Adaptive behavior and Fetal Alcohol Spectrum Disorders

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Adaptive Behavior is a construct originally invented as a prong for diagnosing Mental Retardation, but it has come to also play a role in diagnosing Fetal Alcohol Spectrum Disorders (FASD). In this paper, we: (a) describe the meaning and measurement of adaptive behavior, including the need for improved measures (b) illustrate clinical and research uses of the construct, in establishing the diagnosis and behavioral profile of people who have FASD and (c) discuss the forensic uses of adaptive behavior for people with FASD in establishing a mitigation case in criminal proceedings, including possible extension of Atkins *(death penalty exemption) protection for people with organic impairments who function just as if they have mental retardation in spite of possessing IQ scores in the borderline range.*

KEY WORDS: *Adaptive behavior, FASD, mitigation,* Atkins.

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The term "adaptive behavior" (sometimes referred to as "adaptive functioning") grew out of the animal research literature, and refers to an organism's competence in the real world rather than in a formal and artificial assessment situation (such as mazes for rats, IQ tests for humans). In clinical psychology, special education, and criminal law, the construct is used mainly in diagnosing Mental Retardation (now beginning to be termed Intellectual Disabilities), as the second of three definitional prongs (the other two being low IQ and developmental onset before adulthood) found in both clinical manuals and state criminal statutes. However, adaptive behavior is being used increasingly in diagnosing FASD; for example, the diagnostic protocol used by a prominent FASD forensic consulting group calls for the use of the Vineland Adaptive Behavior Scales (VABS) as one of their diagnostic methods.

This article is divided into three sections. In the first section, we describe the meaning and measurement of adaptive behavior, including the need for improved measures, especially ones which better capture foolish (risk-unaware) social and practical conduct. In the second section, we illustrate clinical and research uses of the adaptive behavior construct in establishing the diagnosis and behavioral profile of people who have FASD, and discuss the forensic uses of adaptive behavior in establishing a mitigation case for people with FASD in criminal proceedings. In the third section, we discuss the role of adaptive behavior in establishing exemption from rigid IQ ceilings in diagnosing Mental Retardation and providing supports and protections for persons with FASD whose IQ scores may be in the borderline or even low normal range.

The meaning and measurement of adaptive behavior

The widespread use of the term adaptive behavior stems from its inclusion in the 1961 classification manual (Heber, 1961) of the American Association on Mental Deficiency (AAMD; later changed to the American Association on Mental Retar-

dation, AAMR; and, recently, to the American Association on Intellectual and Developmental Disability, AAIDD). The idea behind invention of the construct was to reduce the sole reliance on IQ scores when diagnosing mental retardation (a term which was also coined in 1961 to substitute for the no longer acceptable term "mental deficiency"). The driving force behind this development was concern about the over-assignment of the mental retardation label, particularly to minority or low socioeconomic status children and adults. The idea, therefore, was that adaptive behavior would be used to reduce the size of the mental retardation class to those who functioned ineptly both in the classroom (IQ) and outside the classroom (adaptive behavior).

The meaning of adaptive behavior

As is true of many psychological constructs (including intelligence), the term adaptive behavior began to be used in advance of a clear or consensually accepted definition. In such a case, what happens is that measures of the construct are developed, and the construct becomes defined, in circular fashion, by the measure. Thus, there is considerable truth in the humorous definition of intelligence as "that which is measured by IQ tests." The same can be said about adaptive behavior. The first such instrument was the AAMD (later AAMR) Adaptive Behavior Scale (ABS, not to be confused with the more recent ABAS). The ABS tapped two basic areas: activities of daily living, and social functioning.

A major problem with the ABS, and by extension the definition of adaptive behavior in use at that time, was that the social domain was mainly defined by items tapping "maladaptive behavior," i.e., externalizing psychopathology (striking out against self or others) or its absence. A related problem was that the ABS was developed in an institutional setting (Parsons State School, in Kansas) serving mainly lower-functioning individuals, and thus the daily living subscales had items aimed at a fairly primitive level (toileting, dressing, feeding, etc.). Thus, early measures and definitions of adaptive behavior were of limited utility in diagnosing or

specifying the service needs of higher-functioning individuals who, for the most part, were living in less- (or non-) restrictive community settings and who could do many of the things tapped by the ABS even if they had other areas of incompetence that were not tapped by the instrument. Not surprisingly, for a long time adaptive behavior was ignored by clinicians and agencies, a problem that was also attributable to the fact that the authors of the ABS intended the measure to be used descriptively, and thus refused to develop population-based norms.

Around three decades ago, the second author published a number of papers (Greenspan, 1979, 1981) calling for a new approach to defining adaptive behavior and, by extension, to defining mental retardation. Building on a tripartite model of intelligence first formulated by Edward Thorndike (1920), he suggested that IQ tapped the first of the three forms of intelligence (termed abstract intelligence by Thorndike, conceptual intelligence by Greenspan). The other two forms of intelligence, termed mechanical and behavioral intelligence by Thorndike, and practical and social intelligence by Greenspan, could serve as the adaptive behavior piece, and would provide the construct with the theoretical foundation it was then lacking. In this formulation, Mental Retardation would, thus, be defined as a relative absence of three forms of intelligence: conceptual intelligence (IQ), practical intelligence (the kinds of everyday tasks involved in daily living activities), and social intelligence.

This proposal has been influential, in that the current model of adaptive behavior formulated by AAIDD has adopted the tripartite model, but has not gone as far in integrating adaptive behavior with intelligence as was originally intended. A full discussion of this issue is beyond the scope of this article, but can be found in Greenspan (2006). A major concern raised in that and earlier papers has been the lack of sufficient emphasis in various conceptualizations and measures of adaptive behavior on social competence, particularly “social

intelligence" (interpersonal "with-it-ness" or "out-of-it-ness"). Certainly, absence of social intelligence (i.e., presence of bad judgment in dealing with people and social institutions) has been repeatedly noted as a core defining characteristic of people with FASD (Fast & Conroy, 2009; McGee & Riley, 2007; Schonfeld, Paley, Frankel, & O'Connor, 2006). Furthermore, such poor social judgment is especially likely to get someone with FASD into legal trouble, either as a victim or a defendant, in criminal proceedings.

Measurement of adaptive behavior

For at least two decades after its invention (Heber, 1961), adaptive behavior was (to use a legal expression) "honored more in the breach than in the observance." This was due to several factors, including habit (many psychologists continued to believe that IQ alone was sufficient for diagnosing mental retardation), convenience (adaptive behavior assessment, if done properly, requires considerable out-of-office time and effort) and the absence of adequate and norm-based measures. The original idea was to make the IQ criterion (prong one) fairly easy to meet (by setting the ceiling score quite high) and then use prong two (adaptive behavior) to funnel the numbers down. The failure of the field to use adaptive behavior, however, contributed to the decision in the 1973 AAMR manual revision to reduce the IQ cutting score from minus one standard deviation (IQ score of 85, or the 16th percentile) to minus two standard deviations (IQ score of 70, or the 2nd percentile). This had the effect of reducing the class too much, creating a problem of "false negatives" (earlier the concern was mainly about false positives), which is probably the main reason, more than the stated emphasis on instrument error, why the IQ ceiling was raised in the 1992, 2002 and 2010 AAMR/ AAIDD manuals to 75.

Today, formal adaptive behavior measures are much more likely to be used, a development attributable to the publication of more theoretically-grounded norm-based measures and also to the preference by courts in so-called *Atkins* (death

penalty exemption cases involving possible Mental Retardation (MR)) proceedings for prong two data. Technically, a formal measure of adaptive behavior is not a requirement for diagnosing MR in a criminal case. For example, section 1376 (a) of the California Penal Code provides a definition which is typical of those found in other statutes: "'mentally retarded' means the condition of significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 18." There is no specification of how adaptive behavior is to be measured or of what criteria (such as cut-off scores) are to be used to decide whether the prong is met. In theory, therefore, one can produce qualitative/descriptive information to argue that the criterion is met or not met, and that in fact is often what is done. The problem, of course, with using such an approach is that there is a tendency for experts and attorneys on both sides to cherry pick isolated skills that an individual is reputed to be able to do or not do and to then argue for or against a diagnosis of Mental Retardation based on such isolated and nonnormative evidence. Among the many reasons why such an approach is inappropriate, the main one is that people whose intellectual impairments are at the upper, or mild end of the mental retardation spectrum can do many things, including activities (such as working, having sexual partners, driving cars, etc.) that are often wrongly pointed to as evidence that someone cannot have Mental Retardation.

Descriptive information can be useful, however, in gathering information about areas of possible incompetence that are not tapped adequately or at all by items on the adaptive behavior rating instruments described in the next paragraphs. This is particularly important, as noted in the last two AAMR/AAIDD manuals, with regard to gullibility, an area of social adaptive functioning not yet included in existing rating instruments. The importance of gullibility in diagnosing mental retardation (and we would add, FASD) was brought to the attention of the field by the second author (Greenspan, Loughlin, & Black, 2001), although in the 19th Century it was often mentioned

(under the rubric of "credulity") as a core behavioral feature of persons then labeled "mental defectives" (Ireland, 1877).

The most common approach to assessing adaptive behavior is the use of a third-party rating instrument. Currently the three most widely used measures are the Vineland Adaptive Behavior Scale, second edition (VABS-2), the Adaptive Behavior Assessment System, second edition (ABAS-2), and the Scales of Independent Behavior, revised edition (SIB-R). In addition, the AAMR/AAIDD, which in its earlier incarnation as AAMD developed an instrument, the ABS (not to be confused with the ABAS), but later turned it over to an outside publisher, is developing a Diagnostic Adaptive Behavior Scale. This instrument is so-named in order to differentiate it from other measures, which were originally developed mainly to devise individualized service plans, and thus are imperfectly suited to their frequent use in the diagnostic process.

These rating instruments have many items (200 or more), divided up according to various subscales. Raters are asked, either through filling it out themselves or, more typically, through an interview conducted by a trained and qualified professional, to indicate whether the person being rated can always, sometimes or never perform each of the described activities. Raw scores from these ratings are then converted to standard scores from tables which reflect norms gathered on different age cohorts of the general population. These standard scores resemble IQ scores, in that a score of 100 indicates that an individual is at the 50th percentile of the population, while a score of 70 indicates that he or she is at the 2nd percentile. Different forms and norms are available for different categories of raters. For example, the teacher version of the VABS-2 has different daily living activity items than the parent or caregiver version, for the simple reason that teachers generally do not make home visits and, thus, cannot be expected to know if one of their students can cook, clean, operate a washing machine, etc. As a rule, two or more

raters should be used, to correct for the possibility that a given rater's score may be biased or otherwise invalid. Ratings which are in close agreement can, thus, be kept—and used separately or in combination—while highly discrepant ratings (either way too high or way too low, when compared to others') can be confidently discarded.

The various adaptive behavior instruments differ somewhat in terms of items, methods and subscale names. For example, on the ABAS-2 all items are to be administered to an informant, while the VABS-2 (except for the teacher version) uses a difficulty gradation method, in which one establishes a "basal" (giving credit for all items below first occurrence of failure) and a "ceiling" (giving no credit for all items above where failure becomes frequent), thus eliminating the need to administer all items. Although subscales on various measures are differently named, they basically all produce four summary standard scores: Conceptual Adaptive Behavior, Practical Adaptive Behavior, Social Adaptive Behavior, and Composite Adaptive Behavior (summed overall, comparable to Full-Scale). In addition, each of these are divided up into narrower subscales; thus the ABAS-2 has 10 subscales corresponding to the 1992 AAMR adaptive behavior model, and these are then combined into the three broader standard scores (and the overall composite score). Scale scores (standardized scores but with a mean of 10–15 on the VABS-2—rather than 100) can be obtained for these subscales, which is useful in those states whose criminal statutes define mental retardation according to the operational criteria in DSM-IV (2 out of 10 or 11 subscale deficits) rather than AAIDD (1 out of 3 domain deficits) standards.

This latter issue refers to an important point, which is that clinical standards for meeting prong two (and legal standards in those few states with more detailed statutes) do not require global impairment in all areas of adaptive behavior. The explanation given in the 2010 "green book" AAIDD manual is as follows: "a generalized deficit [in adaptive behavior] is

assumed even if the score on only one [of the three adaptive behavior domains] meets the operational criterion of being two standard deviations below the mean" (Schalock et al., 2010, p. 46). Thus, one can qualify as having mental retardation with significant impairment in one or two domains of everyday functioning, while overall impairment (on the composite summary standard score) is not a requirement. Although the green book justification cited above is statistical in nature, there is another reason which may be more important, and that is that for individuals in the higher functioning range of intellectual impairment (where most defendants in criminal proceedings, including those with FASD, are likely to be found), there is typically a mixed pattern of everyday functioning, with significant deficits mixed in with areas of near-normal functioning.

It should be noted that while presence or absence of maladaptive behavior (psychopathology) is no longer used to define or diagnose Mental Retardation, a maladaptive subscale still can be found in some adaptive behavior rating instruments, particularly the VABS-2. This maladaptive subscale is in fact commonly used, along with the other subscales, when diagnosing FASD, as individuals with FASD are very likely to exhibit many maladaptive behaviors, often reflecting inability to say "no" to friends. In fact, it is the continued inclusion of a maladaptive subscale that likely explains the preference among FASD clinicians for the VABS-2, in contrast to mental retardation clinicians who, in our experience, are more likely to use the ABAS-2, which lacks a maladaptive subscale.

Need for improved measures

As noted earlier, a problem with prevailing models and measures of adaptive behavior is that they focus too much on the minutiae of self-care skills (operating a washing machine) and are not sufficiently "cognitive" (understanding the importance of clean clothes), social (understanding their importance for acceptability), and strategic (being able to master the many steps involved in the process besides merely operating the machine). Here is a small sampling of adaptive behavior

rating items, all of them from the ABAS-2, which seem to have little or no connection to cognitive functioning: "controls temper when disagreeing with friends," "has pleasant breath," "offers to lend belongings," "offers assistance to others," "shows positive attitude on job," etc.

Many of these behaviors are performed adequately by cognitively impaired individuals, while we all know intellectually superior individuals who for various reasons are unable or unwilling to do some of these things. Granted, one should not put excess emphasis on isolated items (that is why these measures have many items). Furthermore, people with Mental Retardation do, as a class, demonstrate marked impairment in their levels of adaptive functioning, as reflected in their summary standard scores on instruments such as the ABAS-2. However, the focusing in these instruments on narrow overt behaviors as opposed to underlying cognitive processes—while understandable (the former entities are easier to rate objectively)—is still problematic. That is because they fail to capture the qualities of bad judgment (particularly bad social judgment) which go to the heart of these disorders and which are what puts cognitively- and organically-impaired individuals at social (e.g., legal) and physical risk and in need of services, protections and accommodations.

There is evidence that more cognitively oriented "molar" items can be used reliably and validly in rating instruments. One instrument, used thus far mainly in Australia with elderly individuals, is the Social Vulnerability Scale (SVS) (Pinsker, Stone, Pachana, & Greenspan, 2006). The SVS taps gullibility (which is a big problem in people in early stages of Alzheimer's, as it is, we believe, for people with FASD) and contains items such as "been tricked into giving money or other objects," "been talked into taking the blame for something he did not do," and "easily fooled." It is reported (Novick-Brown, personal communication) that the SVS may hold promise as a diagnostic instrument in assessing the social vulnerability of individuals with FASD.

An example from the FASD literature can be found in the Fetal Alcohol Behavior Scale (FABS) (Streissguth, Bookstein, Barr, Press, & Sampson, 1998). Technically, the FABS is not an adaptive behavior instrument (mainly because it is not labeled as such) but it has many of the qualities of an adaptive behavior rating measure. The FABS is an inventory, which includes a wide range of symptoms that have been found empirically to characterize people with FASD. The importance of the FABS, as a supplement to more general adaptive behavior instruments, is that it captures qualities and symptoms that are specific to FASD. Many of these qualities, such as those reflecting deficiencies in everyday social and practical judgment, are missing from the VABS, ABAS, and other adaptive behavior instruments. More information about the FABS is provided in a later section.

An alternate, but at this point underutilized, assessment approach involves so-called direct adaptive behavior tests. These resemble IQ tests, in that examiners individually present verbal or pictorial stimuli to subjects who are then asked to solve problems posed in the stimuli. Two such instruments are occasionally used: the Street Survival Skills Questionnaire (SSSQ) and the Independent Living Scale (ILS). Both tap mainly the practical adaptive domain, through tasks such as indicating tools to be used for different jobs, selecting correct washing machine settings (both on the SSSQ), and filling out checks to pay bills and using a phone book (both on the ILS).

These two instruments are both in need of norm-updating, and are excessively easy (especially the SSSQ), but the method itself holds promise in our opinion, particularly in getting at the kinds of judgment deficiencies, especially in the social domain, that are central to understanding the everyday vulnerabilities of people with neurodevelomental disorders. One such instrument, currently under development (Greenspan & Woods, 2010), is the Common Sense Questionnaire (CSQ). The CSQ is essentially a problem-solving mea-

sure, in that practical and social dilemmas are presented and subjects are asked to pick or generate a preferred solution. A unique aspect of the CSQ is that characters in the scenarios are depicted leaning towards solutions which have significant risks likely to result from these actions. The subject is asked to indicate whether the proposed course of action is all right or not all right and if the latter, why that might be the case. The instrument is thus intended to determine whether a subject is able to recognize obvious practical or social risk.

The importance of such an approach to adaptive behavior is that a potential for engaging in "foolish" (i.e. risk-unaware) behavior is usually found in people with Mental Retardation and in our view is always found in people with FASD (Greenspan, 2009). Put another way, the instrument determines if an individual lacks "common sense," defined as awareness of obvious risk. The potential utility of the CSQ (not yet normed or ready for distribution) can be found in the following responses from "Roger," a man in his early 20's diagnosed with FASD and facing a possible death sentence.

One story involved a man named Stan who was in a bar when someone mentioned he had a car for sale in good running condition. Stan drove the car home with the understanding he would pay $500 in a few days when the seller signed over the papers. On the way home, Stan noticed the engine was smoking and figured he had been swindled. He decided to abandon the car (which was still running) on the street without telling the seller, as a way of showing the seller that Stan was not someone to be taken advantage of. When asked if this course of action was all right or not all right, Roger responded "all right, if someone does you wrong you need to do him wrong." When asked if he could think of any reason why someone would say Stan's action was not all right, Roger responded "I don't know why anyone would think it is not all right." In contrast, virtually every normally-developing adult interviewed responded along the lines of "not all right, Stan could get arrested if the seller reported it as stolen." Paren-

thetically, this, and most of the CSQ items, were derived from a true story, and the real-life Stan was charged with (and pled to) a felony after the seller reported the value of his missing car as over $1,000. So it is not surprising that Roger was someone who was always getting into trouble with the law, given his dramatic inability to take others' perspectives or to anticipate the potential consequences of his actions.

Clinical, empirical and forensic uses of adaptive behavior with FASD

In the preceding pages we have mentioned Mental Retardation more than FASD, for the simple reason that adaptive behavior was originally invented for use in diagnosing Mental Retardation, and this continues to be the main focus of adaptive behavior scholarship and application. However, the previous discussion does have considerable relevance to FASD, for two reasons: (a) FASD is a major cause of Mental Retardation, and a sizeable subset of people with FASD also qualify for a diagnosis of Mental Retardation, and (b) people with FASD and related neurodevelopmenal disorders, even with full-scale IQ's in the 80's or 90's, function in the world (especially in the social realm) as if they have Mental Retardation, and are often seen by others as having Mental Retardation. It is this "Mental Retardation equivalency" that is at the heart of why people with FASD are entitled to legal protections including *Atkins* (death penalty) immunity. In fact, in terms of their behavioral phenomenology, the main difference between adults with FASD and Mental Retardation and adults with FASD who do not qualify as having Mental Retardation, is their full-scale IQ scores.

In this section, we discuss the role of adaptive behavior measures in both research and clinical applications with FASD-affected individuals, including in forensic settings. FASD is a medical disorder, diagnosed by physicians, using biomedical diagnostic indicators when available. However, because those

biological indictors (such as facial anomalies) are variable and sometimes missing, behavioral indicators such as adaptive behavior data are of great importance. Among the standardized third-party adaptive behavior rating instruments, the Vineland Adaptive Behavior Scale, second edition (VABS-2) is undoubtedly the most widely used, in part because it contains a "maladaptive behavior" scale, in addition to three adaptive functioning domains (Communication, Daily Living, Social) that are comparable to the three domains (Conceptual, Practical, Social) on the ABAS-2 and the AAIDD "green book" (Schalock et al., 2010) diagnostic manual.

The Vineland has long been used as part of the FASD research program led by Ann Streissguth at the University of Washington. In her very earliest studies with young children who have FAS, published in 1973, the original Vineland Social Maturity Scale (the precursor to the VABS) was used. When receiving the Edgar Doll Award from Division 33 (Mental Retardation and Developmental Disabilities) of the American Psychological Association, Professor Streissguth reported that with the early sample of FAS children, maternal ratings from the original Vineland measure (appropriately authored by Edgar Doll) were more powerful indicators of FAS than were the children's IQ scores. Follow-up studies of 61 adolescents and adults who were diagnosed with FAS and FAE also provided strong evidence of the diagnostic importance of adaptive behavior data.

Streissguth and her colleagues looked at all of the psychological measures administered to this sample and asked which ones produced the greatest number of findings that were at least two standard deviations (standard score of 70 or less) below the general population mean on these measures. The VABS won hands down, with the two most important discriminators being the overall "adaptive behavior composite" (71% of the sample below minus two SDs) and the "socialization" subscale (64%). The Vineland's Maladaptive Behavior Index was also a strong indicator, with 62% of the sample

having a "significant" degree of impairment, 38% having intermediate impairment, and zero being nonimpaired. Maladaptive behaviors reflecting impulsivity were particularly common (as is true of individuals with brain damage generally) in this sample, while socialization items indicating insensitivity to social cues were common as well. Streissguth noted, interestingly, that none of the members of her sample qualified technically as having Mental Retardation in terms of their full-scale IQ scores, even though virtually all of them had very significant deficits in adaptive behavior. Streissguth (2006, p. 6) concluded by noting that "it is clear that for patients with FASD, the VABS revealed differences in adaptive functioning that were more profound than the deficits observed in either IQ or Achievement Tests."

Because of the subtle and variable nature of FASD physical symptoms, and the fact that many children and adults (especially with too-high IQs) were consequently not receiving needed educational and social services, Streissguth, Bookstein, Barr, Press, and Sampson (1998) developed a rating instrument intended to "capture the behavioral essence of FAS and FAE, regardless of age, race, sex, or IQ, and thus have utility across various populations and across the life span" (p. 325). The driving force behind the instrument was the observation that individuals with FASD were universally described as exhibiting socially incompetent behaviors not always found in other disorders. Examples of such descriptive comments cited by Streissguth et al. (1998, p. 326) are: "talks a lot but says little," "makes 'off the wall' comments," "overreacts to situations," and "often demands attention or monopolizes a conversation."

The instrument (Streissguth et al., 1998) which emerged from this effort to capture the FASD behavioral phenotype is termed the "Fetal Alcohol Behavior Scale" (FABS). It grew out of research with a large data base of almost 500 subjects, dating from the 1970's. On a subset of 134 subjects with FASD, Sreissguth and colleagues gathered information using

a lengthy "Personal Behaviors Checklist" (PBC) rating instrument filled out by parents or other caregivers. In two derivation studies using factor-analytic methods, the FABS—a more manageable instrument with 36 items—emerged, by taking only those items with high loadings on the first principal component of the PBC.

In a subsequent detection study, the FABS was filled out by prison staff on 81 incarcerated men in a special unit of the Washington state prison system for developmentally disabled and emotionally disturbed (but not psychotic) adult inmates. Information was independently gathered regarding whether the mothers of these inmates had consumed alcohol while pregnant. A normative study was also conducted, involving 186 mothers who were selected at random from a pediatric clinic waiting room.

The detection study found impressive separation on the FABS between the reference sample of almost 500 individuals known to have FASD and the incarcerated adults. While 85% of the FASD sample had FABS scores above 6 or 7 (on an earlier 26-item version of the FABS), 85% of the inmates had FABS scores below 6 or 7. Of the four highest FABS scores in the incarcerated group, three were reportedly born to women who were known to have consumed alcohol during pregnancy. The normative study produced similar results. While about 80% of the reference FASD sample has FABS scores above 11 or 12 (on the later, 36-item version), the mean score among a random sample of children rated by their mothers in a pediatric waiting room was under 7. However, for children born to women in this sample known to have a drinking problem, the FABS scores were in the range expected for FASD children in the reference sample.

In addition to discriminating between individuals with and without FASD, the FABS has also been found to predict degree of disability severity (amount of supports needed) within the FASD population. Adults with FASD living depen-

dently (n = 60) were compared with adults living independently (n = 10) on 36-item FABS ratings obtained several years earlier. The FASD adults living independently had earlier FABS scores at the low end of the FASD range (mean of 8.5), while the adults livingly dependently had FABS scores (mean of 21.5) that were extremely high. Thus, the FABS has been found to be quite valid in identifying individuals with FASD and in predicting later outcomes, in a manner which compares favorably to (and probably exceeds) results from formal measures of adaptive behavior.

An examination of individual item-to-scale rankings for the 36 PBC items selected for inclusion in the FABS is particularly interesting for the purpose of clarifying the precise nature of the FASD behavioral phenotype or "taxon" (a biological term meaning group or family in the classification of organisms). Here are the 13 FABS items most descriptive of people with FASD: "overreacts," "chats, no content," "unusual topics," "demands attention," "unaware of consequences," "incomplete tasks," "inappropriate outside," "likes to talk," "interrupts," "center of attention," "touches frequently," "can't play team," and "can't take hints." In contrast, here are the 13 FABS items that made the 36-item cut, but that were least descriptive of the FASD taxon, going from least to most powerful : "tries hard, but . . . ," "problems in sexual functioning," "poor attention," "mood swings," "noise sensitivity," "loses things," "overly friendly," "loud, unusual voice," "difficulty performing," "poor judgment," "fidgety," "superficial friendships," and "inappropriate home."

While over half of these 26 items involved social incompetence (in contrast to formal adaptive behavior measures), social incompetence items constituted about 80% of FABS items most indicative of the FASD taxon and constituted only about 30% of the items least indicative of the FASD taxon. Furthermore, within the social incompetence items, problems of poor judgment and inadequate perspective taking were involved in almost all of the items. Results from the FABS

development study provide strong evidence, therefore, for the view that FASD is a disorder characterized by social incompetence in general and poor social intelligence and perspective taking in particular. This view of the centrality of social incompetence was supported in a study by Whatley, O'Connor, and Gunderson (2001) who found that while children with FASD are impaired in all areas of adaptive functioning, their relative deficiencies in the "socialization" subscale of the VABS becomes more pronounced over time.

The utility of both the VABS-2 and the FABS in diagnosing FASD, in making a strong case for criminal mitigation, and in illustrating the nature of the FASD taxon, can be seen in a very disturbing case report by the first author (Edwards, 2010). The case involves a woman now 28 years old whom we call "Lisa Jones." Ms. Jones was born three-and-a-half months prematurely to a mother who was known to abuse alcohol and drugs. Lisa went through 27 years of her life, many of these spent in psychiatric settings, before she finally received a diagnosis of FASD a year ago. Lisa had seven foster care placements and 15 psychiatric hospitalizations since the age of four. Over the years, Lisa has been given the following diagnoses: Conduct Disorder, Antisocial Personality Disorder, Bipolar Disorder, Borderline Personality Disorder, Major Depression, Mood Disorder, Oppositional Defiant Disorder, Posttraumatic Stress Disorder, Schizoaffective Disorder, and Separation Anxiety Disorder. We do not dispute the appropriateness of some of these diagnoses (Lisa has serious emotional problems and, as a child, she suffered sexual and other forms of extreme abuse, including being placed in animal cages), but the case illustrates how unfortunately common it is for otherwise qualified mental health clinicians and facilities to fail to diagnose FASD, even when obvious risk factors and overt signs are present.

Among the risk factors and behavioral indicators in this case are the following: (a) Lisa's younger brother was diagnosed with FAS after being removed from the home by a child pro-

tective agency. Studies (Abel, 1988; Spohr, 1996) show that the overall risk for FASD is 170 per 1,000 live births (compared with 2 per 1,000 for the general population) for the older siblings of a person with FASD; (b) Lisa had several early behavioral indicators of FASD, including a sleep disorder (Jan et al., 2010; Landesman-Dwyer, Keller & Streissguth, 1978; Rosett, Snyder, & Sander, 1979; McGee & Riley, 2007), jitteriness or fidgeting (O'Connor & Paley, 2009), and feelings of detachment from others (O'Connor, Kogan, & Findlay, 2002); (c) Lisa was placed in special education classes from first grade on, with a label of severe emotional disturbance.

Like many children with FASD, Lisa had special difficulty in arithmetic calculation (dyscalculia)—that often is associated with very poor social skills (Coles, Kable, & Taddeo, 2009; Koopera-Frye, Dehaene, & Streissguth, 1996; Streissguth, Barr, & Sampson, 1990), (d) while possessing relatively normal full-scale intelligence, Lisa has many areas of specific neuropsychological deficit, including sporadic memory problems, cause-effect reasoning impairment, poor planning, impulse control, and deficient organizational skills (Carmichael Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998; Mattson, Goodman, Caine, Delis, & Riley 1999; Fast & Conry, 2009; Schonfeld et al., 2006), in addition to problems of poor motor coordination and signs of poor executive functioning, including inability to track visual information (Mattson, Riley, Gramling, Delis, & Jones, 1998), develop and maintain appropriate problem-solving strategies, and solve problems in a timely manner. Her levels of executive function deficit are much more severe than would be expected based on her level of overall intellectual functioning but very much in line with the picture of someone with significant brain damage; (e) Lisa talks incessantly, but does not often make sense. This is congruent with the finding (Carmichael Olson, 1994; Burgess, Lasswell, & Streissguth, 1992) that individuals with FASD have a "discrepancy between their relatively good verbal skills and their poor ability to effectively communicate and function in social situa-

tions"; (f) Lisa has great difficulty in handling complexities of peer interaction (Streissguth et al., 2004), interpreting social clues (Coggins, Friet, & Morgan, 1997; Carmichael Olson, 1994) and conforming to social norms. Inept social behavior is in fact a hallmark of FASD and of other neuro-developmental disorders (Greenspan, 2009; Greenspan & Love, 1997); (g) Lisa has a long history of depression, self-injury, and self-loathing, including at least five suicide attempts, starting in childhood. Because of their history of failure and rejection, individuals with FASD have an elevated risk of depression and suicide (Huggins, Grant, O'Malley, & Streissguth, 2008), something that is also characteristic of individuals with "non-verbal learning disabilities," a neurodevelopmental impairment sharing many qualities with FASD (Rourke, Young; & Leenaars, 1989).

A major episode of depression occurred at age 18 after Lisa learned that her foster parents, the only people she has ever loved, decided against adopting her. When stressed, Lisa will regress, drinking out of a baby bottle, curling up and licking herself like an animal, barking at people and eating off the floor. Starting at age 14, she has experienced hallucinations. Lisa has been in many residential placements, typically running away from them or being expelled. Lisa has been receiving SSI payments for mental illness, but no longer has a conservator, causing her to be sometimes homeless, and involved in prostitution and drug use. While these behaviors and symptoms are by no means specific to FASD, they do have a higher likelihood of occurring in individuals with prenatal alcohol exposure (O'Connor & Kasari, 2000; Fryer, McGee, & Matt, 2007).

Lisa has been involved in at least two criminal incidents involving group home placements, one in which she got into an altercation and then attacked a responding police officer with a knife, and more recently, at age 22, when she set fire to an occupied group home from which she had earlier been expelled. After the last incident, Lisa was arrested and charged with arson. Without ever investigating the possibility

of FASD, a court-appointed attorney advised Lisa to take a three-year sentence in state prison. At age 23, while in prison, Lisa made her most severe suicide attempt. After several weeks in the hospital recovering from her self-inflicted injuries, Lisa was returned to prison where she was classified as a "mentally disordered offender" and transferred to a correctional hospital facility. Neither in the correctional system, nor in her many earlier psychiatric placements, was Lisa ever evaluated for the possibility of having FASD or related brain damage. This changed recently, when Lisa's current attorney had her evaluated by a competent psychiatrist who is extremely knowledgeable about the disorder.

An effort to obtain services for Lisa through her state's Department of Developmental Services is being blocked for the usual reason (to be discussed in the final section): too high full-scale IQ score. Over the years, Lisa has had many IQ tests administered to her and these fall generally in the dull-normal range (scores have fluctuated from low 80's to high 90's, with most recent testing approaching 100), but with some scatter (impairment or low average performance on subtests tapping number-symbol translation, arithmetic, short term attention, pattern recognition, and arranging images to create a story). There is also evidence of limitations in working memory (Burden, Jacobson, Sokol, & Jacobson, 2005).

In line with the earlier discussion, useful diagnostic information about Lisa was obtained from both the FABS and the VABS. The FABS was filled out by two raters: Lisa's foster mother and the social worker at her current residential placement. Lisa received scores at the extreme ceiling of the FABS, with virtually all items endorsed as applying to her. Here is the descriptive picture, highly indicative of FASD, which emerged from these combined (and highly congruent) ratings: highly impulsive, often acting before considering consequences; poor judgment in whom she trusts, overly friendly with strangers, and too easily lead by others (all three indicating gullibility); cannot take a hint and needs

strong, clear commands because the fine points escape her; unawareness of the consequences of her behavior, particularly the social consequences; establishes superficial friendships easily but has no close friends in her own age group; very hyperactive and always on the go, runs around a lot; has unusual conversational topics; dwells on one or two particular subjects or speaks about unrealistic topics; often overreacts to things; is fearless and lacks foresight into potential danger. A fuller and more accurate statement of the typical behavioral profile of someone with FASD, with much of it describing foolish (risk-unaware) and impulsive social behavior, would be difficult to provide.

On the VABS-2, with Lisa's foster sister as an informant, Ms. Jones obtained the following standard scores: Communication (conceptual adaptive skills) score of 52, Daily Living (practical adaptive skill) score of 57, Socialization (social adaptive skill) score of 40, and overall Adaptive Behavior Composite score of 49. These are all in the range of mild or moderate Mental Retardation, and provide a much more valid picture of Lisa's disabled level of everyday functioning (as reflected for example in her inability to ever hold a job) than can be obtained from her IQ scores. It is for this reason that several American states and Canadian provinces have moved towards loosening IQ ceilings in FASD and other organic brain disorders where there is very clear evidence of adaptive behavior deficits providing a picture of someone with "Mental Retardation equivalence." This suggestion is fleshed out in the following section.

Role of adaptive behavior in giving FASD cases intellectual disability status automatically

The just-discussed case of Lisa Jones illustrates the serious problems flowing from the current practice of giving prong one (IQ score) a primary role, and prong two (adaptive behavior) a secondary role, when determining eligibility for services and legal protections flowing from application of the Mental Retardation or intellectual disability label. In the case of Ms. Jones, granting of intellectual disability (as opposed to mental illness) status would likely have resulted in an alternative or mitigated sentence more suitable for someone with

her brain-based developmental limitations. It likely would also make her today eligible for a more appropriate range of residential and other supportive service options. If Lisa's arson attempt had been more successful and someone had died in the resulting fire, then the consequence of granting or denying her such status would have been even more serious, in that it would have determined whether or not the state could seek the death penalty.

Our concern about the rigid reliance on prong one to deny services and legal protections to individuals like Lisa Jones is not, however, driven by a blind feeling that anyone seeking developmental services eligibility should be granted it. Rather, it is driven by a concern that eligibility decisions should be fair and just. In the case of Ms. Jones, denial of intellectual disability status seems grossly unfair, in that she exhibits all (actually, more) of the adaptive behavior limitations and related support needs that are found in people who typically are ruled eligible. Furthermore, Lisa's brain-based impairments are clearly developmental in origin. Cases such as Lisa's are increasingly resulting in class action lawsuits, such as recently in British Columbia. These have caused some developmental service agencies to take measures to relax their eligibility criteria, especially when FASD or related neurodevelopmental disorders are medically established. This can be, and has been, done in one of two ways, and in both of them adaptive behavior plays a central role: (a) raise the IQ ceiling (in British Columbia to minus one standard deviation) for individuals with FASD and significant adaptive impairments or (b) rely primarily on adaptive behavior deficit when FASD or related organic disorders are present (this has been done in Colorado, Minnesota, and a few other places).

The idea here is to provide a vehicle for "intellectual disability equivalency" for individuals with neurodevelopmental disorders who exhibit all of the adaptive behavior deficits associated with intellectual disability but whose IQ scores are above the minus two standard deviations cut-off. This can be

seen in language in Washington state's developmental services eligibility law, which after listing various categories, such as "intellectual disability" (which it substituted for the former term "Mental Retardation") has this escape clause for persons such as Lisa Jones: "or another neurological or other condition closely related to intellectual disability or that requires treatment similar to that required for individuals with intellectual disabilities." If the state in which Lisa resides had passed a law as enlightened as Washington's, it is difficult to imagine that she (or others with FASD and a similar adaptive behavior profile) would be turned down for services.

The trend towards increased emphasis on prong two in civil eligibility procedures for individuals with FASD can also be found, to a lesser extent, in criminal matters. For example, the California Supreme Court, *In re Hawthorne* 35 Cal. 4th 40 (2005) refused to establish specific IQ cutoffs for *Atkins* death penalty exemption hearings. This policy was upheld again by the California Supreme Court in *People v. Superior Court* (Vidal) 40 Cal. 4th 999 (2007). In that case a Tulare County judge's *Atkins* finding that Jorge Junior Vidal had Mental Retardation, was made in spite of a full-scale IQ score well above the usual clinical cutoff. The judge's reasoning was that full-scale IQ is not an appropriate prong one standard to apply to Vidal, a man with a medical diagnosis of FASD and with severe adaptive deficits, including extreme gullibility. Instead, the judge found that Vidal's very low verbal IQ score (used to explain his gullibility) was a better measure of prong one deficit in his case. This ruling, in fact, was in line with a statement in the Mental Retardation section in DSM IV-TR to the effect that when there are severe verbal-performance splits, as is often true in brain-damaged individuals, full-scale IQ may be an unreliable index of actual intellectual functioning.

Similar reasoning was used by a Federal judge in 2008, in ordering a reconsideration of the *Atkins* claim of Yokamon Hearn, a condemned Texas man with FASD and very substantial prong two deficits. The original denial of *Atkins* relief

was based on Hearn's too-high full-scale IQ scores (those scores, including a sizable verbal-performance split, were almost identical to Vidal's). In making his ruling, the judge cited an affidavit by the second author, in which the argument was made that for adaptive behavior-impaired individuals with FASD or related neurodevelopmental disorders, the optimal clinical practice is to rely on executive functioning or other non-IQ indices of intellectual impairment.

On a final note, we should point out that the shift from use of the term "Mental Retardation" to the term "intellectual disabilities" offers the possibility of increasing the importance of adaptive behavior in bringing people with FASD under the diagnostic umbrella. That is because there is such a strong semantic association of Mental Retardation with IQ, while the new term intellectual disabilities does not yet have so strong an association. Unfortunately, the AAIDD in its 2010 "green book" did not capitalize on the name change to broaden the diagnostic umbrella. It is our understanding, however, that the committees writing the Intellectual Disability sections of the forthcoming DSM-V and ICD-11 manuals are considering a dual pathway diagnostic approach, with the second path giving more emphasis to adaptive behavior deficits and less to IQ score ceilings for individuals with FASD and related brain-based disorders. Such an approach would, in our view, be more in line with the well-established reality that for people with FASD, adaptive behavior provides the best indication of why these individuals need and deserve legal and other protections.

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