Fetal Alcohol Spectrum Disorders and victimization: Implications for families, educators, social services, law enforcement, and the judicial system

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Individuals with Fetal Alcohol Spectrum Disorders (FASD) are vulnerable to many forms of victimization. FASD is associated with cognitive deficits and a set of behaviors that may limit an individual’s ability to recognize and report victimization experiences and provide testimony in judicial proceedings. Services must be established and provided to educate and train individuals with FASD, their family members, teachers, and social service workers to prevent victimization and report victimization when it occurs. Law enforcement and the judicial system also should develop systems to protect the rights of individuals with FASD who are victimized, especially when they appear as witnesses.

KEY WORDS: FASD, victimization, law enforcement, judicial system.

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Fetal Alcohol Spectrum Disorders (FASD) are the leading known preventable cause of intellectual disabilities, birth defects, and neurobehavioral disorders.\textsuperscript{1} The Centers for Disease Control and Prevention (2002) notes, however, that estimates vary on the prevalence of FASD because Fetal Alcohol Syndrome (FAS) cases may not be diagnosed, medical records of children with FAS may lack sufficient documentation, and some children are not diagnosed until they reach school age. Sampson et al. (1997) estimated that the combined prevalence rate for two types of FASD, FAS and what is now referred to as Alcohol Related Neurodevelopmental Disorder (ARND) was at least 9.1 per 1,000 live births. The effects of prenatal alcohol exposure may manifest themselves in facial malformations, intellectual disabilities, cognitive impairments, and problems with adaptive functioning that render those with FASD particularly susceptible to victimization.

FASD describes the range of effects that can occur in an individual whose mother consumed alcohol during her pregnancy.\textsuperscript{2} The term FASD includes FAS and ARND as well as Partial Fetal Alcohol Syndrome (PFAS), Alcohol-Related Birth Defects (ARBD) and Fetal Alcohol Effect (FAE). While all of these terms appear in medical and academic literature and in the case law, FAS, with some adaptations, is the only diagnosis included in the ICD. It is the most recognizable form of FASD; approximately 20\% of individuals with quantifiable effects of prenatal alcohol exposure meet the standard for a FAS diagnosis.

Individuals with FASD have much in common with others with intellectual, cognitive or behavioral disorders that put them at risk for victimization. Rand and Harrell’s (2009) analysis of the U.S. Department of Justice’s 2007 National Crime Victimization Survey (NCVS) found that individuals age 12 and over with disabilities experienced approximately 716,000 nonfatal violent crimes (e.g. rape, sexual assault, robbery, aggravated and simple assault) and 2.3 million...
property crimes (e.g. burglary, auto and property theft) that year. This survey provided the first national estimates of the prevalence of criminal victimization against this vulnerable population.

The NCVS survey also found that 12 to 19-year-old adolescents with disabilities experienced violence at nearly twice the rate of those without a disability, and those with cognitive disabilities have experienced violent crimes at a higher rate than persons with other types of disabilities. Children with intellectual disabilities are particularly vulnerable. Sullivan and Knutson (2000) found that children with intellectual disabilities were four times more likely to be sexually abused. Moreover, Luckasson (1992) noted that interactions with “protectors” who exploit them, a lack of knowledge on how to protect themselves, and living or working in high-risk environments, increase the vulnerability of individuals with FASD to victimization.

Individuals with FASD also have a greater risk of experiences that can, in turn, lead to victimizing experiences. Streissguth, Bookstein, Barr, Sampson, & O’Malley (2004) for example, report that 60% of those diagnosed with FAS or FAE had a disrupted school experience, 90% had mental health problems, 30% had alcohol or other drug problems, and 50% exhibited inappropriate sexual behavior. Eighty percent of those studied experienced problems with employment and dependent living and half had experienced some period of confinement in a jail, prison, residential drug treatment program, or in-patient mental health facility. Streissguth et al. also note that deficits in adaptive functioning are typically more profound in individuals with FASD than deficits associated with IQ or other measures of intelligence and academic performance.4

The cognitive effects and behavioral manifestations of FASD that have implications for victimization, according to Streissguth et al. (1991), include: impairment in short-term memory and processing speed; poor insight and judgment; attention deficits and a lack of
planning skills; difficulty with abstract thinking, including the concepts of time and space (e.g. personal space); a lack of ability to identify dangerous people and situations; and the inability to apply a lesson from one setting to another. Individuals with FASD also may exhibit impulsivity, inability to distinguish private from public behaviors, and difficulties in understanding the point of view of another. Such individuals also may be easily influenced by others and eager to please, and not be capable of reading social cues, such as facial expressions or body language. These inabilities can lead to difficulties assessing danger, understanding and remembering stranger-safety warnings, and cause-and-effect relationships, thus enhancing vulnerability to victimization.5

Defining “victimization”

Children, adolescents, and adults with FASD are susceptible to victimization, but the nature of that victimization is very often misunderstood, minimized, or ignored by families, educators, social service professionals, law enforcement, and the judicial system. Therefore, to conceptualize the range of experiences that may constitute victimization, it is necessary to take a broad rather than narrow view of the potential for victimization experiences in a variety of settings.

A broad conceptual scheme of victimization of those with FASD includes: (a) victimization that may occur in the home, school or workplace that is often unreported; (b) civil victimization; (c) criminal victimization; (d) the secondary victimization that occurs when those with FASD associate with or are manipulated by victimizers; and (e) the way in which failures in the educational, social service, law enforcement and judicial system extend the victimizing experiences that an individual with FASD may have already experienced. For purposes of this analysis, these categories of victimization are labeled: Silent Victimization; Civil Victimization, Criminal Victimization, Secondary Victimization and Victimization Due to System Failures. (See Table 1).
Victimization that occurs in the home or school setting that does not rise to reportable victimization (e.g., being labeled as a behavioral problem by parents who have not had a child evaluated for FASD; experiencing schoolyard bullying).

Silent victimization may not rise to the level of a reportable event, but may have lifelong negative consequences for an individual with FASD.

Civil victimization also involves wrongful adoption actions brought by parents who are seeking compensation for the costs of raising a child whose FASD was not disclosed at the time of adoption.

Criminal victimization also involves sexual crimes committed against those with FASD and crimes that occur while the individual with FASD is using support services, including transportation services.

Secondary victimization also occurs when the behavioral manifestations of FASD are used against an offender as aggravating factors rather than mitigating factors.

Victimization due to system failures occurs when there is a lack of a skilled professional workforce to diagnose FASD, when an individual with undiagnosed FASD does not receive appropriate school accommodations, when law enforcement officials, prosecutors, public defenders and judges do not receive appropriate training about FASD and its implications for access to justice for those with FASD.

**TABLE 1**

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<th>Types of Victimization for Individuals with FASD</th>
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<td><strong>Silent Victimization</strong></td>
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<td>Victimization that occurs in judicial or agency proceedings involving a “best interest of the child” standard, such as termination of parental rights, foster care and adoption placements, but where the needs of the child with FASD are not adequately addressed.</td>
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Silent victimization consists of experiences of those with FASD that may never surface beyond the home, school, or workplace setting. Such victimization may not be criminal in nature, but it can take the form of abuse or neglect of a child with fetal alcohol exposure that has lifetime consequences. At the root of this form of victimization is a fundamental failure to diagnose FASD and a tendency to ignore a child’s cognitive limitations or problems with adaptive functioning. Failure to address the needs of those with FASD by parents, siblings and other family members, neighbors, and teachers may occur from earliest childhood onward.

Oftentimes, a child with FASD is born into a family with alcoholic parents or parents who themselves have FASD, and are unable to provide consistent caregiving, identify the child’s needs, seek a diagnosis, obtain specialized services, and become a lifetime advocate for the child. A mother also may be in denial that her prenatal alcohol consumption during pregnancy may have affected the developing fetus and instead label the child as having a “behavioral problem.”

The range of manifestations of FASD also may be confusing to parents and teachers of children whose IQ may be in the low-average to above-average range and who have strong expressive language skills, but whose cognitive deficits and issues with adaptive functioning interfere with the child’s ability to engage in day-to-day family activities, to learn, or to interact in appropriate ways with others. Children with FASD may be punished for their perceived failures rather than given the familial, educational and social supports that their disability requires.

School children with FASD may experience bullying, name calling, and other forms of abuse. When a child with FAS has facial features that “look different,” that child may be ostracized by classmates. Academic failure and behavioral outbursts in the classroom may reinforce a label that the child with FASD is incapable of learning and a disciplinary
problem. Yet, the learning disabilities and behavioral problems are the result of the brain damage caused by the prenatal alcohol exposure rather than any deliberate action on the part of the child. The longer that FASD is undiagnosed, the more often silent forms of victimization will linger throughout childhood and into adulthood.

Bookstein et al. (2007) have been engaged in promising research, using ultrasound on newborns with still open fontanels, to assess damage to the corpus callosum which could be attributed to maternal alcohol consumption. Although not in clinical application, this study may lead to procedures for earlier diagnoses followed by service interventions as early as the pre-school years.

Individuals with FASD most frequently encounter civil victimization in cases involving termination of parental rights, child custody, foster care, and wrongful adoption. These cases focus on the diagnosis of FASD and frequently document the way in which FASD is misunderstood. For example, In re Alicia Z., 784 N.E. 2d 240 (App. Ct. 2002) involved a termination of parental rights case in which there was a dispute between physicians testifying about whether a child in foster care actually had FAS. The court upheld the termination of the father’s parental rights because the child and her siblings all had “tremendous needs” but did not address the key issue at trial—whether Alicia Z. had FAS. Regardless of the ruling, an accurate diagnosis of the child, and consensus about that diagnosis, might have resulted in the court making informed recommendations for services for that child while she remained in foster care.

Cases involving wrongful adoption are particularly poignant when parents resort to the courts claiming that they were misinformed by adoption agencies or child welfare systems when they were in the process of adopting that child. Years later, after obtaining a diagnosis, the adoptive parents look to the courts to provide relief for the costs they have incurred in
providing special services for the child, not to undo the adoption itself. Often, the actual diagnosis is not obtained until after the applicable statute of limitations for these claims has expired.

*April v. Associated Catholic Charities of New Orleans*, 629 F.2d 1295 (Ct. App. 4th Cir. 1993) points to the importance of early diagnosis and follow up. The court in this case concluded that parents of a child adopted 6 years previously had waited too long to bring a claim because they had reasonable notice that the child had FAS when a pediatric neurologist told them that the child had FAS several years earlier. In *J.A. v. St. Joseph’s Children’s and Maternity Hospital*, 52 Pa. D & C, 4th 142 (C.P. Lakawanna County 2001), however, the court reached a different conclusion in a case which began as a wrongful adoption action but was later amended to add the child, J.A., Jr., as a plaintiff once he reached the age of majority. J.A., Jr. then alleged that “the defendant’s intentional misrepresentation concerning his medical history caused him to be placed with a couple who neither desired nor were capable of caring for a child with special needs resulting from fetal alcohol syndrome.” The court held that the statute of limitations did not begin to run until J.A., Jr. was actually diagnosed with FAS and from that point the limitation period did not begin to run until J.A., Jr. turned 18.

Children who were prenatally exposed to alcohol should be evaluated in adoption proceedings so that parents and caregivers can receive the educational and social supports needed by these children rather than return to court years later alleging they were not provided information on the child’s FASD. When children who have been diagnosed with FASD or who are suspected of having FASD are placed in foster care, social workers responsible for monitoring their care should take the necessary extra steps to ensure that the foster families have proper training and the children receive appropriate services.
Astley, Stachowiak, Clarren, & Clausen (2002) studied the pictures of foster care children in Washington State to determine if the children had facial morphologies characteristic of FAS. After using this pictorial screening tool, a multidisciplinary diagnosis followed. The study concluded that the rate of FAS in this population of foster children was 10 to 15 times the incidence in the general population. Analyses like this help to alert child welfare workers to the possibility that a child may have FASD, and therefore seek appropriate follow-up diagnoses, and plan for foster care and educational services to meet that child’s need, including appropriate ongoing training and support of foster parents.

Most research on victimization among individuals with FASD focuses on the individual as an offender rather than the victim. In a review of Canadian and American case law, Fraser (2009) notes that there is no consistent approach taken in responding to victimization by those with FASD or in accommodating them as witnesses. Yet, some courts understand the particular vulnerability of those with FASD when they encounter criminal victimization. In Dillbeck v. State, 643 So.2d 1027 (Fla. 1994), the Florida Supreme Court observed, “[w]e can envision few things more certainly beyond one’s control than the drinking habits of a parent prior to one’s birth.”

The University of Washington’s Department of Psychiatry and Behavioral Sciences’ Fetal Alcohol and Drug Unit has summarized over one hundred reported FASD-related federal and state court decisions. The reported decisions rarely cite other FASD-related case law and often demonstrate a misunderstanding of FASD-related symptoms, diagnostic methods, and behavioral consequences. The summary groups cases in the following categories: waiver of rights; false confessions; witness testimony; competency to stand trial; diminished capacity; sentencing; enhancement for vulnerable victims; and ineffective assistance of counsel. A number of
reported cases address sexual offenses in which the individual with FASD was either a perpetrator or a victim. The most relevant of these cases for the purpose of studying victimization of individuals with FASD are the cases involving witness testimony and enhancement of penalties for victimization involving those with intellectual disabilities or FASD.

Individuals with FASD tend to want to please others, particularly those in authority. This tendency may affect their ability to be a victim-witness. They may confuse events that actually occurred with scenarios provided by law enforcement. Like those who provide false confessions in order to please an interrogator, individuals with FASD may be regarded as unreliable witnesses because their answers may reflect responses to leading questions rather than reliable statements about what actually happened.

The University of Washington’s FASD Legal Issues Resource Center’s Website lists three issues likely to affect an individual with FASD in a judicial proceeding: (a) the individual does not have a clear enough grasp of the distinction between reality and fiction and so may impair his or her ability to assist their legal counsel in evaluating and responding to testimony; (b) problems with cause and effect processing may interfere with the individual’s ability to evaluate counsel’s strategic advice; and (c) an inability to follow the interchanges in a courtroom proceeding.

Baladerian (1999) suggests that crimes committed against individuals with FASD may be under-reported at a rate of 25-50% or understated rather than labeled as crimes. Many victims with FASD may not report crimes because they depend on the abuser for their care, as can be the case when the individual with FASD is the victim of domestic violence.

Petersilia (2009) emphasizes that individuals with intellectual disabilities should receive personal safety training that discusses
situations to avoid and how to report a crime when one occurs. Individuals with FASD, however, may not have access to the types of familial or social service support that can assist them in reporting a crime. Or, family members may not recognize some of the indicators of criminal victimization, such as dramatic changes in behavior, including irrational fears or increased aggression signaling that the individual with FASD may have been the victim of a crime. Even when a victim with FASD does report a crime, however, law enforcement may not take the victim’s allegations seriously or be unwilling to invest the time and resources needed to investigate further.

Crimes involving sexual victimization are a special category of criminal victimization. Children and adults with FASD may not understand parental admonitions about sexual contacts with adults and may not realize the dangerousness of situations that they encounter. Streissguth et al. (1996) found that 55-60% of those with FASD had been sexually victimized. Sullivan and Knutson (2000) found that intellectual disabilities, communication disorders, and behavioral disorders appear to contribute to high levels of risk for sexual violence and those with multiple disabilities are even more vulnerable. Those with FASD fall into this higher risk category. During a traumatic event such as a sexual assault, an individual with FASD may experience intense fears and feelings of helplessness. They may not understand that a crime has been committed or may not know how to report it to family members or law enforcement.

One example of sexual victimization that may go unreported to family members or legal authorities, or not prosecuted even if it is reported, is molestation that occurs while the individual with FASD is receiving specialized job, social or transportation services. Sobsey and Doe (1991) found that 44% of all offenders against individuals with disabilities made initial contact with their victims as they participated in social services provided for people with disabilities.
The case history of a 29-year-old woman with FAS commuting home from a support program’s jobsite illustrates this type of criminal victimization. A van driver, hired by the city to provide transportation services to the disabled, molested her during the drive home. Although she told family members and they reported the incident to law enforcement officers who believed her account, prosecutors decided not to prosecute the case, informing family members that the young woman would not make a credible witness. Several years later, that same woman was raped by a cab driver, hired by the city to provide transportation services to the disabled. Instead of driving her to the supported jobsite, he drove her to a secluded park and violently raped her. This time, prosecutors used DNA evidence to corroborate the victim’s testimony, convict the cab driver, secure a 20-year prison sentence, with additional time for harming a vulnerable person.

Even when victim-witnesses do testify, courts may not make an accommodation for children and adults with FASD. Under federal law, for example, children are presumed competent to testify at trial and a party that objects to their testimony must offer compelling reasons to doubt the competency of the child to testify in order to get a competency evaluation. In *U.S. v. Allen J.* (127 F. 3d 1292 (10th Cir. 1997), the court upheld a trial judge’s decision not to order a competency evaluation of an 11-year-old child witness with FAS because, after questioning the witness about whether he knew the difference between the truth and a lie, the court assumed that, at worst, the witness would be “at least as capable of testifying as much younger children.” What the court may not have understood is that while the child victim-witness may have understood the difference between a truth and a lie, the witness may not have understood the difference between fantasy and reality. While certainly those with FASD should be allowed to testify at trial, this case illustrates the problems that their testimony may present and the need for the judicial system to take note of the way in which FASD may affect testimony.
Kelly (2003) elaborates on additional ways in which FASD victim-witnesses testimony may be compromised. Individuals with FASD may believe that the correct answer to a question posed by a prosecutor or defense attorney must be whatever the questioner may appear to want, even if the response is not factually correct. Law enforcement officials that question these victim-witnesses and prosecutors preparing them for trial must be careful not to lead them in a particular direction.

Some courts will apply a heavier sentence when the victim has FASD. In *U.S. v. Janis*, 71 F. 3d 308 (8th Cir. 1995), the court upheld a trial judge’s imposition of a greater sentence in a sexual abuse case because the child had FAS, an IQ of 65, and a learning disability. California requires a 1-year enhanced sentence for those who are convicted of a list of offenses against the developmentally disabled. The State defines the developmentally disabled in a manner that could include individuals with FASD.

Often adolescents and adults with FASD become involved in the criminal justice system as a suspect, defendant or person convicted of a crime. Secondary victimization occurs when the individual with FASD associates with a victimizer and thus becomes guilty by virtue of that association or when the individual is manipulated into engaging in criminal behavior. As noted, individuals with FASD often are overly eager to please others and may not link cause and effect or actions and their consequences. They may serve as patsies for real offenders who use them to commit a crime for the benefit of the perpetrator. If the offender flees the scene of the crime, the individual with FASD is left holding the bag and becomes the person arrested and prosecuted. Often no one identifies the individual as having FASD and no specialized accommodations are provided. This scenario can often be repeated, as the individual with FASD is not capable of learning from the past and may return to interact with and be used again by the perpetrator of the previous criminal activity.
Those with FASD can be impulsive and have difficulty planning activities, traits that work against premeditation. Despite these traits, when a crime involves a plan developed prior to the execution of that crime, the case law oftentimes reveals that prosecutors argue, and juries and judges agree, that the individual with FASD was capable of planning sophisticated criminal actions.

A recent Louisiana criminal case points to the risk of secondary victimization. In *State of Louisiana v. Holmes*, 5 So.3d 42 (La. S. Ct. 2008) the defendant was alleged to have been involved with her boyfriend in a brutal murder and maiming of an elderly couple. She was convicted on all counts after the prosecution in closing argued “[w]e can’t say which slice she inflicted, which stab she inflicted, which one of the times the trigger was pulled [sic] her finger was on it. But we can tell you that she was there helping, participating.”

In *Holmes*, the trial court first denied, and the Louisiana Supreme Court affirmed, the defense’s challenges to potential jurors that they would not consider FAS as a mitigating factor. Even when the defense attempted to present evidence that the defendant had FAS, the prosecution disregarded this evidence as mitigation and instead argued that it was an aggravating factor. The defendant’s mother testified about her history of daily alcohol abuse while pregnant and that she named the defendant “Brandy” because that was the drink she liked most during her pregnancy. Yet, the prosecution portrayed this evidence as “not only not an excuse, it doesn’t mitigate anything.” A psychologist and psychiatrist testified that the defendant’s FAS caused her to have diminished mental capacity that affected her decision-making processes. Nevertheless, during the sentencing phase of the trial, the prosecution characterized her behaviors (lack of remorse, inability to care, previous history of violence)—all traits symptomatic of individuals with FAS—as aggravating rather than as mitigating factors. The jury voted unanimously for the death sentence, which was upheld on appeal.
filed an *amicus* brief to the Supreme Court on behalf of the defendant that summarized Holmes’ history, testing results and diagnosis of FAS and argued that behaviors associated with her FAS were improperly used against her as aggravating rather than mitigating factors. NOFAS also argued that the Supreme Court’s holding in *Atkins v. Virginia*, 536 U.S. 304 (2002), that the execution of mentally retarded individuals violates the Eighth Amendment’s prohibition against cruel and unusual punishment, was applicable in *Holmes*. The Supreme Court denied *cert.*

Individuals with FASD are victimized when they are not properly diagnosed, when the educational and social service systems are not responsive to their needs, and when law enforcement and the judicial system do not factor in cognitive and other limitations associated with FASD in determining appropriate legal procedures to apply.

Diagnosing and treating those with FASD requires an educated and skilled health and social services workforce, yet there are systems barriers that prevent accurate diagnoses and creation of appropriate care plans. For example, there is no distinct category for FAS/FASD in the Diagnostic and Statistical Manual of Mental Disorders (DSM Manual) on which psychiatrists, psychologists and clinical social workers rely. Also, questions on FASD are not typically included on written and oral licensing examinations for addiction professionals. As a result, psychiatrists, psychologists, and clinical social workers may not be informed of the morphological features of individuals with FAS or issues affecting the adaptive functioning of those with FASD. Wedding’s (2008) survey of psychologists found that half of those surveyed considered themselves very unprepared to diagnose FAS and only 23% knew that a smooth philtrum is a diagnostic marker for FAS. Sixty percent of those responding indicated that they were not prepared to treat a patient with FASD.
This level of unpreparedness to work with individuals with FASD causes significant problems. Without an accurate diagnosis, those with FASD cannot receive the services to which they are entitled. In particular, without a diagnosis of impaired functioning due to alcohol exposure in utero and supporting documentation that the individual does not have the ability to support him/herself, an individual may be unable to obtain Social Security benefits.13 Undiagnosed individuals with FASD will remain reliant on family or other forms of public assistance to help them support themselves and improve their opportunity for a better life.

Noteworthy is federal recognition that individuals with FASD should receive some special consideration when they are involved with the judicial system. According to the National Center on Birth Defects and Developmental Disabilities, the deficits in executive functioning and social skills of individuals with FAS “demand that when they do encounter the justice system, their deficits should be taken into account during all aspects of justice proceedings.” This same consideration should be given to individuals with FASD who are victims or victim-witnesses.

Public defenders and other defense attorneys also need instruction on how to identify clients who may have FASD. Fraser (2009) notes that while victims with FASD may appear to understand the judicial process, upon probing, they may not understand legal terminology, may be distracted by other activities in the courtroom, and be unable to focus on questions asked by prosecutors and defense attorneys. As witnesses, they may have difficulty recalling events and timelines, be unable to articulate their thoughts or may easily agree with leading questions.

The Canadian Department of Justice recently began a research study on the experiences of victim service workers with victims and witnesses who have been diagnosed with FASD. The resulting data may help prosecutors in both
Canada and the United States to understand the perspective of those with FASD and the services they need to understand and participate in the judicial process.

Organizations like The Arc have been in the forefront of trying to educate prosecutors, public defenders and judges on the special needs of those with intellectual disabilities, but more work needs to be done to educate judicial system personnel on the needs of individuals with FASD. In the United States, the Queens County Bar Association’s newsletter recently alerted its membership to the way in which FASD may limit the ability of defendants to make good judgments and how their tendency toward impulsivity may prevent them from foreseeing the consequences of their actions. The article contains a list of screening questions and observations that attorneys can use to determine whether to seek an expert FASD diagnostic work-up for their clients. These questions include: Does your client use landmarks rather than street numbers to explain where he/she has been? Do you observe problems with memory, language, reasoning, or attention? Does the client not appear to understand sarcasm or idiomatic expressions? Does the client appear “not to get it”? Did the client’s mother consume alcohol when she was pregnant? Did the client meet developmental milestones, such as tying shoes and riding a bicycle? Did the client exhibit problematic behaviors in school, multiple school placements, or school expulsion? Does the client have problems generalizing from experiences? and Does the client appear eager to please? All of these screening questions also could be used by prosecutors and others in the judicial systems who work with victim-witnesses with FASD.

While there have been some legislative developments on disabilities, the provisions may not fully protect individuals with FASD or other intellectual disabilities. For example, the Volunteers for Children Act of 1998 enables volunteer organizations serving children, the elderly and individuals with disabilities to request nationwide criminal record checks
as a protective measure. However, each state may determine which types of social service organizations are designated “qualified entities” eligible to apply for these background checks. This state option prevents mentoring organizations in 37 states from access to nationwide criminal background checks unless they pay an access fee. By contrast, the United Kingdom requires an enhanced disclosure from its Criminal Records Bureau (including convictions, warnings or reprimands) for any individual that comes into contact with children or vulnerable adults.

The school setting also may not be responsive to children with FASD so as to avail them of federal legal protections. While federal law protects children with intellectual disabilities and extends them the right to receive educational services in the least restrictive environment, children without a diagnosis of a learning disability or a physical disability will not receive special services in the school setting. The FASD case study literature is replete with descriptions of children who failed academically for years, had difficulties in classroom or playground interactions with other children and teachers, and could not exercise impulse control or understand the implications of their actions for others. As these children were never diagnosed with FASD, they received no accommodations or individualized educational plans.

Often, those with FASD do not receive adequate education about sexuality, social and sexual relationships, or pressures for sex and how to resist them. They may not have an understanding of their reproductive systems and may not know appropriate body terminology. Even entering consensual sexual relationships may present problems. In response to this need, Baladerian and Nunez (2002) developed *The Rules of Sex: For Those Who Have Never Been Told*. Vetted by prosecutors, child sexual abuse workers, police and sheriffs deputies, attorneys and disability specialists, the book discusses what someone is allowed to do (sexual civil liberties) and what one is not allowed to do
Cross training among educators, law enforcement and victim assistance agencies, prosecutors, defense counsel and judges may be one way to achieve a more educated system that is sensitive to the needs of individuals with FASD as all of these entities may be involved in any one case of victimization. There is also a need to educate probation officers on the behavioral implications of FASD. Often, individuals with FASD who are on probation may violate a probation rule, such as keeping appointments with a probation officer, but not appreciate the consequences of their actions. Bisgard’s (2010) Fetal Alcohol Spectrum Disorder (FASD) Project trains probation officers in Colorado in how to screen and intervene with youth with FASD. This program should be a model for probation departments in other jurisdictions.

More accurate system-wide labeling of intellectual disabilities would improve the treatment of individuals with FASD. For example, The Twenty-First Century Communications and Video Accessibility Act of 2010, recently signed into law, substitutes the term “intellectual disabilities” for the term “mental retardation” in federal laws. The provision, known as “Rosa’s Law,” responds to a nationwide advocacy effort to remove the stigma associated with the term “retardation” and to improve the manner in which those with intellectual disabilities, including FASD, are perceived and treated.15

Promising models

Although not yet in widespread use, a number of promising models exist to provide services for individuals with FASD, their parents and family members, as well as training for educators, social service professionals, law enforcement, and judges. Wider implementation of these promising models
may help to achieve a better system of services for those with FASD in educational, social service, law enforcement, and judicial settings.

Streissguth and Kanter (1997) found that individuals with an early diagnosis of FASD who lived in a stable and supportive home and received appropriate services were less likely to experience many of the secondary disabilities of FASD, including the inability to live independently or hold a job, and the risks of victimization. In 2004-2006, NOFAS, with a grant from the Substance Abuse and Mental Health Services Administration’s (SAMHSA) FASD Center for Excellence, conducted a series of Women in Recovery Summits that focused on prevention of FASD by targeting both women with addictive disorders and state policy makers. These summits led to the establishment of a nationwide birth mother network, the Circle of Hope-Birth Mothers Network, with funding from SAMHSA's FASD Center for Excellence. This organization helps birthmothers to maintain their sobriety and learn parenting skills that will enable them to become “Warrior Moms” to advocate for services for their children.

In 1991, the Fetal Alcohol and Drug Unit of the University of Washington’s School of Medicine’s Department of Psychiatry and Behavioral Sciences began operating a program designed by Grant and Streissguth for high-risk women with complex problems who abuse substances. This program, known as PCAP, is a home visitation model for pregnant or parenting women whose babies have been prenatally exposed to alcohol or other drugs. The model’s primary goal is to prevent future births of children prenatally exposed to alcohol. Trained and supervised PCAP paraprofessional case managers, with a caseload of approximately 15 families each, develop a positive, empathic relationship with their clients, help them address a wide range of environmental problems, connect women and their families with existing community services, teach them how to independently access those services,
coordinate services among a multidisciplinary network, assist clients in following through with provider recommendations, and assure that the children are in safe home environments and receiving appropriate health care. Clients are assisted in obtaining and continuing inpatient or outpatient addiction treatment and aftercare as well as obtaining and using effective family planning.

Grant et al. (2004) developed a pilot, one-year PCAP community intervention for women who were diagnosed with FASD or who had a suspected diagnosis because of characteristics of prenatal alcohol damage by their mothers. The experienced paraprofessional advocates helped service providers understand the relationship between the organic brain damage sustained in utero by clients with FASD and their sometimes socially inappropriate and otherwise puzzling behaviors, and how to respond in helpful ways. The advocates recommended strategies for community providers to communicate more effectively with their clients with FASD. Improved outcomes included: decreased drug and alcohol use; increased use of contraceptives; increased use of medical and mental health services; and stable housing. The PCAP program, as adapted for those with FASD, demonstrated the potential to improve the quality of life of those with FASD and, ultimately prevent the births of future children damaged by prenatal alcohol exposure.

Programs aimed at reducing the risk of victimization of individuals with cognitive disabilities, including FASD, also may be effective. The Risk Reduction Model developed by Baladerian (1995) uses practical steps that family members and other caregivers can design, practice and implement. Based on the premise that “knowledge is power,” the program includes training on the incidence and prevalence of abuse, its typical perpetrators, the symptoms of abuse, disclosure and response factors, and treatment and interventions for those who are the victims of abuse. Although the model was developed to treat low-verbal children with moderate to
severe mental retardation who had been the victim of a crime, the model can readily be adapted to focus on individuals with FASD and victimization prevention. The model emphasized the importance of understanding types of victimization, responding quickly and appropriately to the victim’s emotional and physical needs, alerting law enforcement, and accessing treatment and counseling help. Families are instructed to practice this model as they would a family escape plan for a fire, so that their response becomes almost “second nature” should victimization occur. Immediate reporting of the abuse enhances the probability that the perpetrator will be identified and apprehended so that the victim will receive the full protection of the legal system.

As children and adults with disabilities, including FASD, are more likely to be victims of abuse than others, appropriate training should be given to first responders, including social service, health care providers, and law enforcement officials who first come in contact with children and adults in distress. In 2004, The Arc of Riverside County received a grant from the California Governor’s Office of Emergency Services to develop a curriculum for first responders to child abuse calls to improve their skills in responding to children with disabilities. Trainers included a law enforcement officer, a child protective services professional, a prosecutor and a disability specialist. A key tenet of the curriculum is that “the first response makes or breaks the case.” If the first contact is not handled properly, the later investigation and prosecution may be compromised or impossible. Another organization, the Institute on Violence Abuse and Trauma, is currently building on that curriculum with a grant from the U.S. Department of Justice’s Office of Victims of Crime (OVC). This project is adding training on forensic interviewing of child abuse victims with cognitive and communication disabilities. This curriculum, once completed, can be adapted to the more specialized case of children and adults with FASD.

In addition, The Arc’s Justice Advocacy Guide (Davis, 2006) offers a resource for disability advocates and victims advocates
as they work together to address victimization among individuals with varying types of disabilities. The OVC funded a team comprised of a national disability advocacy organization (The Arc) and a national victim advocacy organization (National Organization for Victim Assistance or NOVA) to create training materials for use by advocates from both organizations. The Arc then expanded the guide with a step-by-step plan of action on how to advocate for an individual with an intellectual disability once he or she becomes involved in the criminal justice system, either as a victim, a witness, or a defendant.

This same model of cross-training could be applied to the field of FASD, where advocates for those with FASD and their organizations reach out to local victim assistance agencies in order to improve services to those with FASD. Nonprofit organizations like The Arc and NOFAS are beginning to work together to address the issue on a national scale, drawing on their respective expertise to reach their membership about how to prevent victimization and to provide materials, training, services and supports to victims with FASD. The next step is for these organizations to link their efforts to those of victim assistance organizations.

Prevention services

The federal government addresses FASD prevention through the efforts of the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the Centers for Disease Control and Prevention (CDC), the Substance Abuse and Mental Health Services Administration (SAMHSA), and maternal and child health programs, such as the Health Resources and Services Administration’s (HRSA’s) Healthy Start Program. The NIAAA supports behavioral and biomedical research and, along with the CDC, studies to determine FASD prevalence. The CDC funds education programs targeted at increasing the awareness of women of childbearing age to the dangers of alcohol consumption. SAMHSA helps to coordinate services to those who abuse alcohol, including pregnant women.
HRSA’s Healthy Start program funds training and technical assistance to over 100 community grantees to work with women during the prenatal and intrapartum periods to alert them to the risks of consuming alcohol while pregnant. HRSA’s Maternal and Child Health Bureau also continues to fund an initiative, originated in its Bureau of Primary Health Care, to coordinate services between NOFAS and community health centers (CHCs) to improve the prevention, identification, and support of individuals with FASD. The initiative screens pregnant women and nonpregnant women of childbearing age for alcohol-use disorders, trains providers in intervention techniques, and links the CHCs’ clinical services to substance abuse services and other resources. This model has reached 24 CHCs in 10 states and the District of Columbia and can be easily replicated in all of the nation’s 1,700 CHC sites.

Screening and brief intervention models also can be used for women at risk. SAMHSA’s FASD Center for Excellence funds subcontracts utilizing the CDC’s Project Choices in Women’s Substance Abuse Treatment Programs as well as Screening and Brief Intervention (O’Connor & Whaley, 2007) with women enrolled in the Healthy Start program and the federally-funded Special Supplemental Nutrition Program for Women, Infants, and Children.

The State of Alaska has elevated the issue of FASD to an Office of FASD within it’s Division of Behavior Health, Section of Prevention and Early Intervention Services. The Office’s mission is to prevent alcohol-related birth defects and improve the delivery of services to those already affected by FASD through multidisciplinary, culturally appropriate, and community-based approaches. The Office emphasizes systems development and integration of existing systems and processes. The Office funds nine FASD diagnostic teams located throughout the State that staff diagnostic clinics and provide community prevention, education, training and outreach services. Using its FASD Surveillance system,
Alaska also participated in a five-state consortium that in 2002 provided data for the CDC’s Morbidity and Mortality Weekly Report on the prevalence rates for FASD.17

The Canadian Bar Association recently adopted a resolution on Fetal Alcohol Spectrum Disorders in the Criminal Justice System that acknowledges the nature of FASD and the disabilities associated with this condition. The resolution also recognizes the fact that the criminal justice system is based on “normative assumptions that a person acts in a voluntary manner, makes informed choices with respect to the decision to commit crimes, and learns from their own behavior and the behavior of others” that are not valid for those with FASD. The document resolves to urge all levels of government to allocate resources for alternatives to the practice of criminalizing individuals with FASD that will prevent persistent overrepresentation of FASD-affected individuals affected by prenatal alcohol exposure in the criminal justice system, and to urge amendments to criminal sentencing laws that accommodate the disabilities of those with FASD.

Petersilia (2009) notes the need to train law enforcement and the judicial system personnel who generally are unfamiliar with the special needs of persons with intellectual disabilities. For example, the National Judicial College has developed a training curriculum for judges entitled Defendants, Victims and Witnesses with Mental Retardation: An Instruction Guide for Judges and Judicial Educators. Also, The Arc updated a training curriculum originally developed by the International Association of Chiefs of Police about how to interact with individuals with intellectual disabilities. This training could be adapted to include information on the behaviors of those with FASD that may impact their interactions with the law enforcement and the judicial system.

To assist attorneys and judges in effectively handling both juvenile and adult criminal cases, Seattle-based FASD Experts, a multidisciplinary team, offers to conduct clients’ assessment for
FASD. Team members can diagnose FASD, provide expert testimony, when needed, and train other medical and psychological professionals to function as a diagnostic team. Step one in the diagnostic process includes a functional assessment of the individual and the mother’s drinking history, step two involves neuropsychological testing, and step three is the medical diagnosis.18

Streissguth et al. (2004) estimate that approximately 60% of those with FASD come into contact with law enforcement at some point in their lives. Those individuals who have been given a formal diagnosis can carry a card explaining their disability. Should the individual be stopped by police officers for questioning, the card can be provided to the officer. The purpose of the card is to defer questioning of the individual with FASD until a parent, attorney, advocate or other support person can be present. Otherwise, those with FASD may make potentially incriminating statements to police or consent to searches of their person, possessions or homes. If the card is presented and police officers continue to question the individual, a confession obtained under these circumstances could be found by the court to be inadmissible. One side of the card contains the individual’s photograph, name, address and emergency contact information. The other contains the following text:

I have the birth defect Fetal Alcohol Syndrome/Fetal Alcohol Effects which causes brain damage. If I need assistance, or if you need my cooperation, you should contact the person listed on the back of this card.

Because of this birth defect, I do not understand abstract concepts like legal rights. I could be persuaded to admit acts that I did not actually commit. I am unable to knowingly waive any of my constitutional rights, including my *Miranda* rights.

Because of my disability, I do not wish to talk with law enforcement officials except in the presence of and after consulting an attorney. I do not consent to any search of my person or property.19
The Americans with Disabilities Act (ADA) prohibits discrimination against persons with disabilities and may serve to help uphold and protect the civil rights of children and adults with FASD by prohibiting disability-based discrimination. Title II of the ADA covers all activities of state and local governments, regardless of their size or receipt of federal funding, and requires state and local governments to provide individuals with disabilities equal opportunity to benefit from all of their programs, services, and activities. State and local courts, therefore, are subject to Title II.

Some states have taken proactive steps to codify protections for persons with disabilities involved in the judicial process in some way. For example, the California Judicial Council has codified Rule of Court 989.3 which states, “It shall be the policy of the courts of this state to assure that qualified individuals with disabilities have equal and full access to the judicial system. Nothing in this rule shall be construed to impose limitations or to invalidate the remedies, rights, and procedures accorded to any qualified individuals with disabilities under state or federal law.”20 This rule is applied to “any lawyer, party, witness, juror, or any other individual with an interest in attending any proceeding before any court of this state.”21 In a similar spirit, the Florida Office of the State Courts Administrator issued a landmark publication entitled, “Access to the Courts for Persons with Disabilities: Renewing the Judicial Branch Commitment.”22 As prosecutors increasingly invoke protections under ADA Title II, along with any existing local and state procedures that implement related compliance, persons with FASD who are involved in the local and state judicial system may receive the accommodations they need in order to gain the same access to justice as is accorded to persons without disabilities.

Petersilia (2001) describe how an individual with intellectual disabilities may use indirect methods of testimony, admissible as adjuncts to, or in lieu of, the individual’s
testimony. Or, the victim-witness may be able to testify on videotape, outside the presence of the defendant. Title II of the ADA and its accompanying regulations require these and other accommodations to be made for the witness with intellectual disabilities in as nondiscriminatory a way as possible.23

Citing the ADA as authority, communication specialists in Vermont assist individuals with disabilities, including FASD, in communicating with judges, court personnel and attorneys. The communication specialist does not advocate for the client, but rather assists in communication as would an American Sign Language interpreter for a hearing impaired individual.

Recommendations

The following are sets of recommendations for individuals with FASD and their families, school administrators and teachers, social service professionals, law enforcement officials, prosecutors, public defenders and other attorneys, and judges.

- Children, adolescents and adults with FASD and their family members should receive education and training on how to prevent victimization, how to report it should it occur, and how to protect their rights as victims. Training should be repeated at regular intervals so that individuals with FASD and their family members have a plan in place to quickly report victimization when it occurs.
- Individuals with FASD should carry a working cell phone in order to contact a family member, when needed.
- Ongoing discussions and role-playing should occur about stranger safety and sexuality boundaries.
- All cases of victimization should be reported to the police immediately.
- A family member who has been victimized should receive appropriate therapy from a professional with knowledge of
FASD, as well as trauma, and how to support an individual with FASD who has been victimized.

- Teachers should be educated about FASD so they can develop and/or appropriately modify Individualized Education Plans for children who have been diagnosed with FASD.

- Training on the range of disorders included under the umbrella term FASD and the behavioral manifestations of FASD should be a part of school administrators’ and teachers’ continuing education curricula.

- School systems should provide referrals for assessments and/or treatment to providers that are knowledgeable about FASD.

- Students with FASD should be protected against victimization at school by bullying, name calling and other forms of abuse.

- Faculty should have ongoing training in-services on addiction, FASD, and victimization.

- FASD should be included as a topic that all students should learn about throughout their educational experience.

- FASD should be prevented by teaching students about the dangers of drinking alcohol while pregnant using the NOFAS K-12 FASD Prevention Curriculum, NIAAA FASD Prevention Curriculum, Better Safe than Sorry, or other FASD prevention curricula.

- Counselors and therapists should include the entire family when treating an individual with FASD and should consider the possibility of past victimization when treating a client with FASD.

- Counselors and therapists should assist clients with FASD with housing, vocational, educational, day-care, respite, recreational, and parenting programs and transportation services so that individuals with FASD can live in safer environments.

- Counselors and therapists should ensure that clients with FASD have proper family and caregiver support in place to prevent them from being victimized.

- Addiction treatment agencies should pursue assessments and diagnosis for clients (and/or children of clients) when they suspect a person has FASD.
Training officers for local police and sheriff departments should request training on FASD and its implications for law enforcement from knowledgeable FASD or intellectual disability victim-protection organizations.

When interviewing an individual with FASD, law enforcement officers should factor in the behavioral manifestations of FASD and not engage in leading questions, use complicated terminology, or expect victim-witnesses to provide information that links actions to consequences.

Information on FASD and its implications for victims and victim-witnesses should be a part of annual training for judges and continuing legal education for prosecutors, public defenders, and other attorneys.

Questions on whether a victim has been diagnosed with FASD should be part of victim assistance intake processes and victim advocates should receive annual training on FASD and its behavioral manifestations.

Advocates for changes in judicial proceedings should call for the expanded use of treatment-based alternatives to jail and prison—including drug courts and prosecutorial diversion programs—and post-release supervision for offenders with FASD.

Communities should work together to form interagency task forces to address the problem of victimization among those with FASD and initiate public awareness campaigns focused on the prevention of FASD as well as crimes of violence against persons with FASD.

Advocates should call for the amendment of the Volunteers for Children Act to ensure that all volunteer agencies, regardless of the state in which they operate, have access to nationwide criminal background checks for anyone working with children, adolescents, and adults with intellectual disabilities, including FASD.

States should consider elevating the issue of FASD to the state level, as Alaska has done with its Office of FASD and FASD diagnostic teams located throughout the State, for a coordinated approach to the prevention of FASD, early diagnosis, and service provision to individuals with FASD and their families.

Federal policy makers should heed the CDC (2002) call for ongoing, consistent population-based surveillance systems to
measure the occurrence of FASD and the impact of FASD prevention efforts.

- Congress should act to promote change by supporting legislation that would promote public awareness and education on the risks associated with alcohol consumption during pregnancy, advance research on the diagnosis of FASD, and develop and implement state- and community-based outreach systems. Congress also should create pilot programs to help educate youth with FASD and those working in foster care and adoptions that monitor their care and create programs in the justice system to accommodate the needs of individuals with FASD.24

- The Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders, established in 1996 to improve communication, cooperation, and collaboration among federal agencies that address health, education, developmental disabilities, research, justice and social service issues relevant to FASD, should examine the problem of victimization of individuals with FASD and make recommendations to address this issue.

Conclusions

Individuals with FASD may be easily victimized and often do not have the family or caregiver supports in place to report victimization. They may think that the way they have been treated is normal; they may not realize that the treatment is a crime or think of the perpetrator as a “friend.” When a victimizing experience is reported, the individual with FASD may not be regarded as a credible witness and prosecutors may decide not to develop the case.

Families, educators, social service professionals, law enforcement officials and attorneys and judges in the judicial system all have a role to play in improving systems to be responsive to the special needs of individuals with FASD. Much more work must be done to implement more broadly the promising models that address the prevention of victimization among those with FASD. More training should be made available, at every level of the educational, social, law enforcement and judicial systems to ensure that individuals with FASD have full access to justice.
1. FASD is not a clinical diagnosis, rather it is an umbrella term that describes the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. The amount and timing of maternal alcohol use affects the type and extent of the impact on the developing fetus. Although there is no safe amount of alcohol that a woman can drink while pregnant, the risk of FASD increases as the amount of alcohol consumed increases. Pregnant women who binge drink (four or more standard drinks in one drinking session) are at highest risk. Alcohol crosses the placenta and the blood levels in the developing fetus can equal those of the mother within minutes. See Burd, Cotsonas-Hassler, Martsolf, & Kerbeshian, Recognition and Management of Fetal Alcohol Syndrome, 25 Neurotoxicology and Teratology 681-688 (2003); the National Organization on Fetal Alcohol Disorders (NOFAS) Quick Facts, available at www.nofas.org; and The Arc, Fetal Alcohol Spectrum Disorder, available at www.thearc.org.

2. Streissguth and Kanter (1997) list four diagnostic criteria for FASD: (a) prenatal exposure to alcohol; (b) growth deficiency in height and/or weight either prenatally or in the postnatal period; (c) a pattern of facial anomalies that may include short eye slits, smooth or indistinct philtrum and a thin vermillion border of the upper lip; and (d) organic brain damage to the central nervous system that can be demonstrated by microcephaly, tremors, hyperactivity, fine or gross motor problems, attention deficits, learning disabilities, intellectual impairments and possible mental retardation. Streissguth noted, however, that only 25% of those with FAS and 10% of those with ARND have IQ scores within the range of those with mental retardation. See also, Moore & Green, Fetal Alcohol Spectrum Disorder (FASD): A Need for Closer Examination by the Criminal Justice System, Criminal Reports 99-106 (July 2004).

3. See National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Department of Health and Human Services, Fetal Alcohol Syndrome Guidelines for Referral and Diagnosis, (July 2004).

4. The National Center on Birth Defects and Developmental Disabilities considers limitations in three or more functional domains indicative of adaptive functioning deficits related to FAS. These domains include: cognitive deficits; executive functioning deficits; motor function delays; attention and hyperactivity problems; and social skills problems. See National Center on Birth Defects and Developmental Disabilities, supra note 3 at 14-16.


6. An April 28, 2010 New York Times article, Lawsuit Over Adoption Raises Disclosure Issues, quotes an adoptive parent, suing for the
cost of her child’s FASD, rejecting a settlement offer to place her child with another family by saying “He’s not a dog, you cannot take him to the pound.”

7. University of Washington, Department of Psychiatry and Behavioral Sciences, Fetal Alcohol and Drug Unit, Court Cases. Available at: http://depts.washington.edu/fadu/legalissues/

8. See California Pen. Code § 667.9 Sentencing Enhancement for Specified Offenses and Repeat Offenses Against Aged, Disabled or Underage Person. California defines developmentally disabled as “a severe, chronic disability of a person, which is all of the following: (a) attributable to a mental or physical impairment or a combination of mental and physical impairments; (b) likely to continue indefinitely; and (c) results in substantial functional limitation in three or more of the following areas of life activity; self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency. California Pen. Code §667.9(d).

9. Due to the manner in which individuals with FAS involved in the criminal justice system may outwardly respond, people may assume that they appear indifferent and do not exhibit remorse.

10. See State of Louisiana v. Brandy Aileen Holmes, 5 So.3d 42 (La. S. Ct. 2008) See also Brief for the National Organization on Fetal Alcohol Syndrome as Amicus Curiae in Support of Petitioner, Petition for a Writ of Certiorari to the Louisiana Supreme Court, Brandy Aileen Holmes, Petitioner v. State of Louisiana, Respondent. In a pre-trial determination, the trial court also did not apply the ruling in Atkins v. Virginia, 536 U.S. 304 (2002) that the execution of mentally retarded individuals violates the Eighth Amendment’s prohibition against cruel and unusual punishment because it determined that there was no basis to quash the capital prosecution because the defendant had an IQ of 77 and was, therefore, not mentally retarded. The issue of the defendant’s mental retardation was not raised during the penalty phase of the trial. Id.

11. In the past, formal diagnosis has been difficult for individuals with FASD, except in cases of FAS with distinctive facial features. The Centers for Disease Control and Prevention recommends multidisciplinary diagnostic teams composed of physicians, psychiatrists, neuropsychologists, dysmorphologists, developmental pediatricians, social workers, speech therapists, and other specialists.

12. The DSM manual establishes the official classification and nomenclature used in the United States for psychiatric and substance abuse disorders. Because there is no DSM code for FAS, International Statistical Classification of Diseases and Related Health Problems (ICD-9) codes are used as an alternative coding
system. FAS is ICD-9 diagnosis code 760.71. When an individual
does not meet criteria for FAS, they typically receive a DSM code
that best fits their symptoms (e.g. Bipolar, Conduct Disorder,
Attention Deficit Hyperactivity Disorder, etc.).

13. When an individual with FASD needs to appeal the denial of Social
Security benefits, the National Organization of Social Security Claimants’
Representatives (NOSSCR) may be able to provide assistance.

14. See Susan Rose, Fetal Alcohol Syndrome Disorders (FASD) and the
Law, Queens Bar Bulletin, Queens County Bar Association 71:5
(Feb. 2008).

15. The federal definition of “developmental disability” can also be used
to address the needs of individuals with FASD. A developmental
disability is a severe, chronic disability of an individual that: (a) is
attributable to a mental or physical impairment or combination of
mental and physical impairments; (b) is manifested before the
individual attains age 22; (c) is likely to continue indefinitely; (d)
results in substantial functional limitations in 3 or more of the
following areas of major life activity, including self care, receptive
and expressive language, learning, mobility, self-direction, capacity
for independent living, or economic self sufficiency; and reflects the
individual’s need for a combination and sequence of special,
interdisciplinary, or generic services, individualized supports, or
other forms of assistance that are of lifelong or extended duration and
are individually planned and coordinated. 42 U.S.C. 15002 § 102(8).

16. See http://www.hss.state.ak.us/fas/home.htm for more information
on the State of Alaska’s Office of FASD.

17. Arizona, Colorado, New York and Wisconsin also participated in the
consortium. For the period 1995-1997, the CDC estimated that FAS
rates in these 5 states ranged from 0.3 to 1.5 per 1,000 live-born
infants and were highest for African American and American
Indian/Alaska Native populations. See Centers for Disease Control
and Prevention, Fetal Alcohol Syndrome—Alaska, Arizona,
Colorado, and New York, 1995-1997, Morbidity and Mortality
Weekly Review, 51(20), 433-5, May 24, 2002. In February 2010,
Alaska reported a 32 percent decrease in FAS between 1996-2002,
with Alaska Native rates of FAS dropping almost 49 percent. See

18. See http://www.fasdexperts.com for more information on FASD
Experts and the services they provide.

19. A prototype card can be found at http://depts.washington.edu/fadu
/legalissues/

20. California Rule of Court §989.3(a).
21. California Rule of Court 989.3(b)(2).


23. See 28 CFR § 35.104 et seq. and § 35.130(d).

24. In the 111th Congress, Senators Lisa Murkowski and Tim Johnson introduced S. 3154, the Advancing FASD Research, Prevention and Services Act, which included all of these recommendations.

References


