

***Effective Practice & Clinical Strategies across the  
Continuum of Child Welfare Services for  
Addressing the Needs of Children with Fetal  
Alcohol Spectrum Disorders & Other Conditions  
Related to Prenatal Substance Exposure***

**August 2nd, 2016**

**CWLA National Conference**

**Hyatt Regency, Orange County, California**





# PART B

9/30/2016

# PART B

- ✓ Panel – Effective Practices & Clinical Strategies
  - Speakers: Douglas Waite, MD, is Assistant Professor of Pediatrics at Mount Sinai Hospital and Medical Director for the Keith Haring Clinic at Children's Village in Dobbs Ferry, New York. Dr. Waite is also a member of the CWLA Mental Health Advisory Board; Gwendolyn J. Messer, MD, FAAP, Medical Director, Children's Research Triangle, Chicago, IL; and Dan Dubovsky MSW, FASD Specialist, former SAMHSA FASD Center for Excellence
- ✓ Q and A
- ✓ Closing and Next Steps

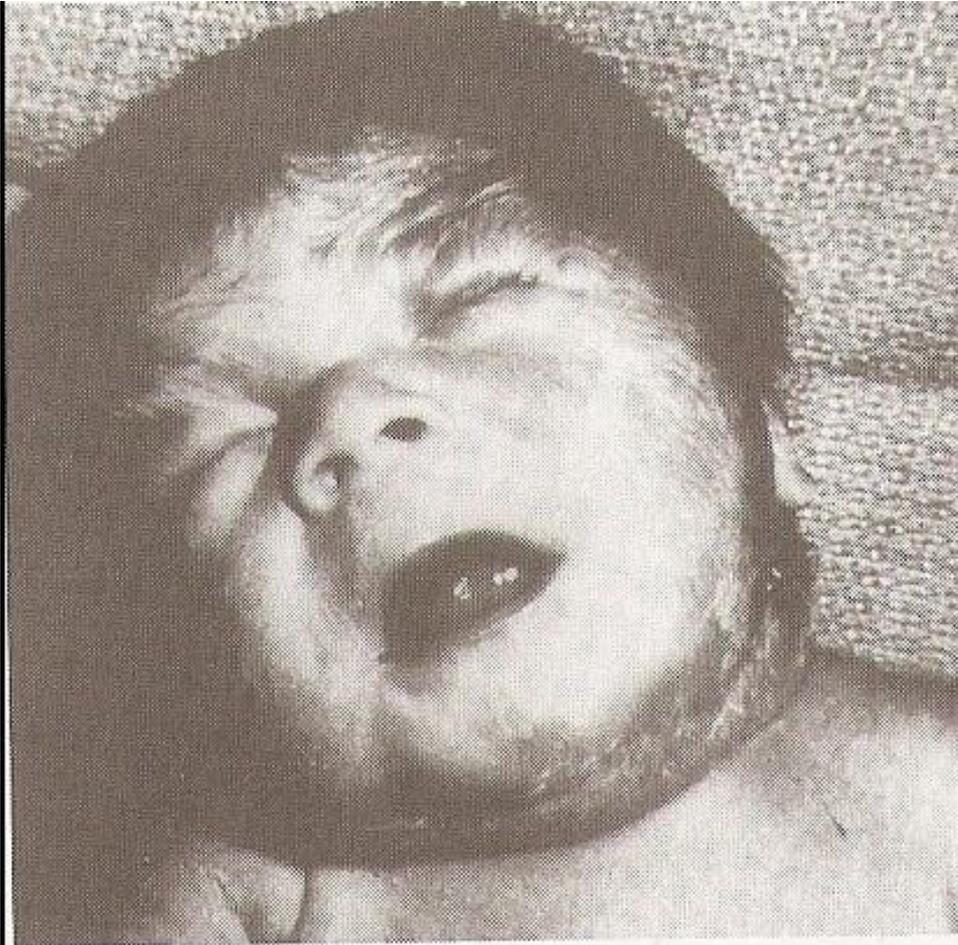
# Diagnosis of Children with Fetal Alcohol Neurodevelopmental Disorder



*Douglas Waite, MD*  
*Assistant Professor of Pediatrics, Mount Sinai Hospital*  
*Medical Director*  
*The Keith Haring Clinic at Children's Village*  
*Dobbs Ferry, New York*



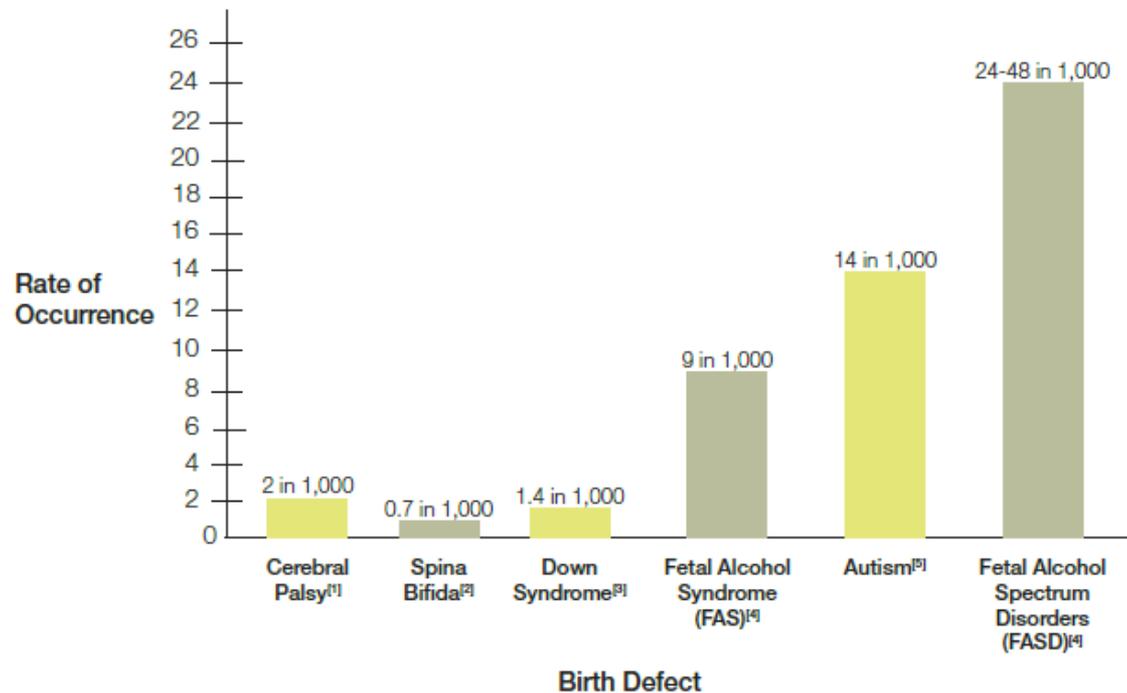
*“Each of their mothers was an alcoholic”*



Jones, Kenneth L, 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 Birth Defects Per 1,000 Live Births



[1] My Child™ at Cerebral Palsy (<http://cerebralspalsy.org/about-cerebral-palsy/prevalence-and-incidence/>)

[2] American Pregnancy Association (<http://americanpregnancy.org/birth-defects/spina-bifida/>)

[3] March of Dimes (<http://www.marchofdimes.org/baby/down-syndrome.aspx>)

[4] Philip A. May, et al, "Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders," *Pediatrics*, Volume 134, Number 5, November 2014.

[5] Center for Disease Control and Prevention (<http://www.cdc.gov/nbdds/autism/data.html>)

[6] 2009 Annual MN Births, Minnesota State Demographic Center X current percentage of pregnant women 15-44 who used alcohol while pregnant, SAMHSA.

# 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

- 80% of foster children referred for FASD evaluation had never been diagnosed as affected by prenatal alcohol exposure.
- There were significant changes in the rate of mental health diagnosis, learning disorders, communications disorders, and intellectual disability
- Objective signs of neurocognitive damage were not recognized in a significant number of children with FASD

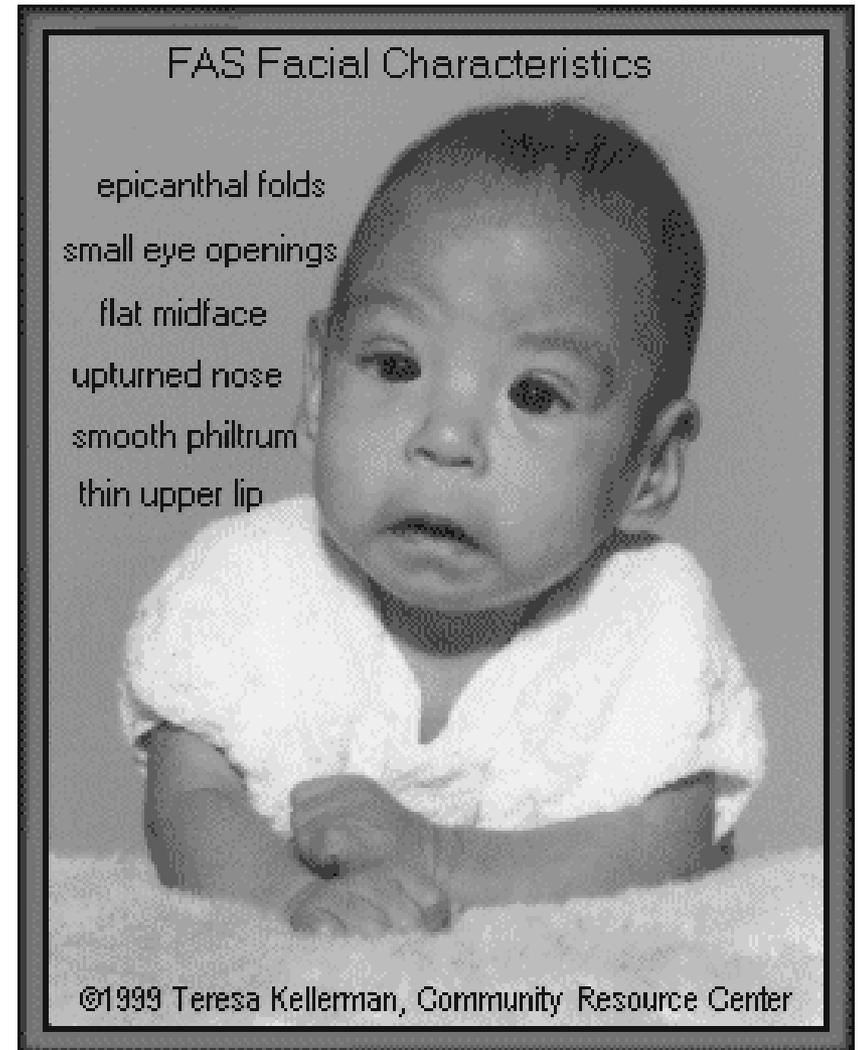
Chasnoff, Ira J., Anne M. Wells, and Lauren King.  
"Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure." *Pediatrics* 135.2 (2015): 264-270.

# 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)

# FAS Identification: the traces of fetal alcohol exposure can sometimes be seen in the face



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



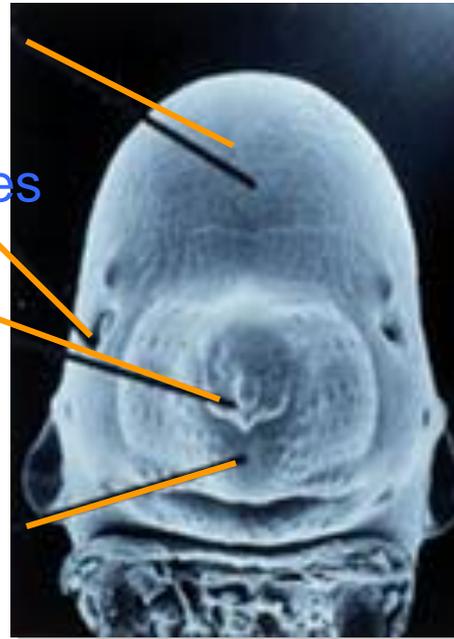
Narrow forehead

Short palpebral fissures

Small nose

Small midface

Long upper lip with deficient philtrum



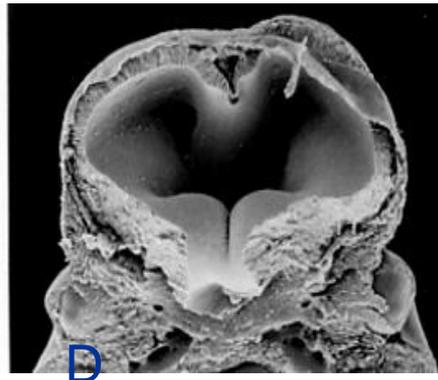
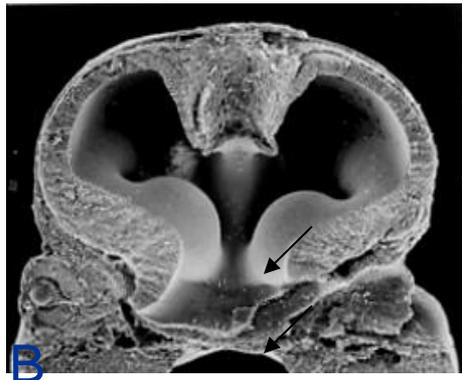
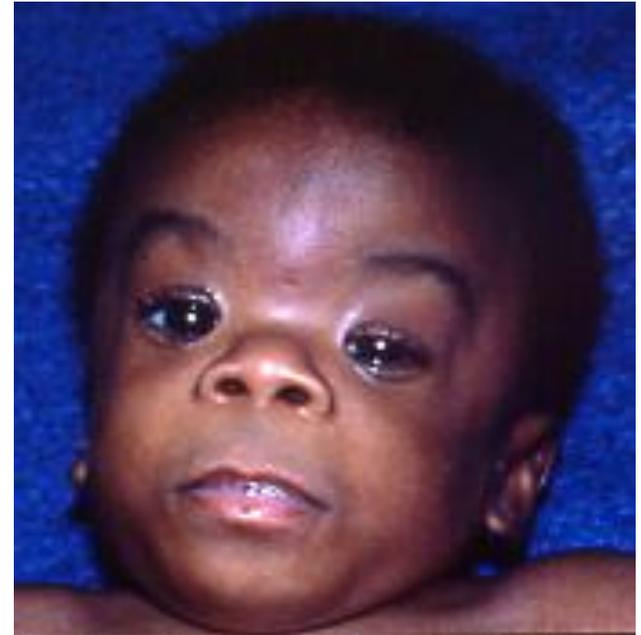
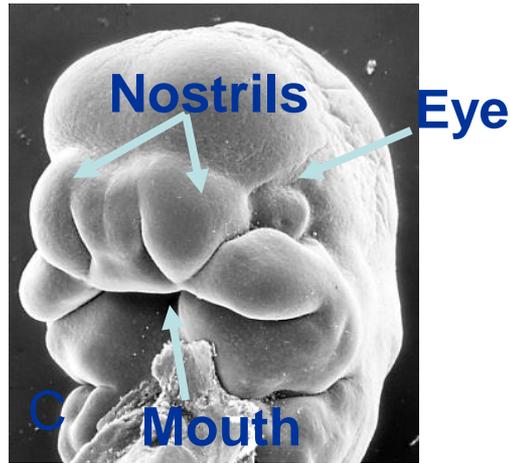
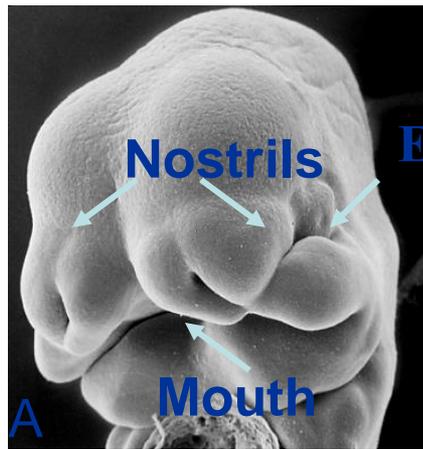
alcohol-exposed

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)—yet diagnosis is often confounded by multiple factors.



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

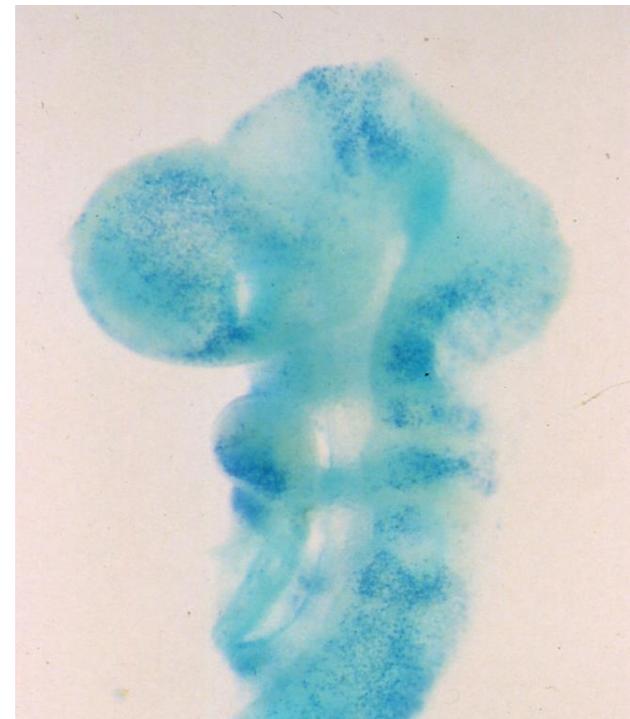


Comparison of the face (A) and interior brain (B) of a normal mouse embryo and one damaged by alcohol (C&D) shows that the nostrils are abnormally positioned (C) and the brain is missing midline structures (D)

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

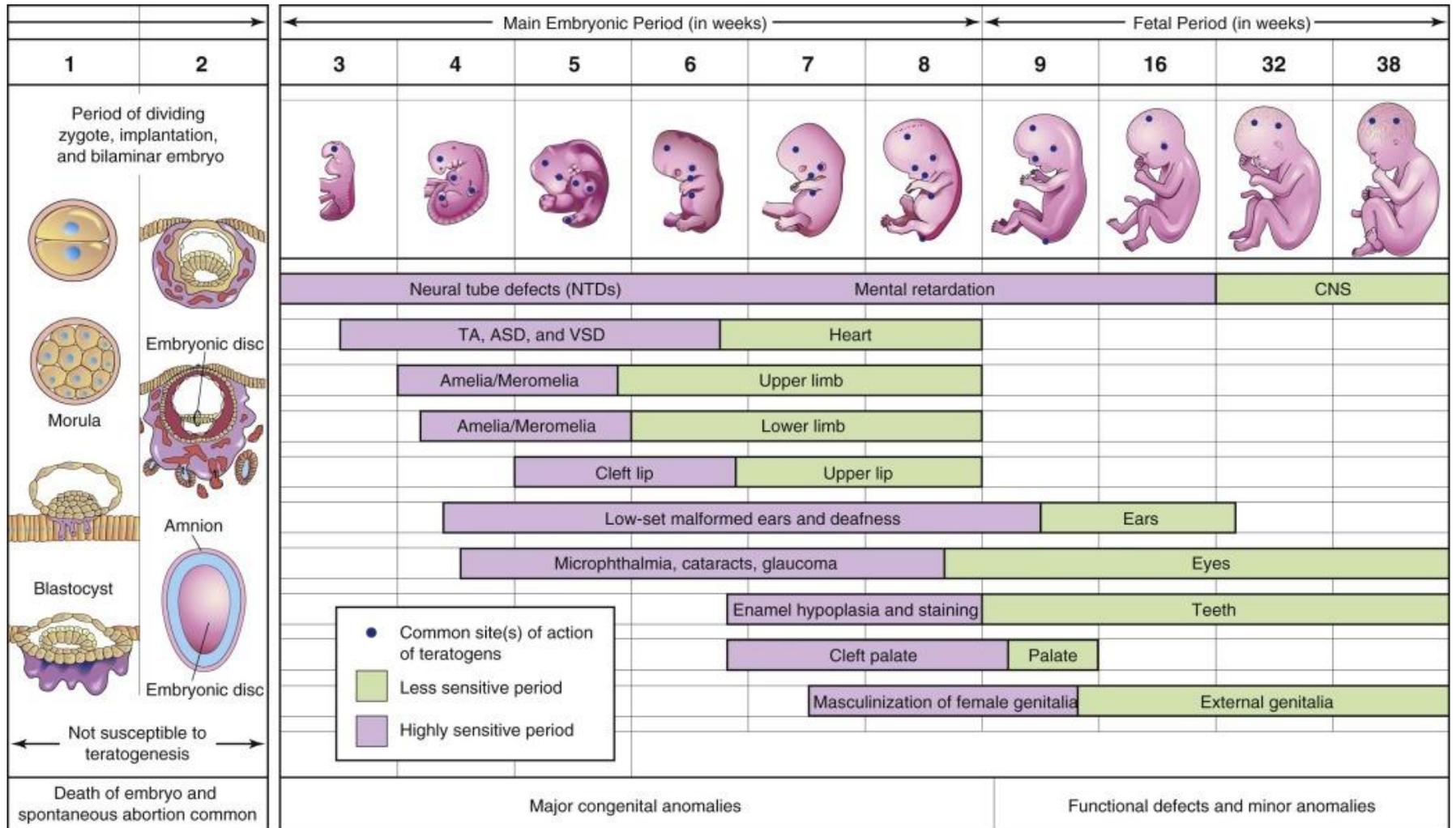


Cells killed by alcohol have taken up dark blue stain

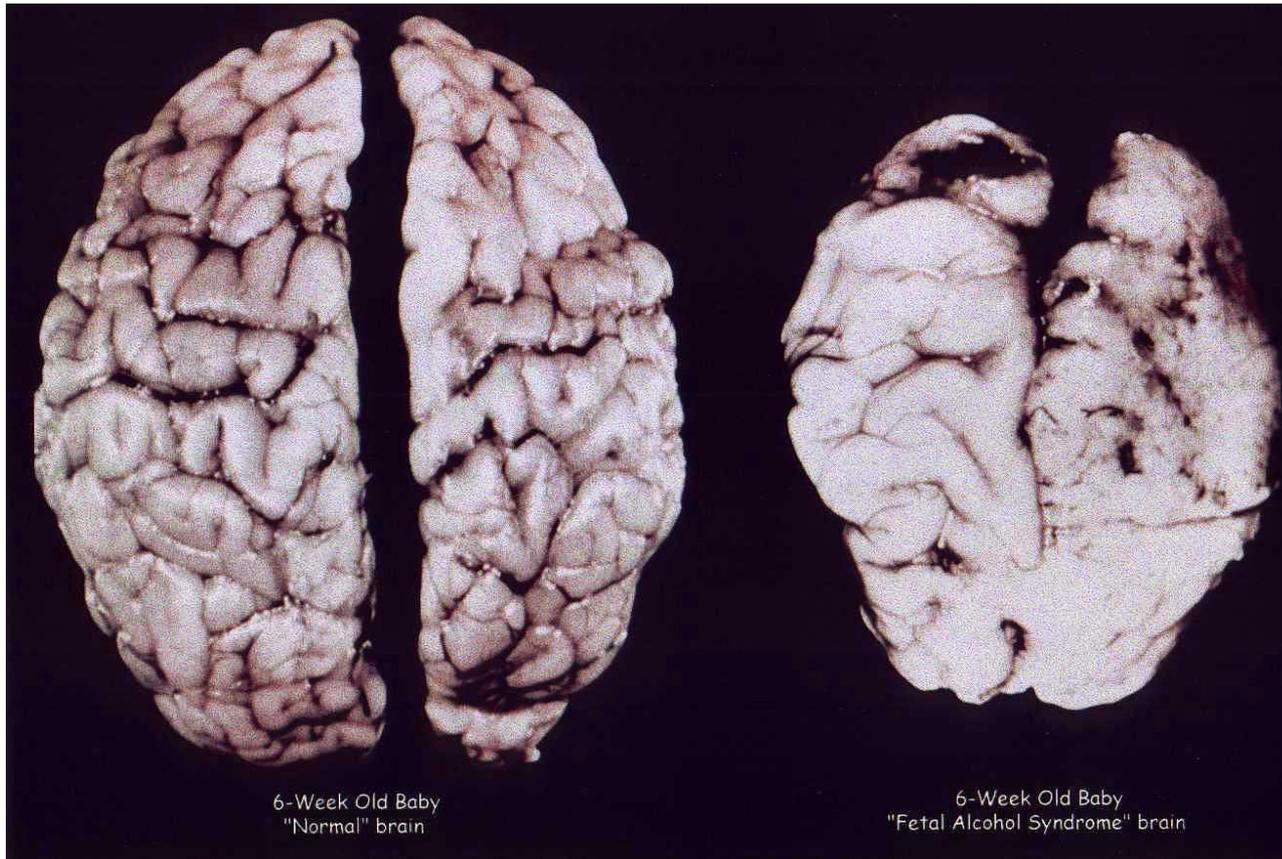


The inside of a 10 day mouse embryo (corresponding to a 28 day human)

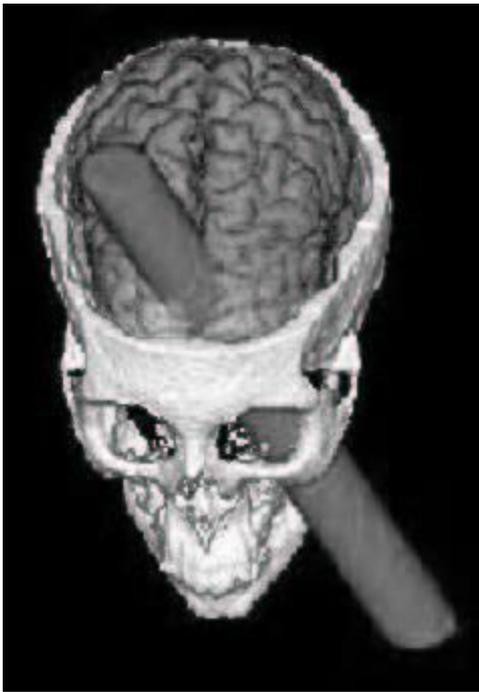
# Sensitive Periods of Embryological Development



# 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 with 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 but score especially low in adaptive functioning (intellectual disability equivalence)

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

# 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

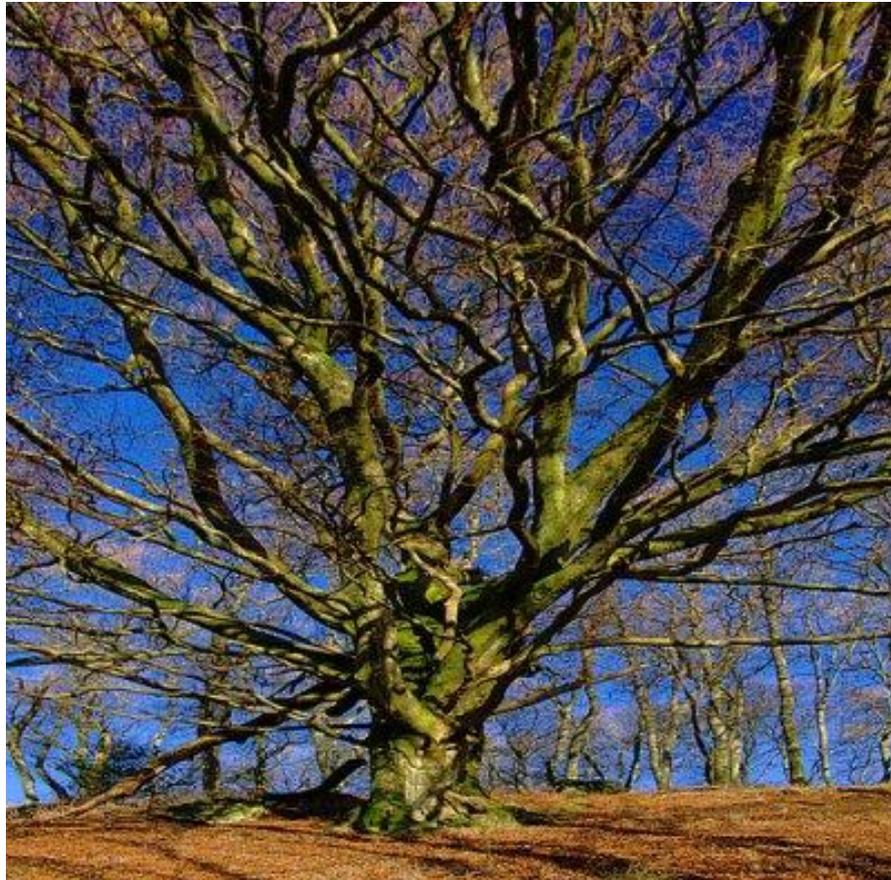


Streissguth, A.P.; Barr, H.M.; Kogan, J.; et al. 1996. *Final Report: Understanding the Occurrence of Secondary Disabilities in Clients With Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*. Seattle: University of Washington Publication Services.

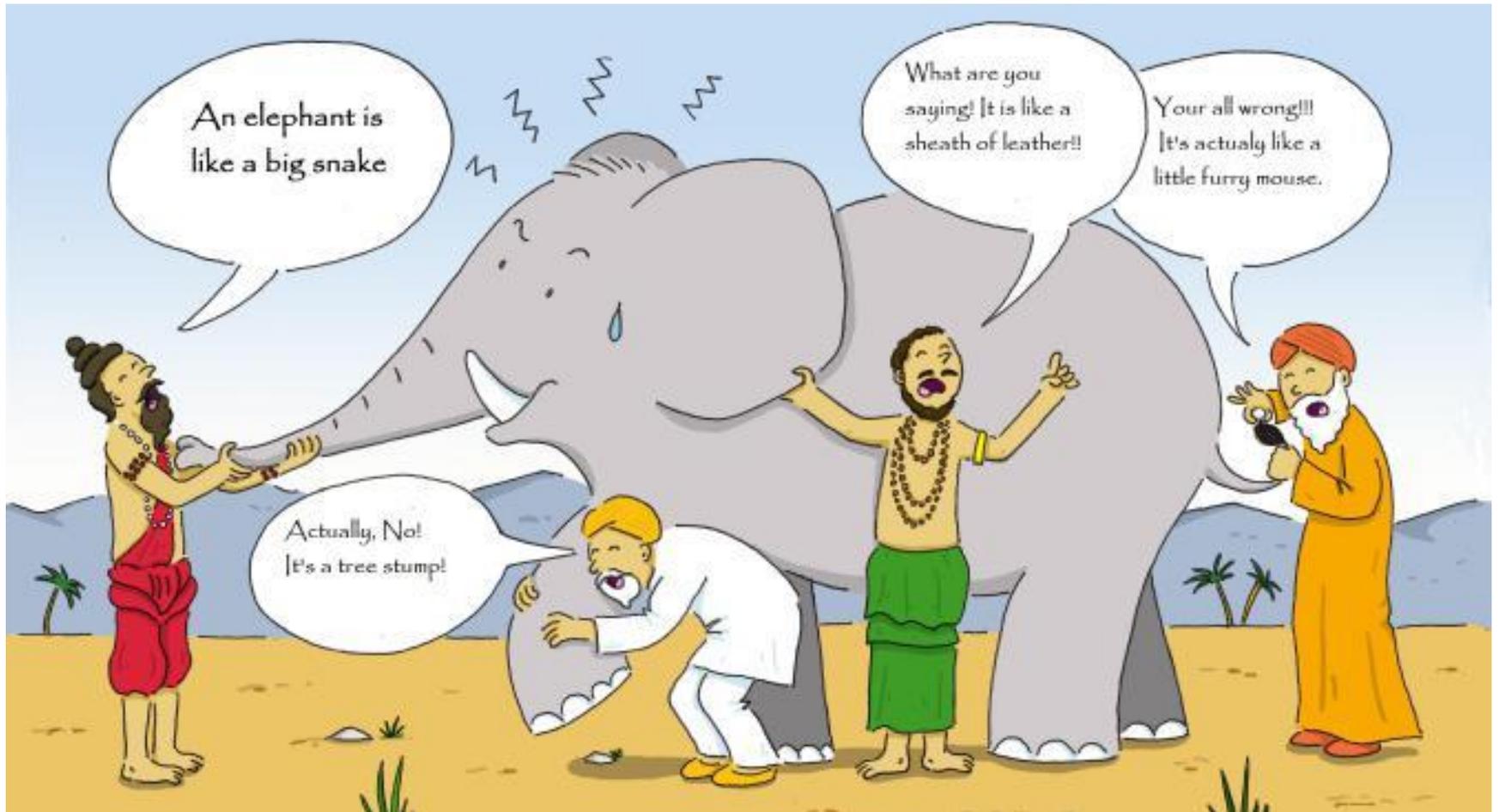
Risk Factors among 2550 FASD Patients	
Prenatal alcohol exposure	100%
No prenatal care	31%
Maternal learning disabilities	36%
Other adverse prenatal exposures	93%
Prenatal tobacco	62%
Prenatal crack/cocaine	37%
Perinatal difficulties	53%
Foster/adoptive care	85%
Physical abuse	34%
Sexual abuse	24%
Neglect	64%
Average Number of Home Placements	3

Astley, Susan J. "Validation of the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code." *J Popul Ther Clin Pharmacol* 20.3 (2013): e416-e467.

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



# The Need for FASD-Specific Interventions



# Histories suggestive of possible prenatal alcohol exposure

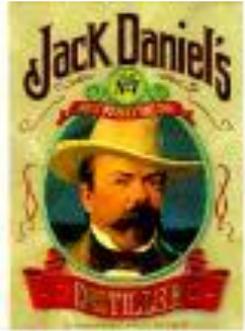
- Early placement in foster care (secondary to abuse or neglect, abandonment, termination of parental rights or early death of mother or father)
- Primary guardian other than the child's mother
- Early childhood behavioral and school difficulties
- Successively poorer pregnancy outcomes, low birth weight, 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

# Interventions

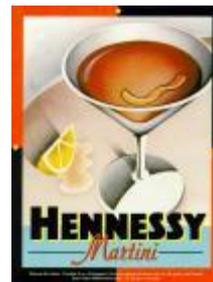
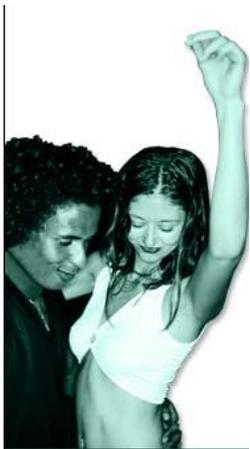
Structured, consistent and realistic interventions

- Realistic expectations
- Consistent routines
- Limited stimulation
- Concrete language and examples
- Multi-sensory learning (auditory, visual and tactile)
- Supportive environments
- Supervision

# It's in the culture



thebarton.com/visit



- Legally sanctioned, yet stigmatized
- **3 in 4** women who want to get pregnant as soon as possible report drinking alcohol.
- **100%** Fetal alcohol spectrum disorders are completely preventable.

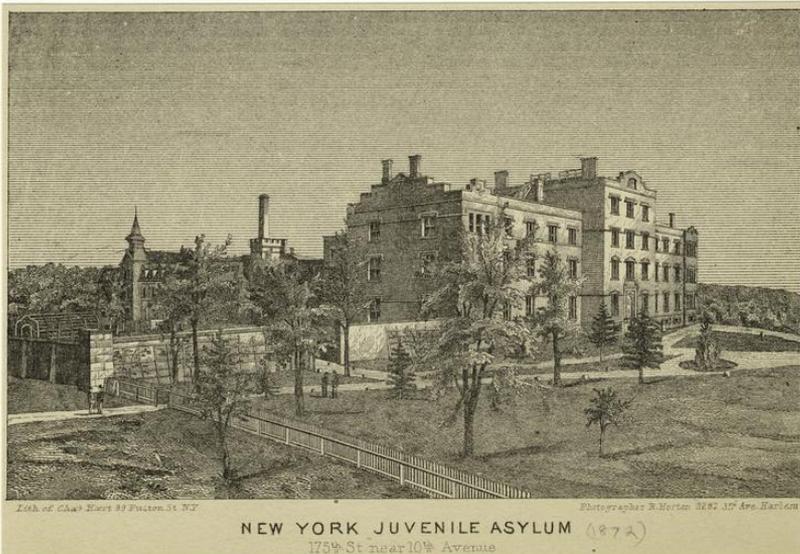
# The Treatment for Alcoholism is Alcoholics Anonymous

WELCOME TO  
ALCOHOLICS ANONYMOUS



AA World Services, Inc.,  
Box 459, Grand Central Station,  
New York, NY 10163  
Tel. (212) 870-3400  
[www.aa.org](http://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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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.

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Families Affected by Parental Substance Use

Vincent C. Smith, Celeste R. Wilson, Committee on Substance Use and Prevention  
*Pediatrics* Jul 2016, e20161575; DOI: 10.1542/peds.2016-1575

Astley, Susan J. "Validation of the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code." *J Popul Ther Clin Pharmacol* 20.3 (2013): e416-e467.

# **CHILD WELFARE LEAGUE of AMERICA**

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**Advancing Excellence in Practice  
and Policy: What Works for Families  
Affected by Substance Use**

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Gwendolyn Messer, MD  
Medical Director  
Children's Research Triangle

# JUSTICE LEAGUE <sup>of</sup> AMERICA



# CHILD WELFARE LEAGUE of AMERICA

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Advancing Excellence in Practice  
and Policy: What Works for Families  
Affected by Substance Use

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**Children in child welfare have  
unique experiences and needs.**

"Of all the substances of abuse, including heroin, cocaine, and marijuana, **alcohol** produces by far the most serious neurobehavioral effects in the fetus."

--Institute of Medicine 1996 Report to Congress

# Protective Factors

- **Early diagnosis of FASD**
- **Stable and nurturing home**
- **No violence**
- **Appropriate services**

Streissguth, 2004

**Why does the  
diagnosis of FASDs  
matter?**

# FASDs are Spectrum Disorders

- Effects of alcohol vary
- Every child presents differently



# Complicating Factors

- **History of Trauma**
  - Physical/sexual abuse
  - Family disruption
- **History of Neglect**
- **Family History of Mental Illness**
- **Other Prenatal Substance Exposure**

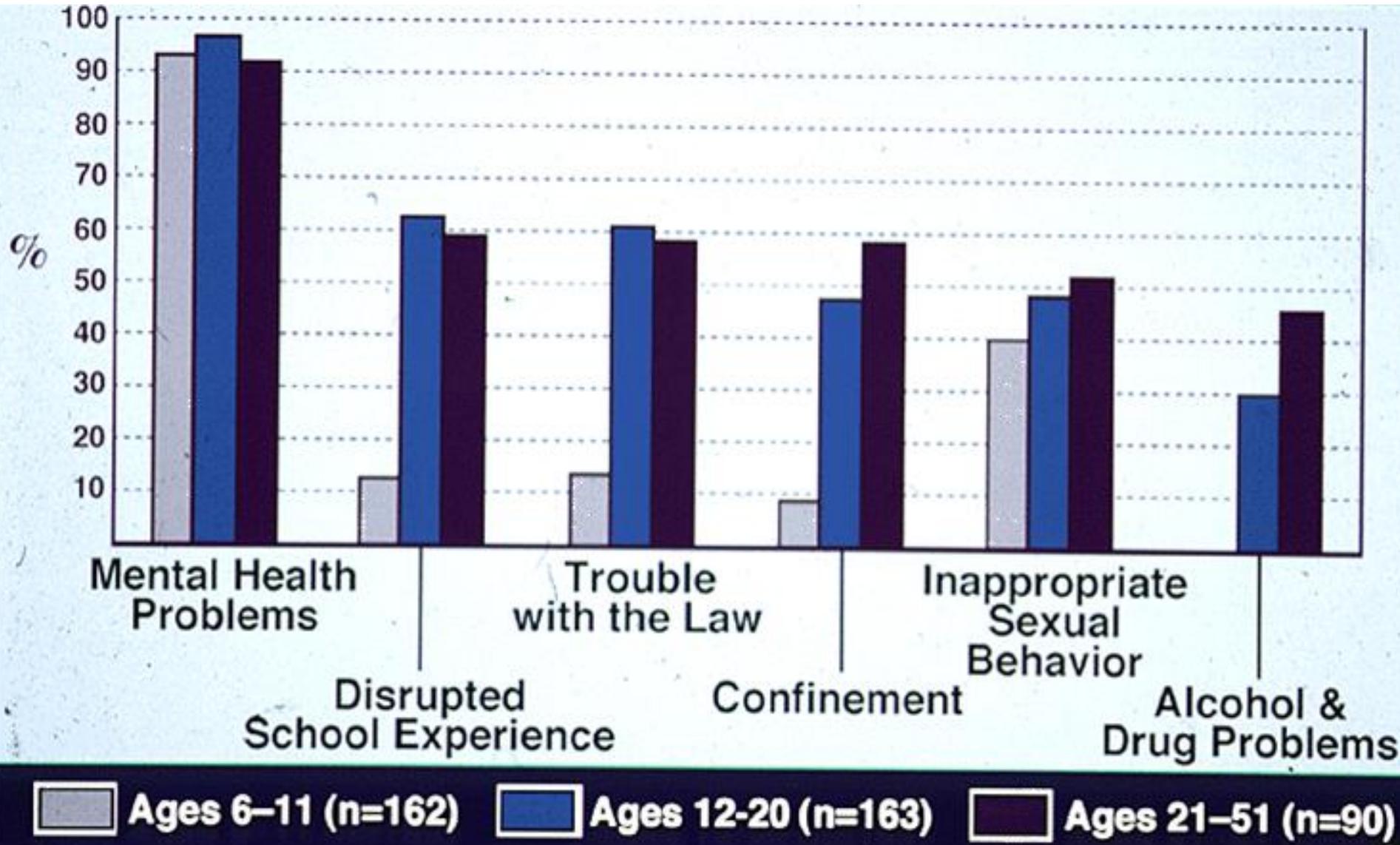
Prenatal Alcohol Exposure

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graph TD; A[Prenatal Alcohol Exposure] --> B[Primary Disability—brain damage, ADHD, sensory]; B --> C[Dysfunctional Behavior]; C --> D[Secondary Disability—school trouble, legal issues, etc];
```

Primary Disability—brain damage, ADHD, sensory

Dysfunctional Behavior

Secondary Disability—school trouble, legal issues, etc



# Co-Occurring Mental Health Issues

- ADHD
- Depression
- Anxiety
- Bipolar Disorder
- Psychotic disorders (e.g. schizophrenia)
- Conduct disorders
- Personality disorders
- Reactive attachment disorder

# What Works

- **Ensure safety and security**
- **Screen and identify**
- **Educate**
- **Understand**
- **Treat**

# What Works

**Ensure safety and security**

Screen and identify

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# What Works

Ensure safety and security

**Screen and identify**

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Understand

Treat

# What Works

Ensure safety and security

Screen and identify

**Educate...the adults**

Understand

Treat

# What Works

Ensure safety and security

Screen and identify

Educate...the adults

**Understand...the child**

Treat

# What Works

Ensure safety and security

Screen and identify

Educate...the adults

Understand...the child

**Treat...**

**the individual, whole child!**

# CHILDREN'S RESEARCH TRIANGLE

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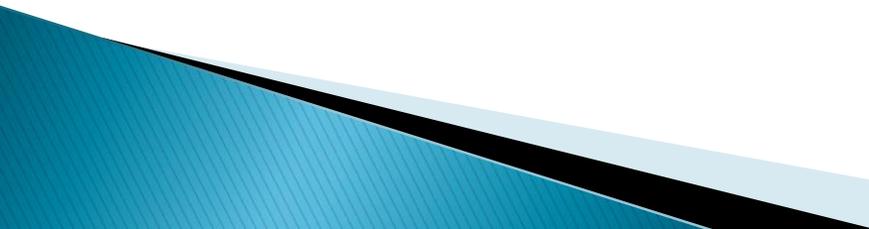
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# Addressing FASD in Child Welfare

- ▶ It is essential to identify youth with an FASD
- ▶ One cannot be successful in supporting youth with an FASD without examining family members who may have an FASD and supporting them
  - FASD is never a diagnosis for one person

# Addressing FASD in Child Welfare

- ▶ Child welfare often sets families affected by FASD up to fail
    - Giving multiple instructions, especially verbally
    - Expecting that if they are motivated, they will follow through
    - Jumping to conclusions regarding ability to parent
    - Making decisions too quickly regarding permanency planning
- 

# Addressing FASD in Child Welfare

- ▶ Child welfare is key in providing positive outcomes for youth and families affected by FASD
  - Train all foster parents and prospective adoptive families in understanding FASD in youth and their families
  - Provide one direction at a time for families
  - Identify what a birth family needs in order to be successful in parenting their child

# Addressing FASD in Child Welfare

- ▶ Child welfare is key in providing positive outcomes for youth and families affected by FASD
  - Do not send parents to parenting classes unless their child is with them
  - Provide a mentor for families when needed
  - Consider developing family foster homes
  - Make informed decisions about termination of parental rights

# Addressing FASD in Child Welfare

- ▶ The SAMHSA FASD Center for Excellence supported the integration of screening youth for a possible FASD and providing diagnostic evaluation and intervention recommendations into delinquency and dependency courts
  - Utilizing facial photographic screen and other “red flags” to identify those with a possible FASD

# Addressing FASD in Child Welfare

- ▶ For older adolescents and adults, we have developed the Life History Screen to identify those with a possible FASD
  - In the ideal world, a positive screen would lead to a diagnostic evaluation
  - In the real world, diagnostic capacity across the country is miniscule
  - We cannot wait for diagnostic availability before we implement modifications
  - A screen should not be used if modifications are not going to be implemented

# Challenges in Recognizing FASD

- ▶ Recognizing an FASD challenges the basic tenets of treatment and interactions with people
  - That people need to take responsibility for their actions
  - That people learn by experiencing the consequences of their actions
  - That people are in control of their behavior
  - That enabling and fostering dependency are to be avoided
    - A person has to learn to do things on her or his own because that's the real world

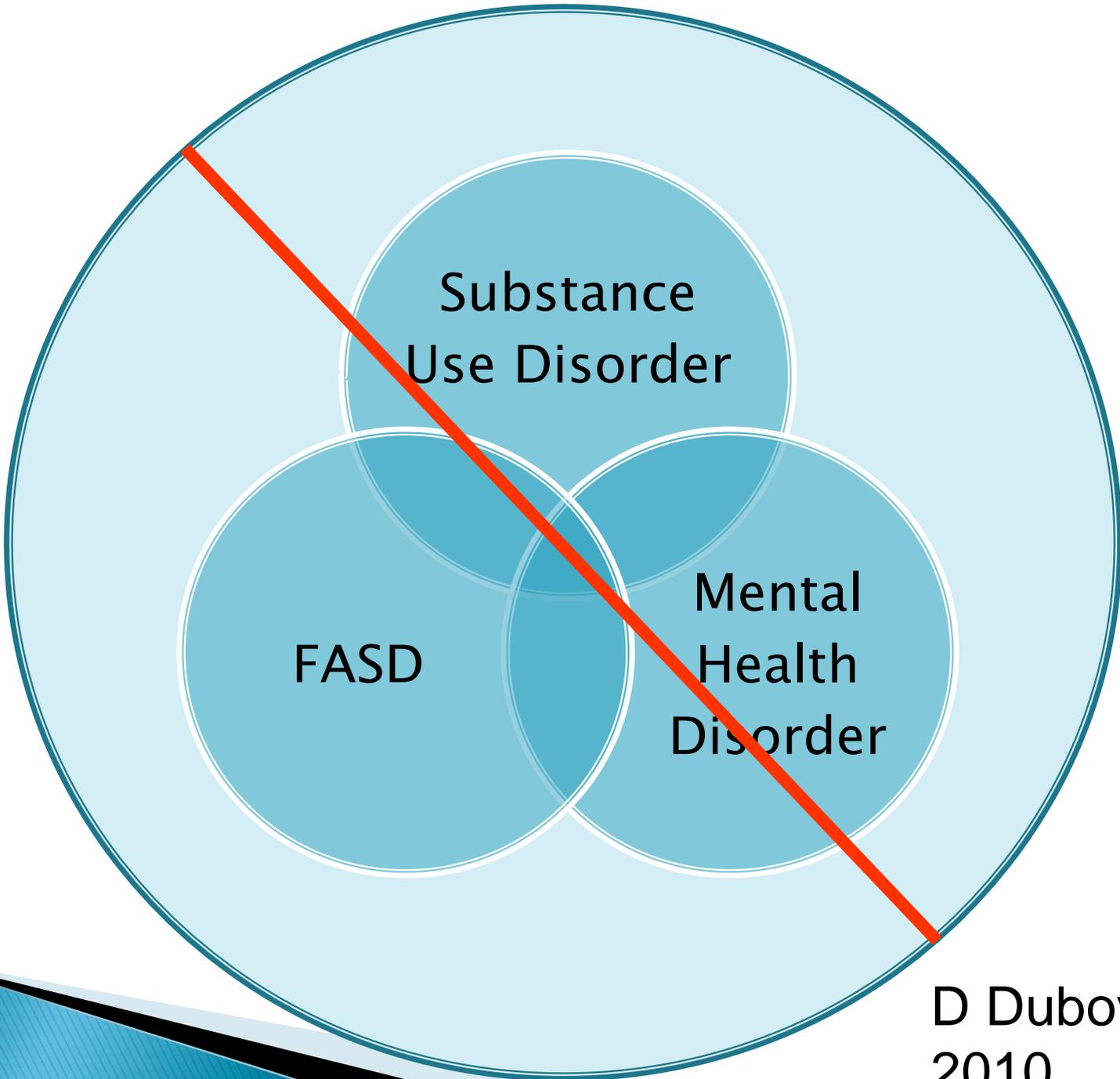
# Challenges in Recognizing FASD

- ▶ Our values and biases may come into play
    - About behaviors
    - About drinking during pregnancy
  - ▶ It may bring up issues in our own lives
  - ▶ It means re-examining our practices
  - ▶ It is easier to view the person as having the responsibility to change
  - ▶ Being equal is easier than being fair
- 



# Challenges in Recognizing FASD

- ▶ In order to improve outcomes, the concepts of dependency and enabling as negative terms need to be re-thought
  - Taking someone to their appointment, checking on the person regularly, or filling out forms with them may be what the person needs
- ▶ Treatment of co-occurring issues must be different if a person also has an FASD

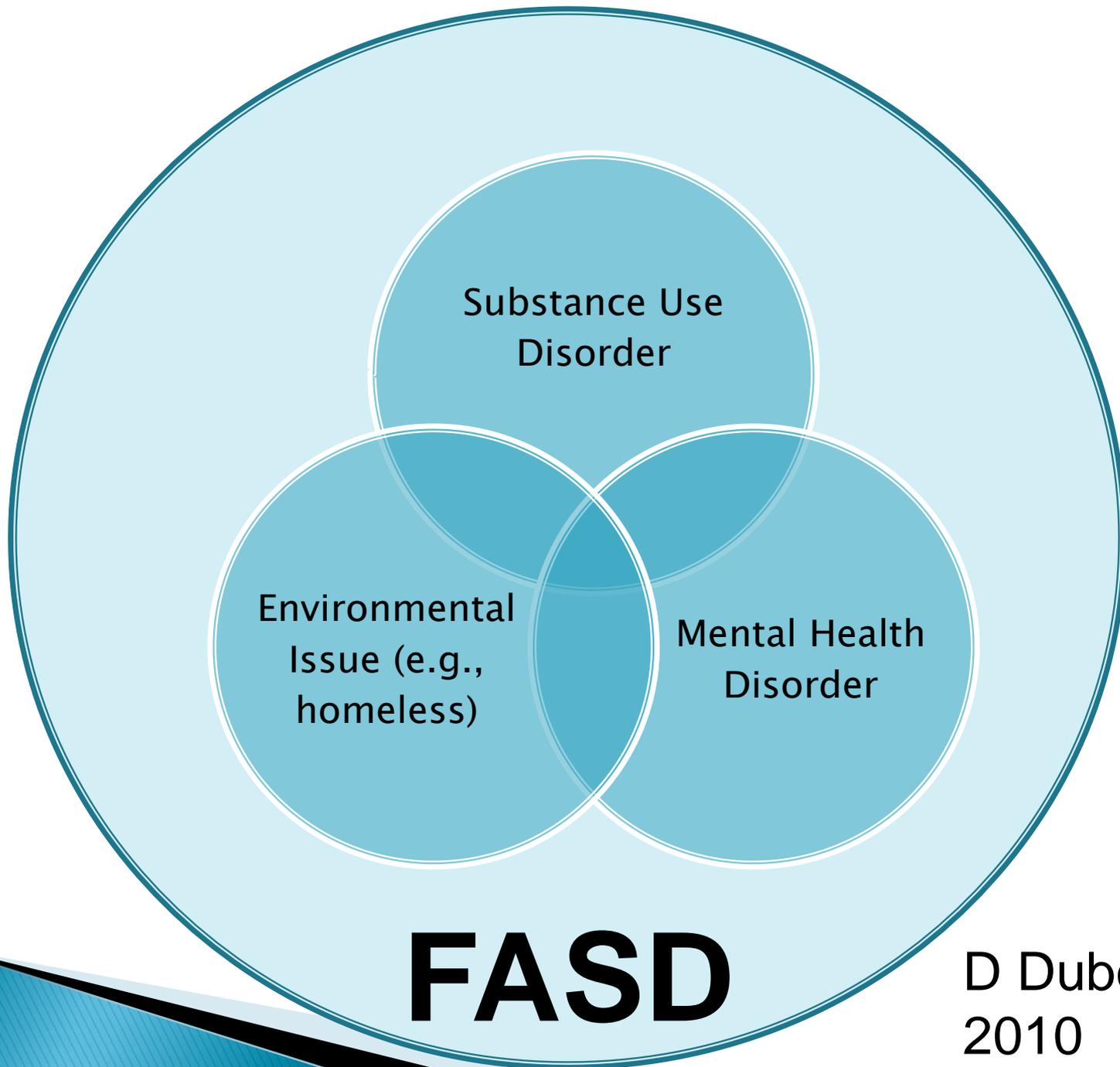


Substance  
Use Disorder

FASD

Mental  
Health  
Disorder

D Dubovsky  
2010



D Dubovsky  
2010

# Comparing FASD, ADHD and ODD

(D Dubovsky 2002)

	<b>FASD</b>	<b>ADHD</b>	<b>ODD</b>
<b>Behavior</b>	Does not complete tasks		
<b>Underlying cause for the behavior</b>	<ul style="list-style-type: none"> <li>• May or may not take in the information</li> <li>• Cannot recall the information when needed</li> <li>• Cannot remember what to do</li> </ul>	<ul style="list-style-type: none"> <li>• Takes in the information</li> <li>• Can recall the information when needed</li> <li>• Gets distracted</li> </ul>	<ul style="list-style-type: none"> <li>• Takes in the information</li> <li>• Can recall the information when needed</li> <li>• Chooses not to do what they are told</li> </ul>
<b>Interventions for the behavior</b>	Provide one direction at a time	Limit stimuli and provide cues	Provide positive sense of control, limits, and consequences

# A Strengths Based Approach to Improving Outcomes

- ▶ Identify strengths and desires in the individual
  - What do they do well?
  - What do they like to do?
  - What are their best qualities?
  - What are your funniest experiences with them?
- ▶ Identify strengths in the family
- ▶ Identify strengths in the providers
- ▶ Identify strengths in the community
  - Include cultural strengths in the community

# Strengths of Persons With FASD

▶ Friendly

▶ Likeable

▶ Verbal

▶ Helpful

▶ Caring

▶ Hard worker

▶ Creative



▶ Determined

▶ Have points of insight

▶ Good with younger children\*

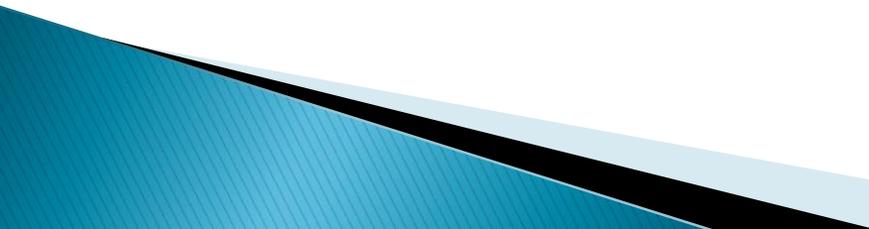
▶ Not malicious

▶ Every day is a new day

# Modifications to Approaches for Individuals with FASD

- ▶ Modifications are based on scientific knowledge of brain damage in FASD
  - ▶ All modifications do not need to be used with every person
  - ▶ The team should identify the modifications to be implemented for a particular individual and family
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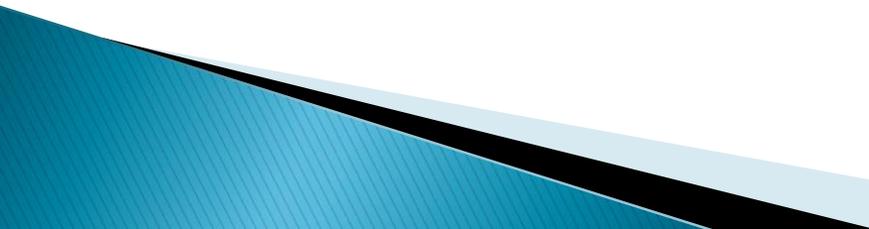
# Modifications to Approaches for Individuals with FASD

- ▶ Reduce stimuli in the environment
    - Their room
    - Treatment settings
    - Visuals
    - Sounds
  - ▶ Use softer lighting and colors
    - Avoid fluorescent lights
- 

# Modifications to Approaches for Individuals with FASD

- ▶ Be consistent in appointment days and times, activities, and routines
    - For groups, therapy appointments, probation appointments, meetings with child welfare, etc.
    - Prepare the person for any changes in personnel or appointment times often
    - Work with the person to set reminders of when they have to leave for their appointments on their cell phone or other device
- 

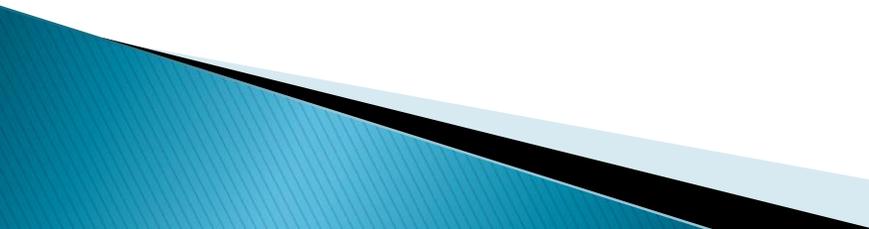
# Modifications to Approaches for Individuals with FASD

- ▶ Be careful about verbal approaches
    - Use multiple senses
  - ▶ Simplify and review routines, schedules, rules frequently
    - Check for true understanding
  - ▶ Repetition, repetition, repetition
    - Due to damage in working memory
  - ▶ Utilize computer learning programs
  - ▶ Utilize role playing
- 

# Modifications to Approaches for Individuals with an FASD

- ▶ Designate a point person for the individual to go to whenever she has a question or a problem or does not know what to do
  - ▶ Provide a mentor/role model
  - ▶ **Any time you need to tell someone “you can’t” you must also say “but you can”**
  - ▶ *Utilize a positive focused system rather than a reward and consequence system*
- 

# Modifications to Approaches for Individuals with FASD

- ▶ If consequences need to be used, they should be immediate, related to what occurred, and finished preferably within the same day
  - ▶ **Any time you need to tell someone “you can’t” you must also say “but you can”**
  - ▶ *Utilize a positive focused system rather than a reward and consequence system*
- 

# A Positive Focused System

- ▶ Utilizes a true strengths based approach
    - Identifies strengths and abilities
    - Focuses on building self-esteem and competence
  - ▶ Consistently tell the person what she or he does well and is good at
    - This is an ongoing process
  - ▶ Point out small accomplishments
  - ▶ This does not mean ignoring challenging behaviors
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# Modifications to Approaches for Individuals with FASD

- ▶ Be careful about using verbal instructions and treatment approaches
  - Use multiple senses (visual, auditory, tactile)
  - Break things down to one step at a time
  - Always check for **true** understanding
    - What does this rule mean? How would you follow this rule? How would you complete this?
- ▶ When a rule is broken, work with the person on how to help them remember the rule when they need it

# Modifications to Approaches for Individuals with FASD

- ▶ Identify signs that the person is beginning to get stressed or anxious
  - ▶ Identify one or two things that help the person calm down when s/he gets upset
  - ▶ Talk with the person about the importance of using those techniques at the moment they are beginning to get upset
  - ▶ This can reduce aggression and getting thrown out of programs
    - But everyone needs to support their doing this
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# Modifications to Approaches for Individuals with FASD

- ▶ Use literal language
- ▶ If you joke with the person, let him or her know you are joking
- ▶ Point out when others are joking with the person
- ▶ Teach the person to check out whether someone is kidding or serious
- ▶ Use person first language
  - “He’s a child with an FASD” not “He’s FASD”
  - “She has an addiction” not “she is an addict”
  - “He has oppositional behavior” not “He is an oppositional child”

# References

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- ▶ Williams SJ, Dubovsky D, Merritt J. *“Legal and psychological implications of nondisclosure in the adoption of a child with Fetal Alcohol Spectrum Disorder.”* Journal of Psychiatry and Law 39: 193-214.



