

Fetal Alcohol Syndrome Disorder Workshop

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**Social-Emotional Deficits of Children and Youth with FASD:
Barriers to Obtaining Appropriate Services**

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I am pleased to be in New York (I grew up in the Bronx) and pleased to be part of this event. I usually do power point slides, but lately have been going retro. So, you will have to look at me rather than my cartoons.

I plan to leave time for questions at the end so probably it is best if you hold off until then. I have a lot to get through, so my New York training in talking fast will come in handy.

My talk today is largely derived from a paper which I believe was made available to registrants. (if you do not have it I will be happy to send it to you, along with this talk. So, there is little need to take notes)

I have been interested for a long time in the unfair bureaucratic rejection of applications for residential, vocational, case coordination or other habilitative services for children and adults who I and others consider deserving. Individuals with FASD are especially likely to have such an experience. (Note: My focus today is not on special education services, but I will be happy to talk about that if there is time).

Part of my interest in this topic of unfair and unjustified rejection of services stems from the fact that my younger brother, who has severe Autism Spectrum Disorder, had great difficulty receiving appropriate services, for the same reason why persons with FASD are often denied services, namely that their full-scale IQ scores are too high, often by just a few points. (With regard to special education, my brother, born in the late 1940s, pre-dated mandated special education, and the only education he received was a visiting teacher who came to the house for a couple of hours per week. It is because of such outrages that Federal special education laws were enacted, a result of furious parent lobbying).

The IQ metric became overwhelmingly popular in North America in the second quarter of the twentieth century, as it proved useful to eugenicists such as Lewis Terman (author of the

Stanford-Binet, a translation and extension of the original French Binet-Simon) in promoting their racist political agenda. The basic idea being promoted at the time was that IQ represented a precise snapshot of the brain that was concrete, immutable, inherited, and incorporative of all that we view as “intelligence.” Now of course we understand that there are discrete cognitive capacities such as “social intelligence” (my specialty) that are not well captured by an IQ score.

The idea of using IQ ceilings to demarcate a dividing line between impairment and “normality” came to the fore a little over half a century ago when the American Association on Mental Deficiency (later, the American Association on Mental Retardation and today, the American Association on Intellectual and Developmental Disability) published a diagnostic manual in which they established a three-prong definition of mental deficiency (later, “mental retardation” and today “intellectual disability”).

The first prong, intellectual impairment, was reflected in an IQ score that fell at least one standard deviation (SD) below the population mean (a standard score equal to or less than 85, or the 17th percentile of the population distribution). The conventional belief, not particularly based on research, was that the incidence of ID was three percent of the population.

This problem was exacerbated by a failure for over a decade to use the second diagnostic prong of adaptive behavior, the intended purpose of which was to bring the actual incidence down to three percent. To correct for this problem, the criterion for prong two was changed three decades ago from one standard deviation (IQ =85, 17th percentile) below the mean to two standard deviations (IQ=70, 2nd percentile) below the mean (Greenspan & Switzky, 2006). However, the minus 2 SD standard was just as arbitrary as the minus 1 SD standard had been two decades earlier.

No apparent rationale was provided for using the minus 2 SD cut-score other than the superficial elegance of using the statistical convention of standard deviation units. Just as the earlier use of the minus 1 SD criterion was too easy a hurdle to clear, this new reliance on a minus 2 SD criterion was too difficult a hurdle, with the result being an excessive number of “false negatives” of people who deserved ID eligibility but were wrongly denied it. Most of the definitional reforms essayed over the past several decades were motivated by an attempt to rectify the problem of false negatives caused by setting the qualifying IQ score too low.

To date, four solutions have been proposed to overcome the problem of false negatives. The first attempted fix in the 1980’s involved encouraging diagnostic evaluators and agencies to take into account the confidence interval of the IQ test (5 points at the 95th percent of confidence) when making ID diagnostic determinations. When this admonition was largely ignored, the second attempted fix, enacted in the 1990’s was to take the suggested five-point confidence interval and make it the new ceiling standard, later modified as the IQ range “70-75.” More recently, this second fix has involved using 75 as the cutoff point which is what both AAIDD and DSM-5 adopted. Part of this fix was to insert the word “approximately” before the

number 70 or, more typically, the term “minus two standard deviations below the mean,” with “approximately” meaning that one should take into account the unreliability or standard error of the IQ statistic.

When changing the ceiling was typically ignored, a third fix was to encourage clinicians to change the number itself by correcting for norm obsolescence, a phenomenon known as the “Flynn effect.” The Flynn correction process involves subtracting 0.3 IQ points per year of elapsed time between the date of norming and date of test administration to correct for the fact that norms are toughened by three years per decade of norm obsolescence to adjust for changes in population performance in the interim. This practice has become commonplace when determining eligibility exemptions in the US under the *Atkins v Virginia* standard but has not typically been used for school, residential or other less catastrophic purposes.

The fourth fix is the one with the most promise for eventually solving the false negative problem and the most relevant for the ID-equivalence issue. It involves approaching the first diagnostic prong of “intellectual functioning” as a broad construct that is tapped by various cognitive measures of which IQ is but one data point. This is the position underlying the ID section in DSM-5 (American Psychiatric Association, 2013), which actually states that neuropsychological tests, particularly of “executive functioning,” are typically more useful diagnostically than an IQ score.

This provision reflects a step away from the “disability” (arbitrary, numbers-based) view of ID to one that views the condition as a brain-based “disorder” determined clinically rather than psychometrically. In such a conceptualization, the key is to look at the individual as a whole person and not just through the narrow lens of a single numeric score.

Part of the reason is with the development and use of eligibility definitions that are improper in one way or another, and part of it is with the overly rigid or unthinking manner in which those definitions are applied in practice. Recently, I have been doing some work in the state of Maryland, both on a system-wide basis, and with regard to a particular possibly landmark case. What they do in Maryland is that the state DD agency contracts with a consulting agency which assigns a psychologist to review the application and then make an action recommendation to the agency (which almost always will follow those recommendations). Based on what I have seen of the documents in that case, the consulting agency seems to see its job as to figure out how to recommend against providing services.

Being a little cynical I think the reason for this is that in Maryland like every other state, there is not nearly enough money to address the needs of every deserving applicant. I am not cynical enough to accuse the actors in this process of being consciously corrupt, but the process is unfair when it takes the form of consistently saying no to persons who in the opinion of knowledgeable persons clearly deserve a yes.

The effect of saying no in a knee-jerk fashion, is that many applicants become discouraged

and go away. I have been involved in a couple of FASD cases in CA, working with attorney and presenter here) Billy Edwards. In those cases, he was able to get the state (through the decentralized “Regional Centers”) to back down and finally grant services. But obviously most applicants are not lucky enough to have a committed lawyer like Billy or his dream team of mostly pro bono experts pleading their case. (Or rich enough to hire a private attorney and experts, which makes for the unfair yet common irony that the poor are doubly screwed.)

As I am now speaking in New York State, I want to turn attention now to the statutes and provisions in New York for addressing the needs of service applicants who might have FASD or a related disorder. (If I had an example of unfair turndown in NY state to share I would. But I hope after today one or more of you will send me such an example).

As with other states, the method in New York to address the needs of broadening ID equivalency for people with disorders such as FASD is under the broader rubric of “Developmental Disabilities” This term owes its origins to pioneering Kennedy-era legislation in the United States which authorized various government-funded disability-related human rights, research, training and facility-building initiatives. The term is now widely used in many state and provincial eligibility statutes. Before turning to how DD concept is used in NY, I will say a little about its origins and evolution.

The original Federal ID legislation — the “Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963” — defined the population addressed by these programs as people with “mental retardation.” Seven years later, the law — renamed the “Developmental Disabilities Services and Facilities Construction Amendments of 1970” — was revised, with the term “Developmental Disabilities” (DD) substituted for “mental retardation.” However, DD was still defined categorically as in this expanded list: “mental retardation, epilepsy, cerebral palsy, and other neurological conditions originating before the age of 18.”

In 1975, the legislation was revised again, and DD was again defined categorically to include mental retardation plus these conditions “closely related to mental retardation”: cerebral palsy, epilepsy, autism and dyslexia, again with a pre-18 age of onset, which were expected to continue indefinitely and that constitute a substantial handicap.” The term “other neurological conditions” was dropped for some reason. In my opinion that was a mistake as such a loophole along with qualifying language such as “producing service needs similar to those needed by people with ID”, has since been added in many places to keep IQ-Equivalency from being unfairly limited to people in only a few, and somewhat arbitrarily chosen, diagnostic categories.

A major revision in 1978, termed the “Developmentally Disabled Assistance and Bill of Rights Act switched from a categorical to functional definition of DD as a “severe, chronic disability... ..likely to continue indefinitely” that resulted in “substantial functional limitations in three or more areas of major life activity.” These functional areas are: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency. These should reflect an individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized

supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.” The 2000 law also clarified the application of the DD definition for children from birth through age nine, by stating that a child could still be considered to have DD without meeting all of the above criteria if “the individual, without services and supports, has a high probability of meeting these criteria later in life.”

The intent of this functional and arbitrary formulation appears to have been an attempt to capture the adaptive limitation profiles of individuals who function as if they have ID in spite of having IQs that fall above the 70-75 IQ ceiling. However, at least two of the skills, language and mobility, are not specific to ID. Likewise, one also could argue that self-direction is not specific to ID-equivalency. It is not clear where this list came from as there is no science to support it. Certainly, a limitation in this list is that none of the items address deficits in social functioning, which many people (and virtually all family members) consider to be at the top of any list of reasons why people with ID need protections and supports.

Another curious aspect of this formulation is that it was never intended to be a diagnostic framework; rather, it was intended to clarify the scope and focus of various federally-funded programs (Developmental Disabilities Councils, Offices of Protection and Advocacy, University Affiliated training centers) and related facilities. Yet, it morphed over time into something approaching a diagnostic framework in spite of the questionable and slap-dash nature of the list of seven life functions. Today, there are many jurisdictions in both Canada and the United States that use the Developmental Disabilities construct, and several that use the 3-out-of-7 life skills areas specified in the 2000 legislation described above.

An obvious advantage of using terms like “such as” or “not limited to” is that ID-Equivalence is then not limited to the few disorders listed but can be much more expansive. Minnesota is one of a very small list of jurisdictions where FAS is specifically included in an expanded disorder list. However, Minnesota’s eligibility document then goes on to state that even if one has a qualifying medical underlying disorder, the condition must still cause “substantial functional limitations,” as established by deficits in three out of the seven adaptive life activities.

So here is how the DD concept is now used in the state of New York. This information is set forth in section 1.03 (22) of NY State Mental Hygiene Law, and can be obtained from the website of the Office for People with Developmental Disabilities (or OPWDD). When an application for services is submitted, typically by a caregiver, guardian or care coordinator, an individual eligibility review is set in motion.

There are four eligibility criteria:

- a) Qualifying diagnosis or condition
- b) Disability occurs before age 22
- c) Expected to continue permanently
- d) Disability causes substantial handicap to normal functioning in society

The qualifying conditions are: ID (formerly MR), autism, CP, epilepsy, familial dysautonomia and neurological impairment (a injury or maldevelopment of the central nervous system)

FASD comes into this formula under the last condition as it obviously is a neurological impairment

[Note: acc. to NIH, familial dysautonomia is “...a genetic disorder that affects the development and survival of certain nerve cells. The disorder disturbs cells in the autonomic nervous system, which controls involuntary actions such as digestion, breathing, production of tears, and the regulation of blood pressure and body temperature.” Certainly it is a severe disorder, but I find it curious that this was added, as there are hundreds of others that could have been mentioned, and this one does not affect intelligence or related cognitive or adaptive skills. Suggests to me the result of some political lobbying, either personal or organizational.] As a rule, whenever a specific disorder is mentioned in a DD list, it is something associated with ID, and where significant impairments in intellectual and adaptive functioning are present. Certainly this characterizes Prader-Willi which is maybe the most common DD add-on.

For young children, up to the age of eight, based on clinical judgment of a child’s needs, OPWDD will grant provisional eligibility, but it needs to be revisited at or before age eight. This is based on the legitimate understanding that children develop at different rates, and it is not uncommon for a child with delays to suddenly make major progress and move into the “normal” range. But as with any reasonable provision, I have often seen it misapplied. For example, in one case in Wisconsin, a provisionally eligible child had her much-needed eligibility taken away when her IQ at reassessment went up a few points. Thus, IQ continues to be a common barrier to service eligibility, in spite of a long and growing recognition that full-scale IQ is an inappropriate standard to rely so heavily on.

OPWDD makes clear that application for DD services can occur at any point in an applicant’s life, including well into middle age. However, the older the applicant is, the more difficult it is to establish onset of the disorder before age 22, especially as is often the case, contemporary evidence of impairment had not been documented, for example through both intellectual and adaptive functioning instruments. For someone claiming a specific syndrome such as FASD, it is important to have medical documentation and diagnosis. For FASD that is often not easy to establish as few physicians are qualified to make the diagnosis, and records (such as evidence of maternal drinking) may be difficult to obtain.

Although DSM-5 states when someone has significant adaptive deficits, full-scale IQ may be insufficient to establish the first criterion (intellectual deficits) and that in such cases, neuropsychological test date, particularly “executive functioning” may be more important. Yet in the Maryland case, a great deal of importance in the consulting psychologist’s rejection report was attached to a single IQ score in the normal range in early childhood, in spite of multiple IQ, EF, and Ad Beh. scores that were quite low.

Here we finally come to the first part of the title of my talk which is on social deficits, particularly gullibility and poor social judgment.

In New York state, and in almost all other states, there is a requirement that the applicant be able to demonstrate the severity and globality of his or her disability (under OPWDD guidelines it requires that the “disability causes substantial handicap to normal functioning in society”).

This is operationalized to require evidence of significant deficits in “adaptive behavior,” also known as adaptive functioning. This is especially important when the individual--because of too high an IQ score-- does not quite qualify for the label of ID. This is a common problem for applicants with FASD because the mean IQ is around 80, which is 5 points above the DSM-5 IQ ceiling for ID of 75. Thus, even though FASD is the number one known cause of ID, a great many people with FASD do not qualify for services through the ID portal. DD allows an alternate portal, but only if adaptive behavior is low enough.

In British Columbia, where I was asked to help with this issue after a deserving youth with FASD in a class action lawsuit had his DD status revoked when his IQ went up a little when he was reevaluated at age 18, the province agreed to use adaptive behavior as the basis for alternate eligibility (something now also the policy in my new home state of Colorado). But in BC they devised the ridiculous and unfair standard for this alternate portal: an adaptive behavior standard score of 55 (minus 3 SDs) rather than 70-75 (minus 2 SDs). This reduced the cut-off from the bottom 2 % of the population to the bottom 1/10th of one percent). The only way this could work would be if the parent informant and/or the hired psychologist lied when filling out the instruments, making the applicant look even more severely impaired. In fact, that is exactly what happened, according to my sources in BC. Needless to say, this is unfair not to mention discriminatory (as poorer or less educated families will lack the resources or knowledge to effectively lie or hire sympathetic clinicians willing to stretch the truth on their behalf.)

Adaptive Behavior as it relates to ID and DD (especially the social competence aspect of adaptive behavior) has been the main focus of my scholarly work over the years. Adaptive Behavior is a concept invented around 1960 to take away some of the exclusive emphasis on IQ. A problem is that it was never adequately defined (and, until, fairly recently, was often not even used.) As a result, in the Federal DD list of seven skills, none of them really focus on social skills and even if it did there is requirement of three out of seven, so social deficit is not even a requirement.

As any parent, or knowledgeable professional knows, social incompetence is a core characteristic of people with ID in general, and certainly is a core deficiency of the adaptive deficits with people with brain-based disorders (such as FASD) deserving of the DD alternate portal. Yet the rating instruments used to determine ID and DD status give very inadequate treatment of the social domain.

For example, the ABAS has ten skills, two of which load on social domain: one termed social and one termed leisure. If you look at the items on the leisure skill category, most of them involve

solitary play skills, and it is a stretch to call this a reflection of social functioning. Furthermore, few of the items on the social component of ABAS have a cognitive wording. By this I mean that they will focus on a behavior, such as “has friends” without focusing on the cognitive understanding of how and why to make and keep friends. This cognitive piece is much more important for diagnosing ID and DD, it goes without saying.

In terms of the social aspect of adaptive behavior, I believe that what is most critical area of impairment for people with FASD is poor social judgment, as reflected for example in vulnerability to exploitation.

Perhaps my main contribution to the DD field lies in my writings over the past dozen years about gullibility as a core area of impairment. (I became aware of the omnipresence of gullibility through my consulting in criminal cases and learning how often a person with FAS or ID was manipulated into giving a possibly false confession and also into participating in a crime by a manipulator who pretended to be a friend). My work on this topic, including my book *Annals of Gullibility*, has had a little bit of impact, as reflected for example in first-time mentions in both the AAIDD and DSM-5 manuals on the need to document gullibility of clients, both through third party rating instruments and through descriptive data. It is also beginning to show up in third-part ratings, such as the Vineland-3, which now has several gullibility items for the first time.

Before I turned my attention specifically to gullibility, I had a long-time interest in social competence generally, especially social intelligence. The tripartite model of adaptive behavior now used diagnostically by both AAIDD and DSM-5 was first proposed by me around 1980. It has three domains: Conceptual (IQ and Executive Functioning), Practical (daily living and work), and Social. The biggest problem, to elaborate on what I said earlier, is that Social has been approached mainly in terms of social behavior rather than social Judgment. This can lead one astray. For example, people with the chromosomal disorder of Williams Syndrome are characterized by low or borderline intelligence, musical interest, and an extremely friendly demeanor. This friendly demeanor led one clinician to tell me how socially competent people with WS are. I pointed out to her that researchers have found that young women with WS have almost universally experienced sexual molestation. Niceness without good judgment (knowing when to be nice or not nice) is a formula for incompetence and exploitation.

I want to end by returning to the problem of unjust rejection of DD service eligibility by pointing to the main reason other than IQ score variability for such turndowns. One provision in almost every state ID/ DD eligibility statute (which is a carryover from original DD legislation) is that the social deficits of people with ID/ DD cannot solely be a reflection of mental illness. The consultant in the Maryland case who rejected a deserving application, seized on the fact that the young woman applicant had a history of emotional problems and had been given a variety of special education labels, some suggestive of a behavior disorder. But people with ID (and brain damage such as FASD) generally are at increased risk of receiving multiple psychiatric labels, and it is not uncommon for a decade or more years to elapse before the underlying brain-based reason for the symptoms is recognized. Furthermore, having mental illness (even if

correctly identified) and ID/ DD are not mutually exclusive. That is why recognizing poor social judgment is critical if one is to know if someone's behavior issues rule out ID/ DD. In sum, the nature of someone's social adaptive impairments, such as gullibility, should be critical in making correct judgments about ID eligibility, regardless of whether the person also has emotional problems. It a shame that this is not yet fully understood by the clinicians and agencies making these important decisions.

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Stephen Greenspan, PhD is emeritus professor of educational psychology at the University of Connecticut. A developmental psychologist with an interest in social cognition, his writings on the social competence and adaptive functioning of people with Intellectual Disability caused him to be the most-cited authority in the two most recent ID classification manuals. His recent work on criminal justice problems experienced by people with DD and FASD resulted in his receiving the Ann Streissguth award for FASD and the Law. He lives in Colorado and can be contacted at stephen.greenspan@gmail.com.