

Spurious Reasons why FASD Individuals are Denied ID or DD Status

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Greetings: Good day. I am very happy to be part of this event but like others, am sorry it couldn't be in person. I was looking forward to being back in Little Rock, a city I have found to be very agreeable. My roommate in college was Gordon Flake, a now deceased medical researcher whose family name, Flake, was as I recall once prominently displayed on the top of a Little Rock skyscraper. Gordon graduated from Central High during the year when Eisenhower sent in the troops, and if I had the time I was looking forward to visiting the school's civil rights museum. Maybe next time. (Might also check out Clinton's triple-wide library).

In my talk I will **not** be using power point slides, but I have written up my comments in this document, which I understand has been made available to you as a handout. The document is somewhat schematic, more like an outline, but I hope in the next few months to expand it into an article or monograph. At any rate, it is not necessary for you to take notes, as everything I have to say should be in the handout. A second handout is a chapter on FASD and the concept of "ID Equivalence" that I co-authored with Billy Edwards and Natalie Novick Brown a few years ago. I will talk at warp speed and try and limit my talk to no more than forty minutes, which should allow fifteen minutes for questions.

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Abstract

Children and adults with FASD often have an uphill battle acquiring an ID or DD designation from experts and agencies, even when such a designation is clearly deserved. Reasons include: the fuzzy nature of the ID and DD constructs; racial and cultural bias, overreliance on IQ cut-offs, salience of other problems, improper pressure to keep agency enrollments down; and a general failure to appreciate or understand the nature and seriousness of FASD as well as other relatively "hidden" forms of brain impairment. Case examples from both criminal and civil proceedings are presented, and encouraging signs of change are discussed.

My Background

I am a psychologist with doctoral training in human development, who then went on to do postdoctoral work in intellectual and developmental disability. Within the section on Intellectual and Developmental Disorders in DSM-5 (the online version as the hard copy lacks citations) I am the most-cited authority. My particular interest is social competence as a basis for diagnosis and definition of developmental disorders. I have testified in numerous cases where Intellectual Disability was a possible diagnosis and have been consistently amazed at the widespread ignorance about developmental disorders in general, and FASD in particular, by experts who testify in these cases and even by staff at the agencies that are charged with making DD eligibility decisions. (Not to mention most judges and many lawyers, who for the most part bring to these proceedings all of the ignorance and biases of laypeople).

In this paper I list most of the reasons that crop up in dubious turn-down decisions I have encountered in many reports that I have seen, both in criminal as well as civil cases. Given that the focus of this training is on FASD, I will mainly talk about cases where the person in question has FASD, but my comments apply to a broader class of people with other known or presumed brain bases for their deserved ID or DD designation. Two related aspects of these cases is that the person's disability is not immediately obvious to casual observers and that their full-scale IQ scores often are too high for them to qualify for a designation as Intellectually Disabled (ID). Thus, my comments, while focused on FASD, applies equally to others (an example is Meconium Aspiration syndrome, characterized by oxygen deprivation at birth) who have Borderline intelligence, especially when they are the result of developmental brain impairments that result in social and academic incompetence the cause of which often goes undiagnosed.

In the balance of this paper I go into four kinds of explanations for spurious turn-downs of eligibility and divide the discussion up into four categories: (1) general reasons, (2) reasons pertaining to intellectual functioning, (3) reasons pertaining to adaptive functioning, and (4) reasons pertaining to developmental onset. I should point out that the last three reasons are the official criteria whose satisfaction is needed to diagnose ID, although these criteria (more broadly approached) also apply to FASD and, under some definitions, to DD as well.

In each of those four sections I indicate whether the purpose of the diagnosis, namely whether it is for a criminal case such as an Atkins (death penalty exemption) proceeding, or a civil case, such as an application for child or adult services. Towards the end of this paper, I discuss why prospects for people with FASD seem to be improving somewhat.

Difference Between FASD, ID and DD

The three terms most used in my talk are Fetal Alcohol Spectrum Disorder (FASD), Intellectual Disability (ID) and Developmental Disability (DD), which can sometimes be termed a Developmental Disorder (also DD). But a disorder and a disability are not the same thing, and this can be a source of confusion. A disorder is a medical or psychiatric category (and psychiatry is a branch of medicine) while a disability is a bureaucratic or legal designation, that serves as a gateway to certain forms of services or accommodations. Someone with a disorder such as FASD is more likely to qualify for a disability category such as ID or DD, but it is not a sure thing. As example, FASD—which typically is diagnosed by a physician—is the most common known medical cause for ID but only about a third of people with FASD qualify for the bureaucratic designation of ID. The reason is that as a bureaucratic category ID has arbitrary decision rules based on things like IQ ceiling scores, and for most people with FASD the full-scale IQ score is a few points over the 75 ceiling for ID. But in terms of adaptive functioning and need for services, there is no difference between those with IQs above the line and those who qualify as ID. The concept of DD was invented in federal legislation around 1970 to cover people who have brain-based disorders with functional impairments identical to ID (the history and meaning of DD is covered in another handout, on ID equivalence, that you should also have received).

The original definition of DD was categorical (ID then termed MR) with a small number of add-ons such as autism) but in the 1980's it evolved into more of a functional definition, specifying typically three out of seven areas of incompetence; a very inadequate framework in my opinion). The original DD concept was meant to designate types of facilities or programs but it has become widely used as an ID-Equivalency diagnostic framework for eligibility for developmental services. The DD definition in Arkansas is basically “old school” (categorical) but with a functional escape valve. It (Arkansas Statute Annotated

§20-48-101 and Arkansas Act 729 of 1993 defines a developmental disability as a diagnosis of mental retardation, cerebral palsy, epilepsy, autism, or is attributable to any other condition of a person found to be closely related to mental retardation because it results in impairment of general intellectual functioning or adaptive behavior similar to those of mentally retarded persons or requires treatment and services similar to those required for the persons...{and] has continued or can be expected to continue indefinitely.” This last section (similar deficits and needs) is an escape valve intended to make it possible to serve people with non-named developmental disorders such as FASD. Such an escape valve is found in statutory definitions in many other states. But in practice it is still an uphill battle in most states (and I assume Arkansas as well) for reasons I will get into to get someone with a hidden disorder such as FASD served.

General Explanations

Wrongful Assumption that Organicity is Just Another Word for Heritability

One reason why FASD is not taken as seriously as it should by experts or agencies is because of a common tendency to think of DD must reflect DNA abnormalities. There are many experts who doubt that biological causes of abnormal brain function can have non-genetic origins. As a result, there is a tendency to assume that FASD is not a developmental disorder because it is not inherited.

Wrongful Assumption that FASD is just another name for ADHD

An even more common wrong assumption is to consider FASD to be the functional equivalent of ADHD. This confusion stems from the fact that attentional issues are universal in FASD and ADHD is a common diagnostic label applied to those with FASD in childhood. Because ADHD is not considered a severe DD, there is an assumption to assume FASD is not severe. As example, in a recent Federal death penalty case (*Floyd v. Filson*), an appellate court ruled that FASD is analogous to ADHD and thus is not a serious criminal mitigator. (Natalie Novick Brown, Billy Edwards and I just finished a paper we can send you that shows why FASD in fact is a very severe disorder.)

Racial and Cultural Bias

A phenomenon that I find very disturbing, and which I have noticed over and over in turndown reports in both criminal and civil cases involving people with FASD or ID, is what has been termed either “cultural overshadowing” or “racial overshadowing.” What this means is that if you are say Black your incompetent, or criminal behavior is assumed to be a function of your social circumstances, even if there is clear evidence of an organic syndrome, and even when everyone else in the family is very competent, and even when the family is anything but poor. Although such a bias pretends to show cultural sensitivity, it is very racist in assuming that everything about a person is explained by their race and very discriminatory in that prevents people who are poor or of color the right to have their brain damage or their disability recognized. One well-meaning, but misplaced variant of racial/ ethnic overshadowing involves so-called “race norming” of IQ tests (norming scores within ethnic or racial groups). At one time, race norming was quite widespread, but it fortunately is generally no longer considered an acceptable practice.

Fuzziness of the Disability/ Normality Boundary

A basic obstacle to recognizing the brain damage (and therefore mitigating) basis of people with FASD is that they do not wear a sign around their neck that says “I am disabled.” In fact, even for the subtype (FAS) with overt facial abnormalities FASD can be considered to be a somewhat hidden disorder for two reasons: (a) typically, there are areas of relative normality mixed in with areas of significant delay, and this can create a mistaken impression that the person is more competent than they are and that the delay areas may in fact be intentionally malingered; and (b) the symptoms of impulsivity and poor judgment, sometimes taking the form of hyperactive, antisocial and delinquent conduct result in a multitude of comorbid psychiatric diagnoses, and there is a tendency to ascribe the life difficulties of the individual to defective character rather than brain damage. The picture is further complicated by the overlap with social class considerations that also helps to fuel the racial and cultural overshadowing phenomenon mentioned above.

Mistaken Use of “Clinical Judgment”

There is definitely a role for clinical judgment when evaluating someone for possible ID or DD but it is often misconstrued as granting an evaluator license to rely on their gut feelings when they assert (as is often the case) something along the lines of “my gut feeling tells me this person does not have ID (or DD)” with that judgment typically based on a particular behavior or accomplishment. There are many reasons why this is a mistaken practice, two being: (a) evaluators vary in terms of their experience and knowledge of ID, and (b) people with ID have areas of competence and accomplishment and no single behavior is incompatible with the diagnosis.

Number Fixation of Experts and Agencies

I have already mentioned the numbers basis for disability categories, particularly the heavy reliance on IQ cut-scores when determining eligibility, but I need to mention the extent to which diagnosing professionals and agencies have been overly quick to embrace these decision rules and accept unquestioningly the idea that a number is an adequate basis for diagnosing a disability. This numbers fixation applies to ID, DD and to a lesser extent FASD.

Ignorance about ID, DD and FASD

It is my experience that most psychologists and psychiatrists do not have meaningful training in intellectual disabilities. It behooves any hiring attorney or agency, therefore, to use only qualified experts. Sometimes an expert will claim expertise in ID but it was years earlier and in a setting (such as an institution) and with a population (typically severely impaired people) different from what is usually found in community or forensic settings today. As a result, experts often operate on the basis of invalid stereotypes. The main stereotype is that to have ID you have to be globally and severely impaired (because that is the population mainly found in institutions).

With regard to FASD, the typical psychologist or psychiatrist (or physician, for that matter), is largely ignorant of current thinking about the disorder. As example, it is commonplace for an evaluator to think that facial signs have to be present, or for someone lacking advanced training or methods, to claim they can rule out FASD just by looking at someone.

Psychiatric Overshadowing

A very common problem in properly diagnosing ID as well as DD is what has been termed psychiatric overshadowing. This can take two opposite forms: (a) when someone has been diagnosed with ID or DD, their mental health issues often go unrecognized or (b) (more relevant to spurious DD turndown) when someone has very salient emotional or behavioral problems, the underlying or accompanying ID or DD often is not acknowledged or recognized (It should be understood that people with FASD, ID and DD have a high rate of co-occurring psychiatric problems is often to rule against a DD designation because of the spurious claim that the person is not eligible.

Physical Overshadowing

A less common problem, but one that occurs on occasion, is what might be called “medical or “physical” overshadowing. This occurs when someone has a medical condition that is very salient and assumed to be the cause of all the person’s problems (even when they also have a FASD diagnosis that is totally separate). A recent example is a young man with Sickle Cell disease plus FASD. He is African American, which means that racial overshadowing also played a role. So, he was denied DD status because DD is usually ruled out if the person’s cognitive limitations are considered to be mainly due to a physical disorder. But there were two problems with this reasoning and which when pointed out led to the turndown of DD status to be overturned: (1) the young man’s cognitive issues could be attributed to his FASD, independent of his sickle cell anemia, and (b) because sickle cell disease causes a thickening of blood, it can interfere with the flow of blood to the brain. In fact, it is now known that sickle cell can cause mini strokes, with the likelihood of progressive decline in intelligence, such that an individual who may have Borderline intellectual functioning during childhood can transition to a much more impaired level during adolescence, but still within the window for the “developmental period.”

Prong One: Intellectual Functioning

Neurodevelopmental Disorders all involve some cognitive impairment. Spurious turn-downs of ID or DD status, therefore usually involve some questionable practices in the cognitive assessment process.

Overemphasis on Full-Scale IQ Ceilings

The first diagnostic prong for diagnosing ID is “Intellectual Functioning.” It almost always involves administration of an IQ test. Typically one will find more than one test score, and occasionally one will find several. An improper practice that is quite common is to find one score over the 70-75 ceiling and argue that it is the only legitimate one (implying the earlier lower ones were invalid, even when they were obtained when the person was young and had no motive to score low).

There is a failure to understand that as with any test, some variability of results is inevitable, and if you have outliers, use the ones in the middle. The diagnostic manuals for ID pay lip service to the idea that one should never be a slave to IQ ceilings. Tell that to evaluators, almost all of whom are unwilling to argue for eligibility for ID if IQ scores are above an arbitrary number. With regard to DD, even though the purpose was to get away from being a slave to IQ, “King IQ” still sits securely on his throne.

Videotaping of Testing is Essential

Experts generally refuse to be taped, giving the BS reason that it violates test copyrights. The real reason is that it makes evaluators more accountable. I know of one psychologist in a Western state who only works for the prosecution, and whose full-scale IQ scores are universally 10 points higher than anyone else’s. There is strong reason to suspect him of fakery but without videotaping there is no way of proving that. (There was a notorious “Doctor Death” in Texas, who was exposed and punished only after he was taped).

Invalid Tests Should Not Be relied Upon

Many tests produce something called an IQ score, but these are short-form or screening tests with questionable validity and reliability (while correlated with the Wechsler scales, they may consistently produce higher scores). They should not be used to determine ID or DD eligibility but often they are relied upon. A test may also have invalid norms. That was the case with the Mexican version of the WAIS-3, which produced results that might as well have been coming from a Ouija board. As a result of a paper by Suen and me, the test publisher withdrew the Mexican norms and said to use the US norms. Just because a test produces a number does not mean the number should be given any weight.

Failure to Recognize the Effects of Multiple IQ Tests

In criminal cases, there are often multiple administrations of the same test (such as a version of the WAIS) with scores going up as a result of the “practice effect.” Experts often point to the high score as the most valid, without acknowledging the learning that undoubtedly occurred from the multiple testing.

Failure to Accept the Flynn Effect as Valid

The full-scale IQ should be adjusted for the “Flynn effect”: upward creep of scores due to obsolete norms. Such adjustment (subtracting 3 full-scale IQ points for every decade of norm obsolescence) is accepted by virtually all intelligence scholars and is an accepted practice in all but one US appellate regional court. Yet there are many experts who insist it is a disputed practice and refuse to make the required adjustment.

Failure to Understand that “Executive Functioning” Can Satisfy Prong One

Neuropsychological assessment, especially of “executive functions” (planning, means-end thinking, etc.) is recognized in DSM-5 as an alternate, and in some ways superior, indicator of “intelligence.” It is almost always impaired in people with FASD. When full-scale IQ is at or above the 70-75 ceiling, then low EF can provide a strong basis for a finding of ID, especially if adaptive functioning is low. But as a general rule, evaluators fail to understand or use this pathway to avoiding turndowns based solely on someone’s full-scale IQ score.

Failure to Understand that Part Scores Can Satisfy Prong One

A current controversy in the ID field involves the new (12th) AAIDD manual saying that only full-scale IQ should be used, while DSM-5 (and forthcoming DSM5-TR) saying that in some circumstances, part scores can provide a more reliable indicator of impaired intelligence. Inflexible reliance on a single number should be avoided, and a variety of methods should be used to determine someone’s cognitive strengths and weaknesses.

Prong Two: Adaptive Functioning

The second diagnostic prong, termed “Adaptive Behavior” (AAIDD) or “Adaptive Functioning” (DSM) has to do with how competent or incompetent a

person is when dealing with social and non-social aspects of everyday life. It is intended to ensure that a diagnosis of ID or DD is given only to people who are truly deserving. At the same time, there needs to be recognition that for people at the upper end of the disability spectrum, one can have aspects of ability while still being considered disabled.

Cherry Picking of Isolated Accomplishments

The most common contributor to spurious turndown of ID or DD is to pick out isolated behaviors that a person can allegedly do and say “this shows the person is normal.” This practice should always be condemned as it is based on an invalid view of ID as involving a degree of global impairment that is invalid. (The Briseno factors in Texas, earlier mentioned, is an example of this).

Adaptation in Jail is Not an Appropriate Frame of Reference

Competence is always situation specific to some extent, and is revealed by the complexity of task requirements. Jail or prison makes far fewer demands on individuals than can be found in the world of temptation known as the “community.” Spurious turndowns often use jail functioning as if it were a valid basis for assessing prong two.

Self-Ratings Should Not Be relied Upon Diagnostically

People with ID or DD usually say “I can do that” even when they clearly cannot. Although some adaptive behavior rating instruments have a self-rating option, they should not be used for diagnostic purposes. But they routinely are.

Inappropriate Belief that Retrospective Assessment is Not Acceptable

In some forensic settings, such as “Atkins” (death penalty exemption) proceedings, where a person may have spent decades in prison, the ID diagnosis that is most legally relevant has to do with how they functioned before the age of 18 (now 22) or around the time of the crime (typically in young adulthood). A solution to this problem is to ask prong two informants to use a particular childhood or adolescent age (depending on when they best knew the person) when discussing adaptive functioning. This is generally accepted as a legitimate practice, but some experts would attack it as a non-approved instrument use.

Mistaken Belief that an Accomplishment Can Rule out ID or DD

It is not uncommon for an expert to point to a particular role that someone played and use that to argue against ID. There are three things wrong with this: (a) sometimes the facts are not as clear-cut as alleged (for example a “welder” may have been re-assigned to just carrying material around), (b) brain damage is modular, and there are usually areas of high as well as low functioning, and (c) most importantly, there are few if any roles that people with high functioning ID cannot be legitimately found to have played. For example, in a longitudinal follow-up study of people who had been in special education for ID when younger, one can find some individuals playing virtually every adult role (marriage, work, driving, etc.) (National Council on Disabilities (NCD), 2000). People with ID can learn to drive, obtain a driver’s license, graduate from high school, use a bank account, hold a basic job, and engage in other basic activities of life. It is for this reason that both clinical ID manuals do not require global prong two incompetence. As for romantic relationships, it is very common for normally functioning women to co-habit with men who have brain impairments, for reasons I can only speculate about.

Facts of a Crime are Used to Infer Prong Two Functioning

As a rule, facts of a crime should not be used to argue against an ID or DD designation. One reason is that we often do not have enough detail (for example, what influence or training was there from a confederate?). Also, we lack norms for such things as what it takes to aim a gun and pull the trigger. What seems to be a sign of competence (asserting one’s will on others) could be a sign of incompetence (panicking when things begin to unravel). Yet some experts routinely attempt to use crime facts to argue against an ID diagnosis, in part calling up the mistaken stereotype of people with ID as uniformly passive.

Prong Three: Developmental Onset

A defining aspect of neurodevelopmental disorders is the idea that the disorder represented an anomaly in the developmental process, particularly as it affected brain development. Prong three is less likely to be the basis for spurious turndown than prongs one and two, but it does occur.

Mistaken Belief that Diagnosis Had to have Occurred Early

Many experts incorrectly interpret the third prong to mean that there must be clear evidence of ID during the pre-18 period, such as qualifying IQ scores or a school diagnosis of ID. But there are many people with ID, DD or FASD who were not tested or correctly diagnosed during the developmental period. It could be because a school district did not have a competent special education program or because a child's parents did not give permission for testing or services. What is needed is to find a "continuity of concern," where red flags (retention in grade, referral for assessment, etc.) suggested the individual was not developing at a rate or level characteristic of age-mates in the same community or family.

Failure to Understand that Prong Three Can Occur Close to Adulthood

While regression in adulthood, such as from a catastrophic car accident or illness, can be diagnosed as dementia (now termed neurocognitive disorder), when it The new AAIDD-12 manual raised the age of onset to 22, while DSM-5 keeps age of onset vague (frontal lobes continue to develop into one's 20s). There are experts, however, who are fixated on the idea that ID or DD must manifest very early.

Conclusion: FASD is Becoming More Recognized

I have been around long enough to remember when ADHD was invented and was just beginning to be widely used. Ditto for autism Now they are both hugely popular categories, and if anything are over-used. I have the sense that a similar corner-turning process is happening now for FASD. Not that long ago, few people knew what you are talking about when you mentioned FASD. Today, that is much less likely to be the case. I should give a shout out to Billy Edwards, who was the driving force in getting today's training to happen. He has been organizing these trainings for many years, and certainly within the legal community, increased awareness of FASD can be traced at least in part to him. A result of this increased awareness is that it is becoming easier to get people with FASD to be found eligible for DD services. As example, in California five years ago you could forget about getting someone with FASD to be found eligible for DD services through the Regional Center system, but we know of several recent cases where eligibility occurred, both with and without the need for an appeal of an initial spurious turndown (and Billy has played a role in some of these turndown reversals as well). In sum, FASD seems to be a disorder on the cusp of becoming widely used.