

**DETERMINING THE SEVERITY LEVEL OF FETAL ALCOHOL SPECTRUM DISORDERS (FASD): FROM FOSTER CARE TO INMATES ON DEATH ROW**

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ALABAMA DISABILITIES ADVOCACY PROGRAM (ADAP)

(The Protection and Advocacy System for the State of Alabama)

OFFICE OF THE PUBLIC DEFENDER, 15th Judicial Circuit ( Montgomery, Alabama)

ALABAMA COUNCIL ON DEVELOPMENTAL DISABILITIES (Montgomery, Alabama)

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City of BIRMINGHAM, DIVISION OF SOCIAL JUSTICE AND RACIAL EQUITY

FAMILIES RISING-NORTH AMERICAN COUNCIL ON ADOPTIVE CHILDREN

OFFICE OF THE PUBLIC DEFENDER, SHELBY COUNTY ALABAMA

CASA of Jefferson County

**Date: July 26, 2024, in Birmingham. Alabama**

Time: 12:30 to 2:30 p.m.

Lunch will be provided to those in attend in person and the event will be streamed virtually for those that cannot attend in person.

**LOCATION: Office of the Public Defender, 950 22<sup>nd</sup> Street, N.  
Birmingham, Alabama 35203**

The following speakers will be presenting:

**Dr. Kenneth Jones, M.D.** University of California at San Diego UCSD  
Dr. Jones Discovered FASD in 1973 in Seattle and is considered the father of FASD.  
Dr. Kenneth Jones testified in the Parkland shooter death penalty trial in Florida.

**Dr. Larry Burd, Ph.D.** Professor Department of Pediatrics and Director of the FASD Clinic at the University of North Dakota, Grand Forks, North Dakota. Dr Burd has published over 240 papers on FASD and Children's Mental Health

**William J. Edwards**, Deputy Public Defender, Los Angeles County Public Defender  
Los Angeles County Mental Health Court  
Advisory Counsel, FASD United, Washington, D.C.  
Mr. William Edwards has been representing clients with FASD for 26 years.

Alabama Disabilities Advocacy Program  
The Protection and Advocacy System for the State of Alabama

**William "Bill" van der Pol**, is a Senior Trial Counsel with ADAP and **Jenny Ryan**, a Senior Lawyer with ADAP and Director of the Children's Clinic at the University of Alabama Law School.

**Dr. Laura McGuinn, M.D**, University of UAB Department of Pediatrics

#### INTRODUCTIONS

Adam Danneman -PUBLIC DEFENDER, Jefferson County  
FEDERAL PUBLIC DEFENDER, Kevin Butler  
Alabama Criminal Defense Lawyers Association, President Justin Forrester  
TOM DONALDSON, FASD UNITED

**Alabama has 58,054 births per year. In 2021, 2,902 new cases of FASD were born in Alabama (55 cases per week or one new case every 3 hours). In the birth through 18 years of age population Alabama has 52,248 children with FASD. We estimate that nearly all are undiagnosed. ( Research by Dr. Larry Burd, 2024)**

FASD is a severe developmental disability that begins at birth. Most children with FASD go through life never being diagnosed. Many of these children are in the foster care system and are not diagnosed with FASD, and as a result do not get diagnosis-informed care. As a result, they often have multiple foster placements and high rates of exposure to adverse childhood experiences (ACE). These lead to secondary disabilities that are largely preventable.

Children with FASD have multiple developmental disabilities and increased rates of mental health disorders (ADHD, intellectual disability, sleep disorders, anxiety, and learning disorders). Reducing the effects of adversity on children's healthy development is essential to the progress and prosperity of any society. Science tells us that some children develop **resilience**, or the ability to overcome serious hardship, while others do not. Understanding why some children with FASD do well despite exposure to adversity is crucial because it can lead to improved interventions. Current prevalence rates suggest that 1-5% of school aged children (1 of every 20) meet diagnostic criteria for FASD. Improving services for

these children and their families is important. In FASD, protective experiences and coping skills on one side counterbalance exposure to adversity on the other.

Resilience is evident when a child's health and development tips toward positive outcomes — even when substantial adversity is stacked on the negative outcome side. Nearly three quarters of all youth with FASD have experienced physical trauma, emotional abuse, sexual abuse, bullying, and many have PTSD.

Access to services for people with FASD should be based on the level of “severity of the disability” rather than the **IQ**. Having an appropriate diagnosis does make all the difference. Treatment matters but more importantly services at an early age can really make a difference.

Because **FASD** is largely an invisible disability (i.e., no outward physical signs), society may not understand that **it** is a lifelong severe developmental disability, which negatively impacts these individuals from birth throughout their entire life span. One of the barriers to getting a proper diagnosis and getting services for the child is the stigma attached to FASD.

Stigma leads to a lack of diagnosis of FASD from many pediatric doctors because they often do not want to ask the mother if she drank during pregnancy. Stigma of a pediatric doctor diagnosing a child with FASD because of the embarrassment of accusing the mother of drinking!

Many pediatric doctors are not trained to diagnose and instead will label these children with ADHD or learning disabled. This then leads to a lack of proper services for these children! Stigma affects the lack of early diagnosis!

Most attorneys have had little or no training to learn about FASD! This training will explore why FASD is a mitigating factor in all cases and why FASD needs to be identified and explored so that these clients get the services they need.

The training will be applicable to foster care attorneys, juvenile justice attorneys, state and federal public defenders, disability rights attorneys, social workers, legal aid attorneys and pro-bono attorneys handling capital cases at the trial level and appeal level.

The training will discuss:

- Look for FASD (learn about screening)
- Address the stigma that is attached to obtaining the maternal alcohol history from the birth mother.
- Improve recognition and treatment (learn how to obtain a proper diagnosis)
- Improve outcomes (early screening, diagnosis, disability services, special education services and mental health treatment)
- What types of experts to use to have your client evaluated?

- Why FASD is a mitigating factor in all criminal cases including the death penalty.
- Identifying why FASD is a severe developmental disability and why FASD is equivalent to having an intellectual disability.
- Learn why IQ is misleading. Adaptive behavior is the key component.
- Learn why people with FASD have very low adaptive behavioral skills!
- How to educate a jury about FASD