# CHANGING PUBLIC POLICY WITH THE JUVENILE COURTS: What Works With Kids With FASD?

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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:
  - 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.

### FASD is a Permanent Developmental Disability

- A. The resulting neurobehavioral, neurocognitive and neurodevelopmental deficits seen following prenatal alcohol exposure are wide-ranging and often devastating.
- B. Fetal Alcohol Spectrum Disorders (FASD) are not something a child will outgrow. These deficits last a lifetime!
- C. In fact, they get worse over time. These children are born with a permanent developmental disability.

### 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:

- Reactive attachment disorder
- Conduct disorder
- 3. PTSD
- 4. Learning Disabilities
- 5. Depression
- 6. Anxiety
- 7. Mood Disorder
- 8. Borderline Personality Disorder
- 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.

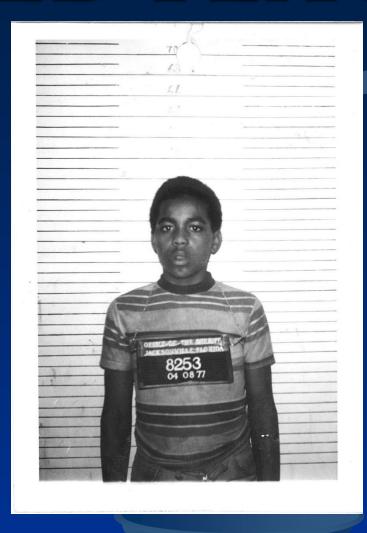
### The Importance of an Early Diagnoses

A. An early and formal diagnosis of prenatal alcohol exposure (PAE) is an important first step in helping a child receive the necessary services and treatment (special education placement, social security disability, mental health treatment, vocational programs, programs through the department of developmental disabilities).

- A. Often court-ordered treatment is the <u>only</u> way for these children diagnosed with PAE to receive the appropriate medical, psychiatric and psychological treatment they need.
- B. 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.

# 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.

- 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

### 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.
- 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").

## EDUCATING THE SYSTEMS





### ABA's Resolution

- A. In 2012 the American Bar Association passed a Resolution on FASD urging all Judges and attorneys working in children's courts and juvenile justice courts to identify and respond to children with FASD.
- B. The ABA encouraged training to enhance awareness of FASD and its impact in the child welfare and the juvenile justice systems.

### Judge's Resolve

- A. As a Judge you can take action to change the life of the birth mother and the child prenatally exposed.
- B. All Judges must first raise the question of whether or not the child may have FASD. We should not assume that the issue has been addressed in the past! Remember, alcohol is commonly used with other drugs.

### Judge's Resolve cont.

- C. All Judges should learn the neurodevelopmental, neurocognitive and neurobehavioral traits that indicate the child may have been prenatally exposed to alcohol during pregnancy.
- D. You can make a difference by identifying resources in the community and asking for screenings and assessments.
- E. Keep in mind there is a strong likelihood that the birth mother herself may have FASD.

### Results

#### An early diagnosis of children with FASD can

- Possibly prevent the need for removal.
- 2. Help establish appropriate placements and services from the state department of developmental disabilities.
- 3. Entitlement to special education services.
- 4. Help the birth parents or foster/adoptive parents understand and meet the needs of the child.
- 5. Reduce the likelihood of failed placements.

### The Judge's Questions

- 1. Is there a history of alcohol or other substance abuse in the family? History of PAE?
- 2. If the birth mother denies alcohol use during pregnancy, remember denial is a hallmark characteristic of substance abuse. A better way of gathering this important information is to ask what her habits were regarding alcohol *before* she knew she was pregnant.
- 3. What is the child's educational history? (special education, school disruptions, unexcused absences, suspensions)
- 4. History of mental illness, ADHD, developmental disability.
- 5. History of multiple placements, abuse, neglect?
- 6. Siblings in foster care, siblings with PAE?

### The Judge's Actions: Diagnosis

- A. Require child welfare agencies to provide birth records and other records that may indicate prenatal alcohol exposure.
- B. Review all social services and psychological, psychiatric and medical diagnostic reports to determine if there is any evidence of prenatal alcohol exposure.
- C. 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.

## The Judge's Actions: Diagnosis cont.

- D. Alert those involved in the advocacy of the child's welfare (e.g. parents, foster parents, social services, CASA, guardian ad litem, educators, child's attorney) that the child may have prenatal exposure and they should consider diagnosis and services including treatment.
- E. If a diagnosis of FASD exists make sure that all future reports ordered by the court reflect the diagnosis and the Judge must order early intervention, treatment, special education services and supportive services.

### The Judge's Actions: Intervention

- A. Document testing, therapy, educational supports and medical treatment in the record.
- B. Assure the educational component is complete.
  - 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?

### The Judge's Actions: Intervention cont.

- C. Make an inquire to make sure the child is getting all the proper services that they are entitled to by the state and federal government.
- D. Judges can hold agencies, foster parents, service providers, educators, attorneys and advocates accountable for ensuring services and treatment are provided in a timely manner.

### The Judge's Actions: Intervention

- E. KEEP IN MIND THAT CHILDREN WITH FASD carry a very high burden of care. The structure and care they must have require a very high degree of positive parenting.
- F. Children with FASD are also a greater risk for suicide.

### Remember

- A. Multiple generations in a family can and often do have FASD.
- B. This chain of damaged lives is broken when the next generation is born free from PAE. Remember a vast majority of children who are never diagnosed and never treated repeat the cycle of substance abuse giving birth to next generation of children adversely affected by maternal alcohol use.
- C. Proper placements include stable, nurturing and supportive environments for the child.

### FASD Paradigm Shift

- A. In order to understand children who have FASD, judges, probation officers, prosecutors, social workers and other professionals must undergo a paradigm shift in approach.
  - 1. The appropriate approach is to accommodate the cognitive and physical disability through appropriate support systems rather than attempt to attain compliance by intermediate sanctions.
  - 2. Support systems need to be instituted both during the prosecutorial process and with regard to post-sentencing conditions of supervision, counseling and treatment.

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

#### Medication

- A. Judges must be educated on medication reviews for children who come into the juvenile court system.
  - Many children may be on medication and have never been screened for FASD.
  - 2. If the child has FASD and medications are withheld (as they may be if the child is placed in protective custody or a juvenile detention facility) or if they are not taken, this greatly diminishes the child's ability to control impulses and behavior.

B. Consider requesting a social history when reviewing a medication request. Social history should include a history of prior diagnosis, medication regime and special education placements.

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

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

## Psychological Testing

#### A. Subject

- 1. Gudjonsson Suggestibility Scale
- 2. Competency Assessment
- 3. Personality Testing (differential Dx)
- 4. Malingering Assessment

#### B. Collateral Informants

- 1. Behavioral Rating Inventory of Executive Functions
  - Adult (executive functioning)
- Adaptive Testing

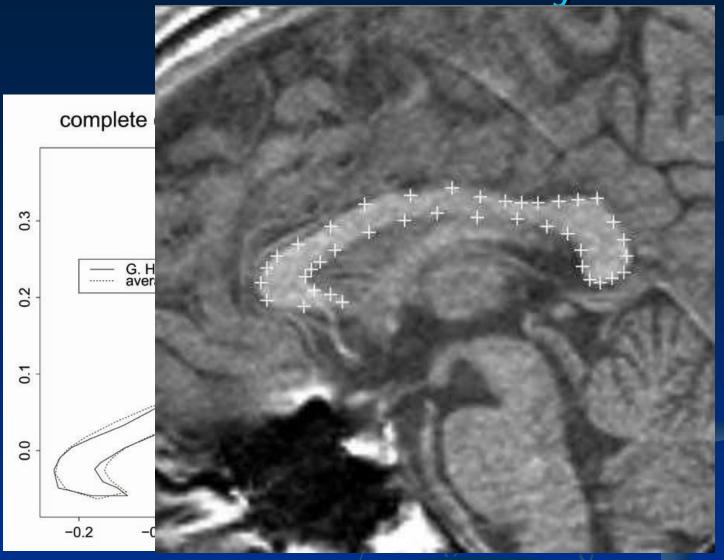
### IQ and Academic Tests

- A. Wechsler Adult Intelligence Scale 3<sup>rd</sup> Edition (WAIS-III) (now WAIS-IV)
  - 1. Generalized IQ
- B. Woodcock Johnson 3<sup>rd</sup> Edition (WJ-III)
  - 1. Variety of academic tasks (reading, spelling, arithmetic, passage comprehension, academic knowledge)

## Adaptive Functioning

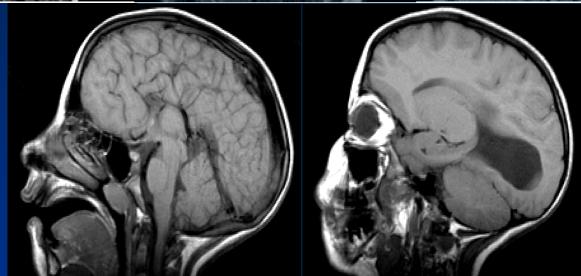
- A. Vineland Adaptive Behavior Scale (VABS)
  - 1. Daily living assessment
  - 2. Communication, daily living skills, socialization
- B. Fetal Alcohol Behavior Scale ("FABS")

MRI Study



# Corpus callosum abnormalities





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

#### Court Sanctions

- Sanctions might be incentives (provides structure and security).
- Do not expect children with FASD to learn from sanctions.
- Because of the brain damage associated with FASD, true Rehabilitation, specifically the ability to learn from past behavior mistakes, often is not possible for these juveniles. But success is attainable.

## 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.
  - 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

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

#### Adolescence

A. 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

- B. 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.
- C. 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

A. 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.

