

AMERICAN BAR ASSOCIATION

Co-Sponsors: ABA Commission on Youth at Risk, Criminal Justice Section, Commission on Disability Rights, Commission on Homelessness and Poverty, Death Penalty Representation Project, Health Law Section, Section of Family Law, Judicial Division, Alaska Bar Association, and the American Judicature Society

APPROVED BY THE ABA HOUSE OF DELEGATES – AUGUST 7, 2012

RESOLUTION

RESOLVED, That the American Bar Association urges attorneys and judges, state, local, and specialty bar associations, and law school clinical programs to help identify and respond effectively to Fetal Alcohol Spectrum Disorders (FASD) in children and adults, through training to enhance awareness of FASD and its impact on individuals in the child welfare, juvenile justice, and adult criminal justice systems and the value of collaboration with medical, mental health, and disability experts.

FURTHER RESOLVED, That the American Bar Association urges the passage of laws, and adoption of policies at all levels of government, that acknowledge and treat the effects of prenatal alcohol exposure and better assist individuals with FASD.

REPORT

Introduction

Fetal Alcohol Spectrum Disorders (FASD) is a serious problem in the U.S., adversely affecting a very large number of children and families, and in recognition of that the U.S. Senate has annually, since 2004, passed a resolution designating September 9th as National Fetal Alcohol Spectrum Disorders Awareness Day. In 2011 Senate Resolution 259¹ called upon the people of the United States to promote awareness of the effects of prenatal exposure to alcohol, to increase compassion for individuals affected by prenatal exposure to alcohol, to minimize the effects of prenatal exposure to alcohol to ensure healthier communities across the United States, and to observe a moment of reflection during the ninth hour of September 9, 2011 to remember that during her nine months of pregnancy a woman should not consume alcohol.

The Report provides background on FASD and discusses its impact on the justice system, the child welfare system, and the disability benefits system. It also describes approaches to improving the various problems identified in individuals with FASD who are in these systems. In addition, it highlights current initiatives that are in place to benefit individuals with FASD.

The essential focus of this Resolution is to encourage: improvement in the civil, juvenile, and criminal legal representation for persons with FASD; increased access to FASD expert screening and assessment; attention to the over-abundance of FASD-affected persons in foster care, juvenile delinquency cases, adult criminal proceedings, and correctional facilities; and the use of FASD knowledge in court for the mitigation of sentencing and alternatives to incarceration and execution, including therapy and comprehensive services to rehabilitate and reduce recidivism. *Neither the Resolution nor this Report should be construed as suggesting that use of alcohol during pregnancy is, or should be, a criminal act.*

¹ The language of the Senate Resolution includes these observations: "...fetal alcohol spectrum disorders are the leading cause of cognitive disability in Western civilization, including the United States, and are 100 percent preventable...fetal alcohol spectrum disorders are a major cause of numerous social disorders, including learning disabilities, school failure, juvenile delinquency, homelessness, unemployment, mental illness, and crime".

The ABA House of Delegates has not previously addressed the issue of FASD. FASD is a disability that cuts across all age ranges, and it is a lifelong disability. There are unique concerns and problems facing children and youth with FASD that need to be addressed. This includes the very large numbers of children with FASD in both the foster care and juvenile justice system, as well as in the adult criminal justice system and correctional institutions. The focus of the ABA Commission on Youth at Risk is on youth, and that is the reason for its principal sponsorship of this Resolution. Given the unique nature of FASD, this Resolution, while addressing and focusing on issues that impact children with FASD, also contains suggestions for actions that would benefit adults with FASD.

This Resolution and its accompanying Report provides a road map, for legal professionals, lawmakers, and those in government who deal with youth at risk, to increase awareness of FASD. It also encourages federal, state, territorial, tribal, and local law and policy makers to implement laws and policies that reflect the serious effects of prenatal alcohol exposure.

Types of Fetal Alcohol Spectrum Disorders

FASD is a group of conditions that can occur in individuals whose mother drank alcohol during pregnancy.² FASD can result in birth defects, growth and development deficits, cognitive and learning issues, executive functioning problems, difficulty remaining attentive, and problems socializing, as well as other behavioral issues.³

The correlation between maternal alcohol consumption during pregnancy and deficits in physical and mental development were first identified in the early 1970s.⁴ The first common symptoms identified among children who had been prenatally exposed to alcohol were growth deficiencies and developmental delays.⁵ Shortly thereafter Kenneth L. Jones, et al., found similar physical characteristics in these individuals.⁶ They included similar patterns of craniofacial, cardiovascular, and limb defects.⁷

A follow-up study followed 11 children whose mothers drank heavily during pregnancy and found many common features among this cohort.⁸ Among this small sample population, all children displayed growth deficiencies (for height, weight, and head circumference), their abnormal craniofacial features had not changed over the past decade, and they all had below-normal intellectual development.⁹ Most of these children had low IQ scores and 8 were either mildly or severely handicapped.¹⁰

Since that time, several disorders related to fetal alcohol exposure have been identified. There are several types of FASD, including Fetal Alcohol Syndrome (FAS), Partial FAS, Alcohol Related Neurodevelopmental Disorders (ARND), and Alcohol Related Birth Defects (ARBD).¹¹ These four diagnoses share certain

² National Institute on Alcohol Abuse and Alcoholism, Alcohol Alert, Fetal Alcohol Spectrum Disorders: Understanding the Effects of Prenatal Alcohol Exposure, No. 82.

³ *Id.* On March 29, 2012 U.S. Senators Johnson, Murkowski, Inoye, and Begich introduced S.2262, the *Advancing FASD Research, Prevention, and Services Act*, that addresses many of the issues included in this Resolution and Report.

⁴ Kenneth L. Jones, David W. Smith, Christy N. Ulleland, & Ann Pytkowicz Streissguth, *Pattern of Malformation in Offspring of Chronic Alcoholic Mothers*, THE LANCET, June 9, 1973, at 7815.

⁵ C. N. Ulleland, *The Offspring of Alcoholic Mothers*, 197 ANN. NYACAD. SCI. 197 (1972).

⁶ Medically referred to as aberrant morphogenesis.

⁷ Jones et al., *supra* note 4.

⁸ Ann Pytkowicz Streissguth, Sterling Keith Clarren, & Kenneth Lyons Jones, *Natural History of the Fetal Alcohol Syndrome: A 10-Year Follow-up of Eleven Patients*, THE LANCET, July 13, 1985, at 85.

⁹ *Id.*

¹⁰ *Id.*

¹¹ National Institute on Alcohol Abuse and Alcoholism, *supra* note 2.

characteristics and fall within the broader category of FASD.¹² All but ARBD involve significant brain damage.

FAS is the most severe of the conditions that constitute FASD. An FAS diagnosis requires three specific deficits:¹³ a characteristic pattern of facial abnormalities known as facial dysmorphism, such as a smooth ridge between the nose and upper lip;¹⁴ growth deficits, such as lower than average weight and/or height;¹⁵ and central nervous system abnormalities or brain damage.¹⁶ The latter may include a diagnosis of Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD).¹⁷ While generally, individuals with FAS tend to be the most impaired, with more severe physical and cognitive issues than individuals with other forms of FASD,¹⁸ those with Partial FAS and ARND tend to show the most severe secondary disabilities.¹⁹ FAS alone costs the United States approximately \$5.4 billion each year in direct and indirect costs.²⁰ It is also the leading cause of non-genetic intellectual disability in the United States.²¹

Partial FAS includes some of the signs and symptoms of full FAS but not all.²² Individuals with Partial FAS typically still present with physical and emotional deficits, but do not have all of the physical characteristics listed in the FAS diagnostic guidelines. ARND includes central nervous system abnormalities and other cognitive/behavioral problems, but none of the outward physical abnormalities.²³ Individuals with partial FAS and ARND present with cognitive issues that can be as severe as those seen in FAS. ARBD is a rarely-used diagnosis that only identifies alcohol related physical abnormalities outside the central nervous systems (e.g., skeletal or organ abnormalities).²⁴

The prevalence of full FAS and FASD has been examined in several studies. In one, the prevalence of full FAS in the U.S. was estimated at 0.5-2.0 cases per 1000 births.²⁵ The estimated rate of alcohol-affected births was estimated to be 5 to 10 times higher, close to 1% of newborns.²⁶ A more recent study reported the FAS prevalence in the U.S. to be at least 2 to 7 cases per 1000 births, with all levels of FASD estimated as high as 2-5% among younger school children.²⁷ There is currently an NIAA initiative to establish more accurate estimates of FASD prevalence.

¹² It is important to note that FASD is not a diagnosis; it is a broader category of related diagnoses.

¹³ National Institute on Alcohol Abuse and Alcoholism, *supra* note 2.

¹⁴ *Id.* at 2.

¹⁵ *Id.* at 1.

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1966). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final Report: Centers for Disease Control and Prevention Grant No. R04/CCR008515.

²⁰ National Organization on Fetal Alcohol Syndrome, FASD: What Everyone Should Know, <http://www.nofas.org/MediaFiles/PDFs/factsheets/everyone.pdf>.

²¹ National Institute on Alcohol and Abuse and Alcoholism, *The 10th Special Report to the U.S. Congress on Alcohol and Health: Prenatal Exposure to Alcohol*, No. Publication No. 00-151583 (2000); Amy M. Schonfeld, Blari Paley, Fred Frankel, and Mary J. O'Connor, *Executive Functioning Predicts Social Skills Following Prenatal Alcohol Exposure*, 12 CHILD NEUROPSYCHOLOGY 439 (2006).

²² National Institute on Alcohol Abuse and Alcoholism, *supra* note 2, at 1.

²³ *Id.*

²⁴ *Id.*

²⁵ NIH Fact sheet; P.A. May & J. P. Gossage, *Estimating the prevalence of Fetal Alcohol Syndrome: A Summary*, 25 ALCOHOL RESEARCH & HEALTH 159 (2001).

²⁶ Diane V. Malbin, *Fetal Alcohol Spectrum Disorder (FASD) and the Role of Family Court Judges in Improving Outcomes for Children and Families*, JUVENILE & FAM. CT. J. 52 (2004).

²⁷ Philip A. May, J. Phillip Gossage, Wendy O. Kalbert, Luther K. Robinson, David Buckley, Melanie Manning, and H. Eugene Hoyme, *Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies*. Dev Disabil Res Revs, 15: 176-192 doi: 10.1002/ddrr.68 (2009).

The intent of this Resolution is to spur development of programs for those living with FASD and their families. This should especially include youth transitioning from foster care and juvenile justice systems, since those with FASD are especially vulnerable to physical and sexual abuse. One study of over 400 individuals with FASD found that 72% had been abused, either physically or sexually.²⁸

Cause of FASD

FASD is caused by prenatal alcohol exposure. There is no safe amount of alcohol to drink during pregnancy, and even small amounts of alcohol may have an impact on fetal brain development.²⁹ A U.S. Surgeon General's 2005 advisory states that: pregnant women should *not* consume alcohol during pregnancy; pregnant women who have already consumed alcohol while pregnant should *stop* to minimize risk; and women who are *considering* becoming pregnant should not drink alcohol.³⁰ In addition, former Surgeon General Carmona recommended that health professionals routinely ask women of child bearing age about their alcohol consumption and advise them not to drink during pregnancy, noting that this is of particular importance since about half the births in the United States are unplanned.³¹ Many professional medical association guidelines also indicate that women should not drink alcohol during pregnancy.³²

Although any prenatal alcohol exposure presents a risk, there does seem to be a correlation between the amount of alcohol a woman drinks during pregnancy and the likelihood her child will have FASD.³³ Some women who consume alcohol heavily during pregnancy do not have a child with FASD.³⁴ However, typically, the more a woman drinks during pregnancy, the higher the risk her child will have FASD and the more severe that child's symptoms will be.³⁵

Diagnosis and Treatment

There are several diagnostic guidelines for FASD, each of which list characteristics required for a FAS, partial FAS, ARND, or ARBD diagnosis. Despite these guidelines, there are still challenges to diagnosing individuals with these disorders. It may be particularly difficult to diagnosis less severe cases of FASD. Individuals with FASD do not always present with observable physical characteristics, making it more difficult to diagnose them.³⁶ In addition, one of the most helpful ways to diagnose FASD is when there is confirmed prenatal alcohol exposure; however, mothers are often reluctant to admit they drank alcohol during pregnancy due to a sense of guilt or shame.³⁷

²⁸ Ann Streissguth, *Attaining Human Rights, Civil Rights, and Criminal Justice for People with Fetal Alcohol Syndrome*, TASH NEWSLETTER, September 1998, at 18.

²⁹ U.S. Surgeon General, Surgeon General's Advisory on Alcohol and Pregnancy, 2005, available at <http://www.surgeongeneral.gov/pressreleases/sg02222005.html>; Claire Coles, *Discriminating the Effects of Prenatal Alcohol Exposure From Other Behavioral and Learning Disorders*, 34 ALCOHOL RESEARCH AND HEALTH 42 (2011).

³⁰ U.S. Surgeon General, Surgeon General's Advisory on Alcohol and Pregnancy, 2005, available at <http://www.surgeongeneral.gov/pressreleases/sg02222005.html>.

³¹ *Id.*

³² See e.g., American College of Obstetricians and Gynecologists.

³³ Susan E. Maier & James R. West, *Patterns and Alcohol-Related Birth Defects*, National Institute on Alcohol Abuse and Alcoholism, available at <http://pubs.niaaa.nih.gov/publications/arh25-3/168-174.htm>.

³⁴ This may be due to a number of factors including, but not limited to, genetic susceptibility, maternal metabolism, drinking patterns,

³⁵ Maier, *supra* note 33.

³⁶ Malbin, *supra* note 26.

³⁷ Kenneth Lyons Jones & Ann P. Streissguth, *Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders*, 38 J. PSYCH & L. 373 (2010).

Individuals with FASD may have IQs that are in the average range and appear to have good verbal skills, making it more difficult to recognize FASD.³⁸ Although these individuals may not have obvious symptoms or characteristics, they typically exhibit adaptive behavior and other deficits that make it difficult for them to function at an age appropriate level.³⁹

There is no cure for FASD, and the deficits associated with these disorders follow children into adulthood.⁴⁰ That being said, early intervention and treatment services may improve a child's development. Strategies include medication for some symptoms, behavioral and educational therapies, special education, social services, and the support of a nurturing and loving environment.⁴¹ These interventions are most effective when a child is diagnosed before age 6.⁴² Children with FASD who were involved in intervention programs to improve social skills showed improvements in both knowledge and behavior.⁴³

It is critical that comprehensive resources be allocated for early identification, diagnosis, intervention, and treatment for those with FASD. Given the array of problems individuals with FASD face, and the importance of early intervention, it is vital that professionals become aware of the issue so that appropriate services can be provided.

Impact on the Justice System

Children with FASD are at high risk of getting into trouble with law. One study looked at FASD in alleged juvenile offenders in British Columbia, Canada during 1995. All youth from the juvenile court who were sent to the Inpatient Assessment Unit for purposes of a psychological and psychiatric study were also assessed for what was then called FAS/FAE and is now called FASD. Of the 287 youth seen over a year's time, 23.3 % had an alcohol-related diagnosis (FASD). The authors also found, among youth in juvenile facilities, an astounding 40 times the expected rate of individuals with FASD.⁴⁴

Individuals with FASD have executive functioning issues that result in difficulties socializing with peers, sharing, and managing conflicts.⁴⁵ This can result in rejection, which leads to a higher probability of individuals with FASD associating with other rejected children and a higher probability that they will be involved in delinquent behaviors and have problems with the law.⁴⁶

A large study at the University of Washington found that about 60% of individuals with FASD had a history of trouble with the law and 50% had a history of confinement in a jail, prison, residential drug treatment facility, or

³⁸ Natalie Novick Brown, Anthony P. Wartnik, Paul D. Connor, and Richard S. Adler, *A Proposed Model Standard for Forensic Assessment of Fetal Alcohol Spectrum Disorders*, 38 J. OF PSYCH. & L. 383, 387 (2010).

³⁹ Kathryn Page, *The Invisible Havoc of Prenatal Alcohol Damage*, J. CENTER FOR FAM. CHILD. & CTS. 1, 10-11 (2002).

⁴⁰ Blair Paley and Mary J. O'Connor, *Neurocognitive and Neurobehavioral Impairments in Individuals with Fetal Alcohol Spectrum Disorders: Recognition and Assessment*, 6 INT'L J. DISABIL. HUM. DEV. 127, 130 (2007).

⁴¹ *Id.*

⁴² *Id.*

⁴³ Mary O'Connor et al., *A Controlled Social Skills Training for Children with Fetal Alcohol Spectrum Disorders*, 74 J. CONSULTING & CLINICAL PSYCH. 639, 646 (2006).

⁴⁴ Malbin, *supra* note 26, citing Julianne Conry and Diane K. Fast, *Fetal Alcohol Syndrome and Criminal Justice*, BC: Fetal Alcohol Syndrome Resource Society (2000); *see also*, Diane K. Fast, Julianne Conry, and Christine A. Looek, *Identifying Fetal Alcohol Syndrome Among Youth in the Criminal Justice System*, *Developmental and Behavioral Pediatrics*, v. 20(5), October 1999.

⁴⁵ Schonfeld, et al., *supra* note 21, at 450.

⁴⁶ *Id.*

psychiatric hospital.⁴⁷ The average age children with FASD begin having trouble with the law is 12.8 years.⁴⁸ This may be in part due to the fact that children with FASD are easily led by others and tend to be impulsive.⁴⁹ Individuals with FASD have various characteristics that put them at a greater risk of ending up in the criminal justice system. For example, as was mentioned, they are typically impulsive and have difficulty predicting the consequences of their actions.⁵⁰

In addition, given their executive functioning problems, these individuals may not always have the legal capacity to commit deliberate/intentional crimes.⁵¹ Given these characteristics:

*...[i]n the criminal context, FASD-associated problems in reflection, forming intent, and carrying out effective goal-directed behavior are directly relevant to mental state...their behavior often breaks down or decomposes in novel high-stress situations...This decomposition often leads to instinctive fight or flight reaction...neglecting previous learning experiences, consequences, and impact on themselves and others.*⁵²

Several issues surrounding individuals with FASD in the justice system include competency to stand trial, validity of expert testimony,⁵³ and mitigation during sentencing.⁵⁴ Individuals with FASD may not understand charges.⁵⁵ Since individuals with FASD cannot always form the requisite intent required for certain crimes and do not fully understand the consequences of their actions, defendants with FASD may face diminished capacity issues.

In *Dillbeck v. State*, the court held that FASD should be considered in the guilt/innocence phase of the trial as well as in sentencing, noting that:

*... Evidence concerning certain alcohol-related conditions has long been admissible during the guilt phase of criminal proceedings to show lack of intent ... then so too should evidence of other commonly understood conditions that are beyond one's control ... [w]e perceive no significant legal distinction between the condition of epilepsy... and that of alcohol-related brain damage in issue here – both are specific, commonly recognized conditions that are beyond one's control.*⁵⁶

This is significant because the court recognized the benefits of considering FASD during both the trial phase and during sentencing.

Confirming a diagnosis of FASD may be critical in designing a sentence or sentencing alternative that will be effective in reducing the risk of recidivism and will avoid causing far greater harm to a defendant with FASD than to a defendant without this disability. Because of their impairments, individuals with FASD, when confined in a jail or prison, can be more vulnerable than those who are not disabled to physical and sexual abuse, and consequently more adversely affected than others.⁵⁷

⁴⁷ Natalie Novick Brown, Anthony P. Wartnik, Paul D. Connor, and Richard S. Adler, *A Proposed Model Standard for Forensic Assessment of Fetal Alcohol Spectrum Disorders*, 38 J. OF PSYCH. & L. 383, 384 (2010).

⁴⁸ *Id.*

⁴⁹ Natalie Novick Brown, Gisli Gudjonsson, & Paul D. Connor, *Suggestibility and Fetal Alcohol Spectrum Disorders: I'll Tell You Anything You Want to Hear*, 39 J. OF PSYCH. & L. 39 (2011).

⁵⁰ Substance Abuse and Mental Health Services Administration: A Fetal Alcohol Spectrum Disorders Center for Excellence. *What You Need To Know: Fetal Alcohol Spectrum Disorders and Juvenile Justice: How Professionals Can Make a Difference*. DHHS Pub. No. (SMA)-06-4240 (Rockville, MD: 2007).

⁵¹ Brown, et al., *supra* note 49.

⁵² Brown et al., *supra* note 47.

⁵³ *See State v. Brett*, 126 Wash. 2d 136, 892 P.2d 29 (1995); *Castro v. State of Oklahoma*, 71 F.3d 1502 (10th Cir. 1995) (discussing who can determine a whether an individual has FASD when it is unknown if the mother drank alcohol during pregnancy).

⁵⁴ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services, *Fetal Alcohol Spectrum Disorders and the Criminal Justice System*, available at www.samhsa.gov.

⁵⁵ *See Dunn v. Johnson*, 162 F.3d 302 (5th Cir. 1998); *People v. Flemming*, 2003 WL 21675890 (Mich. App.); *State v. Lee*, 220 Wis. 2d 716, 583 N.W. 2d 674 (Ct. App. Wisc. 1998).

⁵⁶ *Dillbeck v. State*, 643 So. 2d 1027 (Fla.).

⁵⁷ Kathryn A. Kelly, "Fetal Alcohol Spectrum Disorders and the Law," in *Prenatal Alcohol Use and FASD: Diagnosis, Assessment and New Directions in Research and Multimodal Treatment* (Susan A. Aduabato and Deborah E. Cohen, eds), 2011.

In recent years, FASD has been offered as a mitigating factor during sentencing; there are many death penalty cases in which the defendant's history suggests FASD and a diagnosis of FASD has been persuasive to juries as an explanation for otherwise inexplicable behavior. Also, in *Atkins v. Virginia*, the U.S. Supreme Court held that executing an individual with an intellectual disability violates the Eighth Amendment.

In some cases this will exclude the defendant with FASD from eligibility for the death penalty. However, if an I.Q. score of 70 or below, as many states define intellectual disability, is what disqualifies a defendant from the death penalty then most of those with FASD, because of their typically higher scores, would not be covered by *Atkins*.⁵⁸

Children and adults with FASD are becoming involved in the justice system at an alarming rate. The unique characteristics of these individuals warrant additional attention.⁵⁹ This Resolution encourages increased awareness of FASD among attorneys, judges, other court professionals, and court appointed advocates. These individuals are urged to utilize existing screening tools to identify clients with FASD.

Attorneys, judges, bar associations and law school clinical programs, as well as all other persons and entities involved with youth at risk, juvenile justice, or adult criminal court, should also support training and develop enhanced awareness and understanding of FASD. This can be accomplished by collaborating with medical, mental health, and disability experts on training to enhance representation for individuals with FASD. Current initiatives that strive to achieve such successes are discussed later in this Report and can be used as potential models.

Courts should also be considering FASD disability as a factor in mitigation with juvenile and adult offenders during sentencing, particularly where the death penalty is an option. This mitigating factor should also be applied when considering alternatives to incarceration, including therapy, community-based programs, and other non-custodial measures, in order to rehabilitate the individual and reduce recidivism.

Impact on the Child Welfare System

A large study of over 400 individuals with FASD, ranging from age 6-51, resulted in various concerns about human rights, civil rights, and criminal justice system involvement for individuals with FASD.⁶⁰ An astounding 80% of children in that study had not been primarily raised by a biological parent.⁶¹ In addition, 12% of children and 60% of adolescents experienced significant school disruptions.⁶² This statistic is especially disturbing since children with FASD already face heightened academic challenges based on several of the mental and behavioral characteristics associated with FASD. It is clear that children with FASD are part of the "at-risk" population and should have access to special programs and services.

There are a disproportionate number of children with FASD in the foster care system; the rate of FAS in the foster care system is 10-15 times higher than in the general population.⁶³ In the United States, an estimated 70% of children in foster care are affected by some type of prenatal alcohol exposure.⁶⁴ This is particularly

⁵⁸ *Atkins v. Virginia*, 536 U.S. 304 (2002).

⁵⁹ Timothy E. Moore & Melvyn Green, *Fetal Alcohol Spectrum Disorder (FASD): A Need for Closer Examination by the Criminal Justice System*, 19 CRIM. REPORTS 99 (2004).

⁶⁰ Ann Streissguth, *Attaining Human Rights, Civil Rights, and Criminal Justice for People with Fetal Alcohol Syndrome*, TASH NEWSLETTER, September 1998, at 18.

⁶¹ *Id.*

⁶² *Id.*

⁶³ SJ Astley, J Stachowiak, SK Clarren, & C Clausen, *Application of the fetal alcohol syndrome facial photographic Screening Tool in a Foster Care Population*, 141 J. Pediatrics 712 (2002).

⁶⁴ The National Organization on Fetal Alcohol Syndrome, *FASD in the Foster Care System*, http://adp.ca.gov/women/pdf/FASD_in_the_Foster_Care_System.pdf

worrisome because children with FASD benefit from having a stable environment, a comfort that is, unfortunately, not available for many children in foster care.

Children in foster care are already at high risk for educational disruptions as well as behavioral and developmental issues. This is exacerbated when that child has FASD. It would be beneficial to provide training and education to foster parents on how to identify the behaviors associated with FASD, how to seek a diagnosis of the disability, and how to appropriately respond to characteristics and behaviors associated with FASD. This training could provide foster parents with information about services and programs available for children with FASD.

Full implementation is also necessary for a provision of the federal *Child Abuse Prevention and Treatment Act*⁶⁵ that was intended to provide for more effective screening and referral processes for individuals with FASD, in recognition of the importance of addressing the over-abundance of children with FASD in the child welfare system. Fully implementing that Act's existing mandate of screening and referral processes for children with FASD can help assure their early identification and hopefully prompt access to successful treatment.

Impact on Disability Benefits

Individuals with disabilities may be eligible for medical and cash benefits, such as Social Security Disability, based on their disability. Children and adults with FASD may be eligible for such benefits, but a diagnosis of FASD does not create an automatic entitlement⁶⁶ and they will be required to meet statutory criteria, and establish that such impairment exists.⁶⁷ In some cases, individuals will be required to prove that FASD severely limits their work activities, which may not be the case for many individuals with FASD.⁶⁸

Individuals with FAS or more severe FASD symptoms will have an easier time proving they are eligible for benefits. That being said, even individuals with severe cases of FAS may face difficulties establishing their eligibility because the system is complex and often difficult to navigate.⁶⁹ Also, state law and policy may not list FASD related impairments within their definitions of "developmental disabilities."⁷⁰ Individuals who seek attorney representation may have an easier time establishing eligibility and gaining access to disability benefits that will improve their quality of life.

It is important that FASD, alcohol-related neurological disorders, alcohol-related birth defects, and the effects of fetal alcohol exposure generally, be included within statutory definitions of developmental disabilities and listing of conditions that provide medical and other benefit coverage for screening, diagnosis, and treatment for those with these conditions. Law and policy makers should ensure that individuals with FASD are eligible for disability benefits and appropriate medical services. Eligibility and utilization of these benefits and services will help improve the lives of individuals with FASD, especially youth and those transitioning out of the foster care or juvenile justice system.

⁶⁵ 42 U.S.C. 5106a (b)(2)(B).

⁶⁶ Amy Gilbrough, *Eligibility for Social Security Benefits: Fetal Alcohol Spectrum Disorders, in Alcohol Related Birth Disorders and the Law: How Should Attorneys & Judges Respond to FASD?*, Continuing Legal Education Materials (Feb. 3, 2012).

⁶⁷ *Id.*

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ One state law that does include FASD as a "related condition" within the definition of developmental disabilities is Minnesota Statutes §252.27.

Current Initiatives

There are many beneficial programs and initiatives in the United States focusing on increasing awareness of FASD among legal professionals, identifying individuals with FASD in the justice system, and ensuring that these individuals receive appropriate and necessary services. This section highlights two of these initiatives.

Seventeenth Judicial District Juvenile Court FASD Project

The Juvenile Court of Colorado's 17th Judicial District's FASD Project is working to increase awareness of FASD among judicial officers, attorneys, and court appointed advocates and use referrals as an effective tool for children in the child welfare system.⁷¹ The FASD Project screens children in the Juvenile Delinquency and Child Welfare Courts of Adams and Broomfield Counties for prenatal substance exposure.⁷² By integrating FASD screening, diagnosis, and intervention within the court system, the FASD Project is working to improve the lives of children and youth with FASD.

The FASD Project's key strategies are:

- To integrate FASD screening into Juvenile Court;

- To refer children to a diagnostic center for evaluation and a possible diagnosis;

- To meet with key players in the child's life, including parents, case workers, and probation officers, to develop individualized case plans for children with FASD; and

- To track data and monitor the success of this project.

The FASD project is so important because "it is identifying, supporting and tracking outcomes for children and youths who would otherwise have a high likelihood of failing in school, experiencing multiple placements, and re-offending or violating probation."⁷³ This project provides the necessary care for children with FASD while increasing awareness among professionals who work with these individuals to ensure that the appropriate care and services are provided.

Alaska FASD Partnership

The Alaska FASD Partnership is a statewide coalition of over 75 organizations and individuals working to prevent FASD and improve access to services for individuals with FASD. The mission of the partnership is "[t]o promote awareness, prevention, and effective life-long interventions for those affected by prenatal exposure to alcohol and their families."⁷⁴ Through seven workgroups, the partnership has been able to identify gaps and barriers to services for individuals with FASD.⁷⁵ The workgroups develop policy and funding recommendations and strive to increase awareness about this issue.

In 2010, the partnership's first year, they were integral in establishing state funding for substance abuse treatment programs for pregnant women, parent navigation services, and greater access to services for individuals with FASD.⁷⁶ The workgroups are currently addressing several important issues, including prevention of FASD, diagnosis and access to services, the impact of FASD in the legal and education systems, and professional development.⁷⁷ Identifying these issues and establishing best practices will ensure better services and care for individuals with FASD.

⁷¹ Seventeenth Judicial District Juvenile Court FASD Project, Project Summary, <http://www.fasdcenter.com/files/17thJudicialDistrictColorado-Article.pdf>.

⁷² *Id.*

⁷³ *Id.*

⁷⁴ Advisory Board on Alcoholism and Drug Abuse, Alaska FASD Partnership, <http://www.hss.state.ak.us/abada/fasd.htm>.

⁷⁵ *Id.*

⁷⁶ *Id.*

⁷⁷ *Id.*

The Seventeenth Judicial District FASD Project and the Alaska FASD Partnership are two initiatives that exemplify meaningful work being done around the country to serve individuals with FASD. As highlighted by this Report, legal professionals and individuals involved with youth at risk should be supporting training and awareness of FASD. In addition, lawmakers should be addressing various issues surrounding FASD to ensure that individuals with FASD have access to appropriate services and are treated fairly.

Conclusion

Given the alarming data, and the unique characteristics of individuals with FASD, there is a clear need for increased awareness of FASD. Attorneys, judges, bar associations, law schools, and other entities involved with at-risk youth, juvenile justice, and the adult criminal court should support training and awareness of FASD. These individuals should collaborate 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.⁷⁸ In addition, courts should use FASD as a mitigating factor for juveniles and adults during criminal sentencing.

Federal, state and local law and policy makers should also enact laws and policies that reflect the serious effects of prenatal alcohol use. It is vital to increase public awareness, especially for women who are substance abusers, pregnant, or of childbearing age, about FASD to both prevent its occurrence and to ensure that individuals with FASD, and specifically children and youth with FASD, have access to appropriate services and, if they are involved in the courts, skilled legal representation.

⁷⁸ In August 2010 the Council of the Canadian Bar Association approved resolution 10-02-A, which called for the “initiative of Federal, Provincial and Territorial Ministers responsible for Justice with respect to access to justice for people with FASD,” urged “all levels of government to allocate additional resources for alternatives to the current practice of criminalizing individuals with FASD,” urged “federal, territorial and provincial governments to develop policies designed to assist and enhance the lives of those with FASD and to prevent persistent over-representation of FASD affected individuals in the criminal justice system,” and urged “the federal government to amend criminal sentencing laws to accommodate the disability of those with FASD.”