



FETAL ALCOHOL SPECTRUM DISORDERS

Implications for Juvenile and Family Court Judges



NATIONAL COUNCIL OF
JUVENILE AND FAMILY COURT JUDGES

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The Office of Juvenile Justice and Delinquency Prevention (OJJDP) provides national leadership, coordination, and resources to prevent and respond to juvenile delinquency and victimization. OJJDP supports states and communities in their efforts to develop and implement effective and coordinated prevention and intervention programs and to improve the juvenile justice system so that it protects public safety, holds offenders accountable, and provides treatment and rehabilitative services tailored to the needs of juveniles and their families.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is one of the 27 institutes and centers that comprise the National Institutes of Health (NIH). NIAAA supports and conducts research on the impact of alcohol use on human health and well-being. NIAAA promotes and advances new research on fetal alcohol spectrum disorders (FASD). In addition, NIAAA sponsors and leads the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD) which is chaired by the Deputy Director of NIAAA, Kenneth R. Warren, Ph.D. ICCFASD stimulates communication, coordination, and collaboration of FASD-related activities among federal agencies that seek to solve the challenges posed by FASD. In addition to the work of official representatives from numerous federal agencies, ICCFASD sponsors several workgroups and sub-committees composed of federal representatives and non-federal

experts. The Justice Issues Work Group – one of four work groups established by the ICCFASD to address special issues and to plan and implement directed activities – is led by Karen J. Bachar, Senior Policy Advisor, Office of Juvenile Justice and Delinquency Prevention, and is also the U.S. Department of Justice representative to the ICCFASD where she coordinates the work of the group with Sally Anderson, PhD, NIAAA, FASD Activities Coordinator, ICCFASD. Under Ms. Bachar's leadership, the work group has prioritized its goals to increase awareness of legal and justice professionals about the challenges they face when individuals with an FASD are involved with the justice system. The overall goal of current activities is to help attorneys and judges increase their understanding of FASD so that they may better serve clients with FASD and their families and better consider a broader range of options when they have, or think they may have, a youth with an FASD in their court.

This publication is the result of a partnership among the NCJFCJ, OJJDP, NIAAA, and the ICCFASD. The NCJFCJ has been honored to partner with experts from these and other organizations to produce this Brief. Karen Bachar, OJJDP, and Dr. Sally Anderson, NIH, provided insightful leadership and expertise. Theresa Bohannon guided this project with her passion for and interest in maternal and child health. Charlotte Ball provided structure and content. Eileen Bisgard, Susan Carlson, and Linda Chezem, members of the ICCFASD Justice Issues Work Group, were instrumental in preparing the Brief for a judicial audience. Finally, thank you to the members of the NCJFCJ FASD Judicial Work Group who met in May 2014 to outline the critical components of the Brief.

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Steps taken by the Canadian and American Bar Associations point to the path ahead for all legal professionals – to increase our knowledge of and response to fetal alcohol spectrum disorders.

Introduction

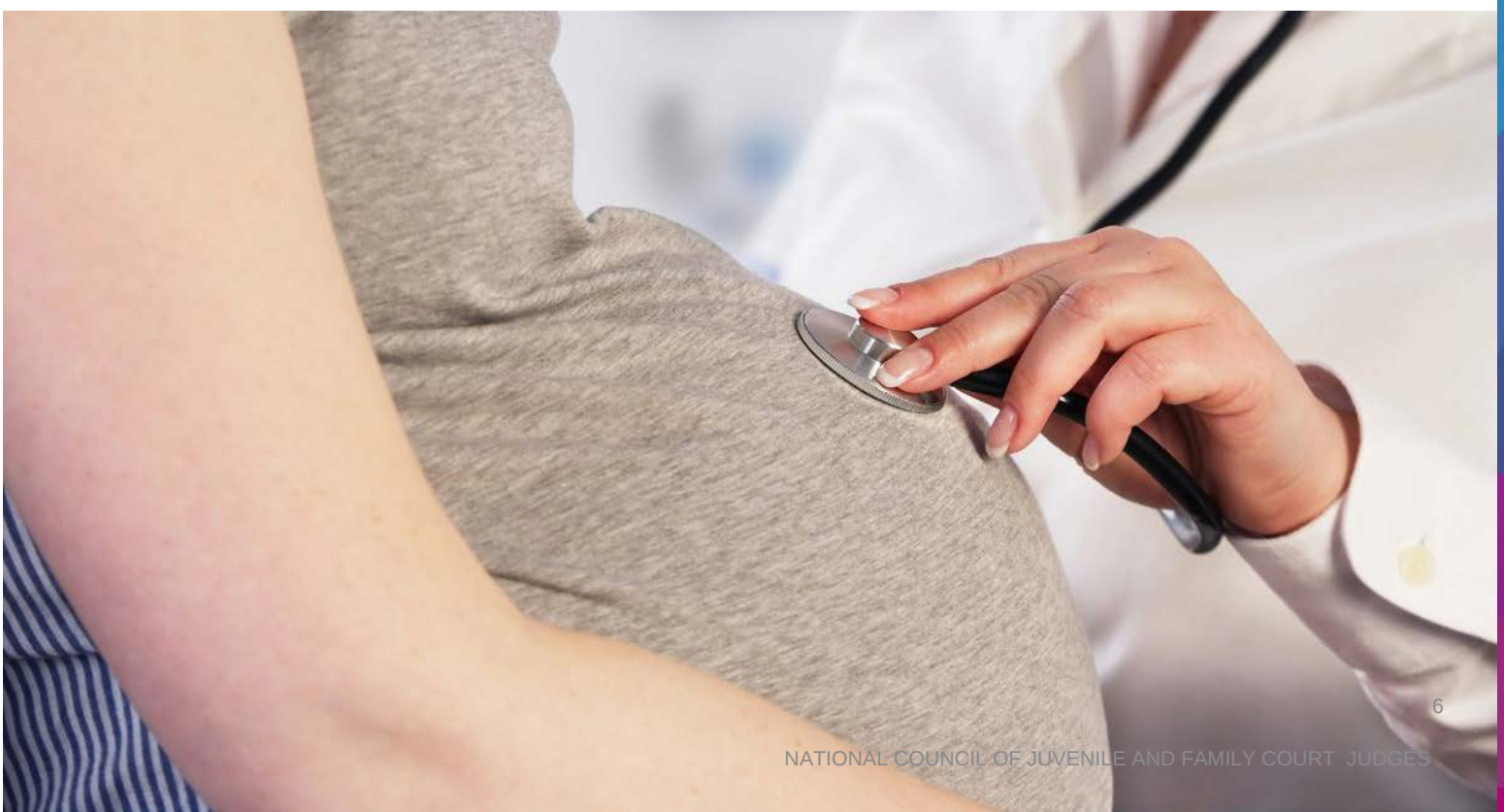
Thirty years ago, Judge Leonard P. Edwards wrote “Juvenile court judges are the gatekeepers for systems which incarcerate society’s children and place society’s children in foster care.”¹ As gatekeepers, juvenile and family court judges make decisions that carry lifelong implications for a child, such as whether a child is ruled delinquent or should be removed from or reunited with a parent. Cases in which a child, a parent, or both may have fetal alcohol spectrum disorders (FASD) are particularly complicated. “FASD” refers to a broad spectrum of disorders caused by maternal alcohol use during pregnancy. The umbrella term, FASD, encompasses several more specific diagnoses. The two features common to all of the medical diagnoses and the new psychiatric diagnosis are prenatal alcohol exposure and brain damage resulting in functional impairments. The majority of people with FASD usually have no physical manifestations of impairments and are frequently undiagnosed or misdiagnosed. For children and adults who become involved in the court system, the permanent brain damage associated with FASD can undermine their ability to understand and participate in judicial proceedings, weigh actions against consequences, and comply with decisions of the court.²

Awareness of FASD in the court has grown and has received increasing attention in the legal community in recent years. The Canadian Bar Association and the American Bar Association have passed resolutions calling for attention to FASD and to the necessary training and resources to address them. Alaska has passed legislation permitting judges to consider FASD as mitigating factors in criminal sentencing.³ These actions point to the path ahead for all legal professionals – to increase our knowledge of and response to FASD. Juvenile and family court judges can take a leadership position in increasing awareness by asking whether FASD are factors that need to be considered in a case and understanding the need for targeted interventions.⁴

In 2013, the National Council of Juvenile and Family Court Judges (NCJFCJ) developed and administered a survey for family and juvenile court judges to gauge their current knowledge about FASD in order to address technical

assistance needs better. The results of this survey highlighted the need for additional training and technical assistance for judicial officers who oversee juvenile dependency and delinquency cases. There did appear to be a general awareness that FASD affect children and families, but how best to handle those cases was unclear for some judges. The results also underscored the desire from judicial officers to understand intervention strategies.

The NCJFCJ created this guide with input from juvenile and family court judges and experts from around the country to increase judicial knowledge of FASD, including their implications for court proceedings and case dispositions involving children and families affected by FASD; increase awareness of available resources and services for children and families affected by FASD; and, provide guidance on judicial leadership. The ultimate goal of the guide is to improve outcomes for children, families, and communities affected by FASD.





Alcohol exposure during pregnancy is a major cause of neurodevelopmental impairments and learning disabilities in the United States and is 100 percent preventable.

Understanding FASD

Fetal alcohol spectrum disorders, or FASD, is a non-diagnostic umbrella term intended to encompass all the diagnostic categories designated by the Institute of Medicine of the National Academies (IOM) along a broad continuum of physical, mental, behavioral, and learning deficits that can result from prenatal alcohol exposure.⁵ The damaging effects of prenatal alcohol exposure (PAE) are found in children born in all socioeconomic classes and in all cultures where alcohol is consumed, and FASD are considered serious health and social problems throughout the world. Alcohol exposure during pregnancy is a major known cause of birth defects, neurodevelopmental impairments, and learning problems in the United States and is 100 percent preventable.⁶ There is no safe time, no safe amount, and no safe type of alcohol during pregnancy.⁷



History of FASD Discovery

In the French medical literature in 1968, Paul Lemoine and colleagues described abnormal facial features, retarded growth, increased frequency of malformations, developmental delays, and behavioral problems in 127 children of alcoholic parents (particularly mothers). Unaware of Lemoine's work, Christy Ulleland and colleagues and David Smith, Kenneth Lyons Jones, and Ann Streissguth in the United States published reports in the early 1970s on what they thought was a previously unknown pattern of developmental problems seen in offspring of "readily recognized chronic" alcoholic mothers. In 1973, Jones and Smith named this condition the fetal alcohol syndrome (FAS).⁸

In 2004, a consensus of governmental, research, and advocacy organizations

accepted FASD as a collective term that supports the existence of a spectrum of diagnostic conditions.⁹ This spectrum includes the more specific medical diagnostic conditions described earlier in the 1996 Institute of Medicine (IOM) report on FAS:¹⁰

- Fetal alcohol syndrome (FAS);
- Partial FAS (pFAS);
- Alcohol-related neurodevelopmental disorder (ARND); and
- Alcohol-related birth defects (ARBD).

In addition to the IOM medical diagnoses, the latest edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) published by the American Psychiatric Association includes the FASD-relevant psychiatric diagnosis: neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE).¹¹

Supporting research on the prevention of maternal drinking during pregnancy, increasing clinicians' ability to identify children with FASD early, both through increased awareness and improved diagnostic methods, and developing more effective interventions to mitigate adverse outcomes of prenatal alcohol exposure are priorities of the National Institute on Alcohol Abuse and Alcoholism (NIAAA).¹²

FASD are worldwide problems that occur wherever alcohol is consumed and affect babies born to mothers of all socioeconomic levels and races/ethnicities.

Estimating the Prevalence of FAS and FASD in the United States

Numerous epidemiological studies funded by the Centers for Disease Control and Prevention (CDC) have used surveillance methods of existing records from several different states and reported estimated FAS prevalence of 0.2 – 1.5 per 1,000 live births.¹³ Recently, CDC funded studies reported estimated FAS prevalence from several states to be 0.3 – 0.8 cases per 1,000 seven- to nine-year-old children.¹⁴ Surveillance methods are passive assessment methods which examine existing records (e.g., birth certificates, birth defects and other registries, hospital discharge records, general medical records, etc.). Although surveillance methods are efficient and cost effective, they must rely on health care providers always assessing whether their patients have the disorder, accurate recognition of the disorder by clinical care providers, and documentation of the disorder in

medical records. Examinations, such as those described above, of existing records usually results in low estimates of FAS.^{15,16}

In order to get more accurate estimates of disease prevalence, health care professionals must be regularly looking for the disorder and be able to identify or test for the disease or for biological indicators of the condition. There are currently no blood tests or other simple tests that identify either FAS or FASD. Expert pediatric dysmorphologists can readily identify FAS in infants, but most family doctors and general pediatricians do not have that expertise. More valid prevalence estimates of FAS and FASD can be made in young school-age children when both FAS and FASD can be more readily identified by trained pediatric health care providers working with experts in measuring functional impairments using neuropsychological testing.

The highest estimates of FAS and FASD prevalence are obtained using active case ascertainment methods when health care providers conduct in-person assessments of all members of a given community. The aggregate or mean prevalence estimates from a variety of several well-selected geographic sites will provide the most valid overall estimate for the United States. The drawbacks to active case ascertainment methods are that they are labor intensive, costly, and very time-consuming. A summary of results from active case ascertainment studies funded by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), a part of National Institutes of Health (NIH), in several different communities has estimated the prevalence of FAS in the United States to be more than two cases per 1,000 first graders and the prevalence of FASD to be at least 20 cases per 1,000 first graders.¹⁷

Key Points

Reliable prevalence estimates are challenging because there are no simple tests to identify FASD.

Accurate diagnoses can only be obtained from qualified medical and mental health professionals.

Most persons with FASD will look normal and not have any physical signs of FASD.

Alcohol Consumption in the United States

Among U.S. adults, 50 percent regularly consume alcohol and another 14 percent are infrequent drinkers.^{18,19} Most U.S. drinkers do not drink alcohol at levels or in patterns considered to be unhealthy. However, a minority of U.S. adults consume unhealthy amounts of alcohol, increasing their risk of mental health issues, social harm, accidental injury, and some of the most common chronic medical diseases in the U.S.²⁰ The majority of persons in the U.S. who drink excessively do not meet diagnostic criteria for alcohol use disorder (AUD) but engage in binge drinking and regular heavy drinking.^{21,22,23} About 30 percent of U.S. adult drinkers engage in binge drinking, usually on multiple occasions each year.^{24,25,26} Binge drinking is defined as a pattern of alcohol consumption that brings the blood alcohol concentration (BAC) level to 0.08 percent or more, which usually corresponds to five or more drinks for men or four or more drinks for women in about two hours.²⁷ The frequency and quantity of alcohol consumption, binge drinking, and more excessive drinking is lower in women than men, but the frequency of binge drinking among both men and women 18-24 years old is very high.^{28,29,30}

Nearly half of pregnancies in the United States are unintended. While most women stop drinking or reduce alcohol consumption after learning that they are pregnant, many women do not recognize that they are pregnant until well into their first trimester.

Alcohol Consumption During Pregnancy

The scientific and medical communities have long been aware of the potential damage to a fetus from prenatal alcohol exposure. The first health advisory warning about drinking during pregnancy appeared in 1977. In 1989, the U. S. Congress began to require warning labels for alcohol to make the public more aware of this risk to unborn children. There is no known safe amount of alcohol use during pregnancy, and the 2005 Surgeon General's Advisory on Alcohol Use in Pregnancy "urged women who are pregnant or who may become pregnant to abstain from alcohol."³¹

And yet, alcohol use during pregnancy remains a known leading cause of preventable birth defects and developmental disabilities and learning problems.³²

In 2013, more than 9 percent of pregnant women admitted drinking in the previous month and more than 2 percent admitted binge drinking in the previous month (four or more drinks per occasion).³³ About 20 percent to 30 percent of women have reported drinking at some time during pregnancy, most typically during the first trimester; and 7 percent to 8 percent have reported binge drinking at some time during pregnancy, most typically during the first trimester.^{34,35,36}

Nearly half of pregnancies in the United States are unintended.³⁷ Most prenatal alcohol exposure takes place during the first trimester of pregnancy, when a woman may not know she is pregnant^{38,39} – even in women intending to become pregnant but who have not stopped drinking alcohol.^{40,41} Many pregnant women stop drinking when they know they are pregnant, others reduce the amount consumed but choose not to abstain completely, and some seem unable to stop all alcohol drinking.^{42,43} Pre-pregnancy binge drinkers are less likely to stop drinking even after pregnancy is recognized, and their pattern of binge drinking remains the same as that prior to pregnancy (on average three times per month and six drinks per occasion).⁴⁴



The likelihood that a woman will drink alcohol during pregnancy is partially dependent on personal circumstances: pre-pregnancy drinking patterns (especially binge or heavier drinking); marital status; whether pregnancy is intended; lack of awareness of FASD; mental health problems; and adverse life events: stress, trauma, interpersonal violence, and social isolation. Environmental factors that influence drinking patterns in both non-pregnant and pregnant women are: excessive drinking by partners, family members and peers; social pressure to drink alcohol; broader social acceptance of binge or heavier drinking; and social acceptance of drinking during pregnancy.^{45,46,47,48}

FASD prevention campaigns are used to target women at high risk who are or may become pregnant. Some campaigns are focused on the individual's capacity for change, some utilize public service announcements (PSAs) to increase public awareness of the risks of alcohol use during pregnancy, and others use clinical practices (e.g., proper screening and education by obstetricians).⁴⁹

Judges and court personnel can utilize information from these campaigns to reiterate prevention messages to women involved in the court system.

Factors Affecting Birth Outcomes Following Prenatal Alcohol Exposure

Not every child who has been exposed to alcohol prenatally will have signs and symptoms of FASD. The primary determinants of alcohol exposure's resulting in clinically relevant damage to the fetus are:

- Quantity – how much a pregnant woman drinks per occasion
- Frequency – how often a pregnant woman drinks
- Timing – in what stage of pregnancy a woman drinks and if she drinks heavily just as the fetus develops a particular feature

Research has shown that binge drinking, which means consuming four or more drinks per occasion (usually within a two-hour period), and regular heavy drinking put a fetus at the greatest risk of severe problems.^{50,51} But even lesser amounts can cause damage.^{52,53,54,55,56} In fact, there is no known safe level of alcohol consumption during pregnancy.⁵⁷

Maternal characteristics that interact with alcohol's prenatal effects and that can affect outcomes at birth are: overall health; diet and nutritional status; maternal age; number of pregnancies; lack of prenatal care; adverse living conditions; and other complex determinants of a healthy pregnancy (e.g., stress, co-occurring diseases, mental health conditions, and use of tobacco and illicit drugs).^{58,59,60,61} Other important factors are a mother's genetic make-up, her child's genetic make-up, and changes in gene activity caused by prenatal alcohol exposure.⁶²

Development of the brain continues throughout all months of pregnancy; therefore, alcohol exposure at any time during pregnancy can cause brain damage, which subsequently compromises brain function.

Effects of FASD

Alcohol is a teratogen, or an agent or factor that causes malformation in an embryo or fetus. In persons with FASD, the types of deficits and their severity are

primarily determined by alcohol exposure, but also by the modulating factors just mentioned.

Alcohol's Effects on the Body

Research data and clinical observations have reported defects in multiple organ systems: nervous, cardiac, skeletal, renal, visual, auditory, immune, and other systems due to prenatal alcohol exposure.^{63,64} Many structures in humans develop primarily during one or two specific months of the prenatal period.⁶⁵ Therefore, alcohol-induced structural damage to some organ systems will be limited to exposure during specific months of pregnancy. For example, structural development and physiological maturation of the heart, arms, and legs take place primarily during the first trimester of pregnancy. However, alcohol can damage the brain throughout pregnancy.



When there is heavy alcohol exposure in the first trimester, readily observable physical outcomes can often be seen: growth retardation (either prenatal or postnatal reduced height and/or weight) and an increase in both major and minor alcohol-related birth defects (heart defects and minor structural anomalies of the ears, eyelids, hands, joints, and digits). In addition, heavy exposure during the first trimester often results in a combination of three specific abnormal facial features that are characteristic of FAS: small palpebral fissures (eye openings), smooth philtrum (the normally grooved area extending from above the lip to the base of the nose), and thin vermilion border (thin upper lip). These facial characteristics have been helpful in diagnosing persons with FAS and pFAS, but such individuals make up a small minority of persons with FASD.^{66,67}

Alcohol's Effects on the Brain

The most adverse outcome of the toxicity of prenatal alcohol exposure is the brain damage that occurs in all of the medical disorders that fall under the

FASD umbrella (i.e., FAS, pFAS, ARND) as well as in the psychiatric disorder: neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). When comparing groups of persons exposed prenatally to alcohol and unexposed controls, group mean differences indicate smaller overall brain size and volume reductions for some specific regions (e.g., areas of the cerebellum, frontal lobes of the cortex, corpus callosum cortex, etc.). However, the toxic effects of prenatal alcohol exposure appear to be widespread and almost throughout the entire brain. Irregularities in brain structure compromise brain function and result in cognitive and behavioral impairments.^{68,69,70} In addition, heavy prenatal alcohol exposure disrupts the normal processes of brain development and neuroplasticity (the brain's ability to change as a result of experience) in children, meaning that brain abnormalities are not static.⁷¹ Development of the brain continues throughout all months of pregnancy; therefore, alcohol exposure at any time during pregnancy can cause brain damage.

Polydrug Use Among Pregnant Women

Animal research studies and epidemiological evidence from populations where alcohol is the only known drug of abuse have clearly demonstrated that prenatal alcohol exposure is the necessary and sufficient cause of FASD.^{72,73,74} However, most pregnant women who use illicit drugs also consume alcohol and tobacco. The mothers of most of the children with FASD seen in both research studies and clinics in the 1980s and 1990s were tobacco smokers. In addition, use of other drugs was reported by more than 20 percent of pregnant alcohol-consuming women who were studied in major longitudinal prospective studies on alcohol and pregnancy conducted in Detroit, Pittsburgh, Atlanta, and San Diego.^{75,76,77,78} A higher prevalence of the use of tobacco and illicit drugs during pregnancy has also been reported in mothers of persons with FASD who are seen in clinical settings.^{79,80}



Maternal use of other drugs during pregnancy can have independent negative effects on a fetus. Similar to alcohol, cigarette and cocaine use during pregnancy can shorten gestation time and increase premature births. Alcohol, cigarette, and marijuana use affect birth weight; smoking has the greatest effect.⁸¹ The recent increases in the use of marijuana in pregnant women (11 percent) and non-

pregnant women of child-bearing age (14 percent) and the high percentage of pregnant marijuana users (18 percent) who meet criteria for marijuana abuse and dependence^{82,83} are reasons for concern, but we know little about the long-term health effects of prenatal marijuana use on children.

In the past decade, there has been a dramatic increase in the therapeutic use of opioids and abuse of medicinal opioids in the United States.⁸⁴ The increased use and abuse of prescription-controlled opioids by pregnant women has resulted in more cases of neonatal abstinence syndrome (NAS). There are many neonatal complications associated with NAS caused by the use of heroin and methadone and other medicinal opioids, including more preterm births, lower birth weights, more cases of respiratory distress syndrome, feeding difficulties, jaundice, etc. The increase in NAS has strained the capacity and resources of neonatal care units and Medicaid funding in many states.^{85,86} The long-term outcomes of opioid use in pregnancy are not well known, and very large longitudinal and sophisticated research studies will be required to define such effects due to the rates of poly-substance use and other co-occurring mental health disorders in pregnant women, and the adverse post-natal environments often experienced by mothers who have used drugs and their children.^{87,88}

Studying the significant effects of maternal use of methamphetamine and cocaine have similar challenges. In spite of reports of short-term changes in stress and arousal in infants prenatally exposed to methamphetamine,⁸⁹ and small studies of behavioral dysregulation in prenatally cocaine-exposed children with and without prenatal alcohol exposure^{90,91} the use of these substances is not as strongly associated with cognitive brain deficits as prenatal alcohol use is,⁹² and many environmental confounds exist.⁹³ In addition, cocaine and methamphetamine use during pregnancy have been associated with alcohol misuse and to a variety of family, social, legal, and psychiatric problems.⁹⁴

Women who use a combination of alcohol, tobacco, and illicit substances during pregnancy are at a greater risk of using substances after pregnancy without appropriate supports (e.g., programs such as the Parent-Child Assistance Program). This situation is likely to create more chaotic, less nurturing, unstable environments which will continue to affect negatively the healthy development and maturation of children.⁹⁵

In spite of withdrawal symptoms seen in some infants prenatally exposed to

opioids, the current evidence indicates that the short- and long-term effects of prenatal alcohol exposure are more severe and longer lasting than outcomes from prenatal exposure to other drugs.⁹⁶ In addition, the high prevalence of alcohol use in pregnancy⁹⁷ suggests that prenatal alcohol exposure is a greater threat to the health of the nation's children than the use of other drugs by pregnant women.

FASD-Related Problems

FASD-related brain damage makes it difficult to deal with routine life situations. It causes people to make bad decisions, repeat the same mistakes, trust the wrong people, and have difficulty understanding the consequences of their actions.

People with FASD may have difficulty in the following areas as well:⁹⁸

- Learning and remembering
- Solving problems and organizing and planning
- Understanding and following directions
- Shifting attention
- Controlling emotions and impulsivity
- Communicating and socializing
- Comprehending complex use of language
- Understanding abstract thinking vs. concrete thinking
- Practicing daily life skills, including feeding, bathing, counting money, telling time, and minding personal safety

FASD cases are seriously underdiagnosed. FASD can be difficult for practitioners to distinguish from other developmental disorders, such as Attention Deficit Hyperactivity Disorder (ADHD), since they share some similar learning and behavioral problems. In addition, people with FASD are also more likely to suffer from the following mental health disorders:⁹⁹

- ADHD
- Depression and anxiety
- Problems with hyperreactivity, conduct, and impulse control
- Increased incidence of alcohol and other substance use disorders

Each Individual with FASD has a unique combination of day-to-day challenges that may include medical, behavioral, educational, social, and legal problems.

Individuals with FASD appear on every court docket. They may be victims, witnesses, children, defendants, plaintiffs, and parents. Juvenile and family court

judges need to recognize cognitive and behavioral impairments and possible FASD and identify the legal implications. It is not a matter of IQ. Most people with brain damage due to prenatal alcohol brain damage will have IQs in the normal range but will have impairments in complex thinking and often experience difficulty in regulating their behavior. The American Academy of Pediatrics has classified babies and children with any type of FASD as “special needs children” who need parents with special training and multiple support systems.

The term FASD is not meant for use as a clinical diagnosis. Instead, there are four diagnostic medical categories within the spectrum and ND-PAE, a relevant mental health disorder in the DSM-5.

Diagnosis, Missed Diagnoses, Misdiagnosis, Co-occurring Disorders, and Interventions

Clinical Diagnosis

The essential features common to the Institute of Medicine (IOM) medical diagnoses and the DSM-5 psychiatric diagnosis are prenatal alcohol exposure and central nervous system involvement (brain damage).

Evidence of central nervous system involvement can be structural (e.g., small brain size, alterations in specific regions) or functional (e.g., cognitive and behavioral deficits, motor and coordination problems).¹⁰⁰ Advanced imaging studies have revealed differences in brain structure and activity that are consistent with deficits in sensory processing, cognition, and behavior in persons with FASD compared to persons without FASD.¹⁰¹

Fetal Alcohol Syndrome (FAS)

Fetal alcohol syndrome (FAS) was the first form of FASD discovered and is the most well-known but the least prevalent form in the U.S. Heavy alcohol use during the first trimester of pregnancy can disrupt development of the face and the brain. In fact, exposure at any point during gestation can affect brain development. An FAS diagnosis requires:

- Evidence of prenatal alcohol exposure

- Evidence of central nervous system abnormalities (structural or functional brain damage)
- A specific pattern of three facial abnormalities: narrow eye openings, a smooth area between the lip and the nose (vs. the normal ridge), and a thin upper lip
- Growth deficits either prenatally, after birth, or both

Partial FAS

This condition involves prenatal alcohol exposure and includes some, but not all, of the characteristics of full FAS.



Alcohol-Related Neurodevelopmental Disorder (ARND)

A diagnosis of ARND requires evidence of both prenatal alcohol exposure and central nervous system abnormalities (brain damage), which may be structural or functional. Functional abnormalities may involve a complex pattern of cognitive or behavioral problems that are not consistent

with developmental level, and that cannot be explained by factors other than prenatal alcohol exposure (e.g., family background, environment, and other toxicities). Facial abnormalities and growth retardation need not be present.

Alcohol-Related Birth Defects (ARBD)

This disorder includes medical conditions linked to prenatal alcohol exposure, such as heart, kidney, and bone problems and other malformations; difficulty seeing and hearing; and reduced immune function. ARBD is rarely seen alone but rather as a secondary disorder accompanying other FASD conditions (e.g., FAS and ARBD).

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

This new psychiatric diagnosis in the DSM-5 requires evidence of both prenatal alcohol exposure and central nervous system involvement (brain damage), as indicated by impairments in cognition, self-regulation, and adaptive functioning. This new diagnosis for use by mental health professionals will improve understanding of the multi-faceted behavioral deficits seen in some people exposed to alcohol prenatally and facilitate improved diagnosis and treatment of these individuals. People who meet the criteria for medical diagnoses within the spectrum according to the IOM may also meet the criteria for ND-PAE.

In previous decades, clinical diagnoses for medical disorders under FASD most often occurred at FASD diagnostic centers and developmental disabilities specialty clinics. However, more recently pediatric health care workers have become more aware of FASD and increased assessments and preliminary diagnoses among their patients. The CDC has developed competency-based educational curricula on FASD for medical and allied health education and practice, and in 2011 established training centers in several regions of the U.S. to increase FASD awareness and educate health professionals about FASD prevention, identification, and care of individuals.^{102,103,104} The CDC has also funded efforts at the American Academy of Pediatrics (AAP) to increase FASD awareness¹⁰⁵ and develop educational tools for screening and diagnosing FASD in primary pediatric health care.¹⁰⁶

FASD-relevant diagnoses are medical diagnoses or mental health diagnoses. In the U.S., medical FASD diagnoses are always performed by a licensed physician often working in collaboration with allied behavioral health experts. The diagnostic assessment of the FASD-relevant DSM-5 psychiatric disorder may be performed by psychiatrists, clinical psychologists, qualified physicians, and by appropriately certified social workers, school psychologists, and other allied mental health care professionals.

The American Academy of Pediatrics (AAP) FASD toolkit's guidance for evaluation of FASD within the "medical home" advises pediatricians to identify patients with evidence of prenatal alcohol exposure as "children with special health care needs"¹⁰⁷ and to consider continuing appropriate follow-up

assessment and comprehensive care through the “medical home.”¹⁰⁸ FASD diagnosis and coordination of treatment for children and youth by pediatricians is expected to increase dramatically in the next decade following the publication of the AAP’s detailed guidelines for identification, diagnosis, and management of neurobehavioral disorders associated with prenatal alcohol exposure (ND-PAE), the FASD-relevant DSM-5 disorder.

A diagnosis within the spectrum means that the individual has been exposed to alcohol prenatally, and there is brain damage resulting in functional neurobehavioral impairments. The cogent information in the report from a diagnostic assessment describes the impairments that particular individual has. Those deficits and impairments will be defined based on results of standard assessments of normal development, neuropsychological tests, behavioral and/or psychiatric symptoms, and sometimes existing school records. The National Organization on Fetal Alcohol Syndrome’s website has a resource directory listing some FASD diagnostic services, various treatment resources, contact information for support groups, and other services available in all 50 states.¹⁰⁹

Missed Diagnoses and Misdiagnosis

FASD are frequently unrecognized, and individuals with FASD are often misdiagnosed due to lack of awareness of FASD among mental health professionals and the considerable overlap between neurobehavioral symptoms of FASD and symptoms of other neurodevelopmental disorders.¹¹⁰ A review of medical records of more than 100 consecutive admissions to a large university medical school’s child inpatient facility indicated that 26 percent of the children met criteria for FAS but had never received an FASD-relevant diagnosis.¹¹¹ A recent review of more than 500 randomly selected medical records of children (4-18 years old) in foster care who were referred for a behavioral assessment to a children’s mental health center in a major U.S. city revealed that 30 percent were given an FASD diagnosis after a full assessment at that mental health center. Eighty percent of those children had not previously been diagnosed with FASD.¹¹² It is important to note that some infants with FASD may appear normal at birth. Children may not begin to show deficits until they are much older, making screening and rescreening at appropriate intervals vital to children who may have FASD.

Many traits or characteristics of prenatal alcohol exposure can be completely missed by practitioners, and others are misdiagnosed as other disorders or issues. For example, depression and anxiety are often under-recognized in children, adolescents, and adults with prenatal alcohol exposure,^{113,114,115} as is the high incidence of suicide attempts in this population.¹¹⁶

On the other hand, children with FASD who present with externalizing behavioral issues are frequently over-diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), Conduct Disorder (CD), and Oppositional Defiant Disorder (ODD). A majority of individuals with FASD seen in clinical settings have been identified as having additional mental health difficulties, including substance use and dependence and other co-occurring mental disorders. One consequence of misdiagnosis is that treatments and interventions that target the misdiagnosed condition are inappropriate and ineffective when applied to individuals with FASD.¹¹⁷

ADHD is the most common mental health diagnosis given to individuals with prenatal alcohol exposure.¹¹⁸ FASD and ADHD share several common features, but individuals with FASD have been shown to have greater impairments in problem-solving, more difficulty shifting attention (compared to the focused and sustained attention issues characteristic of ADHD), more problems with face and emotion processing, problems with over-arousal, and progressive decline in adaptive behaviors with age compared to their peers.¹¹⁹ A careful neuropsychological assessment can distinguish between ADHD and effects due to prenatal alcohol exposure alone. In addition, medications effective for ADHD have often been reported to be ineffective for individuals with similar symptoms due to prenatal alcohol exposure.¹²⁰

Children with prenatal alcohol exposure often have symptoms similar to ODD and CD. Health care

The AAP defines a “medical home” as one in which the care of infants, children, and adolescents is delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them. Ideally, care is:

- accessible;
- continuous;
- comprehensive;
- family-centered;
- coordinated;
- compassionate; and
- culturally effective.

The Affordable Care Act of 2010 endorses the medical home model throughout the lifespan.

providers and parents need to evaluate carefully whether those symptoms are primarily manifestations of the neurocognitive deficits that define FASD. Apparent noncompliant behavior often arises from poor comprehension of what was requested, confabulation is often assumed to be lying, and what appears to be stealing may actually be the result of a poor understanding of ownership.¹²¹

Court-ordered treatment is sometimes the only way for children diagnosed with FASD to receive appropriate medical treatment and environmental interventions.

Formal Diagnoses – and Services for Children and Youth with FASD

A formal diagnosis can be an important first step in helping a child receive appropriate treatment and services (e.g., Social Security disability, appropriate substance abuse and mental health treatment, specialized vocational programs) that might ameliorate adverse life outcomes common to individuals with this disability.¹²² Furthermore, court-ordered treatment is sometimes the only way for children diagnosed with FASD to receive appropriate medical treatment (e.g., for mental health and substance abuse problems) and environmental interventions (e.g., educational or vocational services and behavioral interventions appropriate to their brain function).¹²³

Steps that judges might take in obtaining a diagnosis and services for children and parents are given below:

- Alert those involved in the child's welfare (e.g., parents, social services, caregivers, child's attorney, CASA, educators, etc.) to the possibility that the child might have any of the FASD, and therefore should seek appropriate follow-up diagnoses and services, including appropriate ongoing training and support of parents and caregivers, including foster and adoptive parents.¹²⁴
- Identify people within the child's current support system, or those needed for support, and provide training in order to achieve consistency and reinforcement for the child.
- Require child welfare agencies to provide birth records and other information about prenatal alcohol exposure.¹²⁵
- If there is any evidence that the mother used drugs or drank alcohol during pregnancy, request an evaluation of the child by competent experts who are

trained to diagnose FASD.

- Request that prenatal alcohol exposure be included in existing screening and risk assessment tools.
- Ensure that diagnostic reports indicate a thorough evaluation of the individual and his or her specific impairments and needs.
- Consider requesting a social history when reviewing a medication request. The social history should include a history of prior diagnosis, medication regime, and special education placements.
- If a child receives a positive diagnosis, identify services in the community. Follow up to ensure that the child is receiving mandated services.

Interventions

Training for parents and professionals to help them understand the disabilities associated with FASD is a critical aspect of effective interventions. Learning disorders, deficits in sensory integration, and the need for family therapy are signals that are not often recognized or treated in persons with FASD.^{126,127,128} A Part C assessment,

under the Individuals with Disabilities Education Act (IDEA), is a good starting place for screening for young children. Part C provides services, such as health management, speech therapy, occupational therapy, and other services necessary to support their physical, social, and emotional development, as well as special education services through the school system to children under three years old. For children over three years old, families may be referred to programs under Part B of IDEA.

Several research-based, validated interventions for people with FASD have been developed and are being implemented in many communities in the U.S. and Canada.¹²⁹ Studies of treatments for children with prenatal alcohol exposure have targeted behavioral problems, cognitive and academic skills, and adaptive skills. Positive effects have been demonstrated in studies utilizing supportive behavioral consultation with parents¹³⁰ and socio-cognitive habilitation to improve math skills (exercises in self-regulation to improve learning coupled with mathematics





training.^{131,132} In addition, improvements have been demonstrated with language and literacy training,¹³³ rehearsal training to improve working memory,¹³⁴ a computer-based intervention to increase fire and street safety skills,¹³⁵ and a manualized, parent-assisted social skills intervention.¹³⁶

The National Organization on Fetal Alcohol Syndrome (NOFAS) provides information on research-based and

validated programs for children and families. These include Parents and Children Together, which teaches body and emotional awareness, memory building, and self-monitoring; Families Moving Forward, a parenting intervention to increase caregiver knowledge; Good Buddies, designed to help children with FASD with communication and play strategies; and the Math Interactive Learning Experience Program.¹³⁷ The NOFAS website has information on additional interventions that are currently being used but not yet validated. Some interventions commonly used for other developmental disorders are often effective when adapted for the special needs of children with FASD.

NIAAA is currently funding development and clinical efficacy trials of additional interventions and treatments for persons with FASD. Several in-progress NIAAA-sponsored clinical trials involve nutritional supplements for pregnant women and postnatal supplements for their children and other interventions focused on improving learning, self-regulation, and affect in persons with prenatal alcohol exposure.^{138,139}

*The vast majority of children who are never diagnosed and treated repeat the cycle of substance abuse by giving birth to the next generation of children adversely affected by alcohol use.*¹⁴⁰

Implications of Not Addressing FASD in Children

Every year, about 40,000 babies are born in the United States with symptoms

of prenatal alcohol exposure.¹⁴¹ Annual costs for their health care and special services vary from \$75 million to \$4 billion, depending on the estimated prevalence of FASD.¹⁴²

The failure to address the effects of FASD adequately imposes a severe burden on individuals, families, and society. FASD are conditions, which, if not diagnosed and treated at the earliest possible stages of child development, can lead to costly and often devastating secondary disabilities.¹⁴³ Secondary disabilities include disrupted school experience, mental health problems, alcohol or other drug problems, trouble with the law, and inappropriate sexual behaviors.

Accurate diagnoses are necessary to ensure that children affected with FASD receive the educational and other services to which they are entitled, such as Part C of the IDEA, as noted above. Developmentally appropriate interventions and supports are critical for managing this lifelong impairment.¹⁴⁴ Those who are unable to become self-sufficient are often eligible for Social Security benefits and vocational rehabilitation services as adults. If such services are not provided, affected individuals may remain reliant on family or forms of public assistance to help them support themselves and improve their opportunity for a better life.¹⁴⁵ Obtaining access to needed services and programs requires that judges as well as families understand the policies that govern eligibility. In addition, training of juvenile justice professionals (e.g., judges, probation officers, attorneys, juvenile drug court coordinators, etc.) and treatment providers is also a critical component to ensuring children get appropriate services.

For most children with FASD, there are no obvious physical manifestations or IQ deficits.

Recognizing FASD in Children and Parents

Because the brain damage associated with FASD is irreparable and permanent, intervention in the legal context centers on recognizing the signs of disability and providing external supports in a structured environment to compensate for the deficits.¹⁴⁶ For most children with FASD, there are no obvious physical manifestations or IQ deficits. While prenatal alcohol exposure is arguably the leading known non-genetic *preventable* cause of intellectual disability, most

individuals with FASD have IQs that fall in the average to borderline ranges.¹⁴⁷ Consequently, juvenile court judges should educate themselves about the behaviors that stem from brain damage, and appreciate the critical importance of a structured, stable social environment for children affected by prenatal alcohol exposure.¹⁴⁸ An increased awareness among judges of potential signs could increase the number of children in dependency and delinquency who receive appropriate services for FASD.

Potential signs that a child might have some type of FASD appear in the child and in the mother:

In children

- History of prenatal alcohol exposure
- Siblings with FASD diagnoses
- Multiple failed foster care placements or failed adoption
- Multiple mental health diagnoses (e.g., ADHD, bipolar, Oppositional Defiant Disorder)
- Repeated difficulties in school, with or without an Individualized Education Plan (IEP)
- Lack of response to consequences-based discipline
- Behaviors such as those specified in the “Juvenile Justice” section of this guide Adolescents with multiple status and delinquent offenses

In mothers¹⁴⁹

- Pattern of social drinking when not pregnant and unintended pregnancy or late recognition of pregnancy
- History of DUI
- Medical diagnoses related to alcohol use
- Estrangement from family and friends
- Failed relationships
- Poor employment history
- Daily use of alcohol by partner
- Frequent binge drinking by partner and friends
- Criminal history for substance abuse and multiple forms of theft, including financial fraud or burglary
- Homelessness

Parents with FASD are at much higher than average risk for having their children removed from their custody, typically for neglect (inability to provide a safe or adequate environment) rather than for abuse.¹⁵⁰ Parents with FASD also might have multiple cognitive impairments that are likely to complicate their ability to meet court-ordered requirements for reunification.¹⁵¹

Due to the sometimes intergenerational nature of FASD, judges should consider that the parents of a child affected with FASD should be screened. In one study, one third of the mothers of children diagnosed with FAS were identified as having a type of FASD.¹⁵² A diagnosis of any of the FASD in the parent reframes the circumstances of a case, expands options for interventions, and raises issues of due process.

Protecting Future Children

Later-born children of mothers who drink alcohol during pregnancy appear to be at much greater risk for having FASD than their older siblings.¹⁵³ Dependency court judges who have evidence that the birth mother has a substance abuse problem can order an evaluation to determine her history of alcohol use and misuse, especially during pregnancy. If there is a history of alcohol abuse, the mother can be involved in treatment to help prevent the subsequent birth of prenatally exposed children.¹⁵⁴

Once families come to the attention of the court system, obtaining a diagnostic assessment for potential FASD is often in the hands of judges, attorneys, caseworkers, and advocates for children.

FASD and Juvenile and Family Courts

Children and adults often end up involved in the legal system due to poor self-regulation and self-control. This is often the case with children in juvenile justice (delinquency) cases, as well a critical issue in dependency cases for both children and parents. Courts are challenged when working with people with poor self-regulation, as the services and supports they require need to take this into account and be focused on individual needs. Despite the implications for the judicial system, there are no universal systems of screening and assessment in place for FASD, leaving the initial identification of this issue in the hands of judges, attorneys, caseworkers, and advocates for children.^{155,156} Children and families can be better served when all relevant system stakeholders receive training to recognize the signs and symptoms of FASD so that behaviors are not overlooked or dismissed.

Children often enter the foster care system due to problems such as maternal alcohol and/or drug abuse and child abuse, neglect, or abandonment, which may be related to prenatal alcohol exposure.

Child Abuse and Neglect (Dependency)

Children often enter the child abuse and neglect (dependency) system due to presenting problems such as maternal substance abuse, including alcohol. In 2013, alcohol abuse by parents was listed as one of the reasons that approximately 16,000 children were removed from their homes out of the 254,887 children who entered care that same year.¹⁵⁷ Although no causal relationship has been established, alcohol abuse in the home is an extremely high risk factor for prenatal alcohol exposure and likely results in higher rates of FASD among children involved in the dependency system compared to the general population.

There is no universal screening for FASD in the child welfare system, and existing screening and risk assessment tools fail to ask the simple question regarding prenatal alcohol exposure. Due to the lack of national surveillance of FASD and universal screening among child welfare agencies, the rates among children in foster care are unknown. There is a perception that many children involved in the dependency system have an FASD condition, and this has been documented in two counties in the U.S. through studies that looked at children referred from that system.^{158,159} Likewise, the 17th Judicial District in Adams County, Colorado found that 13 percent of a sample of children removed from their homes because of substance abuse (alcohol or other drugs) were diagnosed with FASD.¹⁶⁰

This is not to say that the majority of children with FASD are in the dependency system. There is no clear documentation of what percentage of children with FASD are involved in the system. Several longitudinal studies involving pregnant women recruited from prenatal clinics at large urban hospitals concluded that, at age six to eight years old, less than 10 percent of the children with FASD were in foster care.^{161,162}

It is common practice in many jurisdictions to refer children in foster care to psychological and mental health evaluations and assessments, which means they may be more likely to be evaluated for FASD, if such screening is done by the service provider. A study by a mental health clinic in Chicago found that

30 percent of school-age children referred by child welfare agencies for assessment of behavioral problems met diagnostic criteria for some type of FASD. A random sampling of the clinical records for more than 500 such children indicated that 80 percent of them had not been diagnosed with an FASD prior to their referral.¹⁶³ This finding stresses the importance of psychological and mental health services for children in foster care and for diagnosticians to be aware of and looking for FASD.



Early and accurate diagnosis of children with FASD in the dependency system can contribute immeasurably to successful case disposition and the best possible outcomes for each child. Early diagnosis can: 1) prevent the need for removal; 2) help establish appropriate placements and required services; 3) allow biological and foster/adoptive parents to be better prepared to meet their child's needs and improve parenting by increasing their understanding of the deficits and behavioral problems of children with FASD; 4) reduce the likelihood of multiple failed placements; and 5) increase awareness and understanding of parents, caregivers, and caseworkers of the consequences of prenatal alcohol exposure.¹⁶⁴

Because of the generational nature of alcohol abuse, parents involved in child abuse and neglect cases may also have FASD. Below is a list of issues a judge in a dependency case may want to consider when one or both parents have been identified with FASD:

- Persons with FASD often have serious problems with self-regulation (e.g., erratic changes in mood, impulse control, easily over-stimulated, etc.) which are apparent from infancy throughout life. These make parenting children with FASD extremely challenging and frustrating for any parent. Parents who themselves have FASD may need assistance in applying the adaptive skills that are often lacking in someone with FASD and are critical to parenting.
- Parents with FASD may have problems with structure for themselves and their children.
- Parents with FASD may have problems with supervision of their children

because parents do not see dangers or risks.

- Parents with FASD may have trouble organizing their own lives, and even greater difficulty organizing the lives of their children.

In order to overcome some of these issues in the court setting, judges should be aware that:

- Court orders and treatment plans should be written as well as explained verbally in concrete language.
- Treatment plans should focus on providing supports to help parents with FASD provide for the needs of their children, include training to enhance or teach specific skills, and include interventions that focus on modifying the environment.
- Parents may need support in getting themselves and their children to appointments.
- Parents may need specific guidance and assistance to follow directions and learn new parenting techniques.
- Substance abuse treatment plans for these parents should be modified from standard treatment protocols to adapt to their functional needs.
- Support for parents needs to be in place and ongoing beyond case closure and may need to remain open for an extended period of time (years, not months).
- It is critical for the court team to include someone with a solid understanding of benefits such as those provided by Supplemental Security Income (SSI) and Medicaid in serving this population.

Considerations in Dependency Cases

Below is a list of key considerations that a judge should take into account when a child has been identified with FASD:

- ☐ Families should be connected with a pediatrician so that early intervention is more likely and care is appropriate.
- ☐ The parents as well as any temporary caretakers should be required to learn about FASD and understand that the child's behavior may stem from prenatal alcohol exposure – not intentional disobedience.
- ☐ Out-of-home placement, visitations, and other changes may be difficult for the child and cause acting-out behavior.
- ☐ Identify someone who can be an advocate or “external brain” for the

child (e.g., CASA, guardian ad litem) who can help the child think through decisions, behaviors, and consequences.

- ❑ Treatment plans should include ongoing developmental and behavioral surveillance of the child by the child's primary health care clinician in addition to efforts to obtain the needed educational and other recommended services.
- ❑ Available resources should be used to identify and notify biological and fictive kin to help establish support systems for the parent and the child.
- ❑ Identify appropriate support services and accommodations for parents living with FASD.
- ❑ Consider the meaning of "reasonable efforts" in the context of serving children and families with FASD; specialized services may need to be identified, and parents or caregivers may need assistance accessing services as well as education on the effects of FASD.

In situations where both a parent and child are identified with FASD, the issues will be compounded.

Child protective agencies and courts should not automatically assume that individuals with FASD cannot succeed as a parent.

Considerations in Dependency Cases for Parents with FASD – Reasonable Accommodations and Due Process

Judges and other professionals should not automatically assume that individuals with FASD cannot succeed as parents or quickly move to terminate parental rights.¹⁶⁵ General guidance in assessing and supporting parental fitness can be drawn from lessons learned in working with parents with other neurodevelopmental disorders, including intellectual disabilities.¹⁶⁶

- ❑ Look at the person, not the label. Avoid the mistaken assumption that individuals with FASD cannot function as parents.
- ❑ Use adequate assessments and targeted interventions to address areas of specific need. Do not base decisions on psychological tests that address general abilities or traits with no relationship to parenting.
- ❑ Encourage parents with FASD to make use of supports, such as extended family members who can compensate, to some extent, for the parent's

deficits. Professionals should use a “wraparound” model to provide a mix of formal and informal supports.

- Use mentoring and coaching. A step-by-step mentoring or coaching approach, geared to very specific “teachable moments,” appears to be more effective than a group classroom approach where material is presented didactically and parents likely will not remember or assimilate the messages.
- Exercise empathy and flexibility. Parents with FASD have difficulty remembering commitments or appointments and do not understand the consequences of expressing anger or failing to appear sufficiently diligent in following directions. Some degree of flexibility – similar to that shown in mental health courts – is called for when working with such parents.

Achieving and Maintaining Permanency for Children with FASD

Judges are uniquely positioned to understand the needs of the family and the child and to order child welfare agencies to ensure delivery of services to address those needs.

Remaining Home and Reunification After Removal



Preventing removal of children with FASD should include intensive in-home services for both the child and parents. Children with FASD carry a high burden of care, because of the degree of disabilities they exhibit and the number of appointments and specialists they need to see. This type of structure and care requires a very high degree of positive parenting and organizational skills, which often need to be built or enhanced in families seeking to reunify.¹⁶⁷ When reunification is the permanency goal, parents should be required to undergo specialized training about FASD. It is important for parents, caregivers, and system professionals to understand that the child’s behavior may stem from prenatal alcohol exposure – not intentional disobedience.

If parents are in recovery, they may have serious impairments in their ability to fulfill their own substance

abuse treatment needs while taking care of children with complex needs. Family reunification in these cases requires substantially more court-ordered support and monitoring for the family. One way to determine the parents' capacity to provide for and meet the needs of their children, after removal, is to have them co-parent with the foster parents and attend all appointments and therapies offering supporting services.¹⁶⁸

Out-of-Home Care (Family Foster Care and Group Homes)

If out-of-home care is the only option, finding a therapeutic foster care setting is most beneficial for children with FASD. A stable, structured, protective social environment involving educated and compassionate caregivers is the single most important key to successful intervention.¹⁶⁹ This can be difficult, because, among all children with neurodevelopmental disorders, children with FASD may be the most difficult to parent, educate, and treat because of their challenging behaviors. They also have problems adjusting to change because new contexts require new behavioral routines, which can overwhelm their cognitive capacity. Consequently, a minimum of placements and the least disruption of routines are in the child's best interest.

An additional concern in their placement and legal disposition is that children with FASD compensate for their learning deficits by mimicking what they see around them. Because these children may adopt adverse behaviors, group home settings may not provide the prosocial environment that is critical for individuals with FASD. Many children affected by FASD, even with the best of care, will need long-term assistance with independent living, and adults and the court and child welfare agencies need to assist in devising plans for case management and assistance into adulthood.¹⁷⁰

Juvenile Justice

Many of the behavioral features that are characteristic of children with FASD, such as attention deficits, hyperactivity, and impulsivity, have been shown in longitudinal studies to be predictors of delinquency and adult criminal behavior.¹⁷¹ In addition, nearly a third of youth in juvenile corrections in the U.S. qualify for special education services because of emotional disturbance, specific learning disabilities, and/or intellectual disability,¹⁷² all of which are commonly seen in

youth with FASD. However, despite these linkages there is currently very little empirical evidence about the prevalence/incidence of FASD in the juvenile and adult criminal justice systems. Professionals do not routinely look for FASD, as the most commonly used screening and/or risk assessment tools do not include questions about prenatal alcohol exposure or possible FASD. There also are no widely accepted tools to screen for FASD specifically, but some progress is being made in these areas in Canada.¹⁷³

Based on a review of available Canadian data on FASD and criminal justice involvement, children with FASD are 19 times more likely to be incarcerated than children without FASD in a given year.¹⁷⁴ The few studies that have specifically screened and identified FASD in the justice system have reported a high prevalence of the disorder. These studies often have been based on individuals for which FASD are more likely to be present, such as those referred to diagnostic clinics for behavioral problems.¹⁷⁵ Multiple studies on learning disabilities, which may or may not be caused by FASD, have shown that 30 percent to 45 percent of children in detention have an educational disability,¹⁷⁶ which emphasizes the need for specialized screening to understand better each child's needs.

Two programs in the U.S. (17th Judicial District in Adams County, Colorado and the 4th Judicial Court in Hennepin County, Minnesota; for more information see “Court Examples” in this guide) have specifically screened for FASD among adjudicated children on probation and found a significant percentage with FASD. What is clear is the need to incorporate screening for FASD as early as possible in the juvenile justice system to ensure a fair and appropriate response to this population.

There is a perception that those identified with FASD are more likely to commit crimes when compared to the general population, but in two studies of individuals with FASD vs. well-matched control groups within fairly homogenous populations, the rates of criminal involvement were not significantly different.^{177,178} However, while studies have shown they are not more likely to commit crime, they may be more vulnerable to being caught up in the justice system.

Standard disciplinary techniques are usually not effective because they presume a person has a normally functioning brain that understands the concept of negative consequences for inappropriate behaviors and can learn from mistakes.

Considerations in Juvenile Justice Cases Involving Children with FASD

Due to the brain damage caused by prenatal alcohol exposure, children with FASD exhibit several social and behavioral deficits that affect their involvement with the legal system. These deficits include:

- ☐ Impulsivity;
- ☐ Social ineptness (i.e., trouble recognizing and interpreting verbal and nonverbal social cues and difficulty learning social conventions and applying them appropriately);
- ☐ Poor judgment (i.e., inability to reason and choose right from wrong);
- ☐ Tendency toward explosive episodes;
- ☐ Problems understanding the consequences of behavior; and
- ☐ Vulnerability to negative peer pressure, bullies, etc.

Adverse experiences, such as having a dysfunctional family background, mental health problems, and substance use disorders, are compounding factors.¹⁷⁹

FASD are not an excuse for breaking the law. However, all children, including those with FASD, deserve to be treated fairly and in a developmentally appropriate manner by the juvenile justice system. Standard disciplinary techniques are usually not effective on this population because they presume a person has a normally functioning brain that understands the concept of negative consequences for inappropriate behaviors and can learn from his or her mistakes.¹⁸⁰ One of the key findings of a federally funded project with the 17th Judicial District in Colorado is that, “the presence of



an FASD Project and the reports of evaluations that have come to the court have created an environment where there is constant awareness of the question of ability to function as expected.”¹⁸¹

Detention also can be counterproductive due to the increased risk of recidivism, as children with FASD might copy the negative behavior of other juveniles. Like all children, if remanded, those with FASD are safer in a juvenile facility than in an adult prison due to potential victimization. During probation or aftercare, they will do best in a highly supervised, structured living arrangement. Corrections workers and probation officers need to be informed about the ways in which FASD affect the offender’s abilities to understand and follow rules and probation orders.¹⁸²

Family Court (Divorce and Custody)

Family courts, like juvenile courts, should not ignore the issue of FASD. There may be many questions about how to handle a case involving FASD. Considering that families with special-needs children divorce at higher rates, this emerging topic deserves additional attention. Like dependency and delinquency, it is equally important for the family courts to identify if FASD are relevant to the case (i.e., the child and/or parent have a diagnosed FASD condition).

If one parent has an identified disability such as a form of FASD, this will impact how to handle custody, visitation schedules, property distribution, and financial arrangements.¹⁸³ A parent with any form of FASD may be more vulnerable during divorce proceedings than the parent without FASD, especially in situations where parents are self-represented. If parents are represented, FASD may impact how a lawyer would approach the case, and it may be necessary to evaluate if the lawyer is a good fit given the client’s disability. Adults with substance abuse disorders and/or FASD may not have stable relationships with spouses/partners, housing may be challenging, and generational substance abuse and/or generational family violence may also be issues. In addition, a characteristic of individuals with FASD is that they try to please those around them, making them potentially more susceptible to violence in relationships.

Considerations in Family Law Cases Involving Children and/or Parents with FASD

Below is a list of issues a family court judge may want to consider when confronted with one or both parents who have been identified with FASD in the context of divorce and custody:

- ☐ The employment status of the parent with any form of FASD may be a consideration. Does he or she have a support system to assist?
- ☐ Can the parent with a type of FASD provide a stable, safe, and structured home environment for a child? Are special modifications or supports needed to provide a safe environment?
- ☐ Adopting standard visitation schedules may not work in a situation where a parent has some type of FASD. More time and work will be required to develop a safe visitation schedule.
- ☐ A parent with any of the FASD should not be denied custody or visitation because of his or her disability. Denying a child a relationship with the parent who has any type of FASD may be harmful to the child.
- ☐ Is a guardian ad litem required or advised? Is the parent with a form of FASD self-represented?
- ☐ A parent with any form of FASD may exhibit the behavior of wanting to please, which may put a parent at a disadvantage during deposition or trial.
- ☐ A parent with any of the FASD may have diminished mental capacity, which could leave him or her vulnerable.

Family court judges will need essential information for determining the best interest of a child who has a form of FASD and should balance this with the interest of the parents (who may or may not have FASD). A child who has a diagnosed FASD condition should be treated as a child with special needs, and adopting special protocols may be necessary to ensure the best possible outcome. When FASD is suspected, judges should immediately appoint a guardian ad litem or the equivalent for the child. If possible, judges should seek input from medical and mental health providers as to the needs of the child with FASD. Courts may want to utilize a special-needs protocol to create an effective parenting plan in divorce/custody cases.

Below is a list of issues a family court judge may consider when confronted with a child who has been identified with a type of FASD and is involved in a divorce/custody case:¹⁸⁴

- ☐ The financial burden of caring for a child with FASD.
- ☐ The time and means to care for a child with FASD.
- ☐ The willingness to attend and participate in the necessary treatments by each parent.
- ☐ How each parent will parent or co-parent a child with any of the FASD.
- ☐ How transitions between homes may negatively impact a child with FASD.

When FASD are identified, family court judges will have additional considerations for these unique cases. Family court judges and attorneys should evaluate their current assumptions about FASD. A family law case that involves FASD will inherently become more difficult to resolve, and judges should strive to achieve a plan that is sensitive to the needs of all involved.

When individuals with FASD become involved with the court, there is a real possibility that they will be unfairly disadvantaged due to their difficulty in fully appreciating their legal rights and options.

Protecting the Rights of Individuals with FASD

Judges have an ethical obligation to protect the legal rights of all those appearing before the court. An integral part of their judicial decision-making process is to ensure that all parties receive the legal and constitutional rights to which they are entitled.

When individuals with FASD become involved with the court, there is a real possibility that they will be unfairly disadvantaged due to their difficulty in fully appreciating their legal rights and options. The judicial process assumes that individuals are capable of making choices, understanding the consequences of their actions, and learning from past experiences. These assumptions fail in light of what is known about the functional disabilities associated with FASD.¹⁸⁵ Individuals with FASD have cognitive and behavioral deficits, such as difficulty with activities that require attention, concentration, and mental control that undermine their ability to understand and participate in court proceedings. They

often have short- and long-term memory gaps or inconsistent memory, leading them to be wrongly perceived as having selective memories. In their desire to please others, individuals with FASD might answer questions according to what they think the questioner wants to hear rather than with facts.¹⁸⁶ Parents with FASD, for example, might inadvertently agree to insurmountable, unrealistic, and unnecessary tasks in order to avoid confrontation with the person in authority and in an effort to expedite the return of their children to their care. The parents might take actions without speaking to a lawyer or being advised of the right to challenge the alleged child protection concerns.¹⁸⁷

Similarly, FASD impair the ability of young people to participate fully in delinquency proceedings. A 2014 study of young offenders with FASD found that 90 percent had an impaired ability in at least one of the following: understanding Miranda rights and criminal procedure, appreciating the nature and object of the proceedings, and participating in a defense and communicating with counsel.¹⁸⁸

Consequently, judges should proceed in ways that protect the rights of individuals with FASD.



See “Communicating with Individuals with FASD” for guidance on adapting proceedings and dispositional orders to compensate for FASD impairments.

Victimization

The deficits that individuals with FASD exhibit, which are similar to those with other brain-based disabilities, put them at a greater risk for victimization. Deficits such as poor insight, lack of ability to identify dangerous people, and difficulty with abstract thinking all contribute to the vulnerability of these individuals to fall victim in many situations that could ultimately place them in the family court system.¹⁸⁹ Victimization of individuals with FASD may be minimized, which highlights the need for judges and child welfare to understand and recognize this issue better. Victimization can occur in the home, school, or workplace and is most likely underreported due to the lack of cognitive ability of an individual with any type of FASD.¹⁹⁰ Those with FASD may be victims of child abuse and neglect, domestic violence, or put in a situation where they don’t understand the consequences of their actions (i.e., juvenile justice). When systems and institutions do not fully understand or lack a skilled workforce to address the needs of individuals with FASD, additional victimization may occur.¹⁹¹ The NCJFCJ supports courts becoming trauma informed, as this may help reduce any potential further victimization of individuals with FASD within the court system.

Because the social-emotional age of individuals with FASD is less than their chronological age, it’s helpful to think of them as younger when questioning and giving instructions.

Communicating with Individuals with FASD

The following communication strategies will help ensure due process and the exchange of information that will enable more informed decisions by all parties. Judges who follow these strategies also will be modeling for others in the legal system how to engage individuals affected by prenatal alcohol exposure fairly.

- ☐ Because the social-emotional age of individuals with FASD is less than their chronological age, it's helpful to think of them as much younger when questioning and giving instructions.
- ☐ Use simple, short sentences and clear, concrete terms. Individuals with FASD have difficulty with abstractions and generalizations.
- ☐ Keep questions short and clear and calmly prompt for answers.
- ☐ Speak slowly, and repeat often.
- ☐ Avoid legalese and acronyms that require individuals to recall information presented earlier.
- ☐ Use visual aids.
- ☐ Take extra breaks to enable a person's lawyer to explain the ongoing process. Confirm personally that the individual understands key concepts and his or her rights.
- ☐ Rewrite commonly used documents so that they are in plain English and have places for people to initial. The use of initialing allows both a judge and the individual to focus on one term of an agreement at a time.
- ☐ Rewrite terms of probation/case plans and prioritize terms so as not to overwhelm parties or set them up for failure.
- ☐ Ask individuals to repeat back their understanding. For greater confirmation that the individual understood, have the person read it, speak it, and write it, if possible.
- ☐ Be attentive to the fact that individuals affected by FASD have a desire to please and fit in and may pretend to understand when they don't.
- ☐ Listen carefully to notice a lack of understanding, miscommunication, or confusion.
- ☐ Be attentive to nonverbal cues from the parties as well as cues that you, as a judge, may be giving (e.g., frustration).^{192,193}

With guidance and more flexibility in the manner in which the legal system responds to the challenges of FASD, coupled with more informed and available support services, the quality of life for those living with FASD and their communities can be improved.

Judicial Leadership

As noted at the outset of this guide, the increasing attention to the impact of FASD on the court system points to the need for greater knowledge and a targeted response among legal professionals. Such a systems-wide change, however, requires leadership from the bench. Because judges see cases from all perspectives, they often can provide a clear vision for others of how the system needs to change to improve outcomes for the people it serves. Simply by asking if FASD should be considered, judges will be encouraging advocates and professionals to learn more about the issue and to take FASD into account when making recommendations to the court. Their involvement, in turn, will generate a demand for greater diagnostic and programmatic capacity and sorely needed resources in the community.

Judges also can lead by:

- Collaborating with medical, mental health, and FASD disability experts to promote appropriate legal representation and advocacy for individuals with FASD and to address the over-abundance of individuals with FASD in the foster care system, the juvenile justice system, and the adult criminal court.¹⁹⁴
- Conveying to the judicial and larger community why screening, diagnosis, and treatment for FASD are important and the benefits to individuals, families, and communities when these actions occur.
- Providing guidance and direction to agencies on the need for flexibility in dealing with families affected by FASD, including a multidisciplinary and coordinated approach to help them navigate complex systems.
- Embracing digital and technological advances that allow for information to be shared among professionals and the court, safely and in realtime.
- Becoming informed about existing resources and advocating for resources to fill in the gaps within the context of judicial ethics. A good starting point to locate resources are the websites of the Substance Abuse and Mental Health Services Administration's (SAMHSA) FASD Center for Excellence¹⁹⁵ and the National Organization on Fetal Alcohol Syndrome (NOFAS).¹⁹⁶



- ☐ Providing oversight for training, implementation, efficacy, and progress of programs.
- ☐ Identifying those who have interests and abilities to lead both in the courtroom and the community on FASD issues.
- ☐ Paying attention to vicarious trauma and strategies to cope with frustrations that accompany working with individuals living with FASD.
- ☐ Advocating, where possible, for legislation similar to that in Alaska, which recognizes FASD as a mitigating factor for juveniles and adults during criminal sentencing.
- ☐ Docketing for a one family-one judge model across case types, which will provide for consistency for those affected by FASD.

With guidance and more flexibility in the manner in which the legal system responds to the challenges of FASD, coupled with more informed and available support services, the quality of life for those living with FASD and their communities can be improved.

Court Examples

Studies in Colorado and Minnesota demonstrated that many children on probation can be identified with FASD and their Terms and Conditions modified so that they can successfully complete probation and remain crime-free.

Probation Screening, Diagnosis, and Intervention

The 17th Judicial District in Adams County, Colorado and the 4th Judicial District in Hennepin County, Minnesota conducted studies in which they completed a FASD screen on children placed on probation and, in Colorado, during the Pre-sentence Investigation (PSI) process. Both projects identified a large number of children who likely had a type of FASD, completed comprehensive evaluations, and modified their probation programs so that the children could successfully complete them.

The screens of these children determined if one of the following was present: 1) report of prenatal alcohol exposure by a parent or other adult in the child's life; 2) a previous diagnosis of any of the FASD; 3) a sibling with any type of FASD diagnosis; or 4) presence of the facial features of FAS or pFAS. Colorado probation officers completed the screens on all of their probation or PSI children and had positive screens on 25 percent of the children. Minnesota FASD staff completed the screens on all of the children who had a positive score on the MAYSI-2 (Massachusetts Youth Screening Instrument), plus those referred by the court or probation; 46 percent of the children had positive screens. Referrals made by the court or probation had a high degree of accuracy with 100 percent receiving a positive screen.

While not all children completed evaluations during the study period, 48 percent of those who did complete in Colorado and 92 percent in Minnesota were given a diagnosis in the FASD spectrum. In both studies, the majority of the identified children were able to receive services that helped them successfully complete probation and stay offense-free following diagnosis. Small numbers were followed for a full year following probation completion, and 85 percent in Colorado and 79 percent in Minnesota were violation and crime-free. The children who received a diagnosis also had increased school stability and success.

These projects demonstrated that children in the justice system can be identified and have increased successful outcomes through recognition of and intervention for their FASD.

Lessons Learned: Role and Recommendations for Judges

The judges' commitment to integrating FASD screening, diagnosis, and treatment into their court system set the tone for the success of these programs. They provided the leadership to organize the FASD screening programs and used their judicial authority to bring people together by chairing or co-chairing FASD task forces. The FASD task forces were instrumental in bringing all partners and providers together to address such issues as screening, diagnostic capacity, payment for the FASD diagnostic evaluations, engagement and training of providers, and appropriate interventions based on the individual needs of the child.

Specifically, regarding the referral for an FASD diagnostic evaluation, the court should not just request a diagnosis or rule out a diagnosis of any form of FASD, but also include the following:

- What types of environments will be most suitable for placement?
- What accommodations need to be made at school or by the court, attorneys, probation, or service providers?
- What can the probation officer do to help the child be compliant with probation requirements?
- What level of supervision would be recommended?
- What do parents need to do to help the child do well in school or work?
- What needs to be addressed to ensure community safety?
- What services does the child need to succeed in school or work?

Judges should also request that the evaluator provide a one- to two-page summary with the FASD diagnostic evaluation report written in plain language that can be used by the parents and staff.

The NCJFCJ's website includes additional resources, including court orders and articles of interest. Visit www.NCJFCJ.org for more information.

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