FASD-A Severe Neurodevelopmental and Neurobehavioral Developmental Disability-Looking Back 26 years

William J. Edwards, Deputy Public Defender
Office Of The Public Defender, Mental Health Court
Los Angeles County, California

Most Children With Prenatal Alcohol Exposure Who Are In Foster Care And Custody of the State Including Juvenile Delinquency Courts Go Through Life Without Ever Being Diagnosed

Most Children Go Through Life without Ever Being Diagnosed with FASD

Most people assume FASD has a low prevalence rate. Every single baby reacts differently to prenatal alcohol exposure.

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

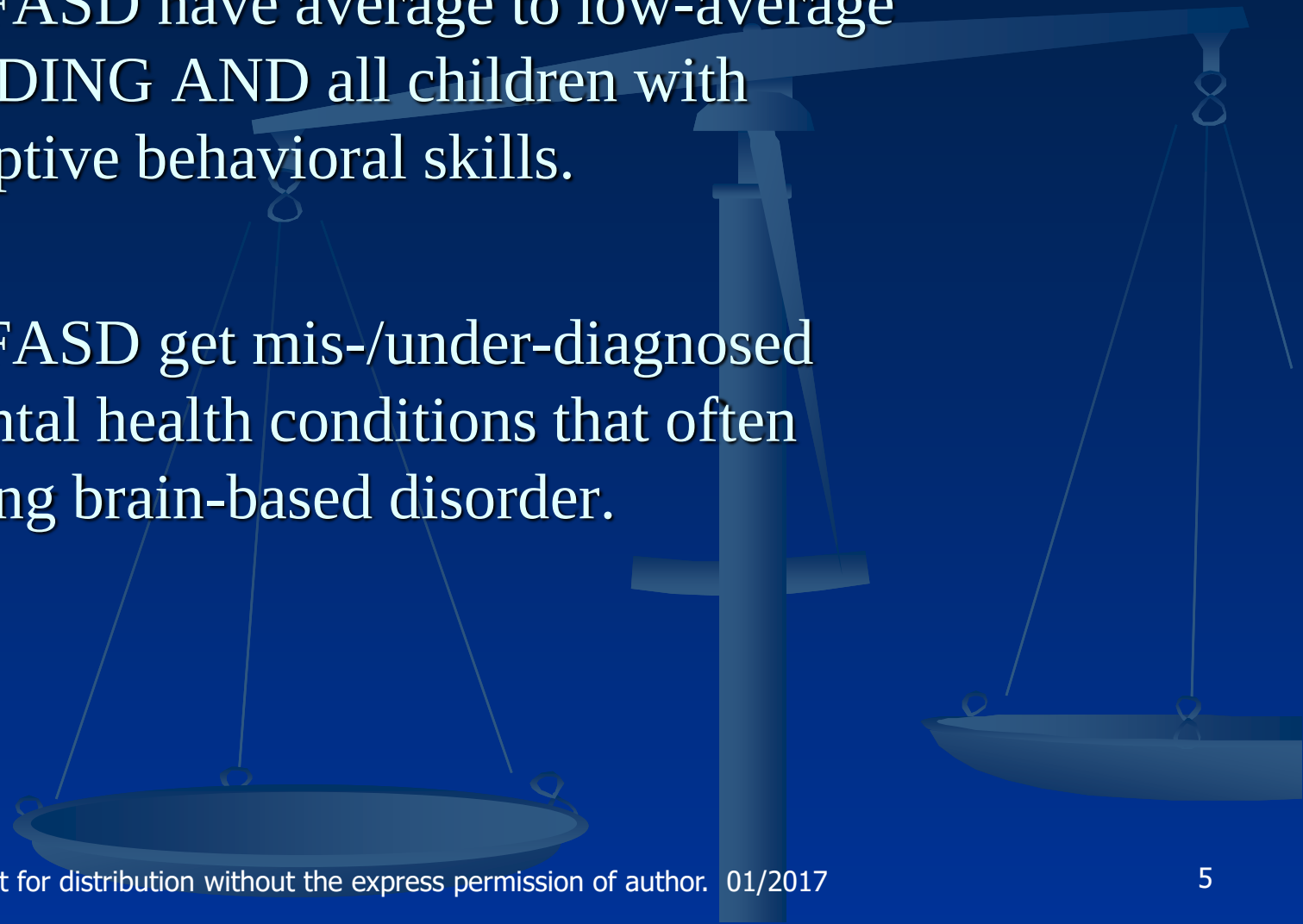
Many school psychologists are not trained to recognize FASD and even make a referral for an evaluation.

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.

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.



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 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.

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

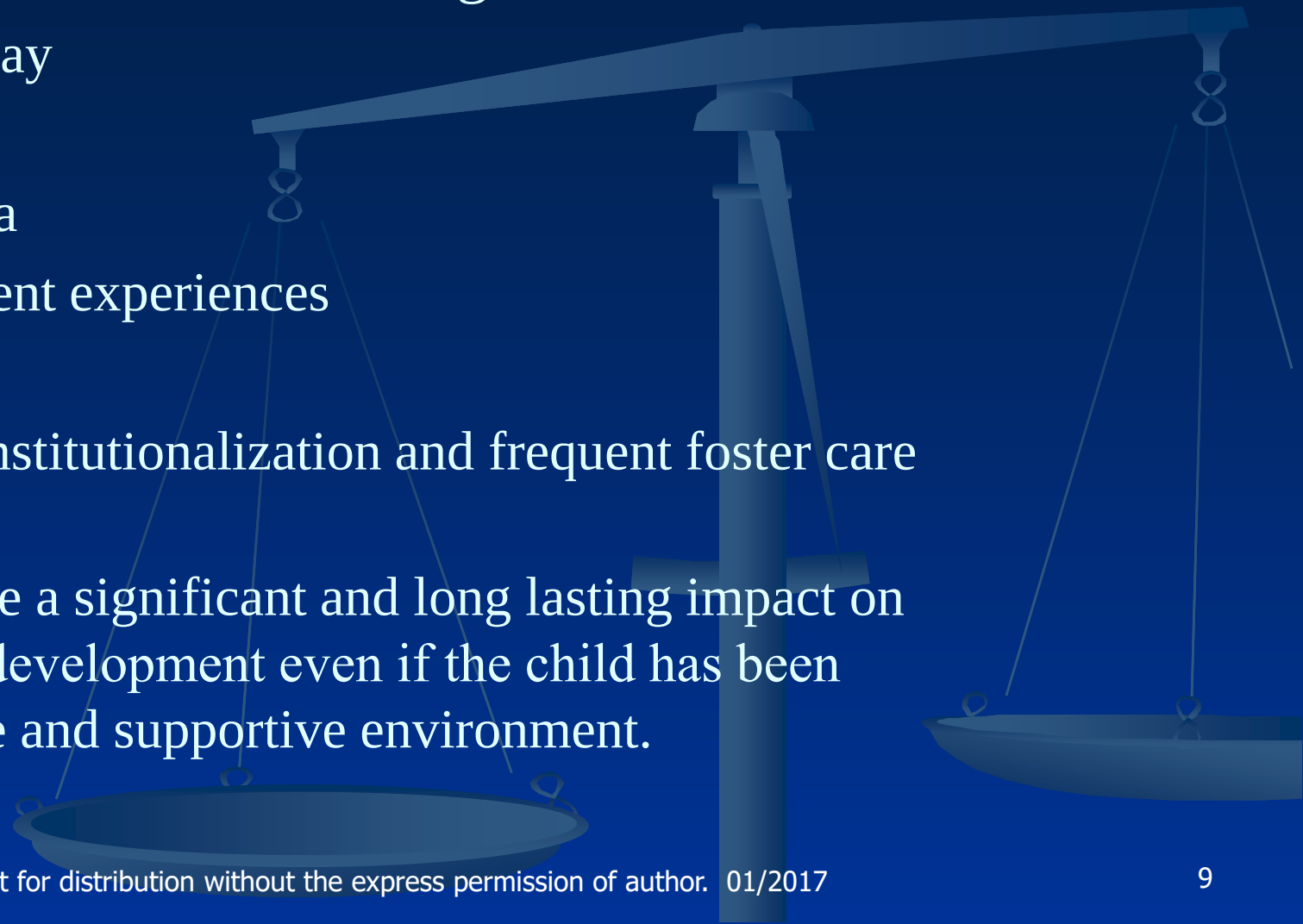
Because of the stigma attached to the birth mother drinking during pregnancy many pediatric doctors and even Judges are afraid to ask the birth mother if they drank during pregnancy.

The Relationship Between Prenatal Alcohol Exposure and Child Maltreatment

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

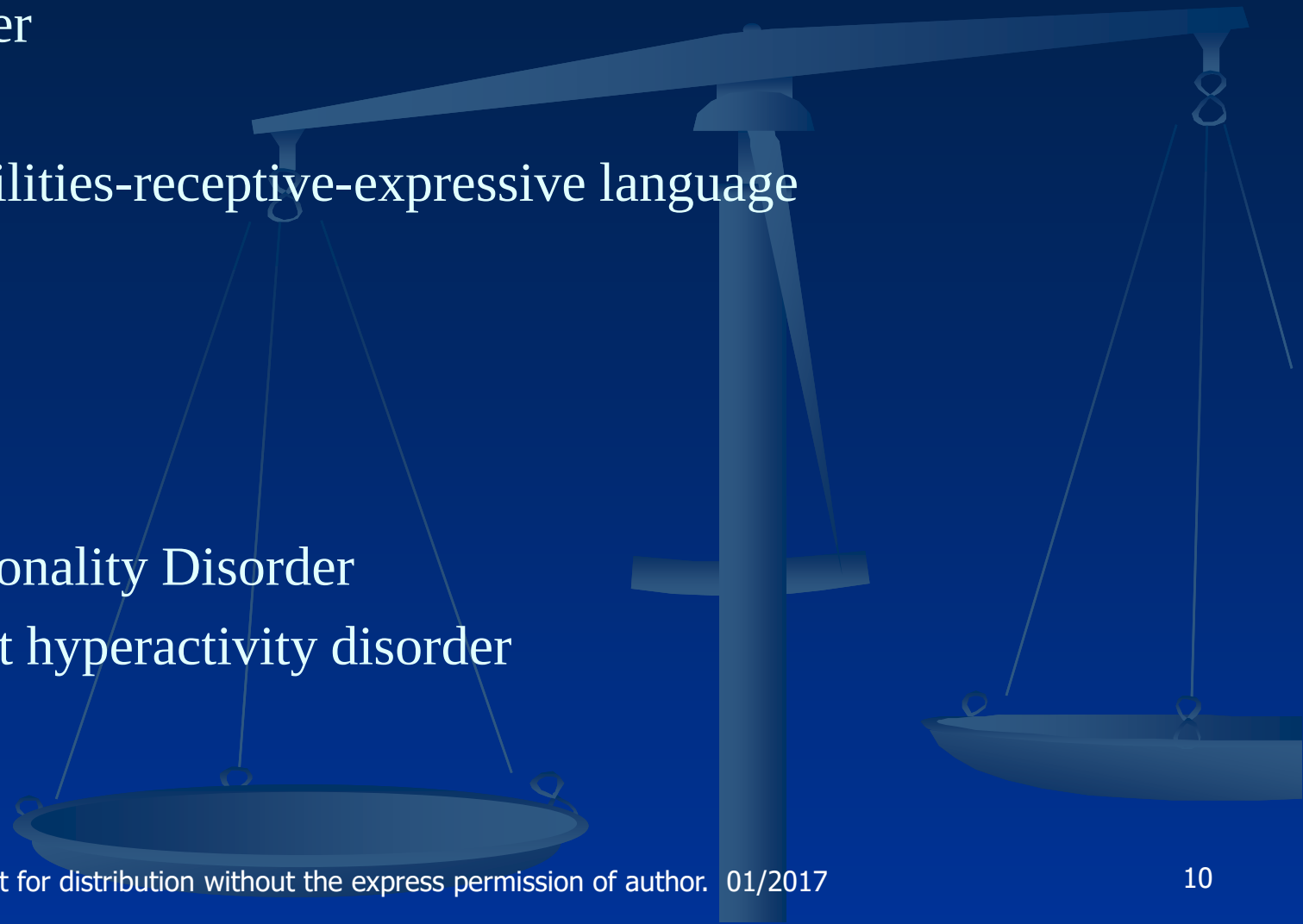
1. developmental delay
2. abuse and neglect
3. exposure to trauma
4. disrupted attachment experiences
5. parental loss
6. hospitalizations, institutionalization and frequent foster care placements.

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.



B. These children are often diagnosed with the following:

1. Reactive attachment disorder
2. Conduct disorder
3. PTSD
4. Learning Disabilities-receptive-expressive language disorder
5. Depression
6. Anxiety
7. Mood Disorder
8. Borderline Personality Disorder
9. Attention deficit hyperactivity disorder



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.

Neurocognitive, Neurodevelopmental and Neurobehavioral Signs of FASD

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.

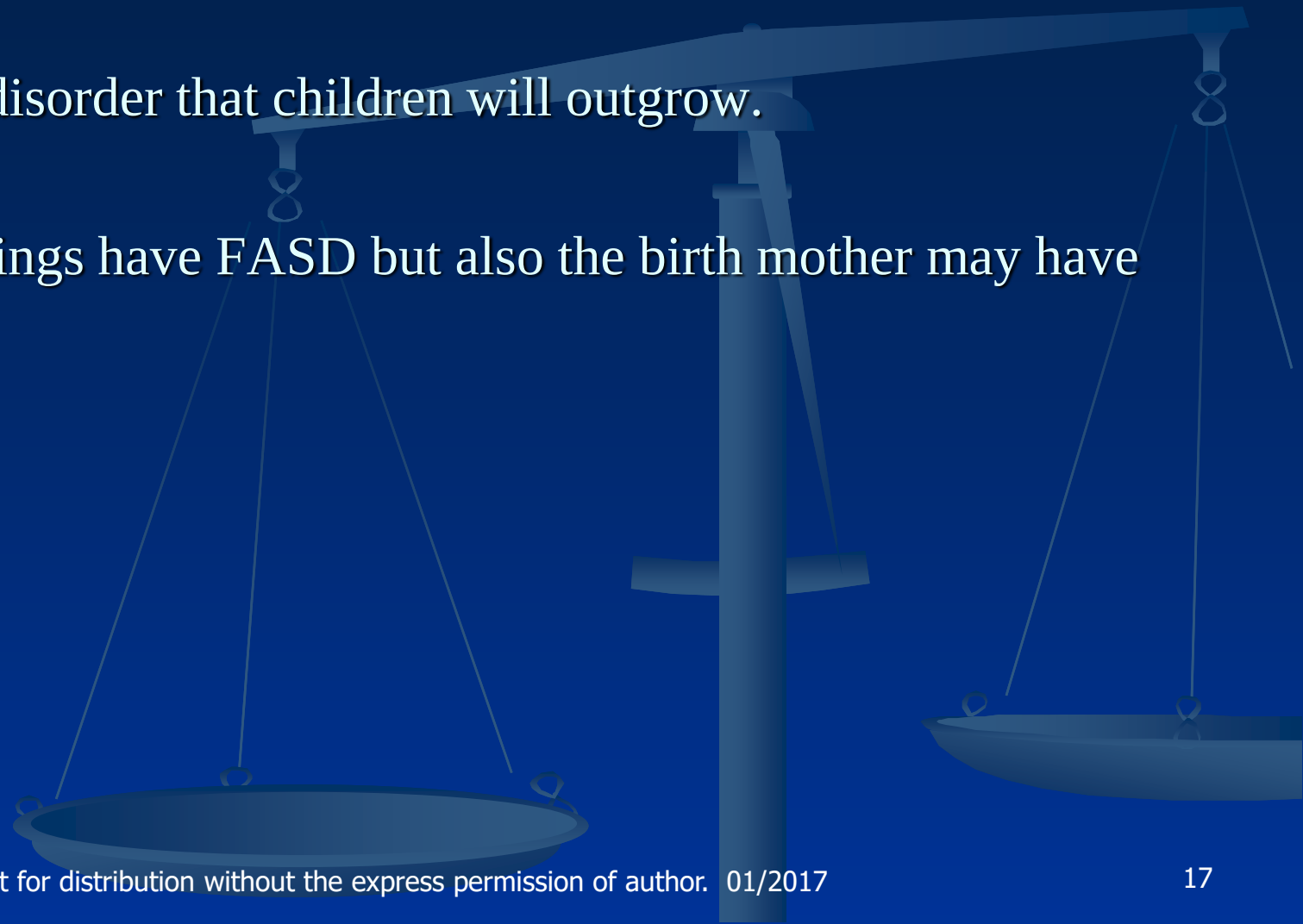
IQ vs ABS, Cont.

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.

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.



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.

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, 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.

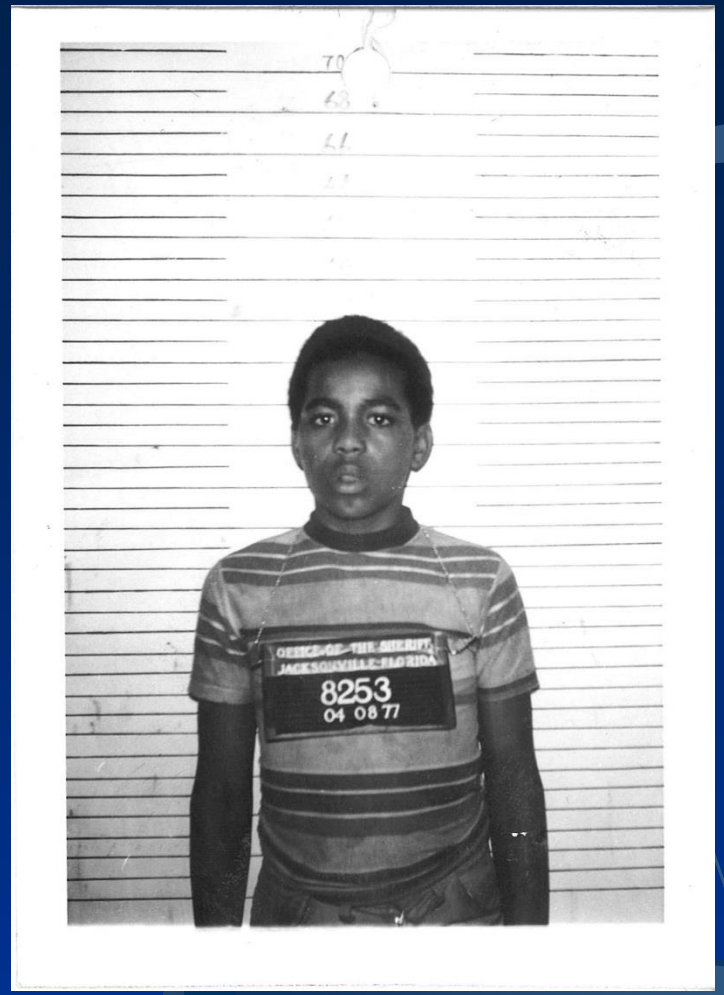
Looking at the Common Secondary Disabilities of Children with FASD

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.

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.

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. 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.

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, Cont.

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.

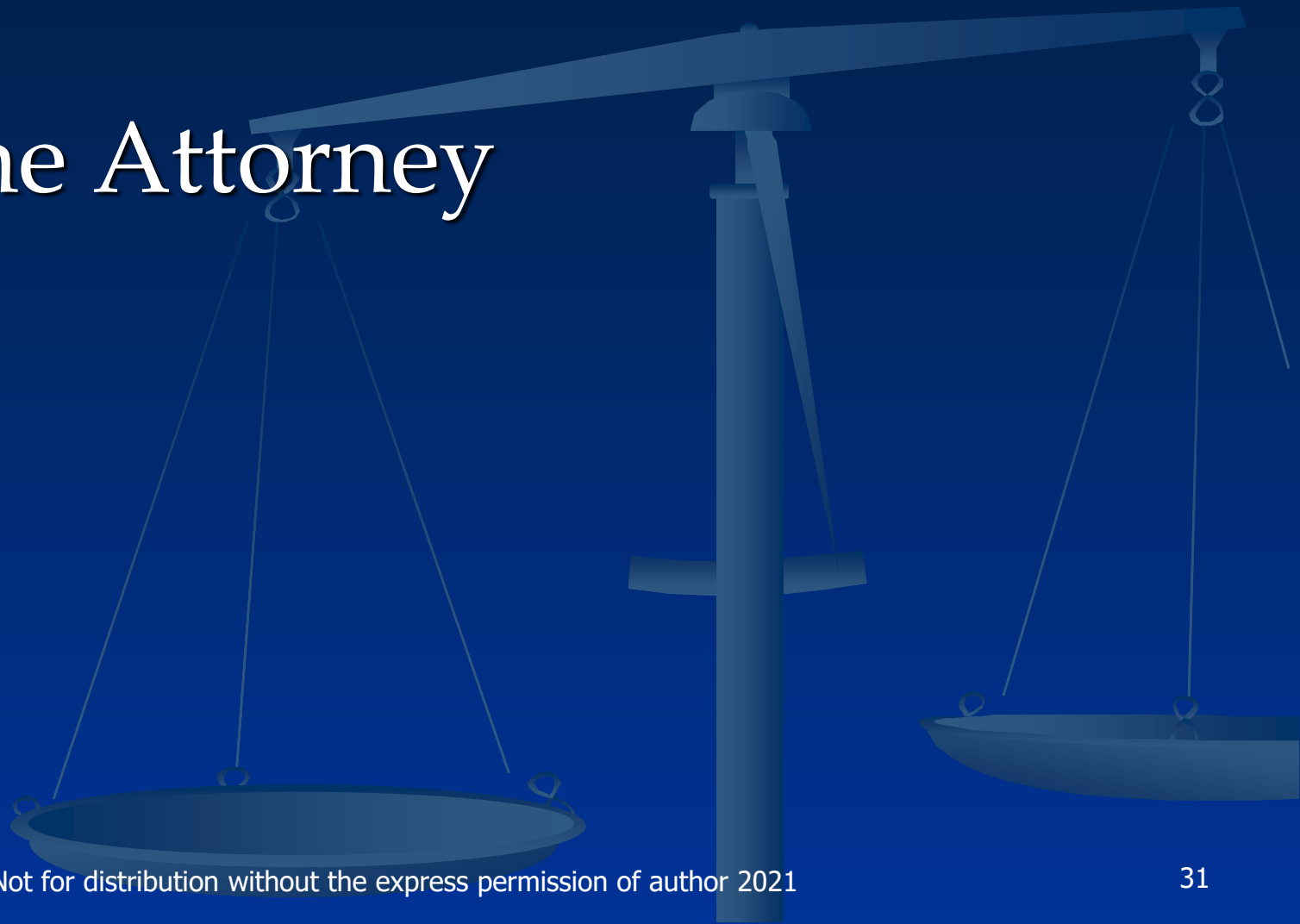
Signs of FASD Adolescence

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

The Attorney



ABA's Resolution

A. In 2012, I worked with the American Bar Association on 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. It also discussed why FASD is a mitigating factor in capital cases.

B. The ABA encouraged training to enhance awareness of FASD and its impact in the child welfare and the juvenile justice systems.

Attorneys Role

A. As an attorney you can take action to change the life of the birth mother and the child prenatally exposed.

B. All attorneys must first raise the question of whether 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. And remember its not the mother that causes the brain damage it's the alcohol.

Attorneys Role

C. All attorneys should recognize 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:

1. 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.**

Questions to Keep in Mind

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 Attorneys 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 Attorneys 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 Attorneys 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 Attorneys 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 Attorneys Actions: Intervention

E. KEEP IN MIND THAT CHILDREN WITH FASD carry a very high burden of care. The structure and care they must have does 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.