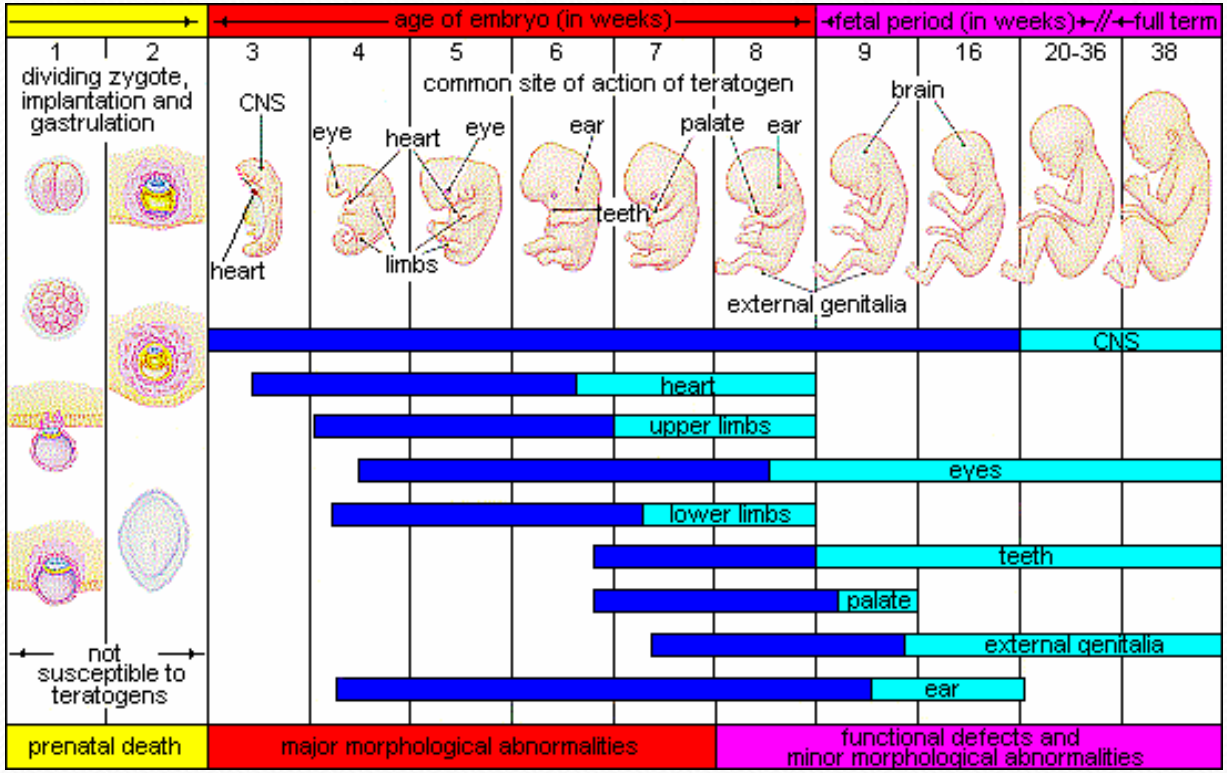
"Alcohol use while pregnant is a leading causal factor in both fetal and infant death."

- Ken Warren, PhD, Acting Director, NIAAA
  NOFAS interview, www.nofas.org

Alcohol is a teratogen (*def.* an agent that can cause malformations of an embryo or fetus). Alcohol can cross the placenta and enter fetal circulation, damaging cells and the DNA they contain.



Impact of Alcohol Use on the Developing Fetus



Adapted from Moore and Persaud, 1993.

Research in Animal Models

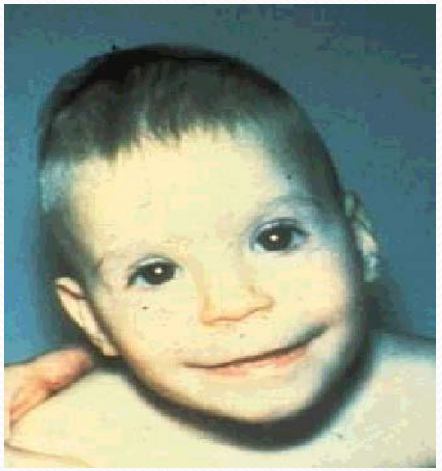
- Effects of Moderate Blood Alcohol Prenatally:
  - Poor sensory motor development, poor suckling, increased hyperactivity, learning and behavioral problems
- Effects 1-2 binge episodes:
  - FAS, physical anomalies, neurochemical alterations in brain

The Three Diagnostic Attributes of Fetal Alcohol Syndrome

GROWTH

BRAIN

FACE



- Small palprebral fissures
- Smooth philtrum
- Thin vermillion

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

child with FAS

Narrow forehead

Short palpebral fissures

Small nose

Small midface

Long upper lip with deficient philtrum

mouse fetuses

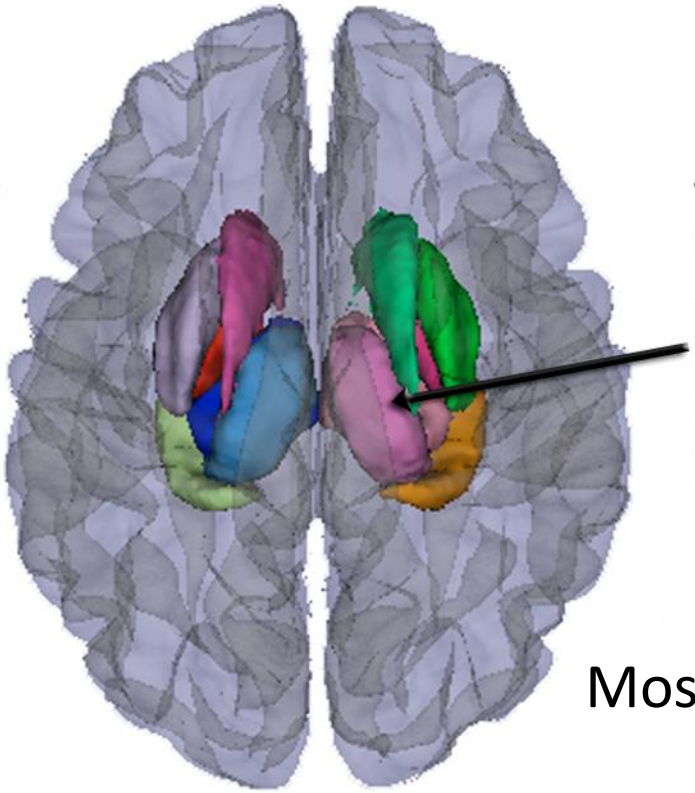
alcohol-exposed

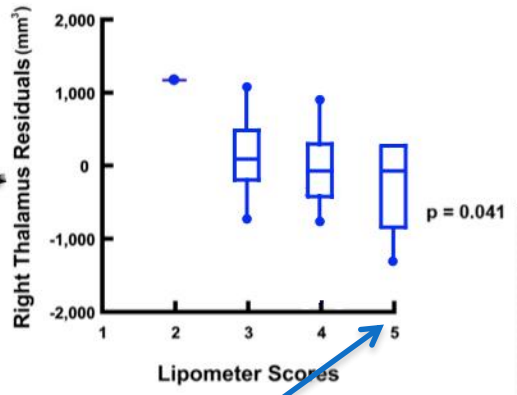
normal

The face is a window into the brain: Not all children with FASDs have the face, but the brain is still affected by prenatal alcohol exposure.

With permission: Susan Astley, University of Washington

Most severe face





Most reduced volume

Children's Hospital LOS ANGELES
DEVELOPMENTAL COGNITIVE NEUROIMAGING LABORATORY

USC University of Southern California

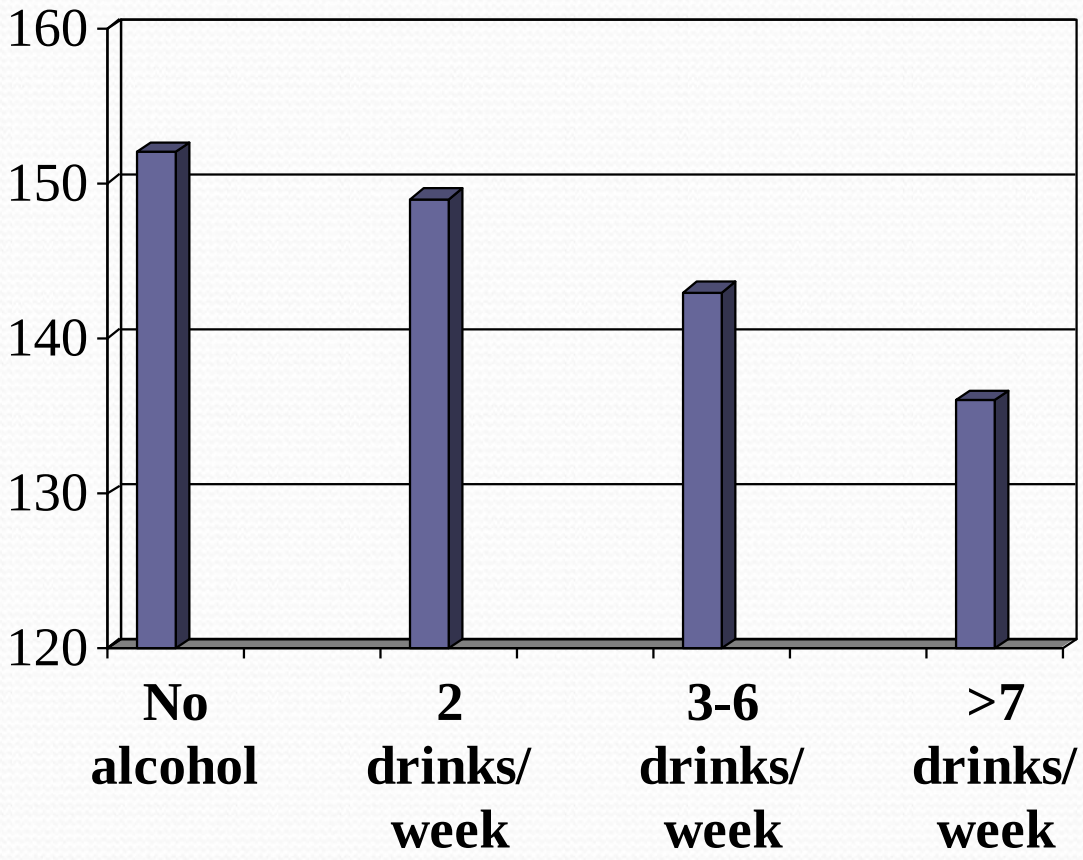
Adapted from Roussotte et al., 2011, CIFASD

Growth (CDC Diagnostic Guidelines):

- Confirmed prenatal or postnatal height or weight, or both, at or below the 10th percentile, documented at any one point in time

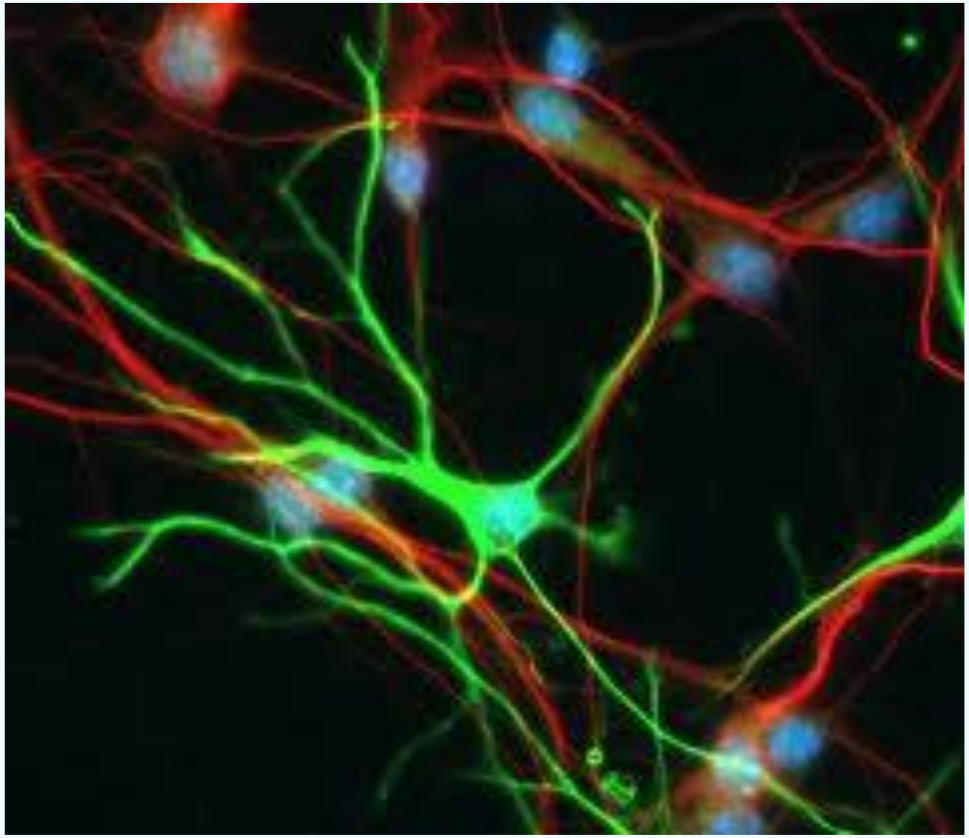
(adjusted for age, sex, and race or ethnicity)

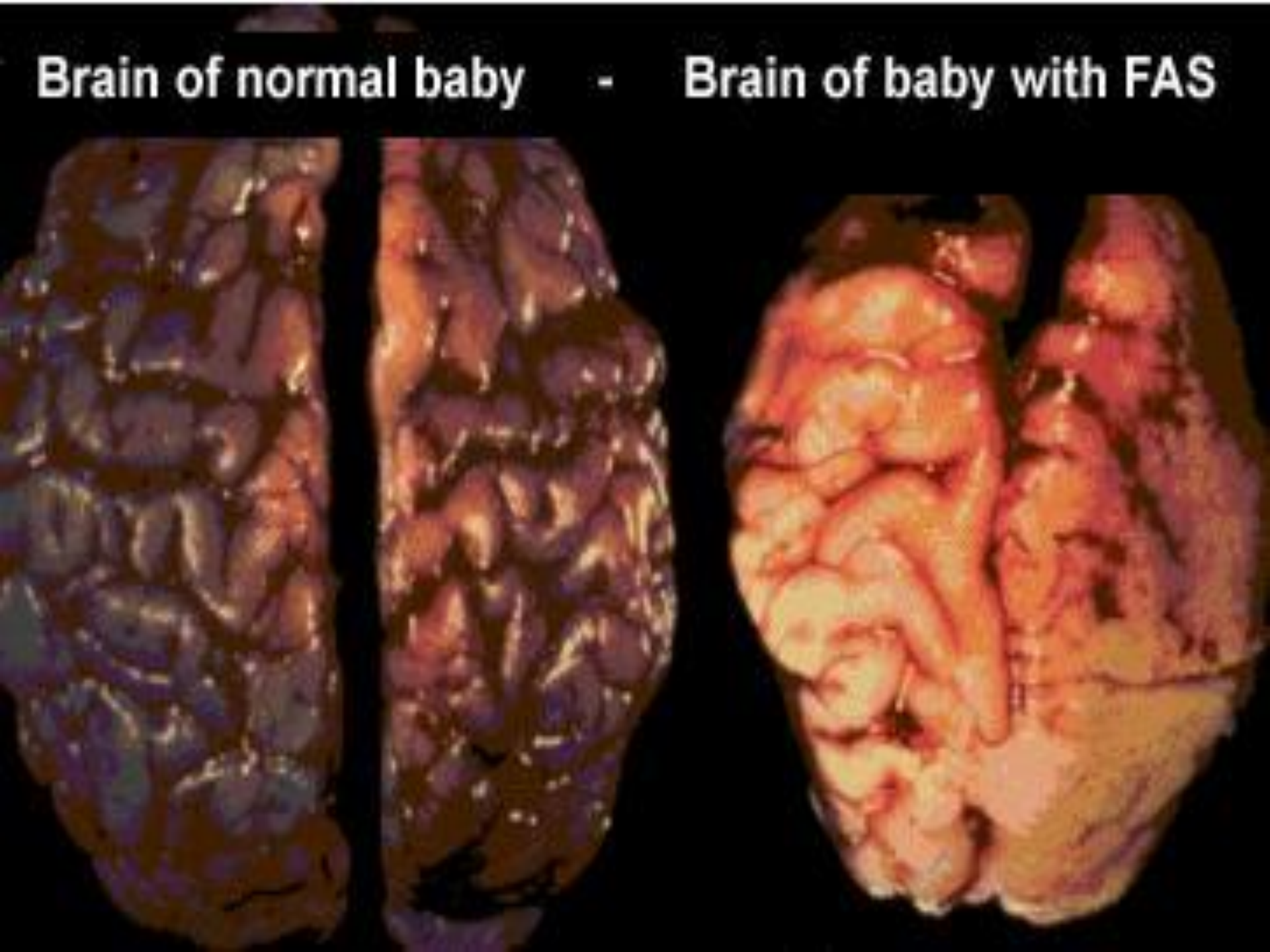
Weight at 14 Years (lb.)



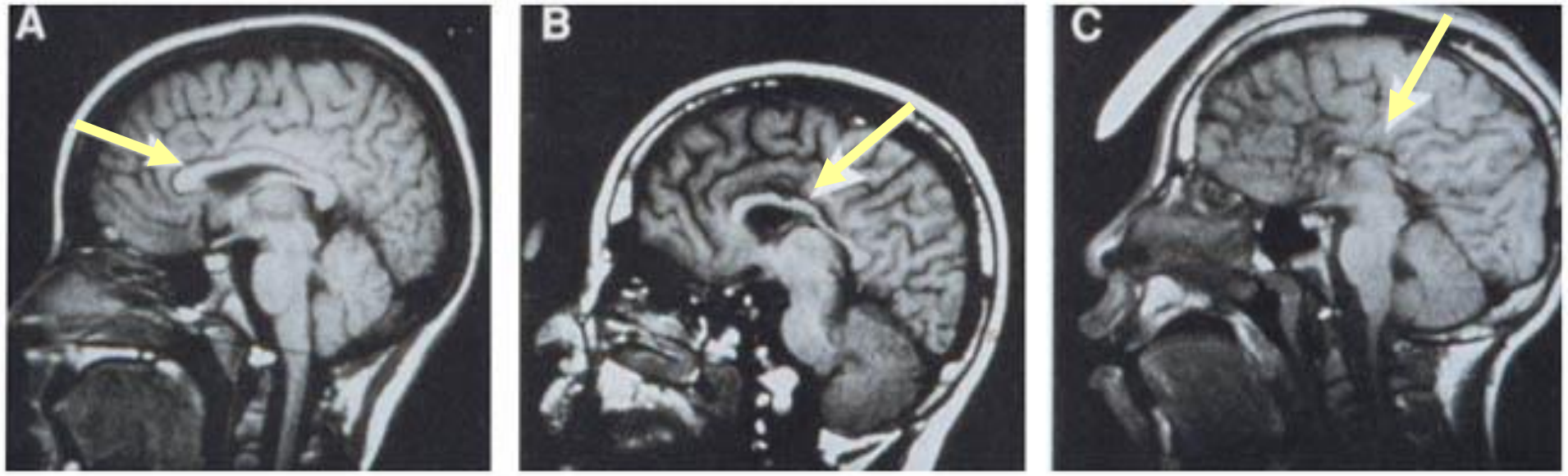
N. Day et al, Alcoholism 2002

Prenatal exposure to alcohol causes the brain to actually be "built" differently …



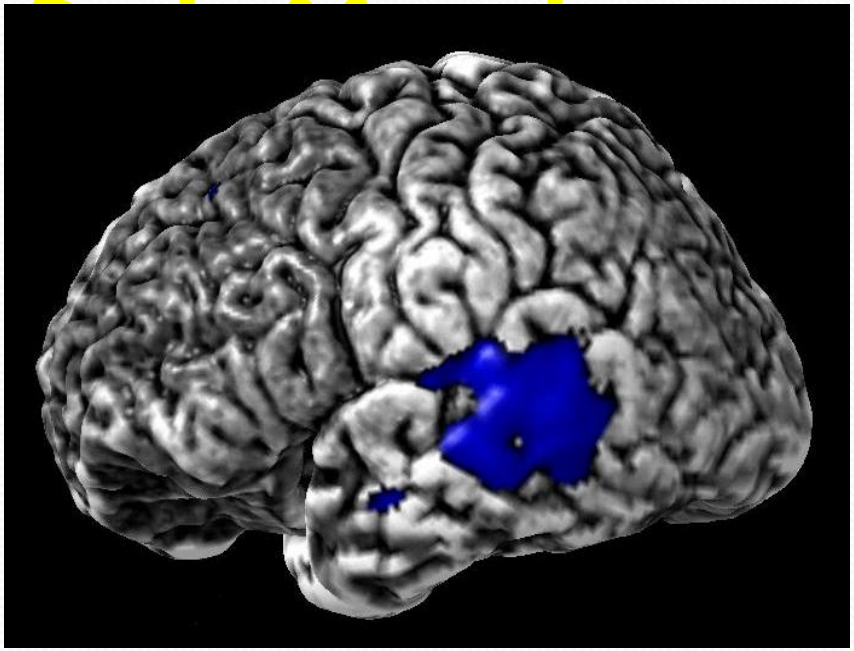

Brain of normal baby - Brain of baby with FAS

Visualization of the brain of a typical (A) and two children exposed to alcohol (B,C) shows permanent loss of the tissue indicated by the arrows (portions of the corpus callosum).



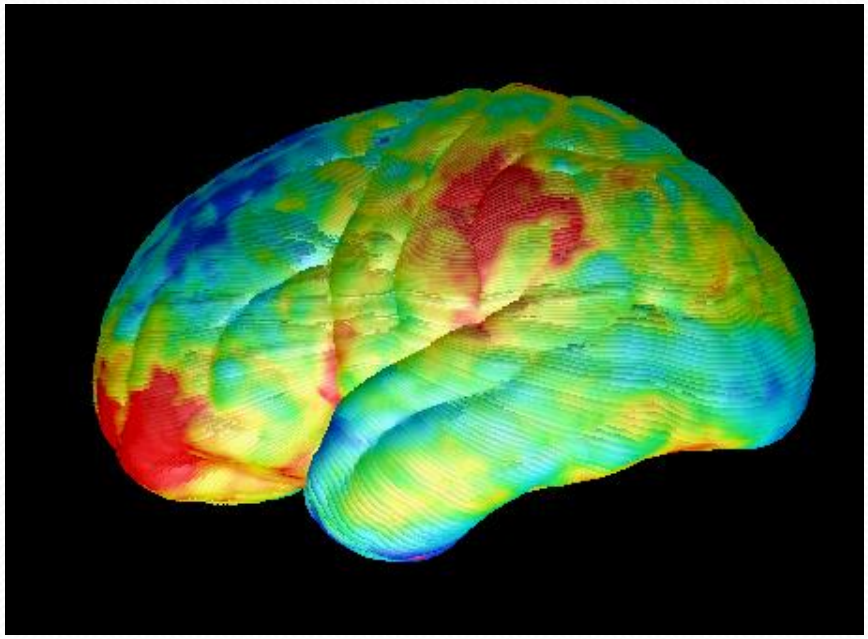
Normal FAS/PEA FAS

Images courtesy of Dr. S. Mattson



Gray Matter Density Increase

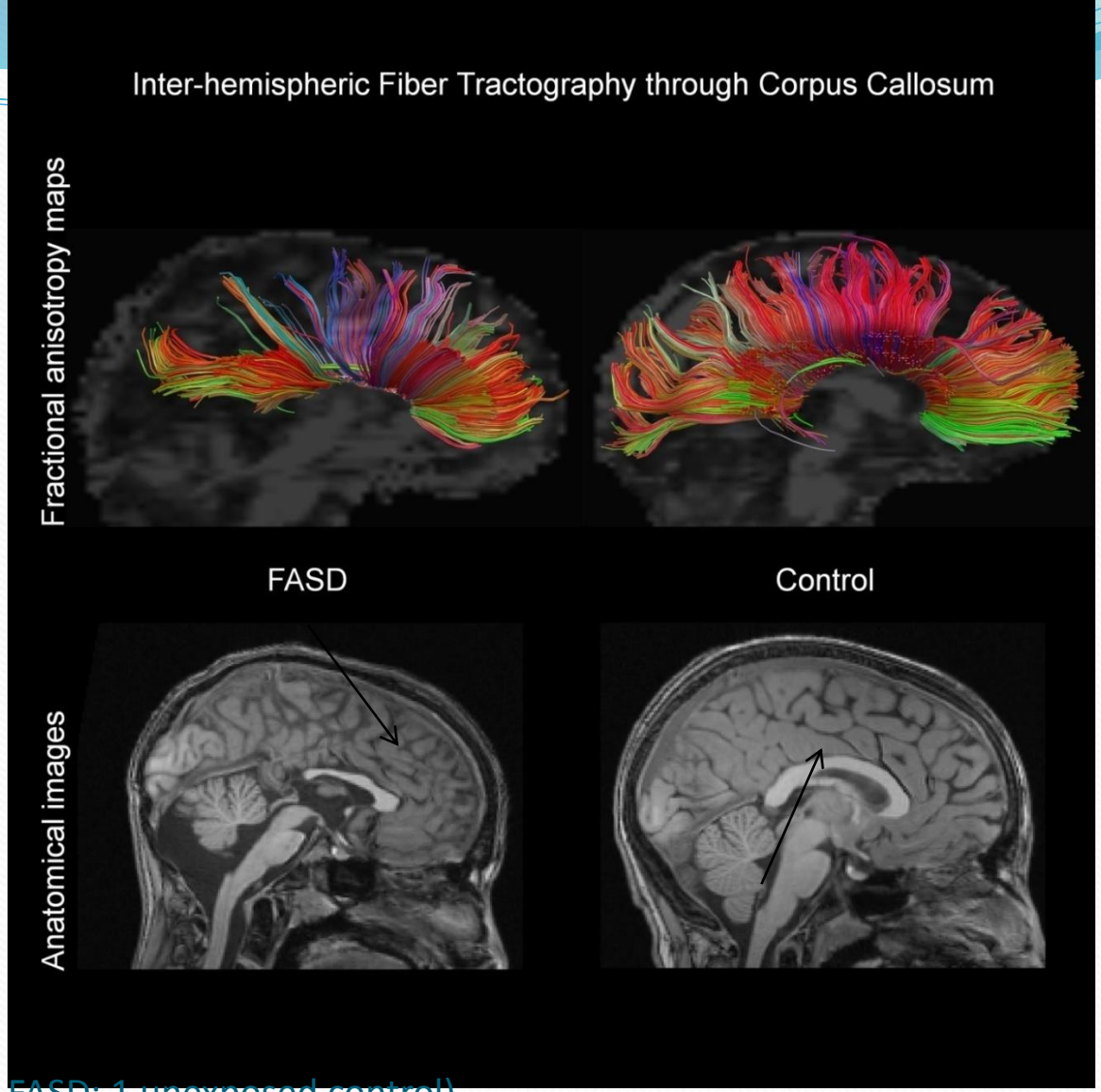
- Sowell et al., 2001a



Shape Distortion in Frontal and Parietal Lobes

- Sowell et al., 2001b

White matter, the fibers that connect different regions of the brain, is also affected by prenatal exposure to alcohol



Pictured are two 12-year old boys (1 FASD; 1 unexposed control)

- Here, Diffusion Tensor MRI reveals the **full extent** of the damage
- It can also **reveal subtle damage** not identifiable by other techniques
- With these methods, more children with subtle damage will be identified and we will better understand how to rehabilitate the damage

Wozniak et al. (2011). Neuropsychology Review, 21(2), 133-147.

Summary of Neuropsychological Findings

- Heavy prenatal alcohol exposure is associated with a wide range of neurobehavioral deficits including visuospatial functioning, verbal and nonverbal learning, attention, and executive functioning

- Children with and without physical features of the fetal alcohol syndrome display qualitatively similar deficits

FASD is a Systemic Disability

Animal Studies (Joanne Weinberg, 2008)

- Study examines how alcohol exposure affect neurological systems in an animal model and implications for intervention.
  - Altered hormonal, immune, and behavioral function
  - Special emphasis on stress

Initial Findings:

- Maternal alcohol consumption increases HPA (hypothalamic pituitary adrenal) activity and alters HPA regulation to the mother and the offspring
- HPA is the stress axis and may be a common pathway for early adverse life experiences

Preventing FASD may prevent many other health consequences

35 Year Old Woman (PAE)

- Systemic lupus
- Idiopathic thrombocytopenia purpura
- Chronic migraine
- Antiphospholipid syndrome
- Fibromyalgia
- Hiatial hernia
- Pituitary microdenoma
- Hysterectomy
- Prolapsed bladder
- Depression
- Anxiety
- Learning disabilities
- Poor executive functioning

Common disorders identified with FASD

- Autism/Aspergers' s Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Borderline Personality Disorder
- Attachment-Bonding Disorder
- Depression
- Learning disability
- Oppositional-Defiant Disorder
- Post Traumatic Stress Disorder (PTSD)
- Receptive-Expressive Language Disorder
- Conduct Disorder

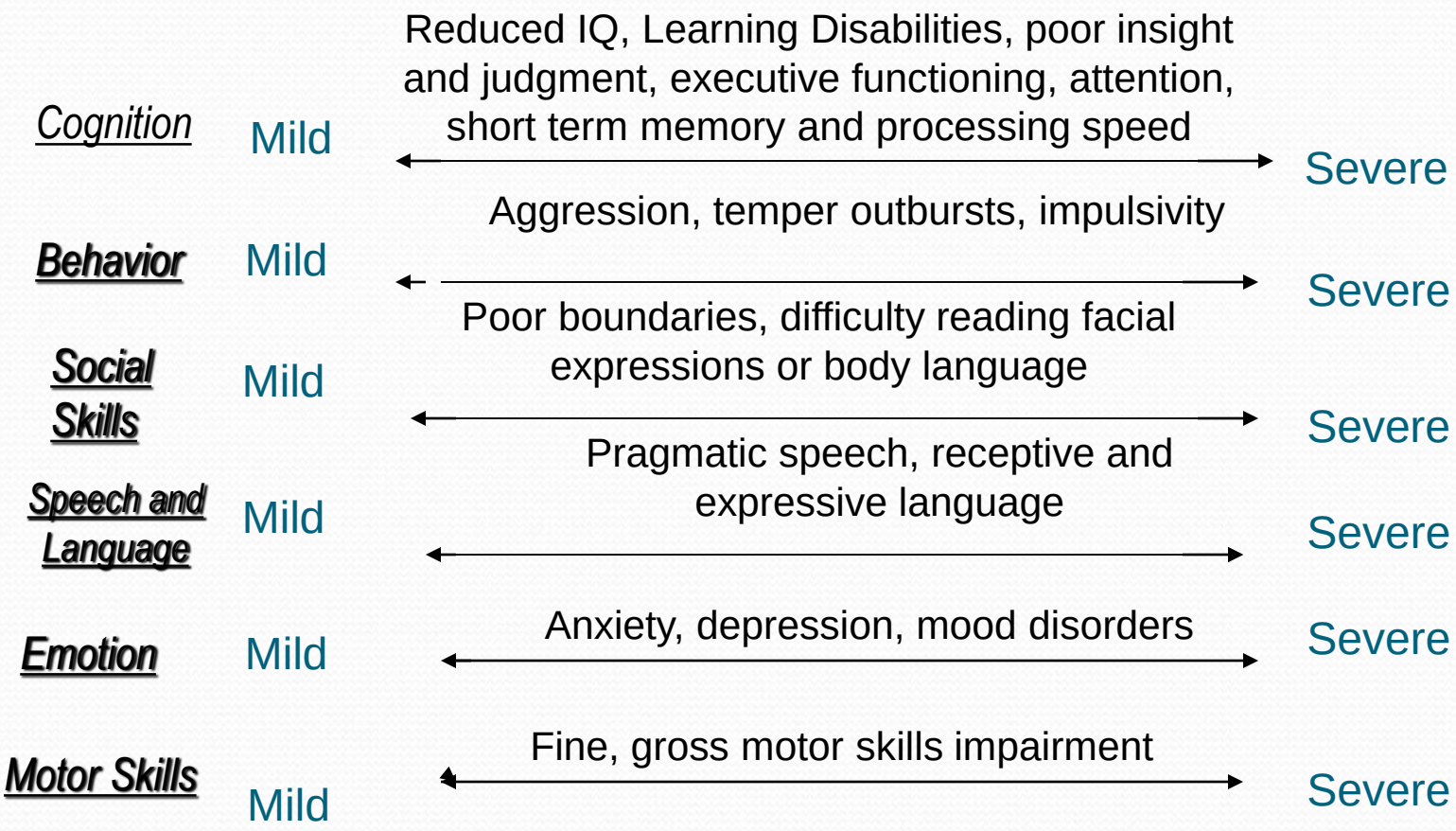
Lifelong Behavioral profile of FASD

- Reduced IQ
- Learning deficits
- Increased activity and reactivity
- Perseverative
- Attentional deficits
- Poor fine and gross motor skills
- Developmental delays
- Feeding issues
- Hearing deficits
- Sensory integration

Concepts that may be problematic:

- **Decision Making**
- **Time**
- **Impulsiveness**
- **Seeing another perspective-point of view**
- **Adaptive behavior-Has no idea what to do, when he does not know what to do**
- **Can't see the *big picture* -only the little immediate picture**
- **Distinguishing between public and private behaviors**
- **Difficulty expressing themselves**
- **Language**
  - **receptive deficits (connecting to meaning)**

Lifetime Cognitive, Behavioral, Emotional and other Problems Appear Across a Continuum of Severity



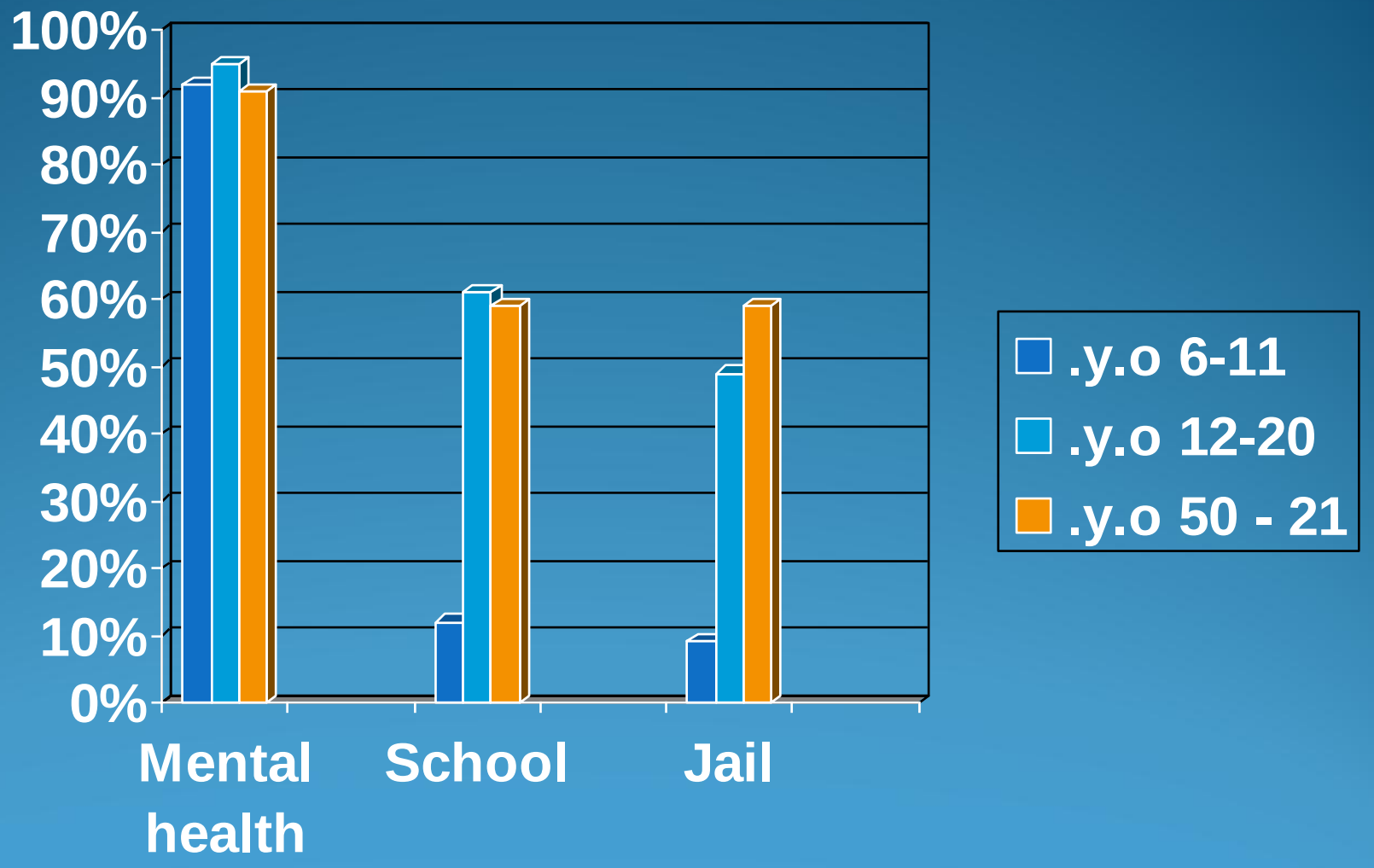
Lockhart, P. 2006

Adults with FASD

- I get you, but I can't figure out how to do it by myself
- I can see what you're saying, but I can't listen to your words
- I know in the moment, but forget later
- I can't do all of the time what I can do some of the time

  - Ory, N 2004

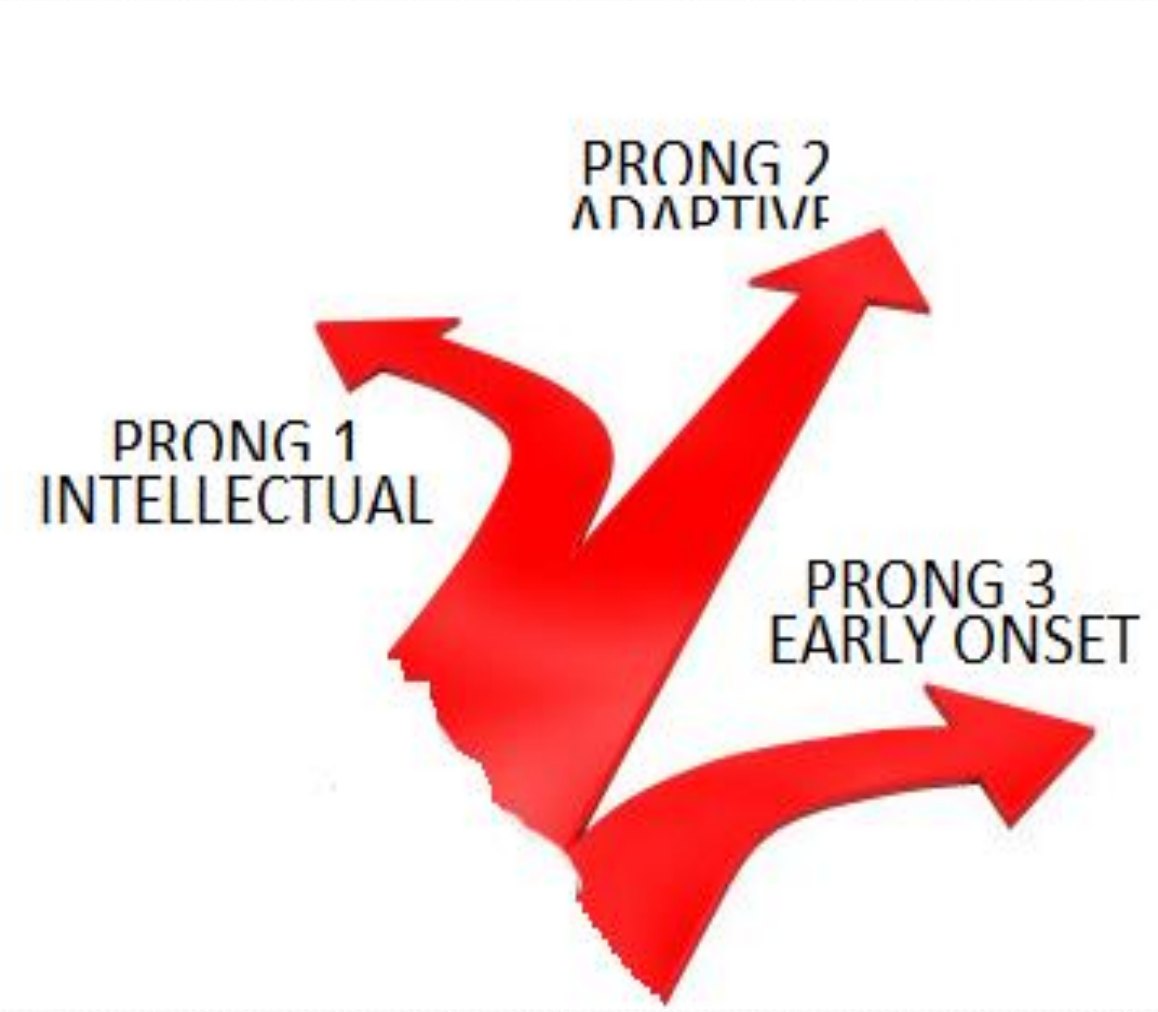
Secondary Disabilities



Individuals with FASD are at risk for victimization….

- Functioning at a lower developmental age, BUT may have appearance of being higher functioning
- Understanding & remembering stranger-safety
- Difficulty with abstract thinking (predicting future behaviors)
- Retrieving information, ST memory
- Difficulty translating from brain to behaviors (thinking-speaking, hearing-writing)
- Difficulty comparing & contrasting
- Understanding cause-effect relationships

THE LEGAL AND CLINICAL DEFINITION OF ID HAS THREE PRONGS: (1) IMPAIRMENT IN INTELLECTUAL FUNCTIONING, (2) IMPAIRMENT IN ADAPTIVE BEHAVIOR, (3) ONSET BEFORE AGE 18 (IN SOME JURISDICTIONS, BEFORE 22)



People with FASD function as if they have ID (i.e., have similar adaptive behavior deficits)

Even though their IQ scores are typically higher, they function in the world (such as in being gullible) in a manner that causes others to view them as having ID

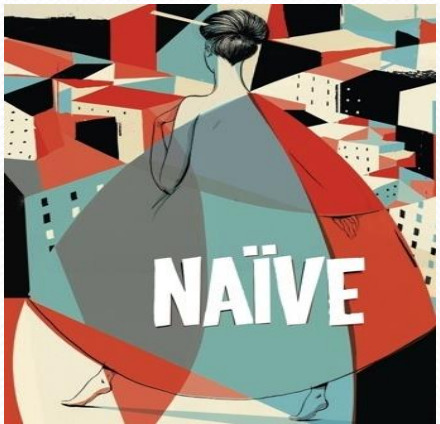
Intellectual Impairment is the first prong of ID. Most assume this means low IQ , but IQ does not capture all (or the most critical) aspects of "intelligence"

"SOCIAL INTELLIGENCE IS MORE IMPORTANT THAN ACADEMIC (IQ) INTELLIGENCE IN DEFINING AND DIAGNOSING ID" S. Greenspan

THE KEY BEHAVIORAL QUALITIES OF FASD AS IDENTIFIED BY THE FABS ARE:

- VERY IMPULSIVE BEHAVIORS
- VERY POOR JUDGMENT IN CHOICE OF FRIENDS
- LACK OF ABILITY TO TAKE PERSPECTIVES OF OTHERS
- FAILURE TO LEARN FROM MISTAKES
- EASILY MANIPULATED AND EXPLOITED

IN OTHER WORDS, THEY ARE HIGHLY



S Greenspan

NAIVITE OF PEOPLE WITH FASD IN RELATION TO CRIMINAL JUSTICE MANIFESTS IN 3 WAYS:

1--NAÏVE OFFENDER

LESS ABLE TO UNDERSTAND THE CRIMINAL NATURE OF AN ACTIVITY OR THE LIKELIHOOD OF GETTING IN TROUBLE

- MAY HAVE GONE ALONG WITH OTHERS WITHOUT FULLY UNDERSTANDING WHAT WAS HAPPENING

- MAY HAVE BEEN LEFT "HOLDING THE BAG"

S. Greenspan

2--NAÏVE CONFESSOR

LESS ABLE TO RECOGNIZE OR PROTECT ONESELF FROM INTERROGATIVE PLOYS

- MORE LIKELY TO WAIVE MIRANDA RIGHTS
- MORE LIKELY TO MAKE INCONSISTENT STATEMENTS
- MORE LIKE TO CONFESS, EVEN WHEN INNOCENT

S. Greenspan

3--NAÏVE DEFENDANT

LESS ABLE TO UNDERSTAND WHAT IS HELPFUL OR HARMFUL IN A LEGAL PROCEEDING

- INAPPROPRIATE COURTROOM DEMEANOR
- DISASTROUS PERFORMANCE ON THE STAND
- UNABLE TO PROVIDE USEFUL INFORMATION TO COUNSEL
- UNABLE TO INITIATE OR CONSIDER A PLEA DEAL

Paradigm Shift:

- Person with a developmental disability
- Can't not Won't
- Need support (External Brain)

Forensic Assessment of Fetal Alcohol Spectrum Disorders

Richard Adler, MD, Medical Director
Natalie Novick Brown, PhD, Program Director
Paul Connor, PhD, Neuropsychological Director
Retired Judge Anthony Wartnik, Legal Director

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FASD EXPERTS SCREENING QUESTIONNAIRE	✓
OFFENSE CONDUCT	
Illogical actions with high detection risk	
"Simple" plan (focus is only on the objective)	
No real exit strategy	
Impulsive and aggressive over-reaction to unforeseen events ("fight or flight")	
More sophisticated/experienced co-defendants	
ARREST CONDUCT	
Immediately or easily waives rights	
Over-confesses (suggestible)	
Brags about prowess or takes full responsibility if co-defendants	
Emotionally detached from crime (shows little remorse or guilt)	
Behavioral regression (breaks down in tears, infantile behavior)	
INTERVIEW WITH CLIENT	
Short stature (not always)	
Unstable lifestyle	
Immature and naïve	
Eager to please or stubbornly resists the obvious	
Can't provide coherent, detailed narrative	
Can't concentrate	
Doesn't add much	
Doesn't seem to remember what you tell him/her from appointment to appointment	
PRIOR LEGAL HISTORY	
Easily led by more sophisticated peers	
Multiple low-grade offenses in teen years, often with co-defendants	
Lots of stealing	
Illogical offenses (e.g., stealing something with little value)	
Oblivious to risk	
Impulsive, opportunistic crimes	
Probation violations	
LIFE HISTORY	
Mom abuses alcohol/drugs	
Involvement with child welfare	
Adoption/foster or relative placements/juvenile commitment	
Special Education / learning disabilities in school	
Multiple diagnoses in childhood (especially ADD/ADHD)	
Rule-breaking behaviors (lies, cheats, steals, fights)	
Disrupted education	
Substance abuse	
Unstable adult lifestyle (improves with structure)	

Juvenile Court and Medical Records

- Obtain all juvenile records.
  - All social services reports, psychological records.
  - If the client was incarcerated you will need to get all educational records, social histories.

- Obtain all medical records.

Client's Educational Records

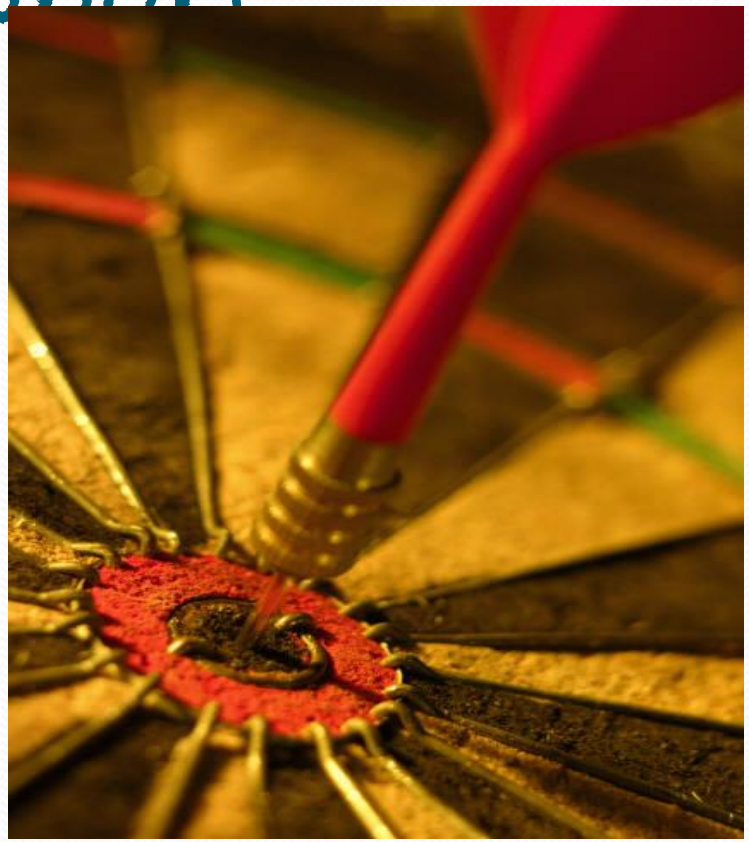
- All academic and attendance records.
- Special education records including eligibility and placement reports (many kids qualify for more than one category).
- All IEP reports (goals and accommodations).
- (Investigate the parent's failure to follow up with the IEP meetings to request the required services for the client).
- Was there any IQ testing completed.

Treating FASD

- There is no one medication to treat "FASD"
- Address presenting symptom
- Choose medication wisely- lower side effects
- Monitor carefully and change if: negative side effects, no positive change, increase of symptoms, developing new symptoms, improvement of symptoms, lack of adherence

Structure & Support

Foundation for success



CDC FASD APP

- http://itunes.apple.com/us/app/fetal-alcohol-spectrum-disorders/id517058288?mt=8&ls=1

- ACOG Webpage on alcohol and women:

http://www.womenandalcohol.org

American Academy of Pediatrics

- Professional education materials to inform pediatricians about prevention, identification, and treatment of children with FASDs

- *Pedia*Link online training course

- AAP FASD Toolkit – www.aap.org/fasd

Stamp Out Stigma Campaign

Join the campaign!
www.nofas.org/stigma

Join NOFAS and the NOFAS Circle of Hope to stop the stigma of birth mothers of children with FASD and the stigma of all individuals and families living with the disorders.

Resources

- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
  - NOFAS Resource Directory: www.nofas.org/resource/directory.aspx
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Clearinghouse for Alcohol and Drug Information (NCADI): ncadi.samhsa.gov

Contact me ANYTIME!
Thank You!

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