

ROADS TO RESILIENCE:
Identifying FASD in Court-Involved Youth

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The Hon. Marian F. Gaston

Question 1: What is the prevalence of FASD in the U.S. ?

- A. 1 per 100,000 livebirths in some areas
- B. 1 per 1,000 livebirths in some areas
- C. 1 per 200 livebirths in some areas
- D. 1 per 20 livebirths in some areas

Question 2: What is the amount of alcohol considered to be risky to the unborn baby?

- A. Two 4-ounce glasses of wine per night throughout the pregnancy
- B. Two 4-ounce glasses of wine per night just throughout the 1st trimester of pregnancy
- C. Three glasses of wine per occasion on 2 occasions during the pregnancy
- D. Three glasses of wine per occasion on 2 occasions per week throughout the pregnancy

Question 3: what is the annual yearly cost to U.S. taxpayers for children with FASD?

- A. 3.4 billion dollars per year
- B. 1 Trillion dollars per year
- C. 750 million dollars per year
- D. 2 billion dollars per year



Question 4: What is the percentage of juveniles with FASD who have trouble with the law?

- A. 30%
- B. 40%
- C. 50%
- D. 60%



Research

JAMA | Original Investigation

Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities

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IMPORTANCE: Fetal alcohol spectrum disorders are costly, life-long disabilities. Older data suggested the prevalence of the disorder in the United States was 10 per 1000 children. However, there are few current estimates based on larger, diverse US population samples.

OBJECTIVE: To estimate the prevalence of fetal alcohol spectrum disorders, including fetal alcohol syndrome, partial fetal alcohol syndrome, and alcohol-related neurodevelopmental disorder, in 4 regions of the United States.

Editorial page 458

Supplemental content

Related article at jamaediatrics.com

Prevalence across the 4 US Communities was 1.1 to 5%

Prevalence in San Diego, CA was 2.3% in 1st and 2nd grade students in the SD Unified School System

There are approximately 200,000 new cases of FASD per year in the U.S.

70% of children in Foster care have Prenatal Alcohol Exposure

U.S lifetime cost per person is \$2.5 million.

Cost in the U.S. is \$3.4 billion per year

**National Institute on Alcohol
Abuse and Alcoholism (NIAAA)
Criteria for Risky
Prenatal Alcohol
Exposure**

- ≥ 6 drinks per week for ≥ 2 weeks during pregnancy
- ≥ 3 drinks per occasion on ≥ 2 occasions during pregnancy



San Diego Regional Center

**Fetal Alcohol
Spectrum Disorder
28.8%**



Not a single child was previously reported by their parents to have FASD

Most children with FASD do not qualify for Regional Center Services despite FASD being the LEADING DEVELOPMENTAL DISABILITY IN THE U.S.

FETAL ALCOHOL SPECTRUM DISORDER
Institute of Medicine of The National Academies of Science
1996



Fetal Alcohol
Syndrome

Partial Fetal
Alcohol Syndrome

Alcohol Related
Neurodevelopmental
Disorder

Fetal Alcohol Syndrome

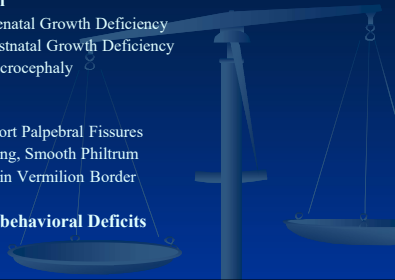
Growth

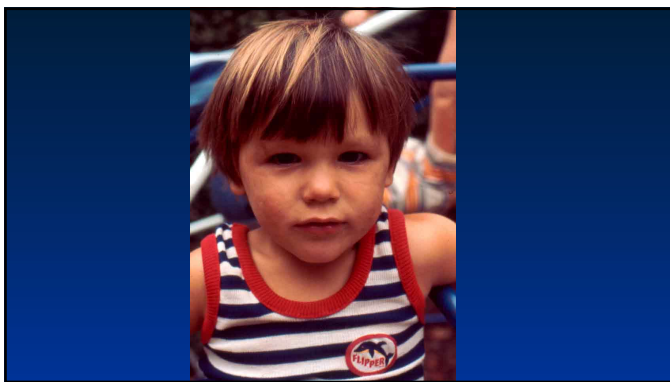
1. Prenatal Growth Deficiency
2. Postnatal Growth Deficiency
3. Microcephaly

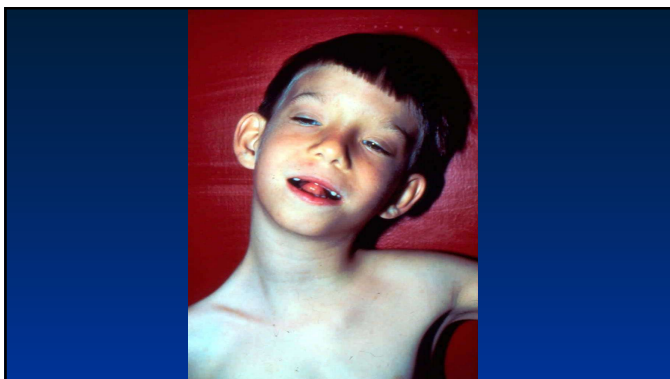
Face

1. Short Palpebral Fissures
2. Long, Smooth Philtrum
3. Thin Vermilion Border

Neurobehavioral Deficits







FASD Phenotype Institute of Medicine -1996

1. FAS with confirmed maternal alcohol exposure.
 - A. Confirmed maternal alcohol exposure
 - B. Characteristic facial anomalies including short palpebral fissures and abnormalities of premaxillary zone
 - C. Growth retardation
 - D. CNS neuro-developmental anomalies
2. FAS without confirmed maternal alcohol exposure
3. Partial FAS with confirmed maternal alcohol exposure
4. Alcohol-related birth defects (ARBD)
5. Alcohol-related neuro-developmental disorder (ARND)

Alcohol Related Neurodevelopmental Disorder (ARND)

- Confirmation of maternal alcohol use during pregnancy is required
- Intellectual disabilities and problems with behavior and learning
- Lacks growth deficiency, small head and typical facial features of Fetal Alcohol Syndrome



Early Hurdles to Overcome for Children with FASD

1. Education Systems
2. Juvenile Justice System



FASD Screening Program Kearny Mesa Juvenile Detention Facility (KMJDF)

- San Diego County Probation Department
- San Diego County Office of the Primary Public Defender, Juvenile Division
- UCSD Department of Pediatrics, Division Dysmorphology/Teratology



FASD Screening Program San Diego Juvenile Detention Facility

134 – total number of juveniles screened

32 (24%) screened positive → referred to clinic

14 (44%) of the 32 evaluated by Dr. Jones

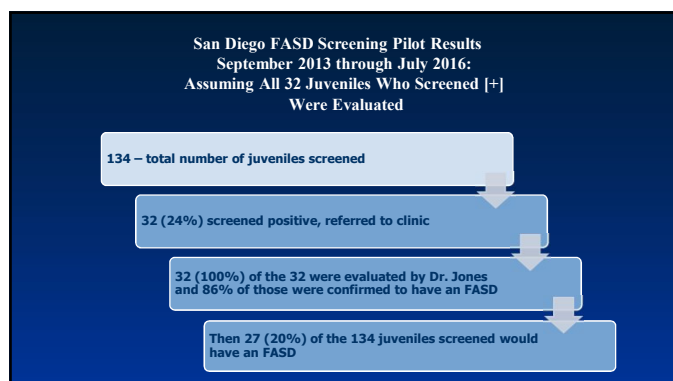
12 of 14 (86%) positive for FASD - overall prevalence rate of FASD of 9% (12/134 juveniles)

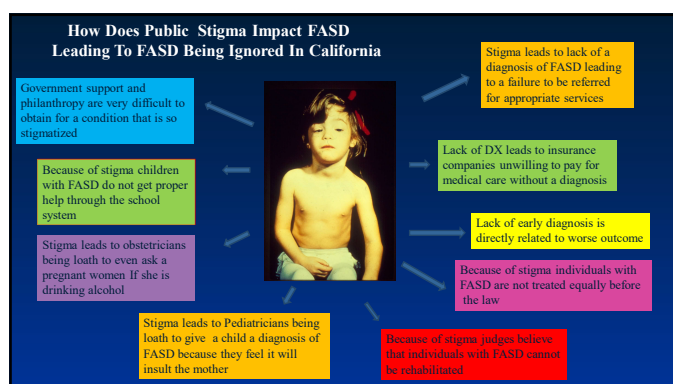


32 referred - 14 evaluated by MD

Of the 18 not evaluated:

1. 5 scheduled but did not show up at clinic and did not return calls to reschedule
2. 2 moved out of state and were lost-to-follow-up
3. 11 did not return call and were lost to-follow-up



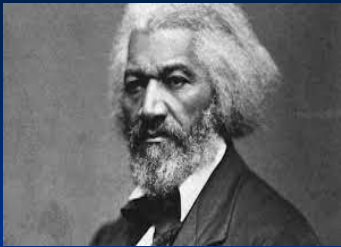


WHY A CALL TO ACTION NOW?

- FASD is more common than autism.
- Alcohol is the drug of abuse that has the greatest adverse impact on development of the unborn baby.
- To create a collaborative approach for treatment that includes the Juvenile Justice system, health care providers, educators, physicians, therapists, social workers, psychologists, caregivers and parents.
- The earlier children with this disorder are identified, the greater the chance that successful intervention programs can be implemented.

It is easier to build strong children than to repair broken men.

- Frederick Douglass





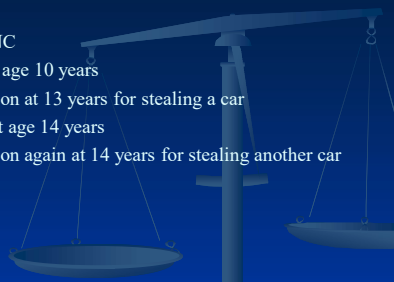
Justice

Pulasky Unit
Texas Dept. Criminal



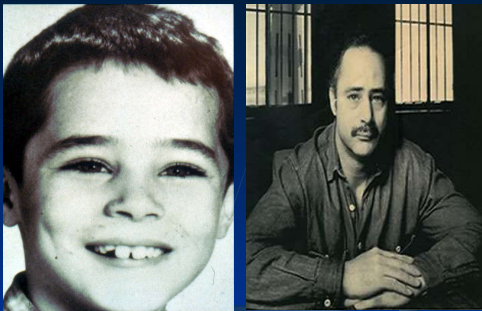
History

- A. Born 1953 in Ft Bragg, NC
- B. Run – ins with the law at age 10 years
- C. Placed in juvenile detention at 13 years for stealing a car
- D. Mother abandoned him at age 14 years
- E. Placed in juvenile detention again at 14 years for stealing another car



History (continued)

- At 22 years imprisoned for manslaughter
- Paroled 3 years later in 1978 at 25
- That same year murdered 2 teenage boys, stole their car, held up a bank
- Arrested less than one hour after the robbery
- Convicted and sentenced to death on 6/3/79
- Executed in San Quinton's gas chamber 21/4/92
- Execution the first in California since 1967



SUMMARY

- A. The prevalence of FASD has created a public health crisis:
 - 1.1 to 5% of students in 4 communities in U.S. are affected
 - 24% of children in San Diego Juvenile Hall screened positive for FASD.
- FASD is all but ignored in CA and throughout the U.S.
- Stigma against FASD, which permeates all sectors of our society, is one of the major reasons this disorder is ignored in the US.
- A. FASD is the #1 recognizable cause of intellectual and developmental disabilities in the U.S.
- B. Alcohol is the drug of abuse that has the greatest impact on fetal development

Most Children Go Through Life without Ever Being Diagnosed with FASD

Most people assume FASD has a low prevalence rate.

Nearly all psychologists and most MDs have never had any training in identifying FASD, much less diagnosing it.

Many school psychologists are not trained to recognize FASD and even make a referral for an evaluation.

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31

Most kids are not screened in foster care. Yet simple screening tools are available for nurses and social workers to implement.

Most children with FASD have no visible signs of a developmental disability. Many of these children are diagnosed with ADHD.

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Most children with FASD have average to low-average IQs. IQ IS MISLEADING AND all children with FASD have low adaptive behavioral skills.

Most children with FASD get mis-/under-diagnosed with psychiatric-mental health conditions that often conceal the underlying brain-based disorder.

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Many children with FASD do not manifest functional impairments until well into the elementary school years.

Self-regulation problems tend to be viewed by adults as either parenting deficiency or, as the child grows older, deliberate misconduct. Many disability organizations like the Regional Centers in California tend to put too much emphasis on the psychiatric conditions these children must face each day and less emphasis on the adaptive behavioral skills or problems with executive functioning.

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Nothing is known/asked/documentated about the birth mother's alcohol/drug use during pregnancy.

Because of the stigma attached to the birth mother drinking during pregnancy many pediatric doctors and even judges are afraid to ask the birth mother if they drank during pregnancy.

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The Relationship Between Prenatal Alcohol Exposure and Child Maltreatment

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A. Research shows that children whose mother drank during pregnancy are more likely to experience a negative early environment including:

1. developmental delay
2. abuse and neglect
3. exposure to trauma
4. disrupted attachment experiences
5. parental loss
6. hospitalizations, institutionalization and frequent foster care placements

These experiences have a significant and long lasting impact on the child's individual development even if the child has been placed in a more stable and supportive environment.

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B. These children are often diagnosed with the following:

1. Reactive attachment disorder
2. Conduct disorder
3. PTSD
4. Learning Disabilities
5. Depression
6. Anxiety
7. Mood Disorder
8. Borderline Personality Disorder
9. Attention deficit hyperactivity disorder (ADHD). According to Dr. Larry Burd, Ph.D. more than 70% of prenatally alcohol exposed children presenting for treatment receive a diagnosis of ADHD.

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C. Often court-ordered treatment is the only way for these children diagnosed with PAE to receive the appropriate medical, psychiatric and psychological treatment they need.

D. A child growing up without the benefit of being diagnosed with FASD and without an obvious "disability" means the child never received the proper diagnosis or received effective treatment.

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Neurocognitive, Neurodevelopmental and Neurobehavioral Signs of FASD

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FASD IS A DEVELOPMENTAL DISABILITY

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FASD is a Severe Life-long Developmental Disability

- A. Fetal Alcohol Spectrum Disorders (FASD) is a "severe lifelong developmental disability" that starts at birth. Most people with FASD are undiagnosed or even misdiagnosed
- B. The neurobehavioral and neurocognitive deficits for children and adults with FASD become worse and more complex over time. We are dealing with a complexity of problems across their entire life span. Growth impairments, speech and language deficits, impairments in adaptive behavior, brain damage, the inability to live independently, poor judgement, impulse control problems.

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IQ vs Adaptive Behavioral Skills

- A. Having very low adaptive behavioral skills is a hallmark characteristic of FASD. People with FASD have IQ scores that will not reflect their full range of deficits. The problem with adaptive behavior instruments like the Vineland is that they focus too much on “daily living” and NOT enough on judgement, suggestibility and gullibility. Especially the issue of judgment in dealing with other people and understanding social clues and boundaries.

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IQ vs ABS, Cont.

- B. Many disability organizations around the country often place over-reliance on IQ scores which is often used to unfairly deny services to children and adults. Many agencies do not understand that FASD is a brain-based disorder and that children born prenatally exposed to alcohol during utero have permanent brain damage. The brain damage occurred at birth and well before the age of 18.

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FASD, life-long and often family problem

- A. FASD is not a developmental disorder that children will outgrow.
- B. Very often not only do the siblings have FASD but also the birth mother may have FASD herself.

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A Proper Diagnosis of FASD can make a difference

- A. A proper diagnosis does make a difference.
- B. Treatment matters but more importantly services at an early age can really make a difference.
- C. A diagnosis helps everyone understand behaviors that would otherwise be incomprehensible. FASD is not an excuse but rather an explanation for their behavior. A valid diagnosis provides visibility! Remember, place more emphasis on the impairment than the behavior.

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ADHD is often a concurrent common diagnosis along with FASD

- A. One thing that is clear through the almost 50 years of research regarding FASD is that ADHD is one of the most common concurrent diagnosis for individuals with FASD. In many cases attention deficit hyperactivity disorder (ADHD) is diagnosed in up to 94% of individuals with heavy prenatal alcohol exposure. Some experts say that 50 % of all people diagnosed with FASD also have ADHD.

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ADHD, Cont.

- B. Many states and Developmental Disability Agencies tend to downplay the severity of FASD by looking at it as a learning disability. In *Floyd v. Filson*, 949 F. 3d 1128 (9th Circuit 2020) the court failed to recognize FASD as a permanent developmental disability that gets worse over time. Instead, the court compared FASD as being equivalent to having ADHD. Unlike ADHD, FASD is equivalent to having an intellectual disability.

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48

Looking at the Common Secondary Disabilities of Children with FASD

- A. Adding to the extreme complexity of this severe developmental disability people with FASD are reported to have many mental health issues. Most state agencies argue that the adaptive behavioral deficits are based “solely on psychiatric issues” which occurs as the secondary disabilities set in for most people with FASD. The diagnosis of psychiatric disorders is secondary to the permanent brain damage that these children are born with and the neurocognitive behaviors and neurodevelopmental disorders are not caused solely by psychiatric conditions.

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49

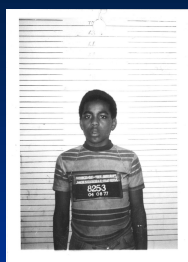
Secondary Disabilities, Cont.

- B. The secondary disabilities also involve the risk of suicide attempts, psychosis, anxiety disorders, eating disorders, PTSD, learning disabilities and other mental health issues. Research shows that about 94 percent of adolescents and adults have such challenges. People with FASD have higher increased rates for secondary comorbid neurobehavioral and neurodevelopmental disabilities including higher prevalence rates for psychosis (24.5 times), intellectual disabilities (22 times), suicide attempts, depression and higher mortality rates.

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50

RED FLAGS



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Signs of FASD in Infancy

- A. Birth defects (heart murmurs, patent ductus arteriosus, kidney, facial, etc.)
- B. Failure to thrive, feeding difficulties, small size
- C. Neurological dysfunction, developmental delay, small head

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52

Signs of FASD in Infancy

- D. Sleeping difficulties
- E. Easily overstimulated, irritable
- F. Tremors, jitteriness, seizures
- G. Prone to infections (ear, respiratory, etc.)
- H. Eye problems, severe nearsightedness, "congenital ptosis"
- I. Orthopedic problems

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Signs of FASD in Preschool

- A. Has sleeping and feeding issues, susceptible to infection, tantrums, irritability and overstimulation.
- B. Risk of developmental delays continue also (speech, poor balance and coordination, immaturity, etc.).
- C. Hyperactivity.
- D. High risk of abuse, neglect, out-of-home placement.

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Signs of FASD - School Age

- A. Children with FASD are at risk for learning disabilities and more likely to be in need of special education services. They often also have poor math skills, language, memory and cognitive disabilities (mental retardation), but may have high IQ.
- B. Attention deficits/Hyperactivity, stimulation seeking or easily overwhelmed.

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Signs of FASD - School Age

- C. Social difficulties: attention seeking, immature, impulsive, emotional, excessively friendly, easily influenced, poor judgment. Poor peer relationships are associated with a significantly increased risks for delinquency and early withdraw from school
- D. Behavioral difficulties: volatile, lying, stealing, oppositional. Behavioral problems and emotional problems are likely to interfere further with their school functioning and academic performance.

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Signs of FASD in Adolescence

The same deficits and behaviors of childhood continue but are perceived as more problematic and are punished much more harshly.

- Difficulty with abstract reasoning, planning ahead, self regulating and predicting outcomes.
- Low self esteem, depression, explosive.
- Truancy, dropout, expulsion.
- High risk behavior, promiscuity, delinquency, gang activity (the patsy, the one "holding the bag").

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57

EDUCATING THE SYSTEMS



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The Courts and the Importance of Educating the Judge

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59

ABA's 2012 Resolution

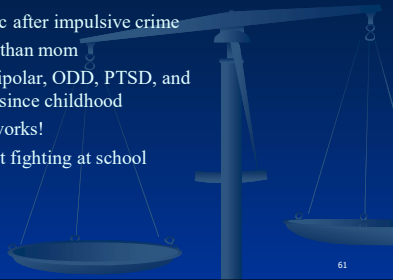
- A. Urges all judges and attorneys working in juvenile justice courts to identify and respond to children with FASD
- B. Encourages training to enhance awareness of FASD and its impact in the child welfare and juvenile justice systems

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60

Have you met this youth?

- Very remorseful/apologetic after impulsive crime
- Lives with someone other than mom
- Diagnosed with ADHD, bipolar, ODD, PTSD, and major depressive disorder since childhood
- Multiple meds – nothing works!
- Trouble sitting still and not fighting at school
- Gullible



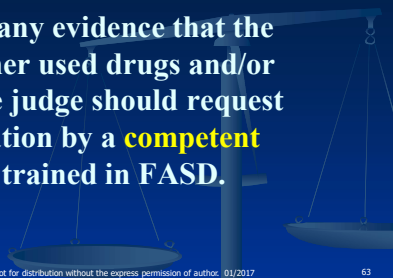
61

1. Not raised by bio mom
2. Bio mom has 647(b) history
3. Sibling with FAS or FASD
4. Bio mom has issues with alcohol
5. Mom's partner was alcoholic
6. + tox at birth
7. Medical problems (e.g. heart, kidney, orthopedics)
8. Multiple psych diagnoses over time
9. Long list of psych meds that have been tried
10. May have IQ over 70 but struggle with numbers and adaptive functioning



62

If there is any evidence that the birth mother used drugs and/or alcohol, the judge should request an evaluation by a **competent expert trained in FASD.**



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63

A more effective way of gathering the mother's drinking history while pregnant is to ask what her habits were regarding alcohol *before* she knew she was pregnant.

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The Importance of the IEP

1. Is the child receiving appropriate special education services?
2. Make sure the IEP mentions FASD.
3. Are the teachers trained?
4. A child in juvenile hall must have all teachers, social workers, psychologist and other professionals aware of the child's FASD diagnosis.
5. Does the child need to be placed under conservatorship?

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QUESTIONS?

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66


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67
