



FASD IS A DEVELOPMENTAL DISABILITY

William J. Edwards, Deputy Public Defender

Office Of The Public Defender

Los Angeles County, California

FASD IS A DEVELOPMENTAL DISABILITY

- Children born with “prenatal alcohol exposure” are born with a “developmental disability”.
- Prenatal Alcohol Exposure (PAE) is considered to be the leading cause of developmental disabilities. It is Really Common.
- Most cases are undiagnosed.

IQ DOESN'T MATTER, ADAPTIVE SKILLS DOES

- IQ can be very misleading. The focuses should be on “adaptive behavior.” This is important since most people with FASD/PAE have higher IQ’s (many above 70 and as high as 98) but they will have very low **adaptive behavior skills**. (Edwards and Greenspan, Adaptive Behavior and FASD, *Journal of Psychiatry and Law*, (2011), 39 (4): 419-447).
- 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.

WHY SHOULD I CARE IF I CARE IF I HAVE A DIAGNOSIS OF FASD!?

- FASD are not disorders that children will outgrow in adulthood.
- In fact, FASD gets worse over time.
- Diagnosis makes a difference.
- Treatment matters but more importantly services at an early age can really make a difference.

DIAGNOSIS & SERVICES MAXIMIZE SUCCESS

- Once a diagnosis is made family members, social workers, teachers and advocates can customize developmental approaches and goals to ensure that the individual reaches his or her goals by having the right supportive services.
- A diagnosis helps everyone understand behaviors that would otherwise be incomprehensible. FASD is not an excuse but rather IT is an explanation for the behavior.
- A valid diagnosis provides visibility! Remember place more emphasis on the impairment than the behavior.



QUALIFYING AS A DEVELOPMENTAL DISABILITY: THE NEED FOR SERVICES

NEED FOR SERVICES IS BASED ON LEVEL OF FUNCTIONING

- Access to services for people with FASD should be based on the level of the disability rather than the IQ.
- Many people with prenatal alcohol exposure (PAE) but without a diagnosis of FAS are likely to be in equal need of services, but they may be less likely to receive them.

FASD IS EQUIVALENT TO INTELLECTUAL DISABILITY

- As mentioned before, many people with FASD/PAE will have IQ's that do not fall within the range of intellectual disabilities BUT nonetheless exhibit significant impairments in the area of executive functioning and adaptive behavior.
- 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 FASD is equivalent to having an intellectual disability.

FASD NEED FOR ACCOMMODATIONS EQUIVALENT TO IDD

- People with FASD, in spite of having average IQ's in the 80's, almost universally function adaptively as if their IQ's were in the 60's or 70's.
- The issue of equivalence refers to accommodations that are made by governmental or quasi-governmental agencies (State Disability Agencies like the ARC) when they provide services, supports or protective arrangements to people who-because of brain impairment-function as if they have IDD but fail to qualify for IDD label because their IQ SCORES are above the arbitrary (minus 2 SD) cut off that typically is relied upon for access to IDD entitlements.

ADAPTIVE BEHAVIORAL SCALES LIMITATIONS

- Adaptive behavior instruments focus too much on “daily living” and NOT enough on JUDGEMENT.
- Especially judgment in dealing with other people. Issues of suggestibility and gullibility need to be taken into consideration when it comes to people with FASD.

PROBLEMS & SOLUTIONS

- TWO MAJOR PROBLEMS with existing measures of “adaptive behavior” for diagnosing FASD:
 - There is no mention of risk-awareness or risk-vulnerability (suggestibility).
 - The items or subscales scores do not translate directly into need for supportive services. For example does adaptive testing reveal that a person’s history of behavioral mistakes reflects a cognitively based unawareness of risk rather than a character-based lack of acceptance of social norms?
- Fetal Alcohol Behavioral Scale (FABS) should be utilized to evaluate the client’s adaptive behavior.



THE SERVICES NEEDED

Types of supported services children and adults with FASD will need to live in the community.

CHILDREN

- Special education services - make sure the IEP mentions FASD.
- Social skills training to increase their awareness of appropriate peer relationships.
- Adaptive behavioral training.
- Social skills training-Children Friendship Training (addresses the social, cognitive and behavioral impairments).

MAXIMIZING INDEPENDENCE FOR ADULTS

- Life skills and vocational skills(supported employment settings) to increase their ability to negotiate the tasks required to work in the community.
- Independent living skills.
- Safety training (gullibility and suggestibility).
- Training for finances (money management) since all people with FASD have poor math skills.

SAFETY NET FOR ADULTS

- Services including supported independent living arrangements with monitoring to ensure that the client is able to maintain appropriate functioning.
- Behavioral modification services to minimize the impact of behavioral and emotional disturbances.
- Transportation services.

PROFESSIONAL ASSISTANCE FOR ADULTS

- Coordinated management services (case manager) to ensure that the client is receiving appropriate and integrated services.
- Medical and psychiatric care.
- Case management for mental health issues. Studies show that as many as 80% of people with FASD have mental health problems including suicide attempts.
- Alcohol and drug treatment.
- Conservatorship or guardianship.