FASD IS A DEVELOPMENTAL DISABILITY

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THE RELATIONSHIP BETWEEN PRENATAL ALCOHOL EXPOSURE AND CHILD MALTREATMENT

A. Many families that enter the child welfare system through the dependency and delinquency courts do so with alcohol and drug abuse as a major component of the familial dynamic that led to the filing of the case.

B. Many children in this country live with a parent/parents who are dependent on or abuses alcohol and other drugs.

C. Prenatal alcohol exposure is recognized as a risk factor for child maltreatment and child welfare involvement (foster care).

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

- developmental delay
- abuse and neglect
- exposure to trauma
- disrupted attachment experiences
- parental loss
- 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.

INTELLECTUAL DISABILITY EQUIVALENCE

In Greenspan, S., Brown, N. Edwards, W., "FASD and the Concept of Intellectual Disability Equivalence" the authors coined the term "Intellectual Disability Equivalence" to explain why people with FASD often have IQ's above 70 and would not qualify for a diagnosis of Intellectual Disability. However their adaptive behavior, i.e., the collection of conceptual, social, and practical skills that all people learn in order to function in their daily lives is **equivalent** to a person with an IQ far lower.

FASD IS OFTEN UNRECOGNIZED

A. These deficits and impairments manifest differently during different developmental periods in the child's life.
B. Given these **neurobehavioral, neurocognitive and neurodevelopmental** deficits associated with prenatal alcohol exposure it is not surprising that these children often are unrecognized, misdiagnosed, underserved and often misunderstood.

C. 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.

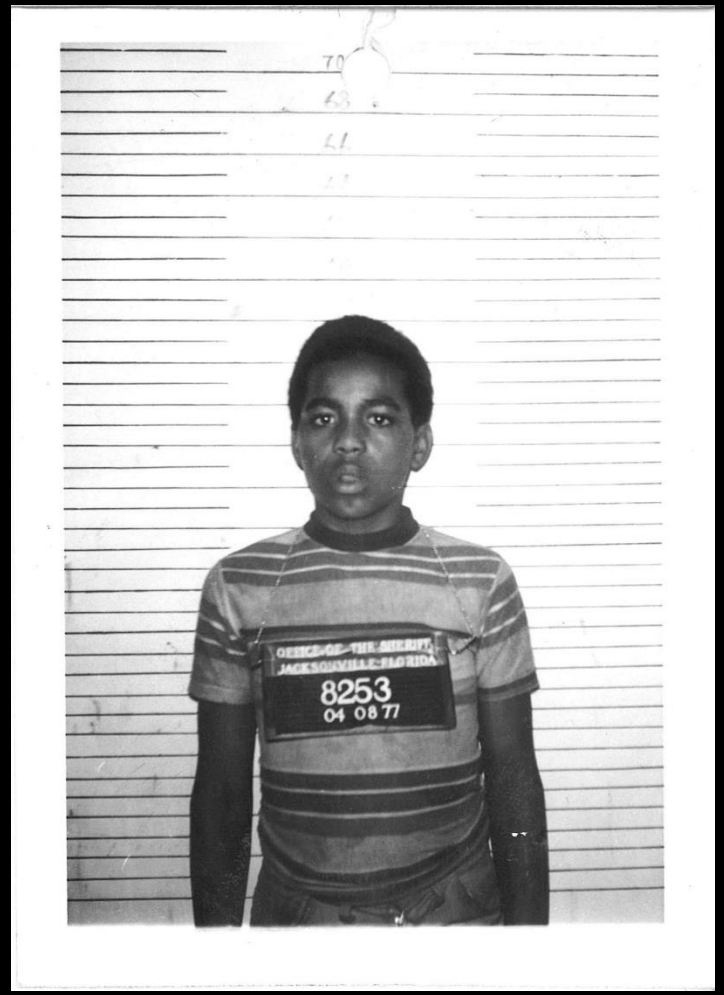
FASD AND FOSTER CARE

A. The foster care system is a very important service system for the identification, screening and treatment of children with FASD.
B. According to research conducted by Dr. Larry Burd, Ph.D. among children diagnosed with **FASD 70% are or have been in foster care.**

C. In a study done in 2015 published in the **Journal of Pediatrics**, the study reported that 86% of FASD cases were either missed (80%) or incorrectly diagnosed (6%) at the time of the referral in a sample of children in foster care and with adoption agencies with the Illinois Department of Children and Family Services.

NEUROCOGNITIVE, NEURODEVELOPMENTAL AND NEUROBEHAVIORAL SIGNS OF FASD

RED FLAGS



SIGNS OF FASD INFANCY

A. Birth Defects (heart murmurs (systolic heart murmur), patent ductus arteriosus, kidney, facial, etc.).
B. Failure to Thrive, feeding difficulties, small size (FAS only).
C. Neurological dysfunction, developmental delay, small head.

SIGNS OF FASD INFANCY CONT.

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

SIGNS OF FASD PRESCHOOL

A. Continue to be small (FAS only), have sleep 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.

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.

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.

SIGNS OF FASD ADOLESCENCE

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

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

FASD PARADIGM SHIFT

In order to understand children who have FASD, judges, probation officers, prosecutors, social workers and other professionals must undergo a paradigm shift in approach.

A. The appropriate approach is to accommodate the cognitive and physical disability through appropriate support systems rather than attempt to attain compliance by intermediate sanctions.

B. Support systems need to be instituted both during the prosecutorial process and with regard to post-sentencing conditions of supervision, counseling and treatment.

FASD PARADIGM SHIFT CONT.

C. The juveniles benefit from understanding the nature of their disabilities.

D. Educate the courts and all others in the juvenile court system that FASD is not an excuse; it is an explanation of the children's behavior.

FASD IS A DEVELOPMENTAL DISABILITY

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.

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.

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. Many other disability organizations throughout the United States look at the person's full scale IQ that is often higher than 70 and place more emphasis on the IQ then the adaptive behavior.

ADAPTIVE BEHAVIOR SCALE PROBLEMS

There is no mention of risk-awareness or risk-vulnerability (suggestibility).

FASD, LIFE LONG AND OFTEN FAMILY PROBLEM

A. FASD is a developmental disability that even though the full ramifications, including cognitive limitations, neurobehavioral and neurocognitive deficits, memory and attention deficits may not be visible for many years after birth and into childhood. Children who are born prenatally exposed to alcohol during the pregnancy are born with this brain-based disorder. The prenatal alcohol exposure affects the child throughout his or her life span. 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.

A PROPER DIAGNOSIS OF FASD CAN MAKE A DIFFERENCE

A. A Proper Diagnosis does make a difference. Treatment matters but more importantly services at an early age can really make a difference. One of the problems is that there are few diagnostic clinics and trained experts to diagnose FASD in the United States. Proper diagnosis improves understanding and leads to services. As a result, almost every person with FASD is destined to be diagnosed with, and treated for, something else. A diagnosis helps everyone understand behaviors that would otherwise be incomprehensible. FASD is not an excuse but rather it is an explanation for their behavior. A valid diagnosis provides visibility! Remember place more emphasis on the impairment than the behavior.

FASD DIAGNOSIS, CONT.

B. Access to services for people with FASD should be based on the level of the "severity of the disability" rather than the IQ. FASD is more severe than ID and ADHD that often ends up being one of the initial diagnosis.
C. There is little screening if any being done in the juvenile and family courts despite research that shows as many as 70% of all children in foster care are prenatally exposed.
D. Many states do not accept a diagnosis of FASD as a developmental disability.

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.

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, 940 F. 3d 1082 (9th Circuit 2019) 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.

LOOKING AT THE COMMON SECONDARY DISABILITIES IN PEOPLE 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.

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.

THE ATTORNEY

THE ATTORNEY

A. Educate yourself with the Red Flags that indicate your client may have PAE.
B. Develop a social history of the maternal alcohol use by the birth mother, including the prenatal alcohol exposure of any siblings.
C. Fight for the best qualified experts, develop your team and collect all records including birth records, prenatal care, social services, special education, IEP's, psychiatric and medical, etc.
D. Identify and address cultural issues.
E. Make a showing that FASD is relevant.

ADVOCACY

F. The attorney should work with all professionals, especially the mental health and medical professionals, who have contact with the client and educate them about FASD.

G. Request periodic conference calls or meetings with all the service providers who work with the child.
   1. Have FASD experts review records and make recommendations for treatment and services.
   2. Does the client need more services?
   3. Are there gaps in services?

H. After the FASD diagnosis, start advocating at all levels.

EDUCATIONAL ADVOCACY

A. Look at the educational component and attend all IEP's.
   1. Speech therapy
   2. Sensory Integration treatment
   3. Request neuropsychological and psychological testing

B. Make sure the client has appropriate school accommodations.

C. Argue that FASD is a developmental disability caused by brain damage that will result in learning and behavioral problems.

EDUCATIONAL ADVOCACY CONT.

D.Make sure the child has an advocate at the school IEP's and hearings.

1. Ask the court to appoint someone or perhaps CASA can advocate.
2. The parents may not available or birth parents may still be struggling with addiction.

SECOND ADVOCATE

A. Second Advocate for the child to receive services from the local or state disability organizations.
B. It is common for them to be denied services.
    1. Ask them why…
    2. Contact Protection and Advocacy to help with the application or appeal.
    3. Reach out to the organizations like NOFAS for advocacy support.
C. Advocate for the child to be referred to the mental health court.

USE OF EXPERTS

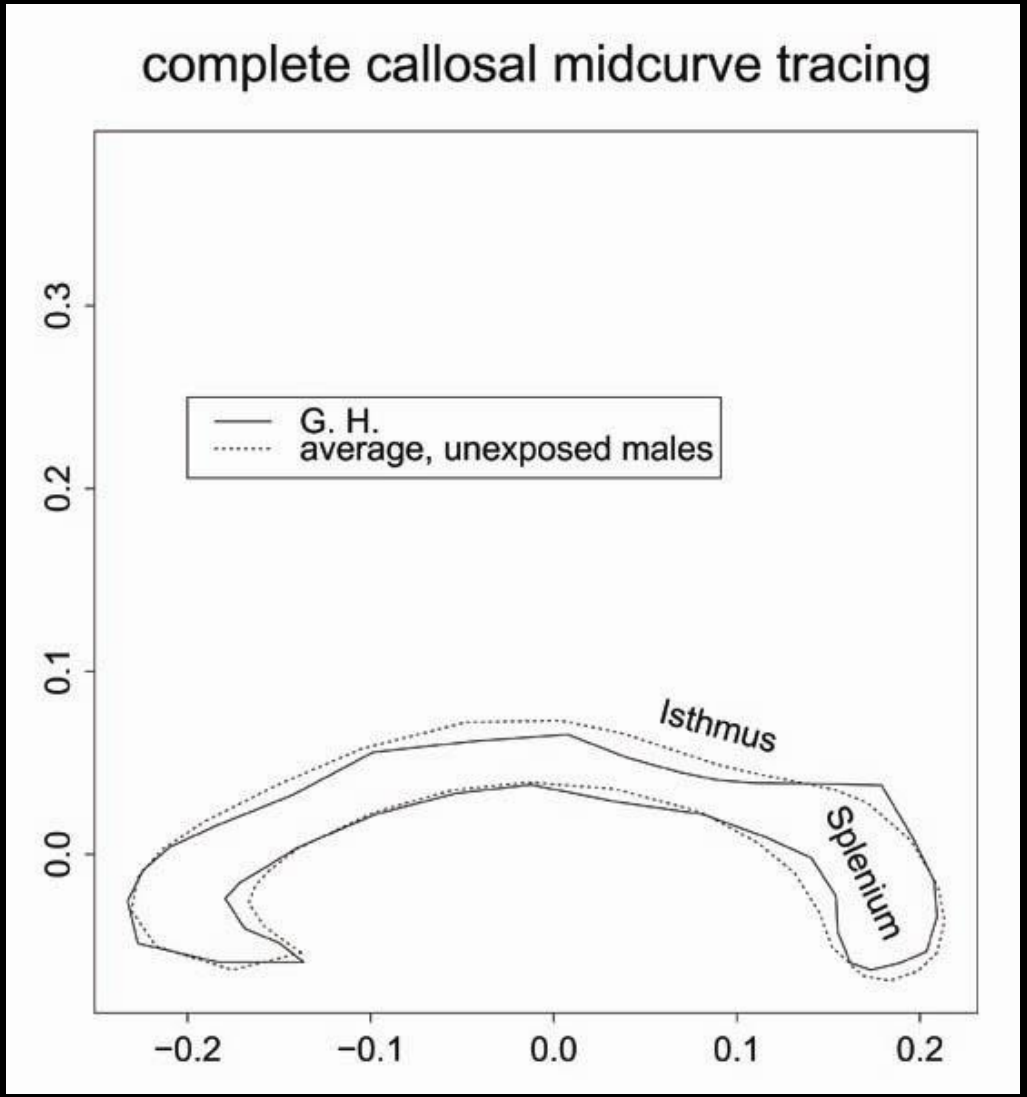
EXPERTS LIST

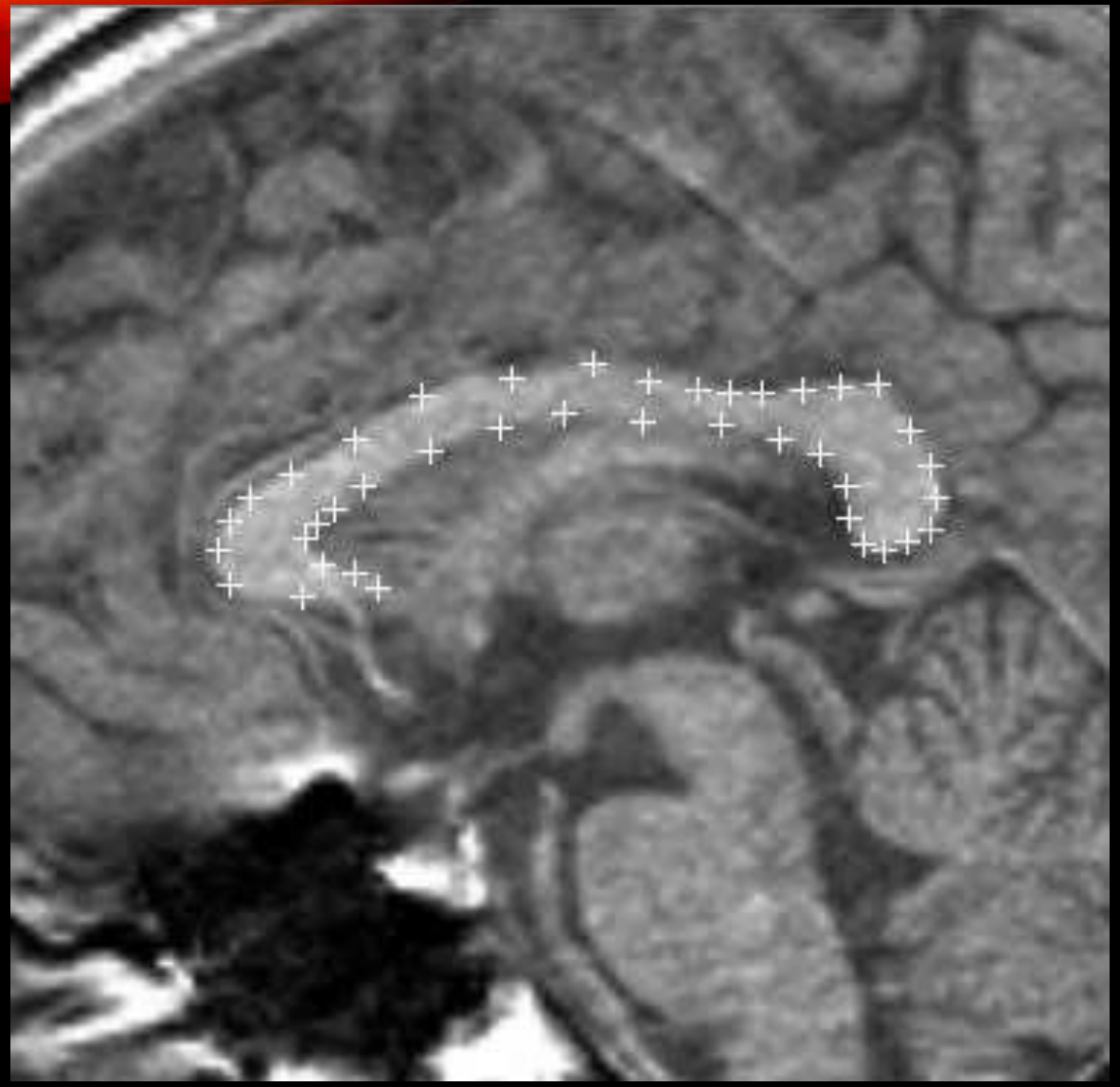
A. Social worker
B. Psychologist
C. Neuropsychologist
D. Neurologist
E. Dysmorphologist and/or Geneticist
F. Pediatric Doctor
G. MRI Specialist (to look at brain damage caused by alcohol)

ADAPTIVE FUNCTIONING

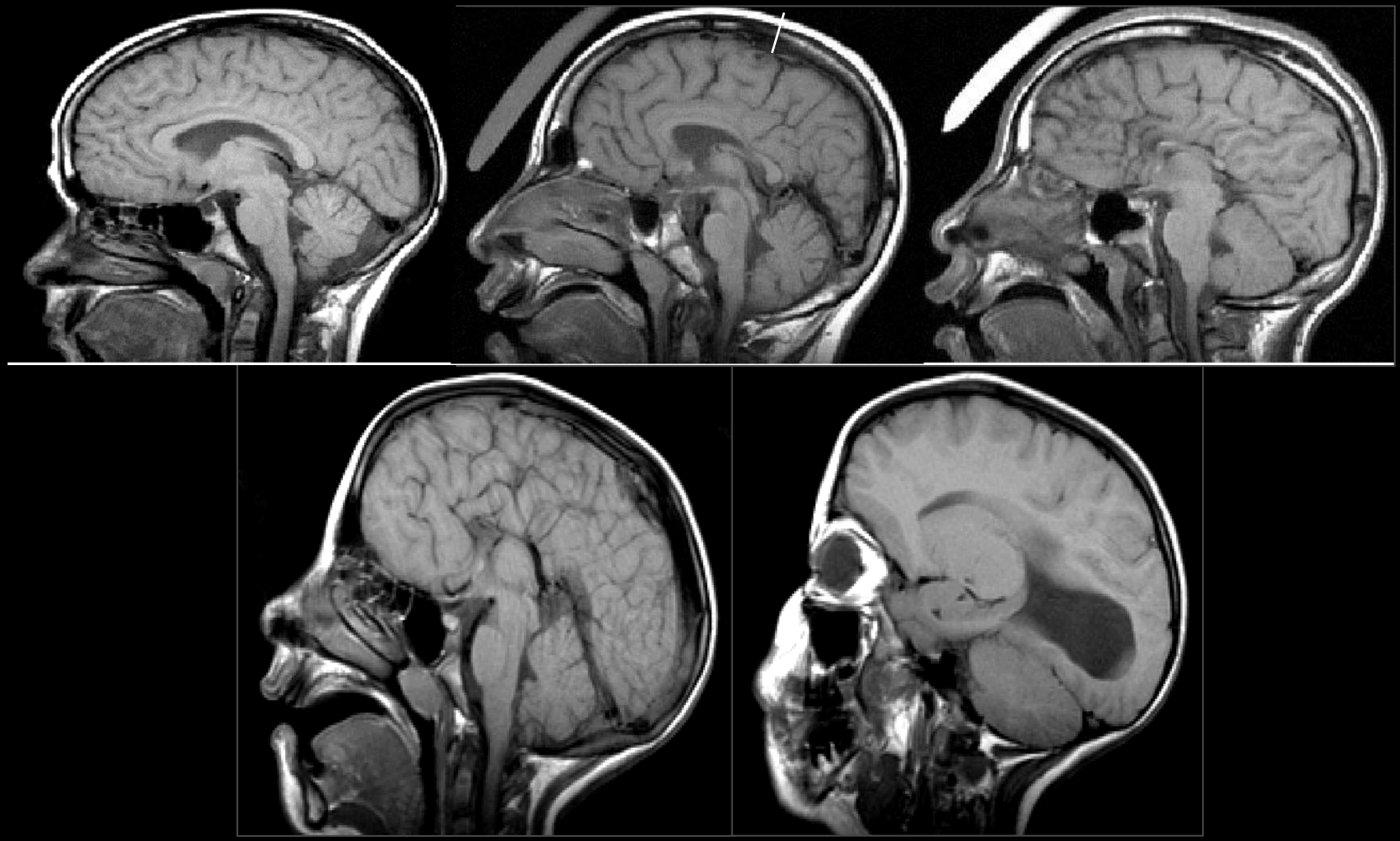
A. Vineland Adaptive Behavior Scale (VABS)
    1. Daily living assessment
    2. Communication, daily living skills, socialization
B. Fetal Alcohol Behavior Scale ("FABS")

MRI STUDY



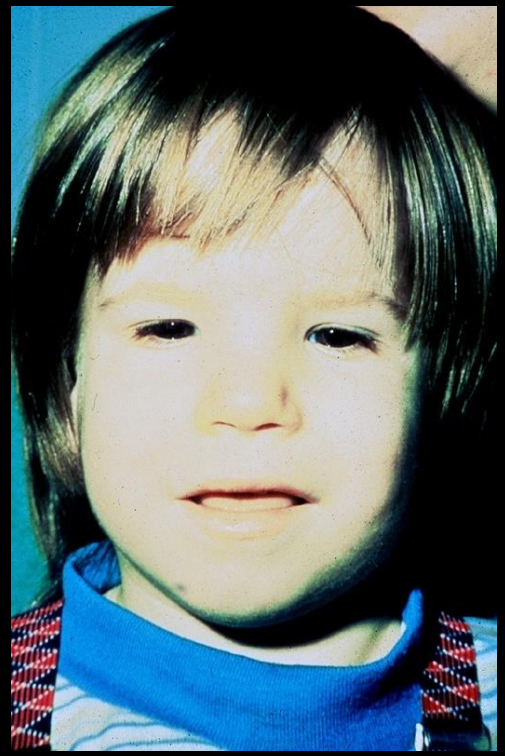


CORPUS CALLOSUM ABNORMALITIES



Mattson, et al., 1994; Mattson & Riley, 1995; Riley et al., 1995

SUCCESS



SUPPORTS AND ACCOMMODATIONS

A. **Removal of supportive services will always invite failure.**
B. Sometimes an individual's success with supportive services is mistaken as evidence that services are no longer needed, however, ongoing support is necessary for continued success.
C. Treatment plans for children with FASD must provide different supports and services for each developmental period.

D. The central component for treatment is to provide accommodations in the child's environment at home and school.
E. The court must support positive behavior in the child and increase the child's opportunity for success.
F. Find talents with each child who has FASD and build on those for success.

SUCCESS

LISA

EARLY HISTORY

A. Born premature to a mother abusing alcohol and other drugs.
B. Removed from mother at age 4 because of complaints of physical and sexual abuse and neglect.
    1. Records document father's sexual abuse and punishment of Lisa and siblings by confining them in animal cages without diapers or clothes.
C. Placements include orphanage, 7 foster care placements and 15 psychiatric hospitalizations since the age of four.

CHILDHOOD

A. Age Four: Developmental delay, sleeping disorder, jitteriness/fidgeting and aggression.
B. Age Six: first psychiatric hospitalization for threatening to commit suicide and breaking windows. Placed in special education classes for severely emotionally disturbed.
C. At age Seven: treating psychiatrist wrote: "Lisa regresses to a baby under any amount of pressure."
D. And at age Ten: Lisa would take a baby bottle, curl up like an infant, cooing and with baby talk.

ADOLESCENCE

Age 14: Auditory and visual hallucinations. Behavior deteriorated to walking on all fours, growling and acting like a dog. Reported she used airplane glue, hair spray and white-out to get "high". Used self-mutilation to get attention and wrote: "when I get angry I need to scratch myself, bite myself, (bang) my head and pull my hair out." Ran away from placement with older peers and turned to prostitution and other drugs.

ADOLESCENCE CONT.

A. Age 17: Attempted to strangle herself with vacuum cleaner hose, threatened to kill staff at group home, bit and attacked police officers, was arrested and taken to juvenile hall.
B. Age 18: Swallowed safety pins and screws. Admitted to the psychiatric hospital she told the treating doctor she wanted to kill her and burn her group home to the ground.

ADULTHOOD

Age 22: kicked out of group home, living on the streets with no money or medication, she returned and set the occupied group home on fire. Arrested, charged with arson and advised by court appointed attorney to take a three year sentence in state prison, Lisa is sent to state prison instead of a state hospital.

PRISON

A. Age 23: In prison Lisa made her most serious suicide attempt with deep cuts that required sutures and a cast. She then pulled off the cast, bit through the sutures and bled so much she required a transfusion.
B. After hospitalization she is returned to state prison labeled a "mentally disordered offender" and was placed in a state hospital where she sits for years.

In her entire 27 year history of contact with the medical, social service, educational, criminal justice and correctional systems she is NEVER evaluated for FASD or diagnosed with an FASD.

FASD

A. At age 28, her current court appointed attorney has Lisa assessed and diagnosed with FASD and applied for services for her through the Department of Developmental Services.
B. Denied services, without funding, the counsel sought out advocacy organizations to advocate on Lisa's behalf and was told: "you will never get your client services. She has an IQ of 98."

LISA

A. Finally, counsel finds an attorney from Disability Rights Organization in California to advocate for Lisa.
B. Under the California "fifth category," we argued that Lisa needed services "similar to a person with an intellectual disability."
C. After two years of litigation and limited funding we finally secured services for Lisa.