

# Fetal Alcohol Spectrum Disorder (FASD) and the Role of Family Court Judges in Improving Outcomes for Children and Families

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## A B S T R A C T

### I N T R O D U C T I O N

The negative effects of alcohol exposure on fetuses have been observed since ancient Greece. Sullivan published the first research confirming these suspicions in England in 1899 (Sullivan, 1899). In 1973, a pattern of malformations was defined as Fetal Alcohol Syndrome (FAS) (Jones, Smith, Ulleland, & Streissguth, 1973). Since then, more than 3,000 research studies have examined the effects of alcohol and other drugs on pregnancy outcome. Most have explored the mechanisms of damage, clarifying the nature and duration of effects. These studies from the United States, Canada, and Europe have consistently found an association between prenatal alcohol exposure, brain dysfunction, and behaviors (e.g., Spohr & Steinhausen, 1987; Clarren & Astley, 1988; Streissguth, Barr, Kogan, & Bookstein, 1996).

Fetal Alcohol Spectrum Disorder (FASD) is a physical disability that is 95% underdiagnosed and 40 times over-represented in juvenile justice. Prenatal alcohol and other drug exposure causes brain damage that affects behaviors, e.g., poor judgment, impulsivity, difficulty learning from experience, and difficulty understanding consequences, leading to multiple diagnoses such as Attention Deficit Disorder, Conduct Disorder, Oppositional Defiant Disorder and Emotionally Disturbed. FASD is an invisible physical disability; most people with FASD have no observable physical characteristics. The courts are in an important position to increase awareness of this problem by simply asking whether FASD is a factor that needs to be considered. The purpose of this article is to support increased recognition and efficacy of services for people with FASD in the legal system. Sections include: (1) Overview of FASD diagnostic criteria and current terminology; (2) Exploration of FASD as a physical disability with behavioral symptoms; (3) Case example illustrating common patterns of behaviors in children and adults with FASD without identification and improved outcomes following identification and implementation of appropriate treatment; and (4) Recommendations for family court judges.

Fetal Alcohol Spectrum Disorder (FASD) is a primary, permanent physical disability. It is largely an invisible disability since, in most cases, there are no observable external physical characteristics. The only symptoms seen in most children and adults with this disorder are behavioral. The wide range of these behavioral symptoms reflects the timing, dose, duration, and types of drug used, as well as the age of the mother, genetics, stress, and nutrition.

FASD is a lifelong disability. Like any other disability, early identification of FASD is vitally important, since once behaviors are understood as symptoms of an underlying disability, interventions may be developed that reflect this understanding.

Parents of children with FASD often themselves

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have undiagnosed brain damage (i.e., FASD) that compromises their ability to successfully complete court-mandated programs. Their own histories include early school failure, multiple diagnoses, abuse, neglect, and addictions, and their behavioral symptoms are often viewed as volitional. Understanding that these parents may also have a problem is useful for a number of reasons. First, it helps clarify family dynamics. Second, identification of FASD at any age reframes problems and expands options for interventions. The value of identification is the same regardless of age.

### Context

1. Fetal Alcohol Syndrome (FAS) is regarded as the leading cause of mental retardation and developmental disabilities in the Western world. This is an especially significant statement because underidentification is still common (Little, Snell, Rosenfeld, Gilstrap, & Gant, 1990).
2. The principal reason for under-identification is that the majority of people exposed to alcohol prenatally have no observable physical characteristics. Because of this, people with FASD are at greater risk for psychosocial failure than those with FAS.
3. The average IQ for full FAS is 74. The IQ *range* for full FAS is 20-130. (Streissguth et al., 1996). The average IQ for FASD is 90.
4. IQ scores in the "normal" range are unreliable and misleading indicators of ability since many with FASD are unable to perform at levels indicated by their IQ scores (Streissguth et al., 1996).
5. Estimates of FAS vary from 0.5 to 3 per 1,000 live births in most populations with higher rates in some communities (Stratton, Howe, & Battaglia, 1996). The number of alcohol-affected births are estimated to be five to ten times greater.
6. The Surgeon General has stated that there is no safe amount of alcohol or level of alcohol below which there are no effects. Between 50% and 75% of all pregnancies are unplanned, and social drinking prior to knowledge of pregnancy is common (Riley, 2003). Binge drinking by pregnant women, defined as five or more drinks per occasion, has been found to be most damaging to fetal development (Ebrahim, Diekman, Floyd, & Decoufle, 1999).
7. Paternal alcohol consumption prior to conception has been linked with subtle neurological effects on fetal development even when there is no maternal alcohol use during pregnancy. These effects include lower birth weight, higher rates of attentional problems, impulsivity, learning disabilities, and others (Abel, 1992; Cicero, 1994; Joffe & Soyka, 1982; Little & Sing, 1986; Yazigi, Odem, & Polakoski, 1991).
8. People with FASD are frequently given a wide variety of diagnoses, e.g., Attention Deficit/Hyperactivity Disorder, Reactive Attachment Disorder, Learning Disorder, Oppositional Defiant Disorder, Seriously Emotionally Disturbed, Antisocial Personality Disorder, and others (Coles et al., 1997; O'Malley & Nanson, 2002). The reason for this is the considerable overlap between neurobehavioral symptoms of FASD and symptoms in many diagnoses. The problem is that most diagnoses describe behaviors and interventions target these behaviors. Treatment approaches that attempt to change behaviors, that are symptoms of this disability are inappropriate and ineffective.
9. Without identification and appropriate supports, the majority of people with FAS and Alcohol-Related Neurodevelopmental Disorders (ARND) develop secondary behavioral problems. These preventable problems reflect chronic frustration and failure and include higher rates of school failure, mental health issues such as depression, addictions, and violence, social isolation, and legal problems (Streissguth et al., 1996).
10. A disproportionate number of people involved in the legal system have FASD. One study of a juvenile detention facility found 40 times the expected frequency of adolescents with FASD (Conry & Fast, 2000).
11. Parents themselves frequently have undiagnosed FASD. In one study, 35% of the mothers of children diagnosed with FAS were identified as having FASD (Astley, Bailey, Talbot, & Clarren, 2000). In this same study, 100% of the mothers of children with FAS had experienced physical, sexual, or emotional abuse.
12. Under-diagnosis of FASD reflects current lack of awareness and knowledge. It also indicates bias, prejudice, and discomfort in medicine, education, mental health, social services, and the legal arena (Chavkin & Breitbart, 1997).

## Current Terminology

The field of fetal alcohol is fairly new, and changing terminology is common for new fields. The original term Fetal Alcohol Syndrome (FAS) was introduced in 1973. This was soon followed by Fetal Alcohol Effects (FAE) that was added to explain neurocognitive characteristics in those who had histories of prenatal exposure but no physical symptoms. In 1996, the Institute of Medicine introduced the term Alcohol-Related Neurodevelopmental Disorder (ARND) to replace the more ambiguous FAE (Stratton et al., 1996). In 2003, Fetal Alcohol Spectrum Disorder (FASD) was widely adopted as the descriptive term encompassing FAS, ARND, and all alcohol-related disorders.<sup>1</sup>

## FASD Identification

The diagnosis of Fetal Alcohol Syndrome requires the presence of measurable physical effects in addition to symptoms of brain damage and is generally made by a multidisciplinary team. It is the only alcohol-related diagnosis that may be made in the absence of a confirmed maternal alcohol history.

The majority of people prenatally exposed to alcohol have no external physical characteristics, since the facial features of FAS result from specific timing of prenatal alcohol exposure during days 18-21 of gestation. However, even with no visible characteristics, a person with FASD may have brain dysfunction as severe as those with full FAS. Identification of this larger group with FASD is crucial since they are at greater risk for failure due to the greater invisibility of their disability (Clarren et al., 1998; Riley, 2003). (Streissguth et al., 1996).

## Definitions: Primary and Secondary Behaviors

Professionals are now using terms to describe behaviors associated with FASD as “primary” or “secondary.”

*Primary behaviors* are those that most clearly reflect underlying changes in brain structure and function. There is wide variability in their frequency and magnitude, and none are exclusive to FASD:

1. Compromised executive functioning; may have difficulty planning, predicting, organizing, prioritizing, sequencing, initiating and following through. Difficulty setting goals, complying with contractual expectations, being on time, or adhering to a schedule.
2. Difficulty with memory; information input, integration, forming associations, retrieval, and output. Difficulty learning from past experiences. Often repeats the same mistake over and over again in spite of increasingly severe punishment.
3. Inconsistent memory or performance; may remember on Monday, forget by Tuesday.
4. Difficulty with abstract concepts such as time, math, or money.
5. Impaired judgment; often unable to make decisions. Difficulty understanding safety and danger, friend and stranger, or differentiating fantasy from reality.
6. Inability to generalize information; difficulty forming links and associations, unable to apply a learned rule in a new setting; learns to not take Johnny's bike, but then takes Mary's bike since it's not Johnny's. The lesson hasn't been generalized and applied to Mary's bike.
7. Communication challenges; appears to understand instructions, nods and agrees, but is not able to comprehend. Often repeats rules verbatim, then fails to apply the rules—“talks the talk,” but doesn't “walk the walk.”
8. Language problems; difficulty comprehending the meaning of language and accurately answering questions. May agree or confabulate—comply or fill in the blanks. Many talk excessively, yet are unable to engage in a meaningful exchange. The sheer volume of words may create the impression of competence.
9. Slow cognitive pace; may think more slowly, says “I don't know,” shuts down, or requires minutes to generate an answer rather than seconds. Those with FASD are “ten-second people in a one-second world.”

<sup>1</sup> This article focuses on the effects of alcohol since, contrary to common beliefs, alcohol has been found to have more prolonged and profound effects on fetal development than other drugs studied to date, including crack cocaine, heroin, and methamphetamines.

10. Slow auditory pace; central auditory delays means language is processed more slowly, requiring more time to comprehend. Many only grasp every third word of normally paced speech.
11. Perseveration; may be rigid, get stuck, have difficulty switching gears, stopping an activity, or transitioning to a new activity. Often reacts strongly to changes in setting, program, or personnel.
12. Dysmaturity; often functions socially, emotionally, and cognitively at a much younger level developmentally than chronological age. A five-year-old may be developmentally more like a two-year-old, a 12-year-old more like a six-year-old, and a 25-year-old more like a 13-year-old.
13. Impulsivity coupled with inability to abstract and predict outcomes; acts first and then is able to see the problem after the fact.
14. Sensory systems dysfunctions; may be over-reactive to stimuli—e.g., tactile defensiveness, may be easily overwhelmed by sensory input, may be unable to filter out extraneous stimuli, symptoms of which appear as increased agitation, irritability, aggression, or others. May be under-reactive to pain, may not complain of earaches, broken bones, and may be unable to experience painful stimuli.

*Secondary behaviors* are defensive behaviors that develop over time when there is a chronic “poor fit” between the person and his or her environment. Defensive behaviors are normal protective reactions to frustration and are helpful cues for identifying points of intervention. By definition, these are preventable when a good fit is provided. Again, these are not exclusive to FASD:

1. Inappropriate humor, class clown.
2. Pseudo-sophistication; may echo words, phrases, manners, and dress in order to “pass” as competent beyond their actual ability, often to their detriment.
3. Fatigued, irritable, resistant, argumentative.
4. Anxious, fearful, chronically overwhelmed.
5. Frustrated, angry, aggressive, destructive.
6. Poor self concept, often masked by unrealistic goals or self-aggrandizement.
7. Isolated, few friends, picked-on.
8. Family or school problems including fighting, suspension, or expulsion.

9. May run away, have other forms of avoidance.
10. Trouble with the law, addictions.
11. Depressed, may be self-destructive, suicidal.

Secondary behaviors often develop in early childhood, frequently becoming patterns of behavior by adolescence. Early identification of both primary symptoms and secondary behaviors is necessary in order to develop appropriate interventions that prevent or resolve secondary behaviors.

**Strengths:** Recognition of cognitive and personal strengths is central for the development of appropriate techniques. With early identification—ideally in early infancy—and prevention of defensive patterns of behaviors, these abilities and strengths are more obvious: Many people with FASD are concrete, experiential, kinesthetic learners who learn by doing. Many are also friendly, verbal, creative, artistic, musical, mechanically inclined, and determined. People with FASD are willing and able to learn when techniques match learning styles and build on strengths rather than focusing on deficits. People with FASD can be and are successful in many professions. Some are accomplished musicians, computer technicians, athletes, electricians, artists, mechanics, carpenters, teachers, and are successful in other areas. Although some continue to need support, for example, managing time and money, accommodations such as electronic organizers and networks of supportive people are effective in minimizing the disability’s impact.

### **FASD and the Legal System**

Standard disciplinary techniques are not usually effective for people with FASD. These traditional methods of punishment presume a normally functioning brain that readily understands the concept of negative consequences for inappropriate behaviors. Unfortunately, these assumptions are rarely examined for their validity resulting in techniques that are often ineffective—like those based on behavior modification. Whether time-out in a chair for a child or incarceration for an adult, the effectiveness of the technique is a function of the ability of the brain to store and retrieve information, form associations, and predict outcomes. These are exactly the kinds of information-processing deficits that are the core characteristics of FASD.

### **What Works: Linking Research with Interventions**

Increased understanding of the brain and its role in behaviors has supported development of a conceptual framework for developing ways to work more effectively with people with FASD.

The logic of this model as applied to FASD is as follows: Since brain damage is a physical disability that has behavioral symptoms, it follows that people with FASD would benefit from interventions based on the same principle as those that are provided for people with other, more obvious physical disabilities, namely environmental accommodations. Just as wheelchairs and ramps provide safety and accessibility for those with paralysis, people with FASD also require accommodations.

Presenting behavioral characteristics of people with other more obvious physical challenges, e.g., physical immobility, are different from behavioral characteristics associated with people with brain dysfunction, e.g., impulsivity and dysmaturity. The obviousness of this statement is intentional: Behaviors that reflect underlying brain dysfunction are rarely framed in a neurological perspective and are instead seen as a function of volition, or psychopathology. Accordingly, the expectation is that the threat of punishment should be sufficient to improve behavior in the future. The problem with this is that behaviors that arise out of the physical condition are not volitional.

Although presenting behaviors indicating the presence of physical disabilities are different, the principles for interventions for both kinds of physically based conditions are the same. This may seem self-evident, but the application of this principle represents a nearly paradoxical way of thinking, understanding, and defining targets for interventions. The shift is from focusing on trying to change behaviors in the child to focusing on changing aspects of the environment around the child, providing accommodations, and achieving changes in the child.

The primary disability of FASD is compounded by underdiagnosis and a chronic poor fit for people with FASD at home, at school, and in the community. Dr. Streissguth et al.'s Secondary Disabilities Study validated this premise (Streissguth et al., 1996). This study found a disproportionately high percentage of secondary characteristics in those with FAS and FAE (74% and 93% respectively) from age six upward,

including trouble in school, trouble with the law, and others.

The most important finding of this study may be implicit. Following diagnosis for FAS and FAE, subjects continued to receive standard interventions, e.g., mental health and school services. The study's findings of high frequencies of secondary problems occurred in spite of these interventions. Rather than suggest the inevitability of deterioration, these outcomes appear to indicate the relative ineffectiveness of conventional interventions based on traditional, learning-theory-based techniques that do not yet incorporate neuroscientific findings.

**Innovativeness:** In medicine, it is said that diagnosis determines treatment, or the definition of the problem determines the intervention. If a behavior is seen as a function of willfulness or choice, interventions typically focus on changing the behavior. When behaviors are recognized as being the result of brain damage, effective treatment focuses on the environment. This shift in definition provides a basis for asking different questions and expanding interventions to include environmental adaptations.

This redefinition is pivotal: When the belief is that behaviors are willful noncompliance, a punitive response typically follows. However, when the belief is expanded to include an understanding of behaviors as symptoms of brain dysfunction, reflecting inability rather than noncompliance, then interventions reflect understanding of the disability.

The idea of reframing perceptions to view behaviors as symptoms, rather than maladaptations, is new. The simplicity of the statement belies the intellectual shift this entails.

### **The Oregon Project: A Case Example**

A recent study tested this idea of focusing on the environment rather than punishment (Malbin, 2002). The State of Oregon Services for Children and Families (SCF) provided funding for Fetal Alcohol Syndrome Consultation Education and Training Services (FASCETS, Inc.) to conduct a three-year demonstration project for children with FASD in foster care. This study tested the hypothesis that identification of FASD as a primary physical disability and providing appropriate accommodations in all settings—home, school, mental health, and

social services—would achieve changes in children and adults: In children, there would be a reduction in challenging secondary behaviors, and in adults there would be reduced stress and an increased sense of personal efficacy. This hypothesis was tested in a study designed as a multisystem, multidisciplinary, collaborative continuum of care. The small study was preliminary and primarily educational, increasing understanding of people from a neurobehavioral perspective. The intervention consisted of educating all adults in children's lives to rethink the meaning of behaviors, to incorporate understanding of the physical disorder underlying behavioral symptoms, and to provide appropriate accommodations at home, at school, and in the community. At the end of the study, statistically significant findings of improvements in all three key variables suggested the viability of the construct.

### Case Study: Fred

"Fred" was seven years old when he joined the Fetal Alcohol Pilot Project. His early childhood was traumatic, including removal from his birth mother, abuse, and multiple foster home placements. He was diagnosed at different times by different professionals with Post-Traumatic Stress Disorder, Attention Deficit Disorder, Seriously Emotionally Disturbed, and Oppositional Defiant Disorder and described as socially inappropriate, unmotivated, easily frustrated, explosive, controlling, avoidant, resistant, and oppositional. He received multiple services including a classroom aide, individual therapy, and behavioral classroom placement. At the time he entered the project, he was in a day treatment setting where staff were considering referring him to residential treatment. None of the interventions by staff stopped his inappropriate behaviors that resulted in daily four-point physical restraints.

His behavioral problems were attributed to an unstable early home environment and poor and inconsistent parenting. Behavioral interventions included verbal warnings, time out, consequences, and physical restraints. In spite of these consistently implemented techniques, he had daily meltdowns, temper tantrums that resulted in four-point physical restraints at home and in day treatment.

### Intervention

Prior to the project, Fred had been given standard academic, intellectual, and behavioral assessments that identified learning disabilities, an IQ of 75, and behavior problems. This information generated interventions that focused on academics and behaviors. Because he had a history of prenatal exposure to alcohol and positive findings on a prescreening for neurocognitive issues, he was given a neurodevelopmental assessment by the FASCETS multidisciplinary team. He was diagnosed with Static Encephalopathy Alcohol Exposed (non-progressive brain dysfunction).

Fred's involvement brought to the project a group of 12 people who had daily contact with him: foster parents, family members, therapist, caseworker, teacher, aide, Court Appointed Special Advocate, school bus driver, and janitor. This group developed into a team following training on FASD and a neurobehavioral approach to understanding behaviors. The training provided information on brain dysfunction and related behaviors, and introduced a framework for exploring Fred's neurobehavioral characteristics.

The intervention consisted of having all the adults in Fred's life share the same understanding of the meaning of his behaviors, and work together to develop accommodations that built on his strengths and prevented problems.

The diagnostic report provided information and a language for deciphering Fred's behaviors as primary and secondary, and provided specific recommendations based on his strengths. Fred's team used this information to rethink his behaviors and consequently a different explanation of many of his behaviors emerged. The poor fit for Fred in different settings was clarified, and this in turn identified points of intervention and accommodations.

The neurocognitive assessment identified the following characteristics in Fred:

1. Significant dysmaturity<sup>2</sup>: At seven, he was functioning developmentally more like a three-year-old.
2. Memory problems: He had difficulty storing and retrieving information, forming associations, and generalizing.

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<sup>2</sup> Dysmaturity is distinct from immaturity. Dysmaturity means a person is functioning at a younger developmental level where immaturity suggests the capacity to catch up with chronological age.

3. Slow auditory and cognitive processing speed: It took him longer to understand instructions and to finish assignments.
4. Rigidity and perseveration: He had difficulty stopping an activity, would become frustrated or resistant to changes.
5. Significant difficulty comprehending language-based communication: He had poor short-term auditory memory; he could complete one direction but not more.
6. Significant sensory issues: He was distractible, easily overwhelmed, and easily fatigued.

The team considered how his behaviors in day treatment and at home might reflect these characteristics. As the source of Fred's secondary symptoms were identified, the interventions became obvious:

1. Dysmaturity: Treatment goals and parenting expectations were based on age-appropriate norms. Expectations for a seven-year-old are considerably higher than for a three-year-old. Fred had been punished for being "socially inappropriate." Once the team understood his dysmaturity, he was recognized as being socially appropriate at a younger developmental level, and expectations were adjusted to be developmentally appropriate.
2. Memory problems: Consequences were imposed when he did not follow the rules. His "intentional" rule breaking was redefined as his having memory problems. He could remember a rule in one setting, but was not able to retrieve and apply it in another. Once this was recognized, adults knew to reteach him each rule in different settings in order to prevent problems.
3. Slow auditory pace: Verbal instruction and redirection were the standard form of communication. His agitation when he was being talked to was seen as resistance. This resulted in staff talking even more which only increased his agitation. Understanding his slow auditory and cognitive pace clarified his difficulty understanding language, and explained his agitation when too many words were used. Once they understood his slow pace, the language-processing problem, they slowed down, used fewer words, and Fred had fewer problems.

4. Rigidity and perseveration: Scheduling required timely transitions. Fred's slower processing pace often meant he had not finished a task. When he was interrupted before he had finished his work, he would resist and have tantrums. This was seen as controlling and oppositional behavior. As adults came to understand his need to finish as symptoms of rigidity and perseveration, they accommodated his need by reducing the amount of work so that he was able to achieve closure in the time allotted.
5. Language-based communication problem and poor short-term auditory memory: Adults were frustrated by Fred's failure to follow through on directions. Originally viewed as noncompliance, this was reframed as incompetence and accommodations included giving him only one short directive at a time.
6. Sensory integration dysfunction: Both home and treatment environments were highly stimulating. Fred was overwhelmed by sensory input that resulted in his becoming fidgety, overactive, exhausted, and having tantrums. Rather than insisting on his sitting still and paying attention, he was provided with breaks and opportunities to move to lower stimulation areas to regroup. Classmates were taught that "fair is not same."

As team members explored the fit between Fred and his environments, they recognized that although certain settings, goals, expectations, and techniques might be appropriate for other children, the fit was poor for Fred. For example, when discussing his dysmaturity, adults noted that parenting and treatment goals and expectations were set at age- and grade-level functioning rather than developmentally. One staff person said, "We have to rethink our program. We're required to write treatment plans with age-appropriate treatment goals. These goals are clearly unrealistic given his developmental level of functioning and need to be rewritten to reflect his actual developmental ability."

Fred's strengths were identified—friendly and cooperative, good visual processing, contextual and experiential learner—and his behaviors were reframed in a manner consistent with the brain damage Fred had as a result of having FASD. As adaptations were provided, power struggles decreased at home and at day treatment.

Techniques reflected understanding of his challenges and built on his strengths. Expectations were adjusted to be more congruent with his developmental level of functioning, parents and staff found it helpful to “think younger” when working with him, and accommodations were provided to meet his academic, social, and emotional needs. His sensory issues were clarified so that parents and staff were able to recognize early signs of overstimulation. He was provided with nonpunitive opportunities to settle down from being overstimulated, and other preventive measures were applied. His slower processing pace was factored in to communication and workload; fewer words were used, and he was provided more time to process information, which reduced his anxiety and improved communication.

There was an almost immediate reduction in frustration for Fred and the adults in his life. Within a week there were no more four-point restraints, his placements at home and day treatment stabilized, he was no longer being considered for residential treatment, parents and staff were less frustrated, and accommodations that prevented problems were more consistently implemented.

Fred now lives with the same permanent foster family and is on an Individualized Education Plan in public school. The team of people around him educates new team members about FASD, for example, new teachers each year, and the ongoing team continues to provide accommodations.

### Discussion

Fred’s case is familiar: In spite of a good, stable, and safe foster home, good educational and therapeutic programs, and well-meaning professionals, he continued to deteriorate. Foster parents who did not understand why their parenting techniques were ineffective became frustrated, and as a result he was moved from home to home. Multiple diagnoses and increasingly expensive services proved ineffective in addressing Fred’s challenging behaviors. Standard assessments that determined his IQ, academic achievement, and behavior profile were descriptive findings that only captured Fred’s symptoms. Fred was diagnosed and treated for behavioral problems, not brain damage.

Years of interventions for his behaviors were ineffective. Improvements were achieved not by employing methods to stop presenting symptoms, but rather by

recognizing their source and providing appropriate accommodations. These were inexpensive and effective. Symptomatic behaviors previously targeted for intervention became cues for identifying points of poorness of fit. The shift was from trying to change Fred and seeing his behaviors deteriorate to providing adaptations appropriate for his disability and achieving changes in his behaviors as a result.

The key for this shift was the neurocognitive evaluation that asked a different set of questions. It explored FASD in a manner consistent with research, and underlying neurocognitive challenges were identified. These questions considered developmental level of functioning, various aspects of brain function including memory, processing speed, sensory issues, and identified strengths. Assessment results clarified the nature and extent of his brain dysfunction which, in turn, helped parents and professionals to reframe perceptions of the meaning of Fred’s behaviors and defined more effective points of interventions.

### Fred’s Mother, Mary, and Adults with Possible FASD

Fred was removed from the care of his birth mother, Mary, after allegations of neglect were made to the Department of Human Services (DHS). She was 27, single, and in early recovery for alcoholism. Her home was disorganized, and she had a poor job history. Fred’s challenging behaviors at school were attributed to poor and neglectful parenting.

Mary’s parents were both alcoholics, and it was noted by DHS that Mary fit an impression of possible FASD, an observation supported both by her family and personal histories. However, this diagnosis was not explored. Mary’s story is not uncommon: marginal parent with a history of trauma, domestic violence, instability, addiction/substance abuse, and failure viewed as “chronically neglectful.” The question is whether with identification of her possible neurocognitive issues and with appropriate goals, realistic expectations, and structured support, Mary could successfully parent her children with FASD.

Mary received a standard psychological evaluation that did not include a neurocognitive assessment. Given her family of origin and psychosocial history, it is likely that Mary had FASD. If true, she would not be unique. In



a study of biological parents of children with FASD, Astley, Bailey, Talbot, and Clarren found that 35% of the parents also had FASD (2000).

Adults with FASD frequently exhibit:

1. Dysmaturity—socially and emotionally more like an adolescent.
2. Difficulty with memory, executive functioning, planning, organizing, following through—may make appointments and show up two days late or call the caseworker 20 times a day.
3. Difficulty understanding or operationalizing language-based interventions—may attend treatment and talk in group, yet not be able to apply information outside of the treatment setting.
4. Difficulty obtaining and maintaining a job—may have a longer learning curve and require alternative job training in order to successfully master skills.
5. Mental health problems—may have a long-standing history of social isolation and failure with corresponding patterns of secondary behaviors including low self-esteem, as well as psychiatric diagnoses of anxiety, depression, and addictions, among others.

For a person like Mary, assigning multiple complex tasks to be completed within a prescribed timeline is not usually realistic. Such tasks may include maintaining a stable, well-organized home, successfully completing treatment, getting and keeping a job, and managing money. Accomplishing these tasks requires autonomy, the ability to initiate, organize, plan, and manage time, and the capacity for flexibility, maturity, and cognitive competence. Again, as with younger children, successful achievement of these tasks requires cognitive skills in those areas affected by FASD and is challenging for adults with FASD to accomplish without appropriate supports.

This does not mean that parents with FASD are not able to be successful. Depending on the severity of the brain damage, even though goals of total autonomy may not be viable, adults with FASD may, with appropriate supports, be able to succeed. The range and variability of social supports, assistive techniques, and technologies reflect the diversity in the population. For example, although adults with FASD have difficulty in cognitive-

behavioral treatment programs, many have been successful in addictions treatment that includes experiential techniques (e.g., art and role playing). They also succeed in programs that involve AA/NA sponsors trained to facilitate early recovery for adolescents and adults with FASD. Difficulty managing time and organizing tasks may be addressed by use of lists, electronic organizers, and supportive friends who serve as “external forebrains.” Money management has been addressed by bank programs that help people manage their funds, and some clients succeed financially in marriages where the spouse simply assumes responsibility for paying bills. Job stability is enhanced when employers are provided with information about how to adapt new employee training and supervision to assure success.

### Recommendations for Judges

FASD is not a new fad or the diagnosis *du jour*. It is an important diagnosis that has been missing from practitioners’ repertoires, one that leads to different and more effective interventions.

FASD has been, and continues to be, under-recognized. Worse, individuals with FASD are frequently misdiagnosed which leads to intervention strategies that fail, perpetuating a downward spiral in the individual’s mental and social health.

One way that judges, especially family court judges, can help address this issue is by asking advocates and professionals one simple question: “Did you consider FASD?”

This one simple question will cause advocates and professionals to become more educated on what FASD is as well as to consider what such a diagnosis would have on intervention.

In addition to asking whether the advocate or professional has considered FASD, a judge can ask a series of questions to make his or her own basic determination as to how important it is to consider the possibility of FASD:

1. Is there a history of alcohol or substance abuse in the family? If yes, the advocates or professionals should be specifically looking at:
  - a. *School History*—Learning disabilities, special education, and school failure or drop out.
  - b. *Mental Health*—Multiple diagnoses, history of failed interventions (including medications and

treatment). Practice tip: The greater the number of diagnoses, the greater the likelihood there is underlying brain damage that has not been diagnosed.

- c. *Social Profile*—Foster care, multiple placements.
  - d. *Legal Profile*—Frequent contact with the legal system.
2. Has the individual been tested for brain damage, i.e., neurocognitive abnormalities? If not, ask whether it should be considered. Suggest a neurocognitive prescreening tool. (Information about the FASCETS Prescreening Tool for Referral for Diagnosis of FASD is available by contacting the author at [dmalbin@FASCETS.org](mailto:dmalbin@FASCETS.org).)

Asking and exploring the question of FASD is pivotal. Even though needed services or funds often are not available, identifying the presence of a neurocognitive component validates the issue and increases awareness of FASD in the community. This, in turn, will contribute to generating sorely needed appropriate resources.

The most important resource is a multidisciplinary team well educated on FASD issues. The team should include at least a medical provider, neuropsychologist, occupational therapist, and social worker. The team should have specific limited objectives: Evaluate for neurobehavioral problems, strengths, and abilities; provide recommendations specific to the assessment findings;

monitor; and re-evaluate. Progress reports should be required every three to six months.

### Conclusion

FASD is a physical disorder that is under-reported and under-identified in infants, children, adolescents, and adults. This failure to identify what has been termed a primary, invisible, physical disability contributes to the failure of the system to provide appropriate supports for individuals in the system and the inadvertent ethical breach of the mandate: "First, do no harm." When FASD is identified, appropriate and successful interventions may be developed for people from infancy through adulthood. Identification and implementation of techniques grounded in understanding of a neurobehavioral approach has been found to be effective.

The courts are in an important position to increase awareness of this problem and support development of effective strategies to prevent reoffending simply by asking whether FASD is a factor that needs to be considered. Just by asking this question, a judge will validate the issue and encourage advocates and professionals to learn more about FASD and to take it into account when making recommendations to the court. This, in turn, will contribute to increasing communities' diagnostic and programmatic capacity and eventually lessen the burden of this at-risk population on the courts.

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## REFERENCES

- Abel, E. L. (1992). Paternal exposure to alcohol. In T. B. Sonderegger (Ed.), *Perinatal substance abuse: Research findings and clinical implications* (pp. 132-162). Baltimore, MD: Johns Hopkins University Press.
- Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000). Fetal alcohol syndrome (FAS) Primary prevention through FAS diagnosis: I. Identification of high-risk birth mothers through the diagnosis of their children. *Alcohol and Alcoholism*, 35(5) 499-508.
- Astley, S. J., & Clarren, S. K. (1999). *Diagnostic guide for fetal alcohol syndrome and related conditions: The 4-Digit Diagnostic Code, 2nd Ed.* University of Washington.
- Chavkin, W., & Breitbart, V. (1997). Substance abuse and maternity: The United States as a case study. *Addiction*, 92(9), 1201-1205.
- Cicero, T. J. (1994). Effects of paternal exposure to alcohol on offspring development. *Alcohol Health and Research World*, 18(1), 37-41.
- Clarren, S. K., & Astley, S. J., et al. (1988). Physical anomalies and developmental delays in non-human primate infants exposed to weekly doses of ethanol during gestation. *Teratology*, 37, 561-569.
- Coles, C. D., Platzman, K. A., Raskind-Hood, C. L., Brown, R. T., Falek, A., & Smith, I. E. (1997). A comparison of children affected by prenatal alcohol exposure and attention deficit, hyperactivity disorder. *Alcoholism Clinical and Experimental Research*, 21(1), 150-161.
- Conry, J., & Fast, D. (2000). *Fetal alcohol syndrome and the criminal justice system.* Vancouver, BC: Fetal Alcohol Syndrome Resource Society.
- Ebrahim, S. H., Diekman, S. T., Floyd, L., & Decoufle, P. (1999). Comparison of binge drinking among pregnant and nonpregnant women, United States, 1991-1995. *American Journal of Obstetrics and Gynecology*, 180(1 pt. 1), 1-7.
- Joffe, J. M., & Soyka, L. F. (1982). Paternal drug exposure: Effects on reproduction and progeny. *Seminars in Perinatology*, 6, 116-124.
- Jones, K. L., Smith, D. W., Ulleland, C. N., & Streissguth, A. P. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet*, 1, 1267-1271.
- Little, R. E., & Sing, C. F. (1986). Association of father's drinking and infant's birth weight. *New England Journal of Medicine*, 314, 1644-1645.
- Little, B. B., Snell, L., Rosenfeld, C., Gilstrap, L., & Gant, N. (1990). Failure to recognize fetal alcohol syndrome in newborn infants. *American Journal of Diseases of Children*, 144, 1142-1146.
- Malbin, D. (2002). Findings from the FASCETS Oregon Fetal Alcohol Project: Efficacy of a neurobehavioral construct; interventions for children and adolescents with Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disabilities (FASD). Unpublished manuscript.
- O'Malley, K. D., & Nanson, J. (2002). Clinical implications of a link between fetal alcohol spectrum disorder and attention-deficit hyperactivity disorder. *Canadian Journal of Psychiatry*, 47(4).
- Riley, E. (2003, September). Keynote presentation: FAS—Not just another pretty face: Alcohol and the developing fetus, center for behavioral teratology and department of psychology, San Diego State University. Hope for Women in Recovery, Baltimore, MD.
- Spoehr, H. L. & Steinhausen, H. C. (1987). Follow-up studies of children with fetal alcohol syndrome. *Neuropediatrics*, 18, 13-17.
- Stratton, K., Howe, C., & Battaglia, F. (Eds.) (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment.* Washington, DC: National Academy Press.
- Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. (1996). 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 #R04/CCR008515.
- Sullivan, W. C. (1899). A note on the influence of maternal inebriety on the offspring. *J Ment Sci.* 45, 489-503.
- Yazigi, R. A., Odem, R. R., & Polakoski, K. L. (1991). Demonstration of specific binding of cocaine to human spermatozoa. *Journal of the American Medical Association*, 266(14), 1956-1959.