

Screening and Intervention for Fetal Alcohol Spectrum Disorders Can Change Lives

Nancy Whitney, M.S.,L.M.H.C



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LEARNING OBJECTIVES

1. State the impact of prenatal alcohol exposure on brain development and how FASD is recognized
2. Describe disabilities and associated behaviors related to prenatal alcohol exposure
3. Explore strategies to decrease behavior issues in custody

WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS?

FASD Terminology

- **Fetal Alcohol Syndrome (FAS)** is a medical diagnosis (Q86.0 in the International Classification of Diseases ICD-10)
- **FASD** is an umbrella term describing the range of effects (and diagnoses) that occur as a result of a mother drinking during pregnancy. FAS is one diagnosis under the FASD umbrella
- **Fetal Alcohol Spectrum Disorder** - FASD is not a medical diagnosis
- DSM V: **Other Specified Neurodevelopmental disorder associated with prenatal alcohol exposure.** (315.8 New to the DSM V)
- **FAS/FASD** are a type of organic brain damage

Can include physical, mental, behavioral, and/or learning disabilities with lifelong implications
- **Prenatal Alcohol Exposure (PAE)** – describes the exposure that may or may not result in FASD



Cause of FASD

The sole cause of an FASD is the fetus being exposed to alcohol during the pregnancy.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

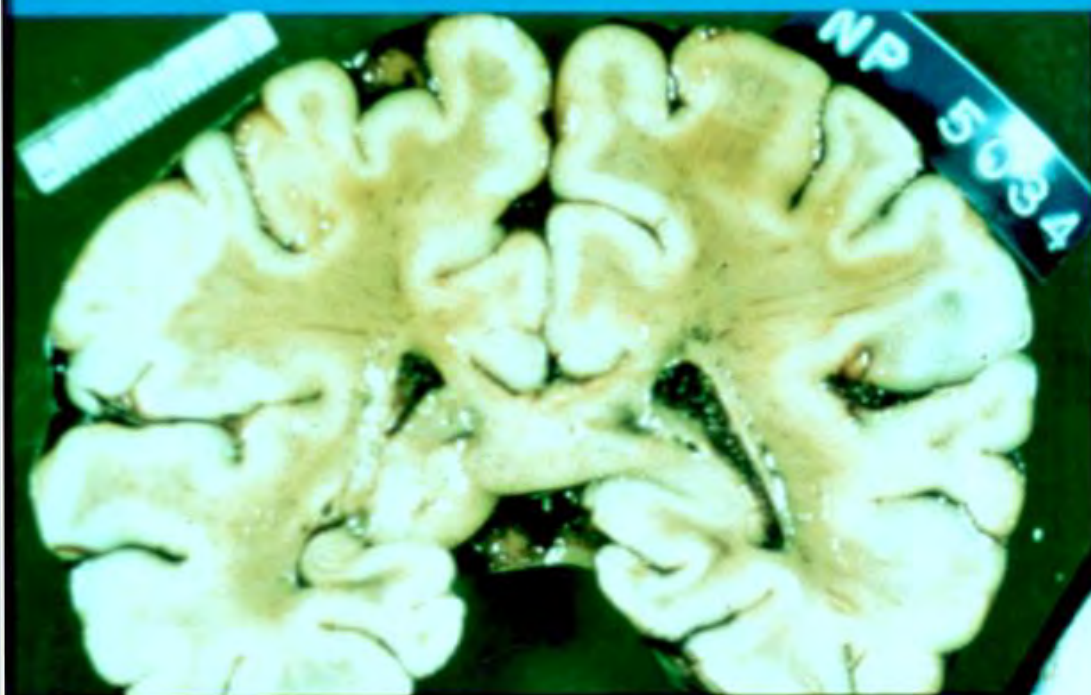
—*IOM Report to Congress, 1996*

Alcohol is a Teratogen

- **Teratogens** are substances that have the potential to damage the fetus when exposure occurs during pregnancy (e.g., radiation, alcohol)
- Degree of damage depends on timing, amount of exposure, genetics, and possibly maternal nutrition

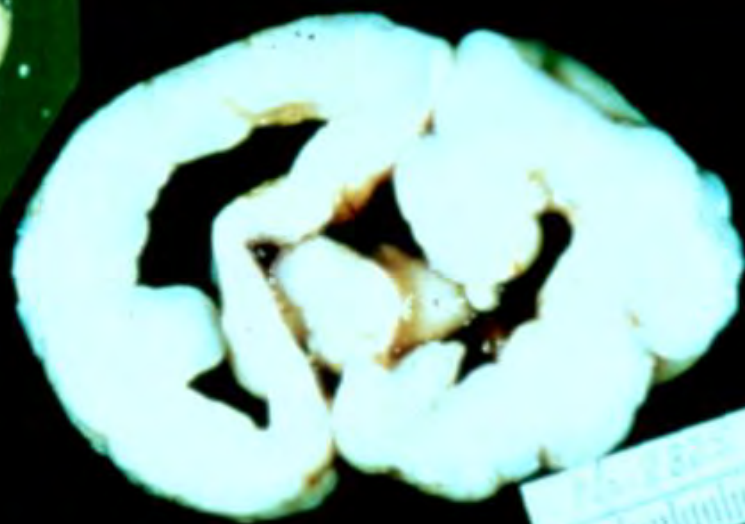


Coronal Sections of Brain



Normal

FAS



Diagnosis of FAS

- **Growth deficiency**

They are born small- head circumference and weight , and stay small, at least until puberty.

- **Distinct facial features**

Also may disappear puberty.

- **Central nervous system damage**

Becomes more apparent as the individual gets older.

- **Prenatal Alcohol Use**

While we know that the more use during pregnancy increases the chances of significant disability, we do not have the ability to predict a 'safe amount.'

GROWTH DEFICIENCY

- Low birth weight
- Small head
- Pattern of being underweight and short throughout childhood
- May disappear in adolescence



Slide by Susan Astley, PhD, UW FAS Diagnostic and Prevention



(a)



(b)



(c)



(d)

Facial Features

- **Rank 1:** no facial features
- **Rank 2:** 1-2 features
- **Rank 3:** 2.5 features
- **Rank 4:** All 3 features

Discriminating Features

short palpebral fissures

flat midface

short nose

indistinct philtrum

thin upper lip

Associated Features

epicanthal folds

low nasal bridge

minor ear anomalies

micrognathia

In the Young Child

Central Nervous System (CNS) Damage

- **Rank 1:** No dysfunction
- **Rank 2:** Moderate dysfunction
- **Rank 3:** Severe dysfunction
- **Rank 4:** Structural/Neurological abnormalities
 - Head circumference
 - Seizure disorder
 - MRI results



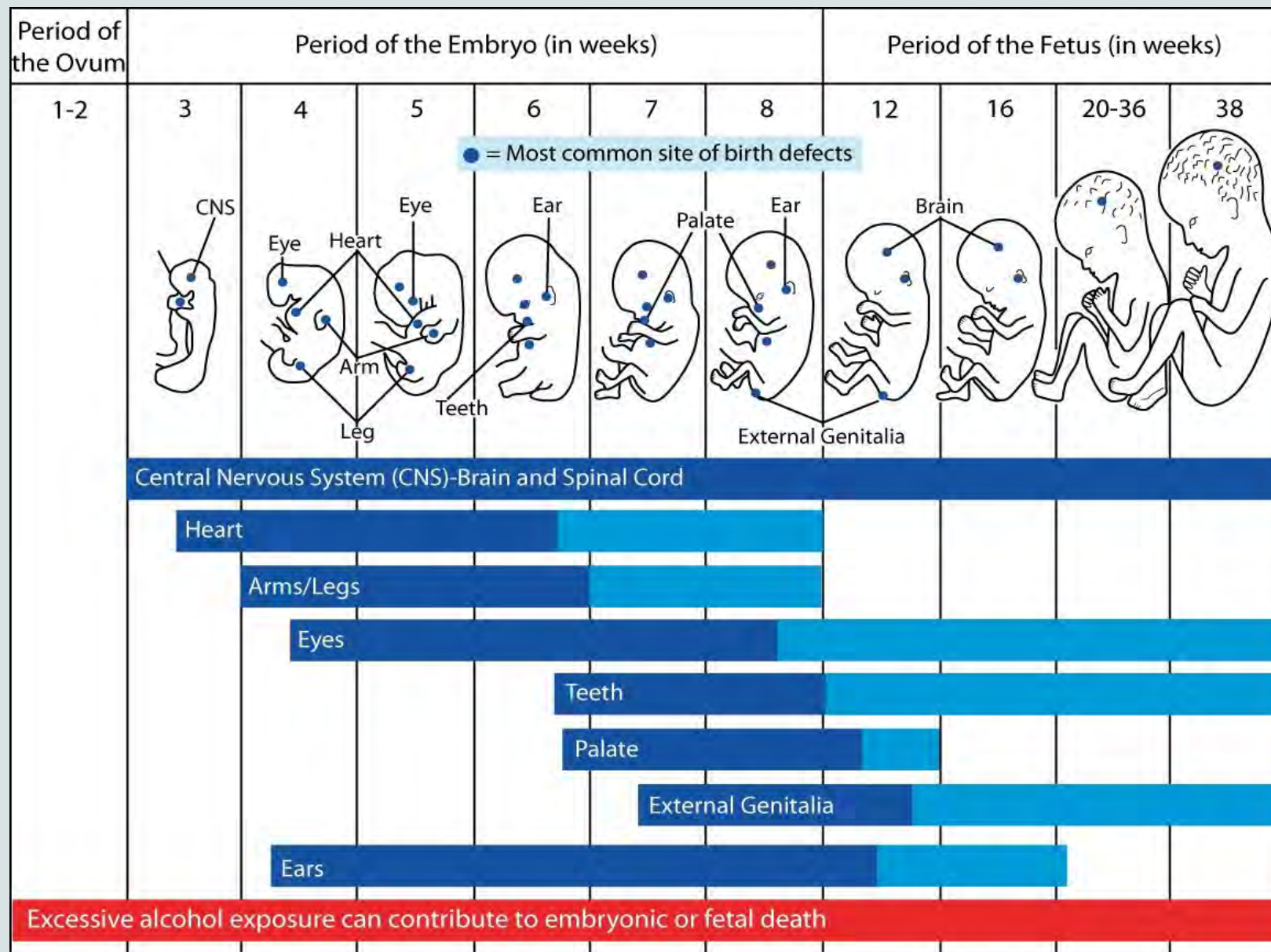
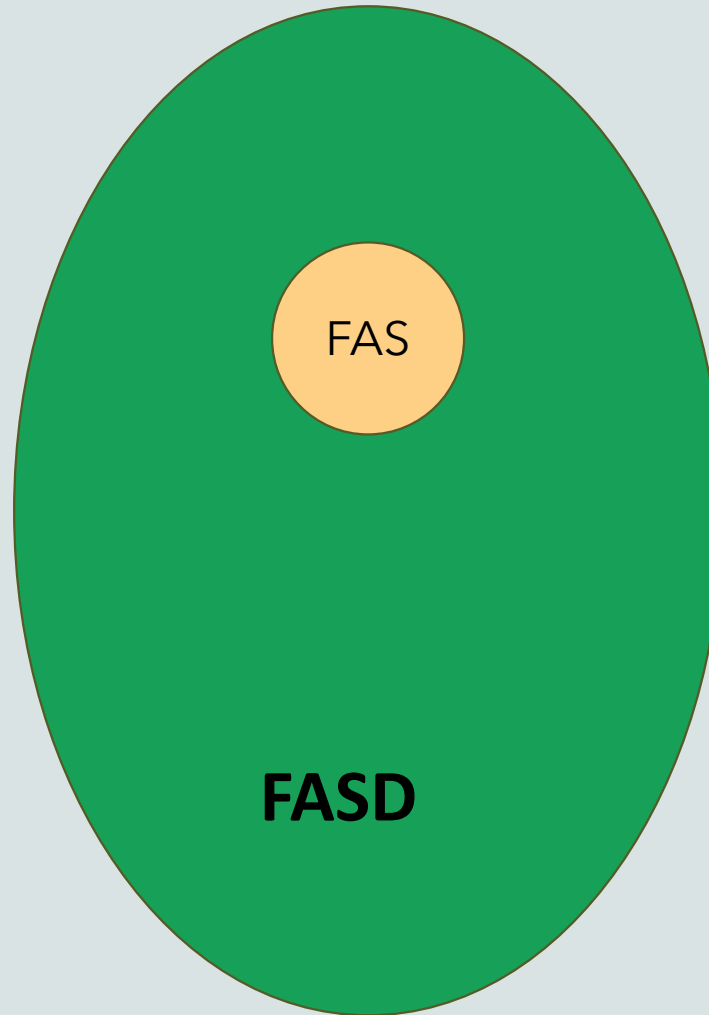


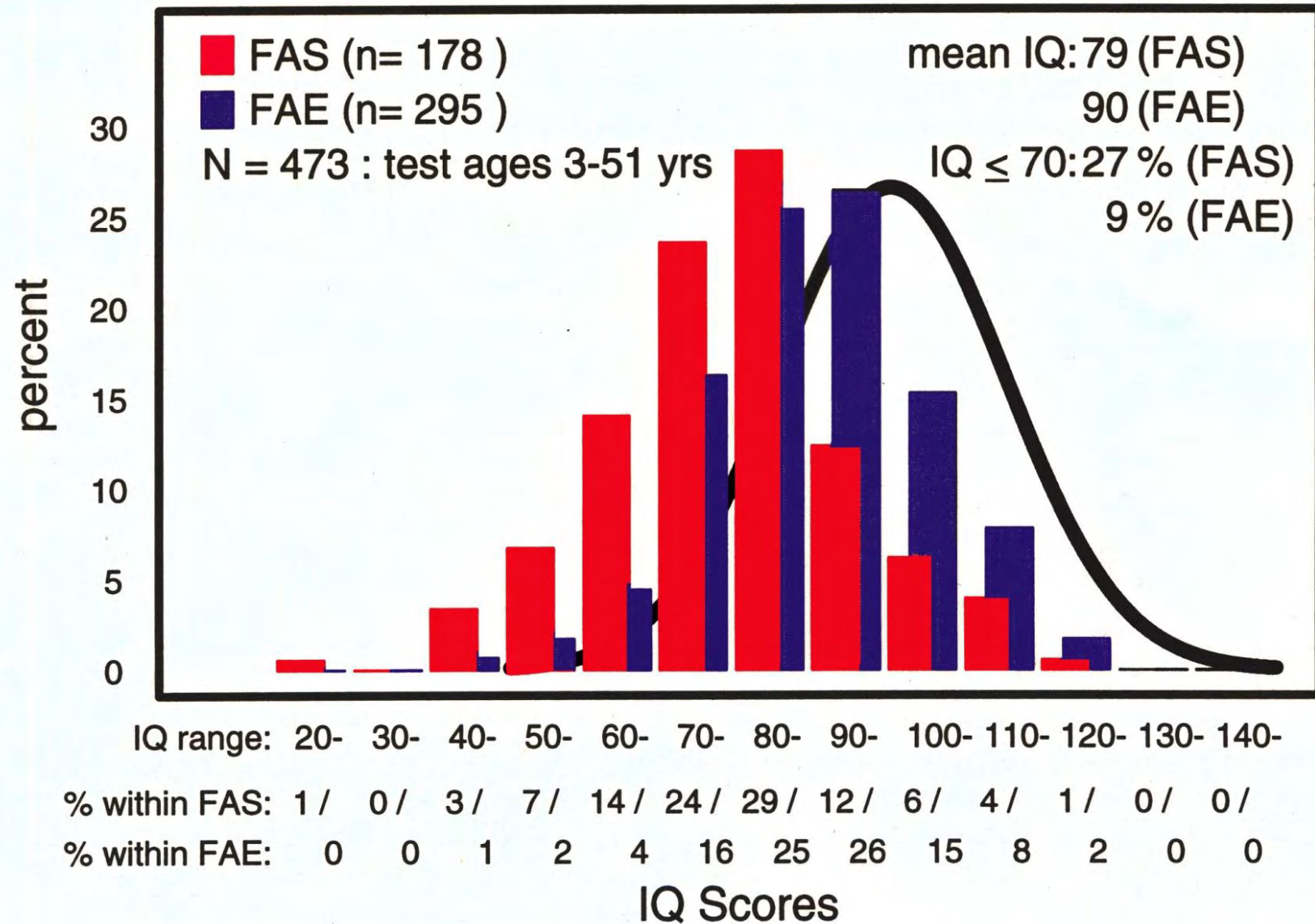
Figure 1 Vulnerability of the fetus to defects during different periods of development. The blue portion of the bars represents the most sensitive periods of development, during which alcohol-induced (i.e., teratogenic) effects on the sites listed would result in major structural abnormalities in the child. The light blue portion of the bars represents periods of development during which physiological defects and minor structural abnormalities would occur. SOURCE: Adapted from Moore and Persaud 1993. Jacobson, S. (1997). Assessing the impact of maternal drinking during and after pregnancy. Alcohol Health Res World 21(3): 199-203.

FAS IS PART OF FASD

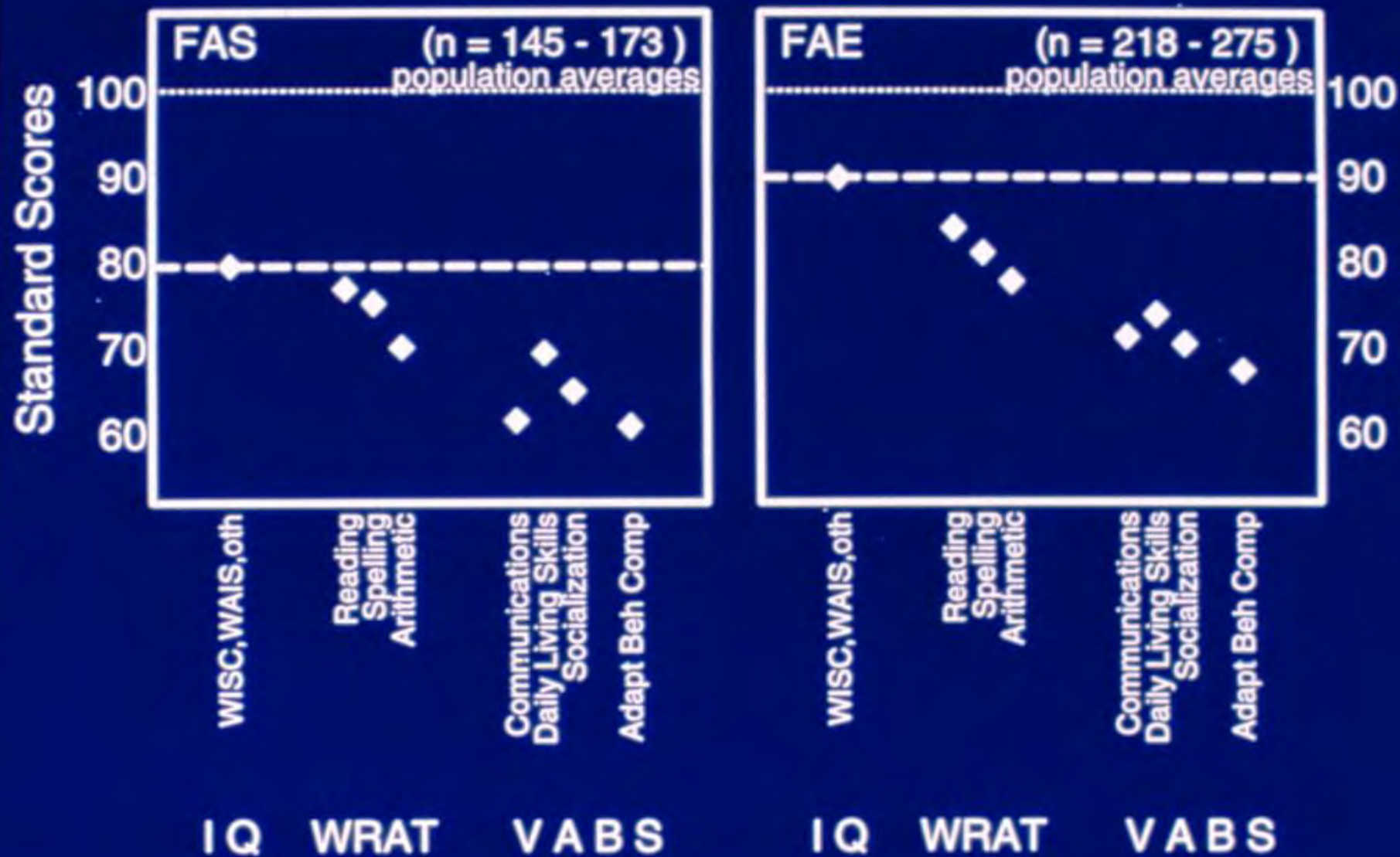


... a very small part of the total effected individuals.

IQ distributions in the Primary Disabilities Sample: FAS and FAE



IQ, WRAT, VABS: FAS and FAE





FASD

Central Nervous System Dysfunction
Organic Brain Damage

- Hyperactivity, attentional deficits
- Intellectual deficits, learning disorders
- Problems with memory, language & judgment
- Developmental delay, microcephaly
- Fine & gross motor problems, seizure disorder
- Structural brain damage

PAE and the Brain: “*Diffuse brain damage*”

Teratogenic effects of alcohol are widespread, affecting almost the entire brain.

Review of MRI studies found: reduced brain volume, shape & thickness changes in corpus callosum; malformations throughout multiple brain regions.

High variability.

New studies link cognition to underlying brain structure.

Regions of the Brain Affected by Prenatal Alcohol

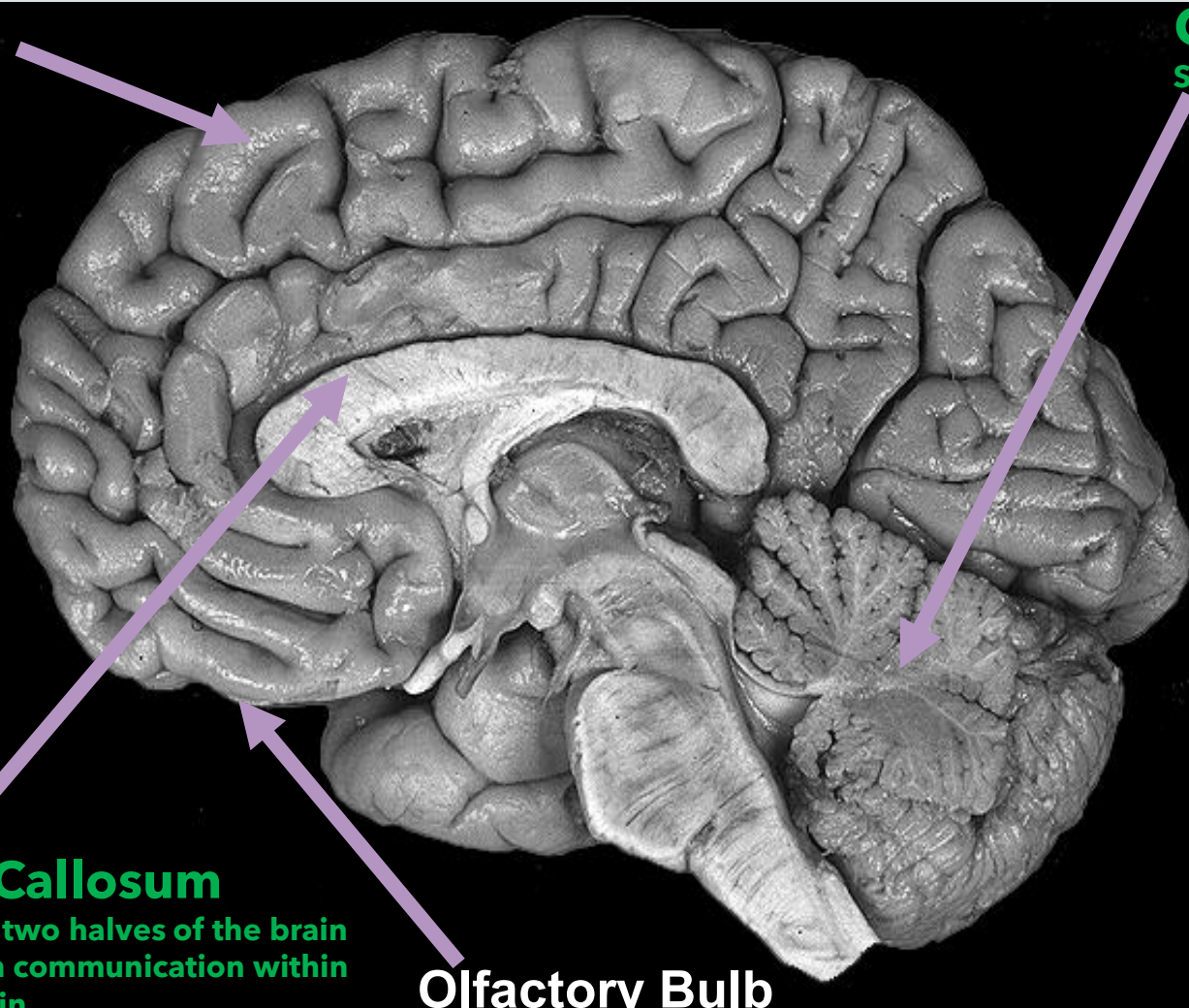
Cerebral Cortex

Cerebellum
Sowell et al, (1996)

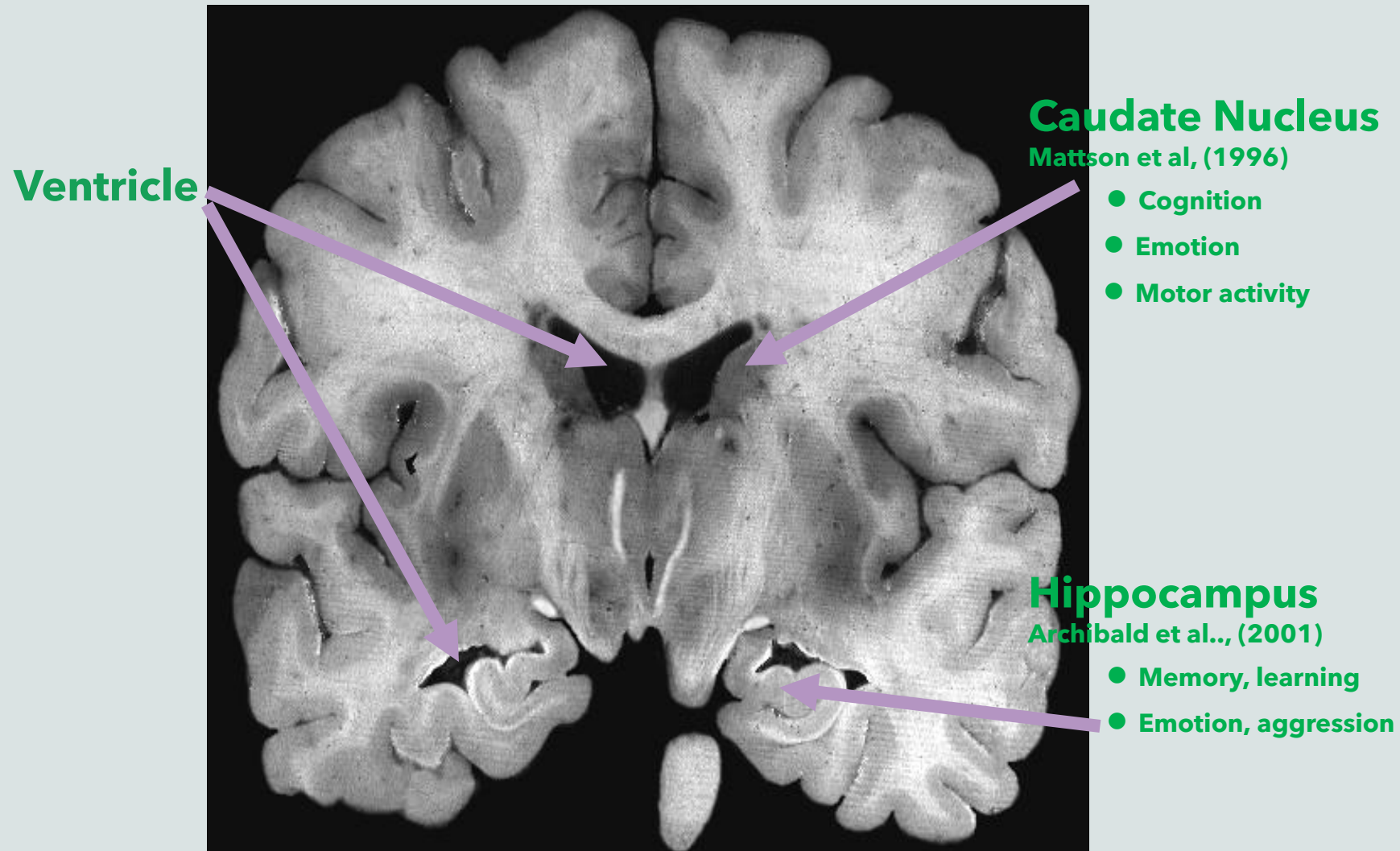
Corpus Callosum

Connects the two halves of the brain
Plays a role in communication within the brain

Olfactory Bulb



Regions of the Brain Affected by Prenatal Alcohol



**Prenatal
Alcohol**



**Primary
Disability**

**Brain
Damage**



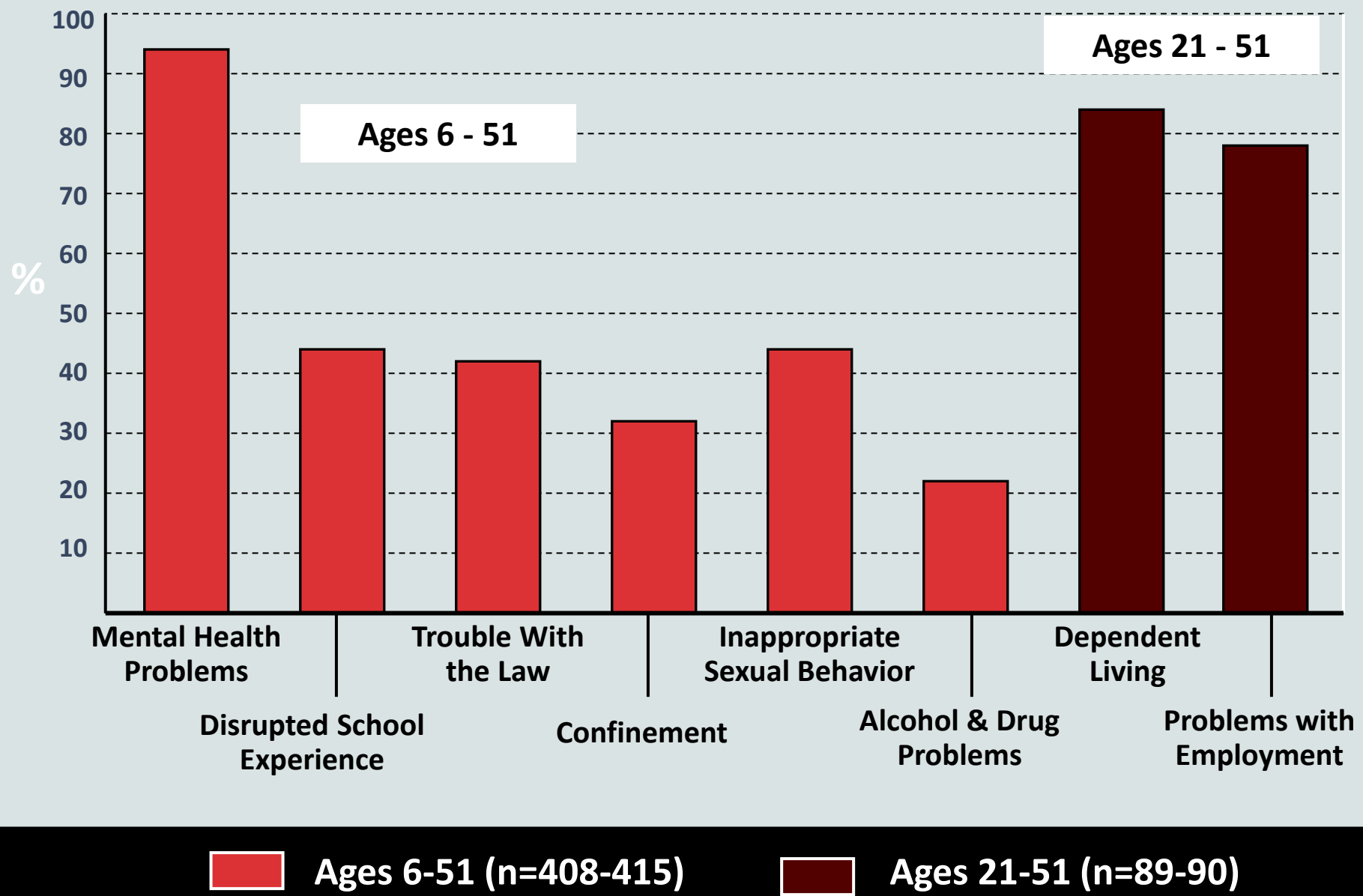
**Dysfunctional
Behaviors**



**Secondary
Disabilities**

**Trouble with the Law,
School Disruption, Etc.**

PREVALENCE OF SECONDARY DISABILITIES Across the Life Span



Prevalence of FASD

Trends in Alcohol Use Among Pregnant Women in the United States, 2011–2018

- A 2020 report published in the *American Journal of Preventive Medicine* found that both current alcohol use and binge drinking among pregnant women aged 18–44 years in the United States increased slightly from 2011 to 2018.
- Current drinking (having at least one drink of any alcoholic beverage in the past 30 days) increased from 9.2% in 2011 to 11.3% in 2018.
- Binge drinking (having four or more drinks on an occasion during the past 30 days) increased from 2.5% to **4.0%** in that same time period.
- The data for this report come from CDC's [Behavioral Risk Factor Surveillance System](#).

- Using medical and other records, CDC studies have identified 0.2 to 1.5 infants with **FAS** for every 1,000 live births in certain areas of the United States.¹ The most recent CDC study analyzed medical and other records and found FAS in 0.3 out of 1,000 children from 7 to 9 years of age.
- Studies using in-person assessment of school-aged children in several U.S. communities report higher estimates of FAS: **6 to 9 out of 1,000 children.**
- Few estimates for the full range of FASDs are available. Based on the National Institutes of Health-funded community studies using physical examinations, experts estimate that the full range of FASDs in the United States and some Western European countries might number as high as **1 to 5 per 100 school children (or 1% to 5% of the population)**

CDC. Fetal Alcohol Syndrome Among Children Aged 7-9 Years – Arizona, Colorado, and New York, 2010. MMWR Morb Mortal Wkly Rep. 2015;64(3):54-57.

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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May PA, Chambers CD, Kalberg WO, Zellner J, Feldman H, Buckley D, Kopald D, Hasken JM, Xu R, Honerkamp-Smith G, Taras H, Manning MA, Robinson LK, Adam MP, Abdul-Rahman O, Vaux K, Jewett T, Elliott AJ, Kable JA, Akshoomoff N, Falk D, Arroyo JA, Hereld D, Riley EP, Charness ME, Coles CD, Warren KR, Jones KL, Hoyme HE. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *Journal of American Medical Association*. 2018;319(5):474–482.

Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities

- 6,639 first graders, in 4 U.S communities were assessed from 2010- 2016
- Children were systematically assessed in the 4 domains that contribute to the fetal alcohol spectrum disorder continuum: dysmorphic features, physical growth, neurobehavioral development, and prenatal alcohol exposure.
- 222 were found to have an FASD. 27 met criteria for FAS
- Only 2 of the children had already been diagnosed
- Conservatively, the estimated prevalence of FASD in the first graders in these communities was 1.1-5%

Prevalence in Special Populations

- The estimated prevalence of FASD in these special subpopulations was **10-40 times higher** compared with the 7.7 per 1000 (95% confidence interval = 4.9-11.7) global FASD prevalence in the general population

Prevalence and Characteristics of Adults with Fetal Alcohol Spectrum Disorder in Corrections: a Canadian Case Ascertainment Study.

- A study done in a Northern Canadian correctional facility found 17.5-25.8 % met criteria for an FASD diagnosis (n=80). Of these individuals, **only two** had been previously diagnosed (14.3%).
- Diagnostic decisions could not be made with reliability in 11 cases (13.8%, considered 'deferred'), indicating that **our prevalence estimate could have been as high as 31.2% with sufficient information about prenatal alcohol exposure.**

Fetal Alcohol Spectrum Disorder Prevalence Estimates in Correctional Systems: A Systematic Literature Review

“There is an urgent need to raise awareness about the prevalence and disabilities of individuals with FASD in the criminal justice system and about appropriate responses. The criminal justice system is an ideal arena for intervention efforts aimed at the rehabilitation and prevention or reduction of recidivism in this unique population.”

AMERICAN BAR ASSOCIATION

APPROVED BY THE ABA HOUSE OF DELEGATES – AUGUST 7, 2012

Co-Sponsors:

ABA Commission on Youth at Risk, Criminal Justice Section, Commission on Disability Rights, Commission on Homelessness and Poverty, Death Penalty Representation Project, Health Law Section, Section of Family Law, Judicial Division, Alaska Bar Association, and the American Judicature Society

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.

Why Screen?

To help you...

- Understand the **nature** of the brain damage that characterizes FASD
- Modify therapeutic approaches accordingly
- Educate your patient about their disabilities

Life History Screen

Screening in treatment programs for Fetal Alcohol Spectrum Disorders that could affect therapeutic progress.

Therese M. Grant¹ , Natalie Novick Brown, J. Christopher Graham, Nancy Whitney, Dan Dubovsky, and Lonnie A. Nelson

- Childhood History
- Maternal Alcohol Use
- Education
- Criminal History
- Substance use
- Employment and Income
- Living Situation
- Mental Health
- Day to Day Behaviors

What did the data tell us?

Comparisons of Group 1 (no PAE or FASD) and Group 2 (Diagnosed or Suspected FASD) on ASI variables corresponding to LHS items

LHS Items	Group 1 No PAE or FASD (N = 463)	Group 2 Diagnosed or Suspected FASD (N = 86)	p-value
Raised by someone other than biological parents	122 (26.4%)	55 (64.0%)	***
Client's mother had a problem with alcohol	138 (29.9%)	67 (79.8%)	***
Client's mother drank when client was a child	172 (37.7%)	68 (89.5%)	***
Educational level 10th grade or lower	154 (33.3%)	42 (48.8%)	**
One or more arrests (and charged) since age 18	354 (76.5%)	65 (76.5%)	ns
Client started using substances before age 12	130 (28.1%)	39 (47.0%)	***
Longest full-time job was less than 12 months	225 (48.6%)	62 (72.1%)	***
Receives Social Security Insurance (SSI)	32 (6.9%)	11 (12.8%)	ns ^a
More than one psychiatric diagnosis	64 (13.8%)	26 (30.2%)	***
History of trouble concentrating	244 (52.7%)	67 (78.8%)	***
Suicide attempt	147 (31.7%)	39 (45.9%)	**

* $p < .05$, ** $p < .01$, *** $p < .001$

^a p - value = .06

CHILDHOOD HISTORY

- **Were you raised by someone other than your biological parents?**
- **How many living situations did you have while you were growing up** (up to the age of 18)?

Prompt: living with your parents, relatives, foster homes, juvenile justice setting, etc

- **Did your mother ever have a problem with drinking alcohol?**

A Prompt: "Can you tell me about this?" (yes) Did she drink alcohol when you were young?

(yes) Did she drink alcohol while she was pregnant with you?

If the client doesn't know, ask "Has anyone ever said anything to you about your mother's drinking? Is there anyone around who knew your mother when she was pregnant with you?"

EDUCATION

- **What's the highest grade in school you completed?**

If you didn't finish school, why did you leave? (too hard, bored, got kicked out, or another reason)

- **Were you ever in "special ed" or did you get any kind of special help in school?**

DAY TO DAY BEHAVIORS

- **When you were a child in grade school, did you often have difficulties with any of the following?**
- Concentrating and paying attention?
- Understanding what adults were telling you?
- Remembering things?
- As a child or as an adult have you often have difficulties with any of the following?
 - *following rules and instructions*
 - *getting along with others, arguing, or fighting*
 - *being on time*
 - *keeping enough money to last you throughout the month*
 - *doing things on the spur of the moment that later you wish you hadn't done*
 - *getting really upset at little things*
 - *forgetting or missing appointments*
 - *being surprised when you get into trouble*

Neuropsychological Testing: Case Example

- Full Scale IQ = 68
- Math Calculation: 8th grade level
- Reading: 4th grade level
- Receptive communication: 8-yr old level
- Personal daily living skills: 22-yr old level
- Community daily living skills: 6-yr old level

What is the relationship between the brain damage and functioning?

- **Cerebral cortex:** Main jobs are sensory integration, thought, voluntary movement, language, reasoning, perception, attention.
- **Cerebellum:** Main job is proper, coordinated movement such as running, walking, writing...
- **Thalamus:** Main jobs are sensory integration, motor integration, sleep, consciousness.
- **Hippocampus:** Main jobs are creating memories, including how to navigate, or move around your environment based on past experience.
- **Corpus callosum:** Main job is connecting the left and right brain.

DAY TO DAY CHALLENGES

DIFFUSE BRAIN DAMAGE CAUSED BY PRENATAL ALCOHOL
EXPOSURE IMPACTS DAILY FUNCTIONING AND THE ABILITY TO
MANAGE IN THE WORLD

As we go through the following slides, please write notes about what issues, behaviors, settings, etc...
you have seen related to the challenges we are going to discuss.

COMPONENTS OF EXECUTIVE FUNCTIONING

- **Non-verbal Working Memory-** allows individuals to create visual representations of activities and event. This allows for imitation of complex events and the development 'hindsight,' thinking ahead, and having a sense of time.

Deficits in this area cause:

- *Difficulty remembering events and/or information*
- *Not having a good 'sense of time'*
- *Lack of self- awareness*
- *Difficulty learning complex behaviors*
- *Limited 'hindsight' or 'forethought'*
- *Generalization*

COMPONENTS OF EXECUTIVE FUNCTIONING

Verbal Working memory or self-directed talk- allows individuals to have language for internalization of rules, expected behavior, and self-regulation of behavior.

Deficits in this area cause:

- *Reduced ability for self-reflection*
- *Impaired problem-solving ability*
- *Impaired ability to follow rules*
- *Impaired ability to generate rules*
- *Difficulty remembering verbal information, esp. a series of verbal instructions*

COMPONENTS OF EXECUTIVE FUNCTIONING

Self- regulation of mood, motivation, and level of arousal- the ability to manage emotions, self-motivation when there are no external consequences, and set future goals.

Deficits in this area cause:

- *Poor emotional regulation skills (many individuals with an FASD are incorrectly diagnosed with Bipolar)*
- *Difficulty with self- motivation*
- *Poor self-regulation and goal directed behaviors*
- *Low frustration tolerance*
- *Deficits in attention (many individuals with an FASD are diagnosed as ADHD)*

COMPONENTS OF EXECUTIVE FUNCTIONING

Problem solving or reconstitution- the ability to analyze a situation, the related past behaviors that are relevant, and then plan new behaviors to reach a goal.

Deficits in this area cause:

- *Difficulty analyzing relevant behaviors*
- *Difficulty finding new solutions for problems*
i.e. 'lack of cognitive flexibility

VERBAL RECEPTIVE LANGUAGE PROCESSING

Inability to accurately process and understand incoming verbal information (poor receptive language skills), although verbal expression is adequate, and the client may be very social and talkative.

Deficits in this area cause:

- *Not being able to accurately understand what is said*
- *Not being able to track a long conversation*

Verbal communication is the primary mode in most settings such as court, classes, treatment, counseling.

IMPAIRED SENSORY INTEGRATION

Difficulty modulating incoming stimulation, e.g., noise, lights, smells, tastes, and tactile sensations.

Example:

All ages- sensitive to noise and or light. Seams, tags, or shoes may irritate them.

Because of this hypersensitivity a patient may become overstimulated in group settings.

IMPAIRED ABILITY TO THINK ABSTRACTLY

May think quite literally and have a great deal of trouble understanding abstract concepts such as time, space, quantities, cause and effect, idiomatic expressions, humor, and sarcasm.

Example: time, money, language,

What in the jail environment would be challenging for people with FASD? (connect to brain issues)

- Strange environment and people
- Change in routine
- Communication

reliance on verbal info

what grade level do they understand

- Social cues
- Noise/ lights
- Increased stress

What other situations can we predict and get a head of?

- Feedback from the group.

Paradigm Shift

“We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed.”

—Dubovsky, 2000

“Think Younger”

**Adjust expectations to be more congruent
with the individual’s developmental level of
functioning.**

Diane Malbin: FASCETS
(Fetal Alcohol Syndrome Consultation Education and Training Services, Inc.)
www.fascets.org dmalbin@fascets.org

Revise Your Expectations

- **Won't vs. can't**
- **Help set up structure**
- **Set reasonable goals**
- **Remember this person's challenges**
 - *Communication & vocabulary*
 - *Abstract vs. concrete*
 - *Ability to function in daily life ex. keeping environment clean.*

ACCOMMODATIONS IN A CORRECTIONAL SETTING

“They keep asking the same thing over and over”

- *what time is it?*
- *when's lunch?*
- *when do I go to court?*
- *can I get a shower?*

PROVIDING SUPPORT TO PATIENTS WILL ACTUALLY MAKE EVERYONE'S JOB EASIER!!!

Help set up structure

- **Provide written schedule and information**
- **Keep them on a schedule**
- **Have a visible DIGITAL clock**

Help set up consistency

- **Use a positive, immediate, very clear reinforcement system- not punishment. 'Catch them doing something right!'**
- **Consequences must be given immediately. They should be short term and related to the action that prompted the consequence.**
- **If you tell the patient he/she is not allowed to do something, also describe what they are allowed to do instead.**

Help client identify stressors and solutions

Help staff learn to identify signs that the client with FASD is beginning to get stressed and suggest the client use the skills to reduce stress at that moment.

Give patient written instructions or pictures to follow

Praise the client every time he/she does this.

Example: Negative feelings = suicidal

Use short sentences, concrete (not abstract) language and examples

- Remember this person's functional age
 - Ability to function in daily life will be at a lower level than their chronological age*
- Set reasonable goals
- Teach generalization: Don't assume a lesson learned in one context will transfer to another

Use individual, not group therapy

If group therapy is necessary, have the client sit next to the facilitator.

Avoid fluorescent lights, use softer lighting. Don't take lack of eye contact as lack of motivation.

Keep the area uncluttered and very simple.

Help client identify physical releases when emotions become overwhelming (e.g., ice cubes on face or wrists, running in place).

Give the opportunity to succeed

Provide only one direction or rule at a time.

Review rules, expectations regularly and repeatedly.

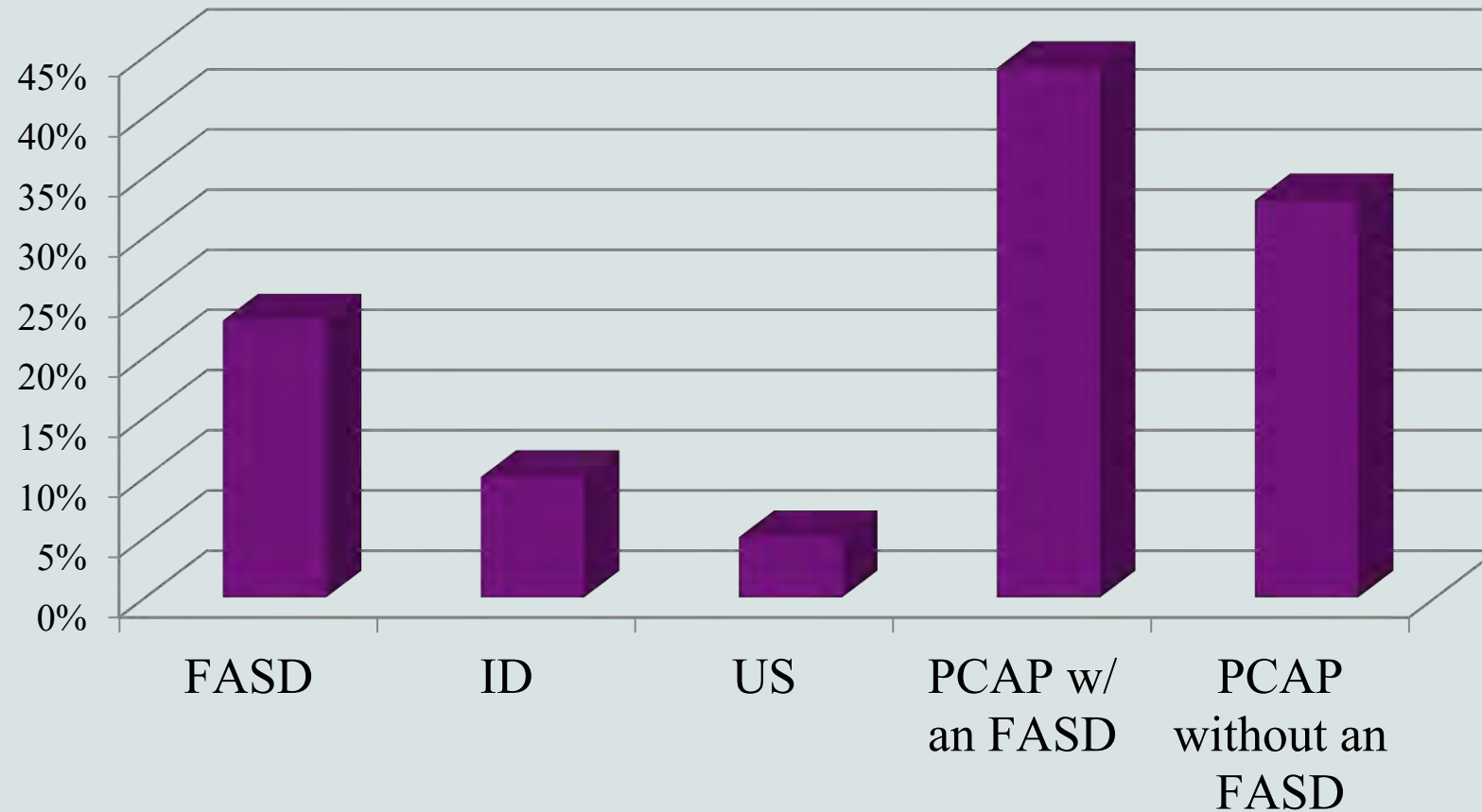
Teach client to carry a notebook wherever they goes, and ask staff to write down instructions, appointment times, etc.

Use a mentor/buddy, i.e., someone they can check with for information, advice.

DISCUSSION:

- Do you have a specific situation that you want some feedback or suggestions?
- What are some suggestions that may be hard to implement and why?
- Do you have examples of things you've done that have been successful?

Adult Suicide Attempts: FASD, Intellectual Disabilities, U.S. Population, PCAP Mothers with and without an FASD



Streissguth, Barr, Kogan, and Bookstein, 1996. Understanding the Occurrence of Secondary Disabilities in Clients with FAS & FAE. Final Report to the CDC, p. 35.
Attempt rate for adults with an Intellectual Disability in mixed clinical & community samples (Hardan and Sahl, 1999; Lunskey, 2004).
U.S. lifetime rate of suicide attempts (1990-1992 National Comorbidity Study; Kessler, Borges, and Walters, 1999).

WITH GRATITUDE

*I WANT TO THANK THE MANY PEOPLE WHO, OVER THE YEARS,
HAVE SHARED THEIR KNOWLEDGE AND WISDOM AND
EXPERIENCES. MUCH OF THEIR WORK IS INCLUDED TODAY.*

- COLLEAGUES @ THE FETAL ALCOHOL AND DRUG UNIT @ THE U. OF WASHINGTON
- DR. ANN STREISGUTH
- COLLEAGUES @ THE FETAL ALCOHOL SYNDROME DIAGNOSTIC PROVIDER NETWORK (AKA THE FAS CLINIC) @ THE U. OF WASHINGTON
- COLLEAGUES AT THE S.A.M.S.H.A. FASD CENTER FOR EXCELLANCE
- DR. STERLING CLARREN
- AND THE MANY MEN, WOMEN, AND CHILDREN WHO HAVE SHARED THEIR STORIES

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