

## Abstract

This article discusses the basics of Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/E): the history, nature, prevalence, causes and effects of prenatal exposure to alcohol. Some of the unique features of FAS/E are explored, particularly those that make it so hard to spot and those that predispose people to nonproductive or criminal activity. The presentation of FAS/E in Juvenile Court is discussed and put in the context of the multiplicity of factors pertaining to delinquency; finally, innovative interventions, approaches and resources are laid out. Issues surrounding FAS/E as they appear in Family Court are then explored, with emphasis on the intergenerational transmission of this array of conditions and how we might interrupt such transmission.

### PRENATAL ALCOHOL DAMAGE: HIDDEN EPIDEMIC IN THE COURTS

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A slight boy with calm brown eyes sat in the windowless room, apparently undaunted by the array of authority figures surrounding him—his probation officer, teacher, principal, aunt and unit supervisor. He was about to be released from Juvenile Hall into the care of his exasperated aunt, for the 8th time in his 16 years. After the P.O. rattled off the conditions of probation, he added a bracing “OK, Bobby (not his real name), remember this stuff. It’s all on you now.” Bobby, looking down at his hands, smiled an angelic smile and said “OK”. Two months later we saw him back in the Hall; he had failed to show up for his drug test.

Bobby lives with his aunt because his mother is in and out of rehab--mostly out. He has 16 credits—all from community or institutional schools. His little cousins love him because he plays with them gently; gangs love him because he will do the jobs no one else will. Practically everybody else is pretty tired of him.

Bobby’s small body is topped with an even smaller head—not noticeable unless you look for it, really not until you measure it, check the chart and find it about average for a 5-year-old. After his most recent infraction, Bobby was now headed for the California Youth Authority, as he was seen to be incorrigible: he runs from the Ranch, he violates Probation, he commits an endless string of little, stupid crimes. He doesn’t seem to learn from his mistakes or their consequences.

Thanks to an alert Fetal Alcohol Syndrome consultant in Juvenile Treatment Court, Bobby was referred to the FAS Clinic at our county hospital where his head was measured, along with his eyes, his upper lip and the little groove that runs from nose to lip. His memory and attention were tested, his visual-perceptual abilities, balance and coordination were tested, and his past history was reviewed in detail. His educational, physical and interpersonal trail was littered with red flags of organic brain damage, yet Bobby’s most consistent diagnosis over the years was Oppositional Defiant Disorder,

which translates in most people's minds as a bad case of simple, voluntary pig-headedness.

It turned out that Bobby truly does have a brain like a sieve: he couldn't remember anything from one moment to another; attempts to touch his nose with his index finger were mostly unsuccessful and he nearly tipped over when his eyes were closed. His ability to narrate a first-grade-level series of pictures resulted in fragmented bits of information with no beginning, middle or end, and he couldn't explain why the little protagonist was afraid (storm noises and lights went out). Bobby had the same benign blankness on his face throughout the diagnostic afternoon, the sympathetic interpretation of his troubles making no more impact on him than the stern warning of his P.O.

### **History**

Damage to children from prenatal alcohol has been noted since earliest times: in ancient Carthage, there was a ritual forbidding the drinking of wine by the bridal couple so that defective children would not be conceived; Aristotle stated that "Foolish, drunken and harebrained women most often bring forth children like unto themselves, morose and languid". In the Bible, Judges 13:7 says: "Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks.

Far from a universally held opinion, however, the idea that drinking could harm the fetus has met with considerable controversy, and despite current and incontrovertible evidence such controversy persists to this day. In 1955, the Yale Center for Alcohol put out a brochure with the statement that the "...old notions about children of drunken parents being born defective can be cast aside, together with the idea that alcohol can directly irritate and injure the sex glands".(as cited in Rosett, 1980)

By 1978, 245 people with FAS had been identified, the "FAS face" widely considered to be uniquely alcohol-related, and prenatal alcohol described as the most frequent known cause of mental retardation. (Streissguth, Herman & Smith, 1978). Since then a vast and mushrooming body of scientific evidence has shown beyond a doubt that prenatal alcohol does indeed damage the fetus (Institute of Medicine, 1996). Most recently, brain imaging techniques are able to pinpoint the areas of the brain that are most affected and sophisticated arrays of neuropsychological testing are being used to illuminate the deficits in functioning that result (Mattson & Riley, 1995).

In the last decade it has become clear that "the face" of FAS is more an artifact of timing (exposure during the third week of pregnancy) than the sole defining marker of fetal alcohol damage. A recent estimate done by eight of the principal researchers in FAS tells us that there are at least three to four times as many fetal-alcohol-damaged people without the telltale features (this is most popularly known as Fetal Alcohol Effects) as there are with such features (Fetal Alcohol Syndrome requires the features for diagnosis) (Sampson, Streissguth, Bookstein, Little, Clarren, Dehaene & Hanson, 1997). They

believe their estimate that one out of a hundred people have alcohol-related brain damage is a conservative one.

### **Causes**

In spite of hard evidence for the widespread damage that prenatal exposure to alcohol causes, drinking during pregnancy persists. Part of this is caused by physicians who will say that a drink or two doesn't hurt; part is caused by conditions of living that beg to be softened by a little daily oblivion; part is caused by cognitive impairment (including not being aware that one is pregnant) and part is caused by addiction.

How much drinking can cause damage? Research evidence on the cellular level and with some animal studies is unequivocal; as little as one dose of alcohol has been demonstrated to reduce brain cell adhesion and cause neurological deficits but research conducted on children with low levels of prenatal exposure to alcohol has been contradictory. There is actually little evidence that one drink or even two a day cause harm (Abel, 1998). Studies that use an average of 14 drinks a week or similar "moderate drinking" do show a decrease in memory and learning—but that weekly dose could well have occurred in a couple of sittings. Most research suggests that a high blood alcohol level is the most important factor in fetal alcohol damage and that binge-drinkers are the most frequent mothers of FAS children; a binge consists of 4 or 5 drinks in a sitting, depending on the expert cited. In any case, one of the large "40-ounce" malt liquors so favored by people without a lot of money to spend on intoxication contains the alcohol of over four standard drinks, so one can qualify as a binge and can significantly harm the fetus.

And what exactly happens to the fetal brain to cause this damage? This is still being explored, but there are at least three mechanisms currently documented: abnormal cell migration patterns, reduced cell adhesion once they reach their destinations, and abnormal cell death all along the way. The cells actually behave a little like drunks: they wander around, slide off the bar stool and then pass out (from various studies cited in Institute of Medicine, 1996). Nothing to take lightly of course; the result is universally awful, but the parallel is hard to resist.

Does heavy alcohol exposure always cause brain damage? No one knows yet. Although a single dose of alcohol has been shown to reduce cell adhesion during the period of exposure, there is no evidence that even high doses are universally destructive to the growing brain. Other factors in combination with alcohol have been demonstrated to make such damage more likely: tobacco, poor nutrition, stress, poverty and other drugs.

### **Effects**

The primary disabilities of FAS/E have been described by researchers, clinicians and caregivers. While a common caveat in FAS/E thinking is that there is no one profile and every person is different, the following core disabilities occur with great frequency:

Cognitive  
Lowered IQ

Interpersonal  
Ability to read social cues

Widely varying abilities  
Math  
Memory  
Fluctuating capacity  
Spatial orientation  
Self awareness, reflection  
Inflexibility of thinking

Empathy  
Bonding  
Inability to distinguish truth from fiction  
Externalization of blame  
Excessive demand for attention

Executive functioning  
Planning  
Judgment  
Delayed gratification  
Impulse control  
Future orientation  
Organization  
Focus, concentration

Medical/Neuromotor  
Sensory integration  
Balance, coordination  
Eating, sleeping  
Allergies, asthma, ear infections  
Heart and kidney problems  
Hyperactivity  
Seizures

Emotional  
Intensity, urgency  
Little ability to recognize feelings  
Little ability to articulate feelings  
Mood disorders  
Rage disorders  
Vulnerability to mental illness

Speech/Language  
Superficial fluency  
Talkativeness  
Parroting of others' speech patterns  
Expressive language better than receptive  
General delay in communication

### **Why FAS/E go unrecognized?**

#### Partial diagnoses that mask the broader dysfunction

The constellation of FAS/E behaviors that most commonly comes to the attention of educational, legal or medical caregivers is really the umbrella of symptoms we call Attention Deficit/Hyperactivity Disorder. From the above list we can pick out the chief features of AD/HD: inattention, hyperactivity and impulsivity; those familiar with this disorder will recognize the many subcategories of ADHD here as well as some of the more subtle accompanying features. (It should be noted that while most researchers are convinced that ADHD is largely of genetic origin, but none of the well-known studies has even asked about prenatal exposure to alcohol. Twin studies provide most of the evidence for genetic transmission—ignoring the fact that fraternal twins will show differential FAS/E, where identical twins will have identical symptoms of FAS/E [Institute of Medicine, 1996]...and that since drinking is often a family tradition, so is prenatal alcohol damage!)

Another common diagnosis that purports to explain behaviors of people with unrecognized FAS/E is Bipolar Disorder. As with AD/HD, Bipolar symptoms are certainly part of the package of fetal alcohol damage, especially in adolescence, when the

mood swings tend to be from depression to rage to irritability, unfortunately bypassing the euphoria that adults with Bipolar often enjoy. Since this mood disorder is seen to affect cognitive, emotional, interpersonal and executive functioning in normal people, it is natural to assign global causality in people with unidentified brain damage.

By far the most common diagnostic category in the juvenile justice system is Oppositional Defiant Disorder, with a scattering of ODD's more dangerous relative, Conduct Disorder. A discussion of the general utility of these two diagnoses will have to wait for another time, but their relation to FAS/E must be explored for a moment: When a person can't communicate his or her needs very well, can't figure out the cues of others, is often physically uncomfortable, does badly in school and at home, can't organize or even remember tasks or materials—and has everybody yelling at him or her to just try harder—we have a recipe for resistance and defiance. As one of our youth put it, "It's better to be bad than stupid."

Any of these diagnostic categories is partly accurate; the problem with each is that they do not begin to cover the broad tapestry of dysfunction suffered by people with alcohol-related brain damage. What tends to happen most often is that unless this tapestry is identified, the real diagnostic label that befalls people with FAS/E is "bad"—but as with the other diagnoses, this label only describes the symptom, not the disease.

#### Talking the talk

This particular kind of brain damage is difficult to recognize for at least two other reasons besides the partial diagnoses that siphon off understanding. Adding to the "stealth" quality of this condition is a language feature common to FAS/E known as "superficial fluency": the ability to sound as if one is carrying on a meaningful conversation when in fact very little is being exchanged. There is difficulty articulating one's own real feelings and thoughts and difficulty grasping the meaning behind others' utterances, but a real ability to produce a reasonable facsimile thereof! If you don't listen carefully and double-check what you hear, you will think the person's cognitive processes are in fine working order.

#### Lack of professional awareness

The final reason FAS/E is not recognized is that few clinicians are trained to look for it. The above-mentioned diagnoses are in the DSM-IV and ICD-9; FAS/E is not. The closest we have is "Personality change due to a medical disorder". Research is far ahead of practice in this area as seen in an OB-GYN's comment last year: "FAS? I didn't think there was much of that around any more."

There are few sources of complete diagnosis around the country; the University of Washington originated a systematic diagnostic approach which has spawned other diagnostic clinics around the state and a few in the Northern Midwest. (Astley & Clarren, 1999) Our clinic in San Jose, California is modeled after this approach as well, and is the only source of fetal alcohol spectrum diagnosis south of Seattle. (See below for further discussion of diagnosis.) There may be others, but people around the country

describe great difficulty finding anyone who understands, let alone can diagnose, this fabric of disorders.

### **How does FAS/E predispose a person to non-productive or even criminal behavior?**

In another article in this edition, Dr. Snyder discusses the connection between AD/HD and delinquency. As noted above, a solid core of FAS/E behaviors fall into the AD/HD realm, with a few added features that make bad behavior that much more likely. These include (usually) a lower IQ, more severely impaired executive functioning, inflexibility of thinking/rigid problem solving, explosive or rage disorders, brain-based difficulty telling truth from fantasy, and sensory integration difficulties.

Let us return for a moment to Bobby, who keeps bouncing back into the system partly because he cannot imagine a future, and thus does not make sure he will make it to his drug testing appointment. This appointment might as well be in the next lifetime for all he knows. As well-known AD/HD researcher Russell Barkley notes, where normal people can imagine a future of around six to eight weeks, people with AD/HD can imagine a future of about 8 hours (Barkley, 1990). This applies on an even larger scale and across more dimensions with FAS/E (Mattson, Goodman, Caine, Delis and Riley, 1999).

### IQ

There are many people with FAS/E with average or above-average intelligence as measured by IQ tests, but little ability to “do life. More often, prenatal alcohol damage has affected general cognitive functioning and is now understood to be the primary known cause of mental retardation. There is a surprising percentage of youth in Juvenile Hall with cognitive impairment. Exact numbers are not available, but Special Education staff in the Santa Clara County facility estimate that out of 300 inmates, at least ten of them have IQ’s under 70 at any given time. Probation staff involved in Special Education referral estimate that three quarters of their referrals fall into the 65-75 range of IQ, and that upwards of 90% of those were exposed to alcohol. With this reduced capacity to reason, remember, solve problems, organize information or grasp concepts, poor decisions are much more likely. One of the most common categories of these poor decisions is related to gang activity: an adolescent with impaired ability to think things through is a good candidate for those gang-related tasks that carry the highest risk of either getting caught or getting hurt; gang leaders instinctively know this and use it to great advantage.

### Executive Functioning—the Big Picture

For people with alcohol-related brain damage (and many people with brain damage in general) this inability to imagine a future is consistent with a general inability to see anything that is not right in front of their noses. Time, space, truth and other people are the most problematic dimensions here.

Imagine, literally, a big picture. There is a lovely sailboat in the sunshine on a calm blue ocean; birds fly above and fishes doubtless swim below. There is also an enormous steamship heading directly for the sailboat. Imagine you are standing one foot away from

this picture and you look at it without turning your head. Asked what the picture is about, you will describe the piece of the scene that is right in front of you. As you step to the side one foot at a time and only look right in front without trying to see what you saw before, your interpretation of the picture will change, one little section at a time. “It’s about a sailboat”...“It’s about some birds”...“It’s about a steamship”.

People with FAS/E only tend to see what is right in front of their noses at any given time. This is independent of IQ, upbringing, other talents or even intention. “Getting the Big Picture” is the general caption for the whole array of executive functioning, and if we can only see the little quadrant directly in our line of vision we will

- Not imagine a future
- Not save money or plan for much of anything at all
- Nap, eat, drink, have sex, no matter what our boss thinks we should be doing
- Not be thoughtful toward other people or understand their reactions when offended
- Forget what we came into the room for
- Drive through the pesky red light if we’re in a hurry
- Not be able to explain our actions
- Not understand that our actions have consequences
- Take things that appeal to us
- Leave dreadful messes for others to clean up
- Not be able to predict what will happen

It is the experience-based belief of this writer that poor executive functioning is behind most of what we normally call “irresponsibility”, and behind a great deal of what we attribute to deliberate bad choices and weak moral character. It is an inability to understand abstract concepts like responsibilities, good choices and strong morals. People with FAS/E can only parrot these principles by rote; they cannot apply them meaningfully to their own lives.

#### Inflexibility and Explosiveness

To this far-reaching bundle of big-picture-challenged behaviors we add a few features of FAS/E that can push a merely wasted life into a destructive one. The brain-based traits of inflexibility and explosiveness are particularly dangerous and often occur together, igniting an all-too-common response to frustration: “If at first you don’t succeed, throw that sucker across the room!” This behavior pattern, identifiable in early childhood, does not lead inevitably to a lifetime of violence, but it certainly makes thoughtful, productive responses less likely.

#### Lying

Another problematic and common side of prenatal-alcohol-related brain damage is the tendency to lie, which often accompanies tendencies to cheat and steal. “Moral retardation” appears with FAS/E even in families where a child has been adopted in infancy, and consistently taught the values of honesty and respect for people and property. It is one of the most heartbreaking experiences of adoptive families that their

children persist in behaving like street urchins despite the best parenting practices possible.

### Sensory Integration Disorders

Sensory integration refers to the system of processing incoming stimuli through the senses. For most of us, the five senses are calibrated to a level of sensitivity that allows us to enjoy this incoming information and alerts us to danger or need through discomfort. For some people, the level of sensitivity is either too high, too low or both in any or all of these areas. Prenatal alcohol exposure often causes such imbalance: the tags on the back of shirts are irritating, only certain foods taste right, one has to keep changing body position, the bell at school sets off a flight reaction—or, in the opposite direction, wounds are not noticed, food is rejected even when needed, sleep is the last thing on a child's agenda when tired.

What turns sensory integration difficulties from private discomfort into troubling behavior has to do with the additive effects of explosivity, poor ability to delay impulses and impaired executive functioning. Chronic discomfort makes it hard for anyone to remain cheerful and productive; people with FAS/E are quicker than most to get upset, slower to calm down, and the least likely to address basic needs like nutrition, shelter from the elements or rest, let alone a toothache. To top it all off, drugs and alcohol offer an appealing respite from all the internal and external noise.

So we have a person in constant upset and discomfort with no reliable remedy, poor impulse control, rage attacks—and high.

### **Juveniles**

The next section explores the evolution of a prenatal-alcohol-affected child into a juvenile delinquent, how he or she often appears to the judicial community, the typical course of that relationship and, finally, what we can do.

### How an FAS/E child can turn into a juvenile delinquent

The primary disabilities of prenatal alcohol damage were listed previously under **Effects**. These disabilities can turn into troubling or dangerous behavior when they are not identified and treated. In a seminal series of studies spanning over 15 years and still going strong, Ann Streissguth of the University of Washington has followed a group of around 500 people with FAS/E. ( Streissguth, Barr, Kogan, & Bookstein,1996). She found that in the absence of identification and appropriate treatment, life outcomes she calls secondary disabilities develop in the following proportions:

**Disrupted school experience** had plagued 60% of the adults and adolescents, stemming from attentional problems and repeatedly incomplete schoolwork. Behavior problems in school fell into the categories of not getting along with peers (60%) and being repeatedly disruptive in class (55%-60%). Sixty % of the adolescents and 14% of the children had had **trouble with the law**, with shoplifting and theft as the most frequent type of crime. Fifty percent of adolescents and adults had been **confined**, either in mental health programs, inpatient drug and alcohol treatment or jail. Forty-nine percent of adolescents

and adults and 39% of children had displayed **inappropriate sexual behavior**. Of people who were at least 21 years old, two additional secondary disabilities were noted: **Dependent living** characterized 80% of the sample, and 80% had **problems with employment**.

Streissguth's explanation for these high levels of secondary disabilities found in people with FAS/FAE is that the primary disabilities of permanent organic brain damage are hidden, leading schools, families, the justice system and society at large to expect normal behavior and reasoning. Without a low IQ score, obvious mental illness or physical signs of birth defect, societal protection is lacking, and blame or punishment is all too often the only response.

This research also examined risk and protective factors associated with secondary disabilities. Risk factors were those that were most associated with elevated rates of secondary disabilities; protective factors resulted in lower rates. Protective factors included:

- 1) Living in a stable and nurturing home of good quality
- 2) Not having frequent changes of household
- 3) Not being a victim of violence
- 4) Having received developmental disabilities services
- 5) Having been diagnosed before the age of 6
- 6) Having a diagnosis of FAS rather than FAE
- 7) Having an IQ score below 70

The last two factors may seem counterintuitive. The reason that having FAE leads to worse outcomes than having FAS is that FAE is truly invisible—at least with FAS there is a chance that the facial features will be recognized as a birth defect signaling brain damage, and the resulting behavior will be interpreted accordingly, unlike someone who looks completely normal. The advantage of the more severe cognitive impairment of the lower IQ is similar—the odd or irresponsible behavior of a mentally retarded person will more likely be met with increased services and support, not punishment and shame.

Streissguth's primary conclusion from this study was a strong recommendation that early diagnosis be made available wherever warranted, so that support services could be mobilized, appropriate educational and parenting practices could be implemented, and self-image could be enhanced rather than continually eroded.

Few of the adolescents in Juvenile Hall have had a stable and nurturing home, least of all those who were exposed to drugs and alcohol since conception. "Frequent changes of household" characterize many, especially the young women, nearly all of whom (in this writer's jurisdiction, Santa Clara County) have spent time in the Children's Shelter. 78% of the youth in our county's Hall were found to have been a victim of or witness to violence, according to an informal study done by the Department of Alcohol and Drugs.

Bobby lived with his mother off and on for the first two years of his life, sometimes at shelters and sometimes with relatives. Then Children's Protective Service intervened; he

lived in five foster homes until the age of 12, when his encounters with the authorities took a more punitive turn. Over the next four years, Bobby was in and out of correctional institutions eight times. He has seen two people killed and was involved in an accidental shooting. Although he received Special Education services, he never achieved anything approaching success in school. After about the third grade he preferred not to go to school, and the system did little to remedy his truancy. Bobby's behavior was never deliberately malicious, but he found himself in the wrong place at the wrong time ALL the time, and almost never in the right place at the appointed time.

Bobby's probation officer had long ago lost patience with this minor who had so often told him the most boldfaced lies, refused to go to school and never bothered to show up for meetings. The P.O. knew that Bobby had an IQ in the 70's and figured that's why he didn't do so well in school, but the rest of it was surely deliberate. He believed that the only way to get Bobby's attention was to send him to California Youth Authority, where they would really teach him a lesson...he wouldn't get away with any of this nonsense there!

Breaking promises, failing to appear, ignoring clear orders—and then lying about it all. This pattern is not atypical of many of our FAS/E youth; the ones who wind up in the juvenile justice system are those who have developed secondary disabilities because they were not identified and treated as people with the primary disabilities associated with brain damage. Youth with FAS/E who do not appear in the system are those who have been supported with appropriate interventions. They may have similar organic tendencies to fall through on promises, forget where they're going, not grasp the significance of instructions—and even confuse truth with fiction, but they have (by definition) been successfully guided to a life with legal pleasures and sufficient impulse-control to avoid criminal activity.

Once in the system, youth with FAS/E generally keep cycling through for curfew violations, associating with the wrong people, drug and alcohol consumption, truancy, shoplifting, or minor sexual offenses (often a matter of accepting the wrong invitation). Normal teens, once they have been caught and want to regain their autonomy, understand how to curb or hide these impulses long enough to get off probation. People with FAS/E do not have the ability, for so many reasons outlined in this article, to plan for their future, curb their impulses or, ultimately, regain their autonomy. And to cement their fate, they haven't been graced with the ability to own up to their mistakes.

#### Where are we now and what can we do?

“External brain” is a phrase frequently heard in the FAS field. With defects in executive functioning, one needs to recruit an outside executive—someone who help will mind the store, captain the ship. Successful early intervention of the sort that prevents secondary disabilities helps a child understand that he or she has some gaps in functioning, that it isn't his or her fault, and that it's important to ask for help. But for the unlucky 99% of kids whose disabilities are not identified, a self image that is rotten with shame and alienation often creates a crust of “I'm fine; my only problem is you; all I need is freedom”...which is exactly what they do not need. As with many allergies, that which

we crave the most is what makes us the sickest--while freedom is what these youth crave, what they really need is external structure. The problem is that until they are able to welcome voluntary structure, they will continue to gravitate toward the involuntary kind.

Ultimately of course the very best we could do is early diagnosis and intervention, with the child and the family. All is not lost, however, with our teenagers. Useful responses for youth with FAS/E include the following: Accurate diagnosis, education of caregivers about the nature of the brain damage, medication support, accommodations in school and the legal system, sentencing alternatives and to whatever degree possible, coaching /mentoring, education of the youth him- or herself

### Diagnosis

As noted above, diagnosis is much harder to come by than it should be, and than it needs to be. The Fetal Alcohol Spectrum Diagnostic Clinic at the county hospital in San Jose began a little over a year ago, and has seen over 50 children in its once-a-week sessions, including several youth from Juvenile Hall. The team is made up of a pediatric neurologist, a speech/language pathologist, a physical therapist or occupational therapist, a psychotherapist, an educational specialist, a public health nurse and a psychologist. Records are reviewed in advance, and on the day of the clinic visit the patient is tested by the speech/language pathologist (using material developed specifically for FAS evaluation in addition to standard testing including learning and memory) and the PT/OT, who checks neuromotor and perceptual functioning. At the same time the caregivers are interviewed to explore real-life behaviors and reactions. After the team meets privately to share findings and discuss diagnostic conclusions, this information is shared with the patient and caregivers, along with recommendations, resources and reading material. The caregiver is then contacted a few weeks later to see if there are additional concerns or questions.

The diagnosis is not a black-or-white decision, FAS or no FAS, because this is a whole fabric of disorders occurring in varying severities--and because many of the findings may be attributable to factors other than prenatal alcohol exposure. If there are significant delays in at least three areas of functioning connected to organic impairment, facial features typical of FAS, growth retardation and documented history of prenatal exposure, then the diagnosis is Fetal Alcohol Syndrome. By far the more common range of diagnoses are in the Fetal Alcohol Effects category (equally brain-damaged without the physical markings).

### Education

After diagnosis comes education with caregivers, teachers, probation officer, counselors, physicians and, as much as possible, the patient him or herself. Aside from specific recommendations for structuring life in such a way that meltdowns are minimized and productive activity is maximized, the main recommendation is to try on the lens of brain damage as explanation for the irritating (or enraging, or hurtful, or destructive) behaviors of the past. Quite often this will start a ripple of changes that serves both the youth and the system. When Bobby's PO heard the results of the testing he said, "You mean when he tells me that he forgot the meeting he's actually telling me the truth?!" Some small

changes were made so that Bobby's memory didn't have to hold more than it was able to; Bobby's behavior on the unit has improved and he is actually helping out in class now.

### Medication

Medication may have been tried in the past with previous diagnoses of AD/HD. Stimulants are successful with these symptoms, although research indicates that short-acting Ritalin is less likely to work well with FAS-related AD/HD than other stimulants. Other aspects of FAS/E are medically treatable as well, especially the mood disorders. Parents report remarkable improvement in ability to relate to others, calm down, focus and stay put. Even parents who are philosophically opposed to medications have found them to be lifesavers with their severely FAS children.

### Alternative Sentencing/Drug Treatment Court

Juvenile Treatment Court is a good example of the "shorter leash" approach that works well with youth in need of a higher degree of external brain than the normal teenager who just happened to get caught. Drug testing in JTC is frequent and random, school attendance is checked, obedience to parents is a condition of probation and is monitored, and appearances before the judge occur weekly during the first phase of JTC. There is a whole team of adjunct caregivers in court every time the youth appears: public health nurse, social worker, FAS/LD/ADHD consultant, lifeskills teacher and community workers, as well as counselors and defense attorney. The circle is a firm, affectionate, often good-humored one with very few cracks to fall through--much to the chagrin of the youth in the beginning of the program. By the end (at least a year later), however, the affection is often mutual and palpable. As part of the program, educational, health, medical, family and mental health needs are monitored and met where possible. The emphasis is on celebrating success and growth while maintaining firm limits with (ideally) immediate consequences for infraction.

### Alternative incarceration

Brain-damaged delinquent youth are not only out of control themselves, they are often the victims of bullying and exploitation. At least three counties are considering providing a separate unit that this writer is aware of for juvenile offenders with FAS/E, traumatic brain injury or other organic disorders. The purpose would be at least protective of both society and the offender, but ideally habilitative: teaching directly aimed at self-understanding and self-acceptance, guidance toward viable work options, lifeskills, interpersonal relations and emotional self-regulation.

### **Family Issues**

Most of the children seen in our FAS clinic are or have been in the Dependency system; information available on their birth parents suggests that many of them were also graduates of foster care, and were themselves saddled with impaired cognitive and self-regulatory abilities.

### Raising FAS/E children

Children with prenatal alcohol exposure are difficult for anyone to raise, as well-prepared adoptive parents attest. A child who is quick to upset, slow to obey, impossible to calm

or console, generally complaining about some discomfort or other and often sick would be hard enough without the rage disorders, lying, inability to read social cues, remember yesterday's learning or express needs. These children rarely reflect back the calm, happy, interactive impression of a well-cared-for child, no matter what the level of parenting actually is, making it harder to keep the bonding cycle going. Marriages have broken under the strain, as each partner accuses the other of causing the child's problems.

People raising children diagnosed with FAS/E report significant depression, exhaustion and anxiety. When a desperate parent seeks professional advice, clinicians almost invariably suggest another parenting class, or chore charts with gold-star stickers. When the child doesn't respond to the methods that the parenting class swears by (and all the other parents report such success with), a parent who hasn't considered organic causes will turn with the force of gravity to the belief that "something is rotten in Denmark here, and it's either the kid, my husband or me." Drinking and drug use have been known to begin or increase under the confusion, pressure and shame.

Early and accurate diagnosis is thought by some experts to be the single most effective intervention with FAS/E. On top of this base of knowledge and compassion, appropriate services can then be gathered from the school district, county mental health or medical staff, and parental efforts can be aimed in the right direction. A great many parents, both biological (in recovery) and adoptive, share stories of children who are now reasonably happy and productive, thanks to appropriate diagnosis and intervention.

#### FAS/E parents

The same qualities that make an FAS/E child so difficult to parent translate naturally into qualities that interfere with good parenting. Telling the parent with FAS/E to put a chart with stars on the refrigerator is really whistling in the wind. Of course if the parent is still using drugs and/or alcohol on top of neurological impairment, the chances for adequate parenting sink to approximately zero.

#### What can we do

Screening and assessment is recommended with people in our system suspected of having brain dysfunction, especially those charged with raising a child. Once identification has occurred, appropriate, supportive scaffolding can be put in place. Many family courts around the country already use some combination of supports, with mentors, parenting programs, specialized family reunification programs for substance-abusing parents, family conferencing and so on. Some of these use principles appropriate to FAS/E parents already, including a simple, comprehensive, very tightly structured and encouraging approach.

A few innovative programs briefly described below are likely to succeed with FAS/E as well as non-brain-damaged clients. The only missing element, common to all such programs, is longevity: people with serious impairments in executive functioning will need external structure all their lives, and the likelihood of reappearance in the system is high without such structure in place.

**Family Drug Court** combines dependency and treatment issues, tightening the net of monitoring and support, with regular drug testing, identifying and addressing related needs, frequent encouragement and mentorship; specific aspects of this new court vary across the country.

**Epiphany Center** is a program in San Francisco with short-term infant residential treatment for drug and alcohol exposed children. The goal is to reunite infants with their birth parents, extended family, or an adoptive family within six months of placement. The program includes early intervention to promote healthy physical development, positive neurobehavioral organization and positive attachment to significant adults, developmental assessment and followup services, case management, well baby care, substance abuse treatment, parenting classes, life skills training and in-home services.

**Shared Family Care (SFC)** places an entire family with a host family trained to mentor and support the biological parents. Outcomes range from reunification and prevention of removal to the decision to terminate parental rights. SFC programs exist around the country: Minnesota has a Whole Family Placement Program, Crime Prevention Association operates A New Life program in Philadelphia, PA., and pilot programs are being evaluated in California and Colorado.

**Multi-Systemic Therapy** makes high-quality, on-call psychological services available to at-risk families at any hour of the day or night, in addition to regular counseling and addressing educational, vocational or other needs. This collaborative program operates on the premise that advice or counseling must be in a real-life context, aimed at concrete needs and problems rather than theoretical “issues,” and must stay oriented to the clients’ own expressed priorities. It is an intensive wrap-around-style approach with specific training and monitoring for its providers.

**The Parent-Child Assistance Program (P-CAP)** in the state of Washington addresses the risks of neurological impairment and compromised home environment that threaten the children of substance-abusing mothers. Its goals are to help mothers build and maintain healthy independent family lives, to assure that children are in safe and stable homes, and to prevent future births of alcohol and drug-affected babies. P-CAP uses trained and supervised paraprofessional advocates who each work with 15 clients for three years, assisting in identifying personal goals, obtaining alcohol and drug treatment, staying in recovery, choosing a family planning method, connecting with community services, transportation to appointments, solving housing, domestic violence and child custody problems and resolving system service barriers.

### **Conclusion**

This article has outlined the prevalence, causes and effects of FAS/E, and explored some of the ramifications of this condition throughout our juvenile and family court systems. It was the intention of this writer to raise awareness of the depth, breadth and nature of the havoc wrought by prenatal alcohol damage, so that interventions can be aimed at the actual target of neurological impairment instead of the shifting masquerade of deliberate disobedience. Where brain damage is thought to be present, thorough diagnosis, a tight

structure, appropriate medications and community support are infinitely more likely to prevent re-offense and keep society safe than the revolving door of detention, release and “OK, Bobby, it’s all on you now”.

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