

# Fetal Alcohol Spectrum Disorders (FASD): How Judges Can Improve Outcomes for Affected Children and Parents

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**Summary:** The authors provide extensive background on FASD and its prevalence among court-involved children and their parents, and introduce a draft of the FASD judicial bench cards.

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The adverse effects of alcohol on the developing fetus have been documented for centuries (Sullivan, 1899, Jones & Smith, 1973). Despite this, 53% of women in the United States in their childbearing years used alcohol in 2006, and 12.5% of pregnant women reported frequent alcohol use in 2001 (Floyd et al., 2008; Floyd & Sidhu, 2004); 4.6% reported still drinking in their third trimester (Floyd & Sidhu, 2004). In the United States, these rates translate to 500,000 pregnant women drinking at least weekly and about 80,000 drinking at very high levels. The cumulative number of infants, children and adolescents with prenatal alcohol exposure in the United States is likely in the millions.

Adverse outcomes from prenatal alcohol exposure result from the interaction of several variables including: dose and timing of the alcohol exposure during prenatal development, other prenatal exposures such as smoking, poor diet, other drug use and genetic risks. One message is clear: *there is no known safe amount of alcohol women can drink during pregnancy.*

Children who are exposed to alcohol prenatally are at risk for fetal alcohol spectrum disorders (FASD). FASD comprises four diagnostic categories: fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol related neurodevelopmental disorder and alcohol-related birth defects (Stratton, Howe, Battaglia, & Institute of Medicine, 1996). These diagnostic categories cover a range of lifelong alcohol-related damage including: birth defects; central nervous system or brain damage; cognitive abnormalities; behavioral abnormalities; neurodevelopmental abnormalities; growth impairment; facial abnormalities; and vision or hearing abnormalities (Herrick, Hudson, Burd, 2011). Outcomes from exposure change over time in response to age and development.

Infants and toddlers with FASD may have difficulty feeding; experience delays in walking, talking and toilet training; suffer from frequent sleep disturbances; become easily distracted; be sensitive to sound and light; and be incredibly irritable. Older children with FASD may display other behavioral problems (Herrick et al., 2011). Adolescents with FASD experience many of the same symptoms as older children, and are at increased risk for substance abuse and involvement with the corrections system (Streissguth, Barr, Koga, & Bookstein, 1996). At all ages, children affected by FASD have difficulty with impulse control and behave in ways more consistent with children much younger than their chronological age.

If an accurate diagnosis is not made, children with FASD are at risk for acquiring secondary disabilities related to incorrect diagnoses and treatment strategies. Developmentally appropriate interventions and supports are critical in managing this lifelong impairment. An important component of services is risk reduction. By decreasing the affected child's exposure to stressors (e.g., neglect, abuse, malnutrition, stressful life circumstances) it may be possible to prevent—or at least ameliorate—the catastrophic outcomes of misdiagnosis.

Because children in foster care are at increased risk for FASD, judges are in the unique position to act on behalf of affected children. First, judges can require routine screening for prenatal alcohol use. A bench card is provided here with questions that will help a judge ascertain the mother's drinking history. If the screen determines that prenatal alcohol exposure did occur, the judge can order an FASD assessment for the child, which can be discussed at subsequent hearings. Once diagnosis is made, the judge may order developmentally appropriate services with an emphasis on risk reduction to prevent substance abuse and school failure. Siblings of children with a diagnosis of FASD should be routinely referred for FASD assessments.

Children with an FASD diagnosis require extremely predictable family interactions and routines. This makes safe, stable and loving homes tremendously important if they are going to thrive. Case plans should focus on reducing the number of placements, and making sure that any caregivers have adequate training and community resources to meet the needs of an FASD-affected child for the long term. If reunification is the ultimate goal, frequent visitation allows parents to become accustomed to the child's needs and routine, and allows the child the opportunity to become accustomed to parent-child interactions.

Finally, due to the intergenerational nature of FASD, judges should consider that the parents of an FASD-affected child may need to be screened for FASD. Adults with FASD may have multiple cognitive impairments that are likely to complicate completion of substance abuse treatment and meeting other court ordered requirements for parents working toward reunification. Table 1 lists some of these impairments and compensatory strategies. As a result, judges must tailor the adult's case plan to ensure inclusion of developmentally appropriate treatment and intervention strategies for these services. Table 2 provides an overview of training needs identified by corrections facilities that serve people with an FASD.

Two bench cards have been drafted to help promote these considerations in court. They will be reviewed by the NCJFCJ Permanency Planning for Children Department Advisory Committee.

#### **Author biographies:**

**Dr. Larry Burd** is a professor in the Department of Pediatrics at the University of North Dakota School of Medicine and Director of the North Dakota Fetal Alcohol Syndrome Center and FAS Clinic. Dr. Burd has been with the Pediatric Therapy Program for 31 years, where he has evaluated over 15,000 children with birth defects, developmental disorders and mental illness. He has ongoing longitudinal studies of linked cohorts of subjects with Tourette syndrome, autism, fetal alcohol syndrome and infant mortality risk that are in their 26<sup>th</sup> year of data collection. He published over 130 professional papers on topics dealing with development and behavior in children and adolescents. Dr. Burd is a consultant for the ZERO TO THREE Safe Babies Court Team Project.

**Katrine Herrick** joined ZERO TO THREE in October 2010 as the Court Teams Project coordinator. She provides oversight and management of the Court Teams database by ensuring consistent, thorough, and accurate data entry, and contributing to data analysis. She also develops written products, serves as liaison with the ZERO TO THREE Policy Center, and manages the submission of progress reports. She completed a three month internship with the Court Teams Project in August 2010. She researched and reviewed resources on fetal alcohol spectrum disorders (FASD) and the relationship to the work of the Court Teams Project. She holds her MA in child and family policy from Tufts University.

**Juvenile Court Judge Peggy H. Walker** serves on the Executive Committee of the [National Council of Juvenile and Family Court Judges](#) (NCJFCJ). Spanning the next five years, Judge Walker will serve as NCJFCJ secretary, treasurer, president-elect, president and immediate past-president, respectively. Her election continues a notable history of Georgia juvenile court judges chosen to join the NCJFCJ's Executive Committee.

Since 1998, Judge Walker has served as juvenile court judge in Douglas County, GA, and a member of NCJFCJ's board of trustees since 2005. She has also served as president of the Council of Juvenile Court Judges, chair of the Georgia Commission on Family Violence and as a board member for the Georgia Court Appointed Special Advocates.

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Judicial Bench Card			
Fetal	Alcohol	Spectrum	Disorders

### Adverse outcomes from alcohol use during pregnancy

In the United States about 50% of pregnancies have some alcohol exposure. In most cases women find out they are pregnant and quit drinking. However, around 12% of women drink during pregnancy and 4-5% drink throughout pregnancy. Most of these women also smoke and many have other problematic life circumstances (other substance abuse, smoking, poor diet, late or no prenatal care).

The United States has about 40,000 new cases of fetal alcohol spectrum disorders (FASD) each year. For most affected people the primary problem from prenatal alcohol exposure is brain damage/dysfunction. For most people this will result in lifelong impairments which will change in response to age and development.

### Fetal Alcohol Spectrum Disorders Comprised of four diagnostic categories

#### Fetal Alcohol Syndrome (FAS)

- Growth Impairments (height and weight < 3d)
- Abnormal Facial Features (2+)
- Brain Damage/Dysfunction
- Thought to result from prenatal alcohol exposure

#### Alcohol Related Birth Defects (ARBD)

- Birth defects thought to be due to prenatal alcohol exposure.
- Not commonly diagnosed
- Prevalence is as yet unknown

#### Partial Fetal Alcohol Syndrome (pFAS)

- Missing one or two key findings
- Prenatal Alcohol Exposure

#### Alcohol Related Neurodevelopmental Disorder (ARND)

- The primary features are brain damage /dysfunction (developmental delays, mental illness or cognitive impairments) thought to result from prenatal alcohol exposure.
- Most common FASD
- Often undiagnosed
- Changes across the lifespan

Judicial officers often see people with prenatal alcohol exposure and FASD should be a frequent consideration.

## **Mortality**

People with FASD have increased mortality rates. Mortality risk is also increased for siblings (even if they do not have a diagnosis of FASD). Mortality rates are also increased for mothers of cases and siblings.

Miscarriage, stillbirth, sudden infant death syndrome (SIDS), birth defects, infectious illness other causes.

## **Prevalence**

1% live births  
Highly recurrent in families  
Some families FASD is generational  
Most affected people are undiagnosed

## **Cost of Care**

US lifetime cost is \$2.5 million per person  
Service systems most impacted are health care, foster care, education/special education, developmental disabilities, mental health systems, corrections systems and substance abuse systems.  
Annual cost in US \$3.4 billion.

## **Outcomes**

Manifestation of FASD changes over lifespan.  
A two year old is at low risk for a substance abuse disorder, but adolescents are at very high risk.  
Low rates of independent living  
In Canada a juvenile with FASD is 14 times more likely to be in Corrections System than unaffected peer.

**Every day in the United States we have 120 new cases. FASD has an exceptional recurrence rate and younger siblings tend to be the most severely affected. Diagnosis matters and appropriate services improve outcomes.**

## **Actions from the Bench**

### Systems-Level Actions

- Make prenatal alcohol exposure (PAE) screening\* a regular component of child welfare cases.
- Assess the community's diagnostic capacity.
- Assess interventions and treatment facilities for facilities that have appropriate training on, and services for, FASD.
- Train systems of care personnel on FASD and work to expand the community's capacity to screen, diagnose and provide interventions for affected persons.

### Case-Level Actions

- Screen all children for PAE.
- Refer children with PAE for FASD assessments.
- If positive, refer child for developmentally appropriate and proactive treatment. Follow up on service utilization in subsequent hearings.
- If positive, screen siblings and parents.
- Pick placements carefully. Placements should be safe, stable and loving homes with caregivers willing to adopt if reunification fails.
- Tailor affected parent's case plans to meet their developmental needs.

\*To learn more about prenatal alcohol exposure (PAE), please see the PAE Judicial Bench Card.

# Judicial Bench Card

Prenatal	Alcohol	Exposure

## Prevalence of Alcohol Use

- Non-pregnant women during child bearing years: 54%
- Month before pregnancy: 50%
- Pregnant women: 12% (1 in 8)
- Third trimester of pregnancy: 4.6%

## Rates of Prenatal Alcohol Exposure (PAE)

- Children of women in Substance abuse treatment: near 100%
- Children of women in prison: 80%
- Children in foster care: 70-80%
- Increased in women with other drug use

## Drinking and Pregnancy

In the majority of cases, drinking primarily occurs on weekends, but for women with alcohol use disorders drinking may occur on most days.

Alcohol rapidly crosses from the mother to fetus. Increasing maternal blood alcohol can be detected in fetus in 1 minute. Maternal-fetal ethanol concentrations reach equilibrium in about two hours after women quit drinking.

Alcohol elimination from the fetus and amniotic fluid relies on mother's alcohol metabolism. The alcohol elimination capacity of the fetus is 5% of the mother's capacity. Promptly after birth, alcohol elimination rates reach 83.5% of maternal elimination rate.

## Variation in Blood Alcohol Concentration (BAC)

BAC varies from person to person. For example, BAC varies by about 4 fold for women of the same weight consuming the same amount of ethanol.

## PAE is an important marker for increased risk of postnatal environmental adversity

PAE is associated with increased rates of environmental adversity including other substance abuse, smoking, neglect, abuse, malnutrition, stressful life circumstances and mortality. These often persist throughout infancy and childhood. PAE should also be considered in risk stratification for alcohol exposure in both previous and future pregnancies.

## Screening for PAE\*

When was your last drink?

Before	PREGNANCY	
	Pre-awareness	Post-awareness
Unexposed	Exposed	Exposed & High Risk

Other useful screens; TACE, TWEAK, AUDIT or AUDIT-C.

## What we might want to know about drinking during pregnancy

### SCREENING FOR ALCOHOL ABUSE ASSESSMENT OF EXPOSURE DURING PREGNANCY

On average how many days per week did you drink during pregnancy? \_\_\_\_ (a)

On an average drinking day during pregnancy how many drinks did you have? \_\_\_\_ (b)

How many days per month did you have 4 or more drinks during pregnancy? \_\_\_\_ (c)

What is the most you had to drink on any one day during pregnancy \_\_\_\_ (d)

### EXPOSURE PARAMETERS (Cumulative exposure during pregnancy)

**Pregnancy Drinking Days =** (a x 40) = \_\_\_\_ (e)  
Estimates number of drinking days during pregnancy

**Percent of Days Exposed During Pregnancy**  
Estimates days exposed during pregnancy = (e ÷ 280) = \_\_\_\_

**Number of Binge Days (4 or more drinks in one day) =** (c x 9) = \_\_\_\_  
Estimated number of binge days

**Number of Drinks During Pregnancy =** (a x b x 40) = \_\_\_\_ (f)  
Estimates cumulative number of drinks during pregnancy.

**Ounces of absolute alcohol =** (f ÷ 2) = \_\_\_\_  
Estimates cumulative absolute alcohol exposure during pregnancy.

**Effective intervention NOW reduces risk for alcohol exposure in subsequent pregnancies**

### Getting Services for Mothers

- Ask “when was your last drink?”
- Ask if she has been in treatment previously. Should she return to the same program or does she need a different treatment provider?
- Determine if she may have an FASD. If yes, what modifications does she need to improve her response to treatment?
- Ask “what is the success rate of the treatment program for similar women?”
- Ask if planning to create a substance use free environment needs to start now. Who will participate and when will they report back to the court?

\*If the screening reveals a child was prenatally exposed to alcohol, see the Judicial Bench card on FASD for more next steps.

**Table 1. Important issues in formulating and implementing treatment programs for people with FASD:**

- ✓ *Consider the duration*—treatment or interventions need to last longer
- ✓ *Make it concrete*—picture guides are helpful for teaching key concepts
- ✓ *Work in small groups*— allow more attention to topical material
- ✓ *Minimize anxiety, which increases impairment*—especially important in treatment of substance abuse, sexual abuse or PTSD
- ✓ *Address one problem at a time*—allow participants to learn and apply solution before moving on to next topic
- ✓ *Understand impairments*—some problems cannot be treated and we need to learn how to adapt to them and minimize their effects
- ✓ *Planning for aftercare is essential*—improves generalization of learned behaviors
- ✓ *Provide short directions*—an essential key for successful interventions
- ✓ *Address mental health concerns*—need appropriate treatment

<b>Table 2. FASD Corrections System Training Recommendations:</b>		
Who	When	Content/Format
All Staff	At orientation	Overview of FASD
	Biannual in-service training	Anticipated prevalence in corrections  Prevalence of cognitive and mental health impairments  Effects of schedule and structure
Medical Staff	Pre-service In-service Biannually after initial training	Expected prevalence of FASD

<p>Substance Abuse Staff</p> <p>Disciplinary Staff</p> <p>Parole Planning Staff</p> <p>Educational Staff</p>		<p>Screening strategies</p> <p>Diagnosis—referral services</p> <p>Comorbidity</p> <p>Benefits of routine and schedule</p> <p>Potential for abuse</p> <p>Exploitation</p> <p>Medical/behavioral needs</p>
<p>System changes</p> <p>Monitor staff awareness and competency</p>	<p>Within 2 years</p>	<p>Complete above</p>
<p>Strategies for screening and identification of FASD</p>	<p>Within 3 months of incarceration</p>	<p>Screening strategy</p>
<p>Assessment—Resources</p>	<p>Within 3 months of positive screen or referral</p>	<p>Identify referral source</p>
<p>Planning and Intervention</p>	<p>Within 3 months of completed assessment</p>	<p>Track progress</p> <p>Need to maintain services across placements</p>
<p>Ensure substance abuse treatment and mental health staff have competency and adequate time to implement program goals</p>	<p>Within 3 months of hiring and biannually</p>	<p>Modifications in treatment strategies and content for people FASD</p>