FASD and the Concept of "Intellectual Disability Equivalence"

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Introduction

The term "Intellectual Disability (ID) equivalence" refers to accommodations that are made by legal and other governmental entities when they provide services, supports or protective arrangements to people who—because of brain impairment—function as if they have ID but fail to qualify for the ID label which is needed for access to many programs because their IQ scores are a few points too high. Fetal Alcohol Spectrum Disorder (FASD) is a logical candidate for such an accommodation as (a) it (like ID) involves brain impairment, (b) people with FASD have adaptive deficits and support needs that are identical to those with ID, and (c) while many people with FASD do qualify as having ID, the majority do not, because full-scale IQ scores are typically too high.

ID-equivalence accommodations are an attempt to free the human services field from the straight-jacket that has been imposed by over-reliance on full-scale IQ ceiling scores, which functioned as a gate-keeper and barrier for developmental services eligibility. In this chapter, using specific examples, we review some of the forms that these ID-equivalence accommodations have taken, point out problems with those forms, and suggest improvements for implementing this concept. First, we provide a brief historical overview of the role of intelligence in intellectual disability and the growing belief that an IQ score provides an inadequate basis for determining whether someone may or may not have that disorder.

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M. Nelson and M. Trussler (eds.), *Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives*, International Library of Ethics, Law, and the New Medicine 63, DOI 10.1007/978-3-319-20866-4_15

Limitations of IQ and IQ Cut-Offs

Intellectual Disability, under various names and most of them now offensive, has been around for centuries, as seen in references to it in Egyptian, Greek, Roman and other ancient documents (Scheerenberger 1983). Until the advent of intelligence testing in the early twentieth century, individuals with ID were identified by how they functioned in the everyday world or what has come to be termed "adaptive behavior". Specifically, people with ID were differentiated from the general population by the perception that they lacked ability to survive on their own. With the invention of the IQ statistic, diagnostic emphasis shifted from everyday functioning as seen by others in one's environment to "intelligence" as measured on a one or two hour test of mainly academic problems, administered by a psychologist who typically did not know the child or adult being tested.

The original Binet-Simon scale, on which most subsequent tests were modeled, took progressively more advanced items from the educational curricula. Thus, as was argued by Anastasi (1983), there was essentially no difference between a measure of aptitude (IQ) and a measure of academic achievement, as seen in the extremely high correlations among the two types of instruments and extremely good predictive validity between IQ and academic performance. When there was divergence between aptitude and achievement scores, as in former but now largely abandoned operational definitions of "learning disabilities," these often reflected differences in test reliability as well as the fact that achievement profiles were typically differentiated in most people, including those with brain impairments. The question thus becomes: "how appropriate is it to place central reliance on a measure essentially of academic potential as a gateway to receiving developmental services, subsidies and entitlements?" The answer, it seems to us and many others, is "not much."

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 (Blumenfeld 2011). That agenda included shutting down immigration to the United States from Southern and Eastern Europe, placing individuals with below-average IQ in gender-segregated institutions before subjecting them to involuntary sterilization, and otherwise preventing those termed "morons" (many of whom today would likely not be considered to have ID) and "imbeciles" (people who today would be considered to have mild ID) from transmitting their "diseased germ plasma." The implementation of that agenda depended on being able to persuade legislators and the public through quasi-scientific or outright fraudulent studies such as Henry Goddard's (1912) book on the "Kallikak" family, that low-IQ people posed a threat to society and to the continued superiority of the "white race." Much evidence that Goddard faked his Kallikak data can be found in Smith (1985).

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" that are not well captured by an IQ score. We also recognize that some cognitive measures such as "executive functioning" are better indices of intelligence than IQ, and that cognitive profiles across batteries of IQ and other tests are more useful than a single index score (McGrew and Flanagan 1998). It is also accepted that there are environmental as well as other biological (e.g., brain injury) contributors to poor intellectual functioning (Ceci and Williams 1997), and that instruments which purport to measure IQ are not equally reliable or valid and are affected by well-known psychometric variables, such as experience with prior tests, obsolescence of test norms, problems with test construction and statistics, and normal variation in performance that is random or due to examiner incompetence or bias (Greenspan and Olley 2015).

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 this manual, they established a three-prong definition of mental deficiency (later, "mental retardation" and today "intellectual disability") as a condition in which 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 3 % of the population. Therefore, a standard that took in the bottom 17 % of the population was obviously too high as it created many "false positives" of individuals labeled ID who should not have been. 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 3 %. 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 and 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 1980s (Grossman 1983) 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 1990s (Luckasson et al. (1992), was to take the suggested five-point confidence interval and make it the new ceiling standard, later modified (Lucksson et al. 2002) as the IQ range "70–75." More recently, this second fix has involved using 75 as the cutoff point (Schalock et al. 2002), which is also what DSM-5 adopted. Part of this fix was to insert the word "approximately" before the number 70 or, more typically, the term "approximately 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" (Gresham and Reschly 2011). 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 3 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. This position will be explored more fully in the concluding section of this paper, but first we will look at how various government entities have put in place ID-Equivalence provisions intended to get around our slavish and inappropriate reliance on arbitrarily-instituted full-scale IQ ceilings.

Forms of ID-Equivalency Accommodation

Various attempts have been made over the years to address the inequitable obstacles to ID service eligibility posed by the continuing rigid reliance on full-scale IQ cutoffs. People with FASD are among those most victimized by the current practice and therefore stand the most to gain from efforts to develop more flexible frameworks. In the following pages, we describe some of these ID-Equivalency approaches, and point out both their strengths and limitations.

Building Policy Around an Individual-Driven Lawsuit

Neal Fahlman is a young man in British Columbia, Canada, of First-Nations ethnicity who was adopted at age five weeks. As a child he had three diagnoses: FASD, ID and what today would be termed ASD (Autism Spectrum Disorder), in addition to ADHD (a common co-morbid problem for people with FASD). As a child and pre-adolescent, Neal qualified for developmental disability (DD) services as his full-scale IQ was below the minus two standard deviation threshold used in BC by Community Living British Columbia (CLBC, a Crown Corporation) to determine eligibility for residential DD services. He also met the other two criteria for a diagnosis of ID: onset in the developmental (pre-age-18) period and significant deficits in adaptive functioning. Starting at age 15, Neal was funded by CLBC for living in foster homes and eventually in his own small home due to behavior outbursts, with one-on-one daily supports but with continued involvement by his adoptive parents. The program was costly ($77,000 per year) but less expensive than institutional alternatives (such as prison), given Neal's very poor judgment and impulse control problems (e.g., lashing out at others).

When Neal reached age 19, his eligibility for CLBC services needed to be re-established. However, his newly-obtained IQ score of 79 was now a few points above the approximately minus two standard deviations level, which was cited as the basis for denial of services even though his adaptive behavior scores were still in the moderate (minus three standard deviations) range. In many other states or provinces, once someone is in the system and begins receiving services, eligibility remains intact, regardless of any change in IQ. Neal's family sued CLBC and a panel of judges ruled that the use of a specific IQ cut-off to determine continued eligibility, which had never been discussed in the agency's authorizing legislative history, was arbitrary and unfair. The agency was ordered to continue serving him and to devise a more equitable, and less IQ-driven, formula for making eligibility determinations for other applicants.

After considering a framework with broader applicability, the BC Ministry of Community Living Services (the government agency over CLBC) came up with a formula that appears to have been very narrowly tailored to people exactly like Neal Fahlman. Essentially, they established two pathways to residential services: (a) the traditional one, for people who qualified for a diagnosis of ID, which required an IQ below 70 along with adaptive deficits and onset in childhood; or (b) an alternative pathway, only available to people who—like Neal—had ASD or FASD. In addition to having onset in the developmental period, successful applicants needed to have deficits in adaptive and intellectual functioning, but IQ scores could be above the traditional 70–75 ceiling. However, to ensure that applicants were sufficiently deserving of services, prong two (adaptive functioning) required a score that fell at least three standard deviations below the population mean on a standardized rating measure. This happened to be the precise profile characterizing Neal Fahlman.

There are three problems with the ID-Equivalence solution in British Columbia that was devised in response to the Neal Fahlman lawsuit. The first problem was that the BC "fix" continued to be based on artificial and arbitrary numeric criteria, i.e., the numbers were adjusted to make the judges in the Fahlman case happy. The underlying issue raised by the court—namely the need to look at the whole individual—was not really addressed at all.

A second problem with the BC solution was that adaptive deficiency was defined as minus three standard deviation units, which was far too stringent a requirement as it included only a fraction of the first percentile of the population. This was also grossly inconsistent with the usual prong two criterion, which at minus two standard deviation units (at or below the second percentile) was more in line with the population for whom ID-equivalence relief was being sought. Our guess, which has been confirmed by conversations with experts and applicants in BC, is that adaptive behavior informants such as parents and even evaluators such as psychologists are then motivated or perhaps forced under the BC solution to exaggerate the severity of an applicant's deficits. There is obviously something wrong with such a state of affairs, as it is inequitable to reward those savvy or dishonest enough to exaggerate, while punishing those too unsophisticated or honest to do so.

The third problem with the BC solution is that the ID-equivalency pathway was made available only to people with one of the two disorders—ASD and FASD–which applied specifically to Mr. Fahlman. What about people with the dozens if not hundreds of other brain-based developmental syndromes who have the same problem of significant adaptive needs but whose IQs straddled the minus two standard deviation demarcation line? For example, do individuals with Prader-Willi syndrome or Dandy-Walker malformation, where there is an ID-equivalent need for services but where IQs sometimes fall above 70, have to file their own lawsuits when they are denied services? A more equitable solution would have been to use general language, such as "persons with brain-based neurodevelopmental disorders" rather than "persons with autism or FASD." Consideration of equity applies here as well, as it is unfair to give relief to very politically influential advocacy groups (such as parents of autistic children) and deny it to equally deserving clients (such as individuals with, say, Dandy-Walker syndrome, where IQs also fall on both sides of the 70–75 barrier) whose disorders are less known and thus lack comparable visibility or influence.

Building ID-Equivalency Around Prader-Willi Syndrome

Just as FASD is granted ID-Equivalency in British Columbia (as long as the minus three standard deviation criterion on prong two is met or faked), other specific syndromes have been specified in various jurisdictions for ID-Equivalency. A difference is that for these disorders, eligibility is sometimes met automatically if the syndrome diagnosis is established without any, let alone a more severe, adaptive

behavior deficit finding. Perhaps the most prevalent of these exemption examples includes Prader-Willi syndrome (PWS), a rare (1:10,000 to 1:25,000 live births) developmental disorder caused by a deletion or partial expression of several genes on chromosome 15. Among the symptoms of PWS are cognitive deficits typically, but not always, involving IQ below minus two standard deviations, significant adaptive deficits, and a compulsive need to eat constantly often resulting in morbid obesity.

A statute in Connecticut gives automatic ID-Equivalency status exclusively to applicants for ID services who have PWS, regardless of IQ. According to a 2006 website description of the Connecticut Department of Mental Retardation (since renamed the Department of Developmental Services): "An application for eligibility determination may be made by… any person who is a resident of Connecticut at the time application is made, or by someone on the person's behalf, and who is, appears to be, or believes him/herself to be a person with mental retardation, as defined in Connecticut General Statutes 1–1 g or Prader-Willi Syndrome…" Later, the eligibility criteria are spelled out thusly: "…The process by which the Department examines information relative to an applicant for Department to determine if the applicant meets the statutory criteria for mental retardation or Prader-Willi Syndrome," and PWS is described as "a neurobehavioral genetic disorder that has been diagnosed by a physician utilizing medically appropriate criteria." Such a diagnosis, which until the 1990s was based mainly on clinical criteria (e.g., hypotonia, hypogonadism, inability to achieve food satiation), is now derived from extremely reliable DNA-based genetic testing methods.

The relevant aspect of the Connecticut exemption is that applicants with PWS do not have to meet any other criteria for eligibility such as level of adaptive behavior impairment. Apparently it is just assumed that an individual with PWS, a spectrum disorder with varying levels of severity, has significant enough service needs to merit DD services whether or not his/her IQ score falls below 70–75. Several other states also list PWS in their eligibility criteria but embed it within a slightly broader list of neurodevelopmental disorders and also specify that an individual still has to meet prong two, the adaptive functioning deficits. An example is Wisconsin, which specifies that developmental services are for people who have "…a disability attributable to brain injury, cerebral palsy, epilepsy, autism, Prader-Willi syndrome, intellectual disability, or another neurological condition closely related to an intellectual disability or requiring treatment similar to that required for individuals with an intellectual disability, which has continued or can be expected to continue indefinitely and constitutes a substantial handicap to the afflicted individual…." Similarly, Massachusetts affords ID-Equivalence status to people with "… cerebral palsy, epilepsy, autism, Prader-Willi or other condition other than mental illness or an emotional disturbance; closely related to mental retardation because the condition results in impairment of general intellectual functional or adaptive behavior similar to those with mental retardation; manifests before 22 years of age; [is] likely to continue indefinitely; [and] results in substantial limitations in three or more of major life activities: self-care, understanding and use of language, learning, mobility, self-direction, [and] capacity for independent living."

PWS is not the only chromosome abnormality syndrome given special ID-Equivalency status, but it is the most widely-noted. In Manitoba, special mention is given to Patau syndrome (a trisomy on chromosome 13) and Edward syndrome (a trisomy on chromosome 18). An advantage of the Manitoba legislation is that it is worded as "chromosome disorders *like* [emphasis added] Patau syndrome and Edward syndrome," so that the conditions are illustrative of a broader class of disorders. In contrast, Connecticut mentions only PWS. Patau syndrome has about the same incidence as PWS, while among the chromosomal disorders, Edward syndrome is more prevalent (1:6,000 live births), second only to Down syndrome (1:1,000 live births). Although one of the most common biological causes of ID, Down syndrome (DS) is not mentioned in ID-Equivalence statutes—except in Arkansas–perhaps because there is rarely any straddling of the 70–75 divide and therefore virtually all people with DS have no problem qualifying for ID services. Yet, we have found specific mention of Patau or Edward syndromes as ID-Equivalency triggers only in Manitoba, while PWS is mentioned in many places. The likely explanation for this discrepancy is that PWS parent support and advocacy groups are found virtually everywhere, while the "International Trisomy 18/13 Alliance" is much less visible. However, it does have an active presence in Western Canada, which may explain why it is mentioned in the Manitoba legislation.

According to a PWS researcher with first-hand knowledge (Dykens 1996), the legislation that established automatic ID-Equivalence for applicants with PWS in Connecticut occurred as a result of successful legislative lobbying of the state legislature by PWS parents and advocates. Not long after this legislation was enacted, a request was made for similar special treatment (i.e., ID-Equivalence) by parents of children with autism which is also a spectrum disorder straddling both sides of the 70–75 IQ divide but with virtually all diagnosed individuals exhibiting severe adaptive deficits and service needs. However, this request was turned down for three related reasons: (a) autism is diagnosed clinically without absolute certainty of a biological (DNA) test as in PWS; (b) the diagnosis of autism is made too freely (which reportedly is why DSM-5 eliminated Asperger disorder) and consequently includes many individuals unlikely to ever need disability services; and (c) even if an autism diagnosis was reliable and valid, the numbers of affected individuals would be enormous (perhaps as high as 1 %) in comparison to PWS; thus granting automatic ID-Equivalency to all autistic individuals would likely have severe fiscal consequences for any state or provincial human services budget. Unfortunately, ID definitions and diagnoses are in part driven by political and economic considerations, much as we might wish that were not the case.

By implication, therefore, the political initiative of PWS advocates on behalf of automatic ID-Equivalency status was more likely to be successful because diagnosis of PWS was highly reliable, virtually all affected individuals needed and deserved DD services, and—last but not least—the prevalence rate for PWS was low enough that such a scheme was financially viable. Still, one could make the same inequity argument against singling out PWS in Connecticut as we made against singling out FASD (and Neal Fahlman's other diagnosis, autism) in British Columbia.

Moreover, the case against PWS could be made even more strongly, as the lawsuit-driven solution in BC still required significant evidence of adaptive deficits. In fact, this was so excessive as to almost ensure fraud, while such (or any) evidence of adaptive deficits was not a requirement in Connecticut for PWS eligibility. Looking at this history and convoluted bases for "fixes" to the eligibility criteria, it seems questionable to us that a single genetic disorder is singled out for special ID-Equivalency treatment when there are so many other syndromes (Patau and Edward, to name but two) that are equally deserving. It is clear then that the broader problem goes beyond the naming of a specific ID-qualifying disorder and involves the somewhat outdated emphasis on underlying specific medical categorization itself.

Developmental Disabilities Solution

A major way in which government entities increase the population eligible for ID services beyond those with IQ scores at or below 70–75 is to use the broader term "Developmental Disabilities" (Administration for Community Living 2013; Disability Law Center, undated; National Council on Disability 2012; Zaharia and Moseley 2008). 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 (Gettings 2011). The term is now widely used in many state and provincial eligibility statutes. The original 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 our 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," raised the age-of-onset from 18 to 22 and switched from a categorical to functional definition of DD as a "severe, chronic disability…attributable to a physical or mental impairment…likely to continue indefinitely" that

resulted in "substantial functional limitations in three or more areas of major life activity." A final revision in 2000 [note: the unusual reversal of typical order of Roman numerals is reported here as it actually was in the statute] defined DD as "a severe, chronic disability of an individual that (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following seven areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the 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 functioned as if they had ID in spite of having IQs that fell above the 70–75 IQ ceiling. However, at least two of the skills, language and mobility, were not specific to ID. Likewise, one also could argue that self-direction was 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. One place that mentions FASD as an IQ-equivalent condition example is Minnesota, whose statute 252.27 (2012) notes several "related conditions," defined as: "a condition that is found to be closely related to a developmental disability, including but not limited to, cerebral palsy, epilepsy, autism, fetal alcohol spectrum disorder, and Prader-Willi syndrome." Like most statutes, the one in Minnesota excludes mental illness, but states that autism (at one time thought to be a form of childhood schizophrenia but now listed as a neurodevelopmental disorder) is not considered a mental illness and thus is not excluded.

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.

The "Similar Services" Solution

As noted in the previous section, a number of jurisdictions have a mixed categorical/functional approach to ID-Exemption, but these generally lack an explicit statement that ID is the core construct upon which they are basing the expanded category list as well as the functional life skills impairment list. Such a statement would be a useful addition, as it would indicate the real purpose of an expanded list, which is to enable agencies to do the right thing, namely grant DD services and protections to people who clearly deserve them but are denied them solely because their full-scale IQ is above the arbitrary 70–75 full-scale IQ ceiling. Such a statement also would enable eligibility determiners to avoid being limited to the disorders in an expanded list, as adding four or five such categories (e.g., autism, FASD, Prader-Willi, etc.) still fails to include dozens of other disorders involving full-scale IQ scores that straddle the 70–75 barrier known to cause or be strongly associated with ID and serious adaptive deficits.

A good example of an ID service eligibility framework that went from an expanded categorical definition with a functional overlay to adding a similar-services component is California's vast regional center system. The regional centers are state-funded agencies that act as the gateway through which applicants for ID services in the state must pass (Disability Rights California 2012). The authorizing legislation, the Lanterman Developmental Disabilities Act (AB 846), which is widely known as the Lanterman Act, was initially proposed in 1973 and passed in 1977. The Act significantly expanded upon the Lanterman Mental Retardation Services Act (AB 225), initially proposed in 1969. Although originally created to serve people with mental retardation, the regional centers were later mandated to serve persons with four conditions: mental retardation (today termed ID), cerebral palsy, epilepsy and autism. This list obviously was directly modeled after Kennedy-era federal Developmental Disability legislation. To be eligible for services under the Lanterman Act, a person had to have a "substantial disability." Thus, people with epilepsy, who are at risk for cognitive impairment but often have superior intelligence, would not be eligible automatically for ID services.

In 1976, the Lanterman Act was amended to establish the right to treatment and habilitation services for persons with developmental disabilities. In 2003, the definition of "substantial disability" was amended to require the existence of significant functional limitations in "three or more…areas of major life activity…."

Previously, having a "substantial disability" only required the existence of a significant functional limitation in one area of major life activity. In these "major life activities" were self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. It is noteworthy that this is the same list (and 3-out-of-7 formula) previously developed in federal Kennedy-era legislation. As mentioned, that legislation was originally intended mainly to authorize programs (such as state DD councils), and the life skills list and formula were not necessarily intended to be a guide to diagnosis or service eligibility. However, practical application of the legislation has morphed into that in spite of the fact that the list and the numeric formula do not appear to have any convincing empirical or theoretical rationale.

Further delimiting the scope of the regional centers, the Lanterman Act specifically excluded "conditions that are considered solely a learning disorder, solely a psychiatric disorder or solely a physical disorder" (Cal. Code Regs., Tit. 17, Sec. 54000[c][3]). This obviously could be a source of confusion, as people with ID often have psychiatric and motor problems. A major innovation in the Lanterman Act, which keeps it from being unworkable with its very outmoded and overly limited list of four disorders, is what has been referred to colloquially as California's "fifth category" (Disability Rights California 2012). The fifth category is made up of "conditions similar to mental retardation, or conditions that require treatment similar to the treatment required for individuals with mental retardation." The "similar conditions" and "similar treatment" formulations make it possible in theory for people with a wide range of brain-based conditions that produce adaptive needs similar to those found in people with ID to receive the services to which they are entitled. The legislation does not specifically refer to a too-high IQ as the reason for this Fifth Category loophole, but obviously that is its justification, as is the case with any ID-equivalency provision.

In practice, attaining service eligibility for a too-high IQ applicant under the Fifth Category has proven to be anything but easy, as the application process often involves initial disapproval followed by one or more appeals and even a lawsuit before, in some cases, a successful resolution. Undoubtedly, the reason for this difficulty reflects insufficient funding to serve a large and growing pool of applicants, but it also may reflect the insidious survival of an IQ-ceiling-driven mindset, in spite of legislation which seems to explicitly allow IQ ceilings to be ignored when appropriate. Two court cases have served to clarify the intent of the Fifth Category provision and force the regional centers to more fully live up to their obligation to serve people who fall within the purview of the Fifth Category: *Mason* v. *Office of Administration Hearings* (89 Cal.App.4th 1128, 2001), referred to as "Mason," and *Samantha C. v. DDS* (185 Cal.App.4th 1462, 2010), referred to as "Samantha C."

The issue in Mason was whether having a "condition similar to mental retardation" meant one had to have an IQ in the same 70–75 IQ range as found in regular old-fashioned MR/ID. Of course, such an interpretation was a perversion of the ID-Equivalency purpose of the Fifth Category, but it was made possible because the Act failed to specifically mention IQ-ceiling waiver as a major reason

for the provision. This position is reflected in the following exchange involving Dr. Bob Chang, a psychologist employed by the plaintiff in the lawsuit, and the Inland (San Bernardino area) Regional Center (IRC). When Dr. Chang was asked in a hearing if a person could fall in the Fifth Category with an IQ score in the low-average range, he answered "No. Low-average intelligence is not a condition similar to mental retardation. It is statistically significantly different. Low-average general intelligence is very different than somebody who is mentally retarded." So much for the idea of ID-Equivalency as a way out of the straightjacket imposed by rigid adherence to IQ ceilings!

The 2010 Mason case involved an appeal of a turn-down by IRC of ID services for a child who had a seizure disorder at birth and actually was institutionalized for a while in the now-shuttered Lanterman Developmental Center (earlier known as Pacific State Hospital). The IRC refused Mason for ID services because of an IQ score that was a little too high in spite of substantial adaptive deficits. In addition to arguing that the Fifth Category did not apply to applicants like Mason with above-75 IQs, the IRC also argued that the Fifth Category was unconstitutionally vague. The court rejected the IRC's position, stating that the wording of the Fifth Category was sufficiently clear, and that it made no sense to use as a criterion for the Fifth Category the same exact criterion that was used to define ID. However, while a victory for Mason in providing a broader interpretation of the Fifth Category, the decision of the appellate court was a loss for him in that it did not insist that he qualified for ID services, even under an expanded approach to eligibility. The reason given by the court was that Mason had a diagnosis of Learning Disability (LD) and consequently could be educated in a regular classroom. Plus, there was no evidence that a child with LD, defined in part by having an IQ score above the ID range, needed services similar to those provided to children with ID. Thus, in spite of the intention that the Fifth Category would provide an alternative to IQ-based eligibility determination, the Mason decision illustrated just how pervasive and persistent such views continued to be and how little weight was given to adaptive behavior scores in eligibility determination decisions.

The 2011 Samantha C case represented a leap forward in interpretation of the Fifth Category, particularly in clarifying the meaning of the "similar treatment" clause. The better outcome for the plaintiff in this case likely reflected advances in ID services philosophy and understanding of cognitive disabilities in the intervening 9 years, but undoubtedly it also reflected differences in the impairment severity profiles of the two plaintiffs. The basic facts of the case were that Samantha was deprived of oxygen for 30 min during the birth process and experienced significant cognitive and adaptive problems as a result. The plaintiff in this case, Harbor (Long Beach area) Regional Center (HRC), argued that Samantha was not entitled to state ID services because she had been labeled LD and ADHD. The court sided with an expert who said that Samantha's problems were better attributed to significant anoxia (oxygen deprivation) at birth and that her need for services similar to those required by people who were labeled ID because of low-enough IQ made her clearly eligible under the Fifth Category. HRC was ordered by the court to provide Samantha with appropriate ID services.

As the focus of this book is on legal issues involving people with FASD, it is important to include a brief account of a recent case–with some similarities to Mason and particularly Samantha C—involving a service applicant with FASD. The case is not cited in any court ruling because it was successfully resolved through the application appeal process before court intervention had to be sought. Nonetheless, the case is somewhat known in the literature as a profile of the petitioner—whom we refer to as "Lisa"—was contained in an article on adaptive functioning and FASD, which two of the authors published in a special FASD issue of the *Journal of Psychiatry and Law* (Edwards and Greenspan 2011). The account that follows is basically an update to the earlier one.

Lisa, the daughter of a woman who abused alcohol and lived in Los Angeles, was diagnosed with FASD as a young adult. She had two siblings who were diagnosed with FASD during childhood. Lisa suffered very severe abuse from her father, who went to prison as a result. She and her brother, who became a regional center client, were discovered by police living unclothed in dog cages when she was age four. Lisa was placed in a series of foster and institutional settings, where she received a great many psychiatric diagnoses. Lisa had a temper, and as a young adult, she got into a dispute with a caregiver that led to her setting a small fire outside a group home from which she had been expelled. While in jail for 2 years following the arson incident, she attempted suicide (one of several attempts) and almost succeeded. When her sentence was completed, she was committed to a secure psychiatric facility, where the state sought to have her permanently incarcerated.

Due to the efforts of her new attorney, Lisa eventually received a diagnosis of FASD from a team of knowledgeable experts. Using this diagnosis, and based on the experts' opinions that with proper care Lisa would no longer be a threat to herself or others, the attorney was able to persuade a judge to release her from confinement if a suitable residential and case management plan could be developed. An application was made to a regional center for ID services under the Fifth Category, but the application was turned down on the basis that Lisa's full-scale IQ (in the 90s) was too high and that her problems were mainly psychiatric and therefore not covered under the Lanterman Act. A disability rights group took Lisa on as a client. They used the fact that she was living temporarily in a different and better funded jurisdiction to make a new application to a different regional center, one which they believed was more likely to be sympathetic. This time, the application was successful on the basis that Lisa had a neurodevelopmental disorder (FASD) that produced cognitive deficits. These included major problems in executive functioning that impaired her judgment and made it necessary for her to live and work in supervised settings and receive case management services similar to clients with ID, many of whom also had psychiatric difficulties. As of today, Lisa is happy and thriving in an environment that is much more supportive, skilled and loving than would have been the case had she continued to be served through California's mental health and correctional systems. Lisa's case is relevant and

potentially important on two related grounds: (a) she qualified for ID services with an IQ score that was essentially normal, and (b) the outcome establishes, at least in California, a *prima facie* case that people with FASD should be served by the ID service system if they have sufficient service needs that can be shown to be congenitally brain-based.

Adaptive Behavior Substitution for IQ

Adaptive Behavior, also known as Adaptive Functioning, plays an important role in determining ID eligibility even if IQ meets the minus two standard deviation criterion. When using this more conventional route, having low adaptive behavior by itself is not sufficient for ID eligibility if the IQ criterion is not met. In the Developmental Disabilities solution with singled-out diagnostic categories such as autism or cerebral palsy, service eligibility still requires significant deficits in adaptive behavior, even if it the criterion is not as stringent as that used in British Columbia. In the Similar Solutions approach described in the preceding section, adaptive behavior plays an important role, as seen in the case of Lisa. That young woman, who had a clear-cut diagnosis of Partial Fetal Alcohol Syndrome (PFAS), was granted ID-Equivalence status through California's so-called "fifth category" only because she has very significant support needs which were reflected in substantially impaired levels of adaptive behavior. An even more explicit emphasis on adaptive behavior as a basis for ID equivalence can be found in Colorado's recent reformulated eligibility standard (Block 2013).

Colorado revised its eligibility criteria in April 2014 for the usual reason: too many children and adults with brain-based developmental disorders (such as autism) and very significant support needs were being denied service eligibility because of IQ scores over 70. The solution devised is that a developmental disability "means a disability that is manifested before the person reaches 22 years of age, which constitutes a substantial disability to the affected individual, and is attributable to mental retardation or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions when such conditions result in impairment of general intellectual functioning or adaptive behavior similar to that of a person with mental retardation. (C.R.S. 27-10.5-102 11 (a), as amended)." The innovative thing about this provision is that for ID-Equivalency qualifying purposes, adaptive behavior now has a status equal to that of IQ, and too high IQ score is no longer an impediment to receiving ID services. Mentioning "neurological conditions" is also an important feature, in that it reinforces the critical (but rarely stated) notion that ID reflects a failure of brain development.

The Colorado emphasis on similar "impairment" differs from the California emphasis on similar support needs in that the former is more grounded in psychometrics, while the latter is more grounded in qualitative and subjective perceptions of need. Specifically, the Colorado statute specifies that a deficit in General Intellectual Functioning is to be determined by an IQ score below 70 (for the first

route of MR/ID), while a deficit in Adaptive Behavior is to be determined by deficits on a standardized instrument of adaptive functioning, such as the Adaptive Behavior Assessment System, second edition (ABAS-2). According to Block (2013), who analyzed the revised Colorado standards while still in the proposal stage, the adaptive behavior standard was to be met by significant deficits in two of the eleven adaptive skills in the old (2000) DSM-4TR definition and the very old (1992) AAIDD definition of ID. This antiquated view of adaptive behavior/adaptive functioning is obviously problematic, in part because the taxonomy on which it is based lacks content validity (Zigler et al. 1984). The content validity of adaptive behavior is a topic outside the scope of this chapter, but suffice it to say that the absence of an adequate model or measure of adaptive behavior has obvious relevance for devising alternative (ID-Equivalence) eligibility pathways. This is because impaired functioning in the various community contexts (i.e. school, social relationships, independent living, etc.) is used as a prime reason for giving less weight to IQ, and adaptive behavior is, in theory, a way of getting at community functioning. A brief discussion of the DD behavioral phenotype—indicating why many people with FASD and related brain-based disorders deserve services or other accommodations—is therefore in order and will be provided later.

FASD and ID-Equivalence in Civil and Criminal Contexts

As noted, FASD is one of the brain-based syndromes mentioned for ID-Equivalency consideration in DD service systems in some jurisdictions. An example is Alaska (Title 47, chapter 20, Alaska Stat. § 47.20.290, 2012), where the term "Developmentally Delayed or Disabled" is used to describe children eligible for early intervention services. Developmentally delayed is defined as "… functioning at least 15 % below a chronological or corrected age or 1.5 standard deviations below age appropriate norms in one or more of the following areas: cognitive development, gross motor development, sensory development, speech or language development, or psychosocial development, including self-help skills and behavior, as measured and verified by appropriate diagnostic instruments and procedures or through systematic observation of functional abilities in a daily routine by two professionals and a parent, developmental history, and appropriate assessment procedures."

The term Developmentally Disabled is defined as "…having an identifiable physical, mental, sensory, or psychosocial condition that has a probability of resulting in developmental delay even though a developmental delay may not be exhibited at the time the condition is identified…" This list of such conditions is then supplied (note: we have changed the format slightly to fit it into a paragraph style): "…(a) chromosomal abnormalities associated with delays in development, such as Down's syndrome, Turner's syndrome, Cornelia de Lange syndrome, or fragile X syndrome; (b) other syndromes and conditions associated with delays in development, such as fetal alcohol syndrome, cocaine and other drug-related

syndromes, metabolic disorders, cleft lip, or cleft palate; (c) neurological disorders associated with delays in development, such as cerebral palsy, microcephaly, hydrocephaly, spina bifida, or periventricular leukomalacia; (d) sensory impairment, such as hearing loss or deafness, visual loss or blindness, or a combination of hearing and visual loss, that interferes with the child's ability to respond effectively to environmental stimulus; (e) congenital infections, such as rubella, cytomegalovirus, toxoplasmosis, or acquired immune deficiency syndrome; (f) chronic illness or conditions that may limit learning or development, such as cystic fibrosis, bronchopulmonary dysplasia, tracheostomies, amputations, arthritis, or muscular dystrophy; (g) psychosocial disorders, such as reactive attachment disorder, infant autism, or childhood schizophrenia; or (h) atypical growth patterns consistent with a prognosis of developmental delay based upon parental and professional judgment, such as failure to thrive."

This statutory provision is aimed specifically at early intervention service eligibility which, admittedly, is different and usually more inclusive than eligibility for adult residential or case management services might be. However, the approach offers some innovative aspects which could possibly serve as a model for adult services eligibility. Here are the innovations in this document as we see them: (a) a more flexible approach to standard score ceilings, in that the cut-scores mentioned (minus 1.5 standard deviations equates to a standard score of 81.5, which is at the 11th percentile of the population; also mentioned is the 15th percentile, which is a standard score of 85.5) is considerably higher than the more usual 70–75 cut score, and likely to cover a substantial percentage of the population of children with FASD or other neurodevelopmental disorders, thereby considerably reducing the problem of false negatives; (b) the use of a broader list of deficit areas without limiting deficits to cognition only, and also defining cognition more broadly than just IQ; (c) the listing of many different types and categories of disorders strongly associated with ID, but including the expansive term "such as" rather than simply limiting the possibilities to a few named conditions; specifically mentioning FAS (and presumably other FASD conditions) under a category termed "other syndromes and conditions associated with delays in development"; and (e) mentioning the possibility that bases may include the possibility of observations by qualified assessors rather than limiting the bases to just measures or statistics.

Although our emphasis in this paper is on service eligibility formulas, it is worth mentioning that the issue of ID equivalency also comes up in the criminal arena, with FASD being a prime focus of such discussion. In the case of Brandy Aileen Holmes v State of Louisiana, a young woman with FAS in her early 20s was condemned to death in 2006 along with a male co-defendant after shooting an elderly man (who died) and his wife during a home-invasion robbery in 2003. In 2009, a petition to the Supreme Court of Louisiana asked for reconsideration of her conviction on the basis that Ms. Holmes' FAS diagnosis should have been taken into account in combination with her uncorrected IQ of 77 as a mitigating factor when determining her sentence. In particular, the defendant's apparent lack of empathy or remorse (symptoms of her FAS) were held against her as an aggravating factor. In an amicus brief from the National Organization for Fetal

Alcohol Syndrome (2009), it was argued that FASD causes adaptive deficits very similar to those found in people with ID and thus should have resulted in a finding of reduced moral culpability and execution exemption, as in the US Supreme Court's 2002 *Atkins v Virginia* decision, which exempted people with ID from facing execution. The Supreme Court of Louisiana rejected the *certiori* petition, but a dissenting opinion from the court's chief justice made a convincing case that Ms. Holmes likely qualified for a diagnosis of ID, given her FAS, low IQ, overt signs of brain damage, and poor adaptive behavior.

The State of Alaska, already a leader in recognizing FASD as a basis for ID Equivalence in determining human services eligibility, is also a leader in asserting the role of the disorder as a mitigating factor when determining criminal culpability and punishment. One assumes the advanced awareness of FASD in that state stems at least in part from the existence of a very large native Eskimo and Aleut Indian population, which is the US racial sub-group with the highest incidence of diagnosed FASD (Tenkku et al. 2009). In June 2012, both houses of the Alaska legislature unanimously passed SB 151: "An Act relating to mitigation at sentencing in a criminal case for a defendant found by the court to have been affected by a fetal alcohol spectrum disorder." According to the Alaska FASD Partnership Newsletter (2012), the bill was put forward by a large workgroup, including court personnel, concerned by "the large number of people affected by… FASD in the state's criminal justice system."

The essence of SB 151 is to allow judges flexibility in sentencing people with FASD if it is established that a defendant has the disorder and that it "substantially impaired the defendant's judgment, behavior, capacity to recognize reality, or ability to cope with the ordinary demands of life, and that the fetal alcohol spectrum disorder, though insufficient to constitute a complete defense, significantly affected the defendant's conduct." Three limiting aspects of the Act are that: (a) a judge is not required to use FASD as a mitigating factor, (b) the defendant would have to prove "by clear and convincing evidence" that he or she has FASD and it was a factor in the alleged criminal offense, and (c) the Act applies only to crimes "not against the person," and thus does not apply to sex acts, assault or homicide. Two other factors not in the Act but which limit its application are: (a) it takes resources to establish FASD convincingly, and these resources typically are not available for defendants accused of minor crimes, and (b) unless someone has previously been found to have an FASD, relatively few attorneys will recognize it as a possible diagnosis, especially for the large percentage of people in the spectrum who lack obvious physical signs (e.g., Alcohol Related Neurodevelopmental Disorder or ARND). In spite of the Act's limitations (which according to an Alaska lawyer informant, has resulted in its very infrequent application thus far), it represents a major step forward toward what its supporters term "smart justice," namely a more individualized and humane approach to punishment which recognizes that people with FASD (and organic disorders generally) should not automatically receive a lengthy, or any, mandated jail sentence for an act which reflects a brain-based condition for which they are not responsible.

Although the language in SB 151 does not explicitly make an argument for ID-Equivalence, it can be inferred from the comments of its supporters that such was the intent. SB 151 was intended to divert offenders with FASD from trial or jail, while another statute–Alaska 12:55.155 ("Factors in aggravation and mitigation")–was aimed at more serious offenses and the imposition of reduced sentences when certain conditions, including ID, were present. Under section (34) (d) (18), it was specified that a sentence less than the minimum might be imposed if a defendant committed an offense "while suffering from a mental disease or defect…that was insufficient to constitute a complete defense but that significantly affected the defendant's conduct." Mental disease or defect specifically included ID, as indicated in Alaska statute 12,47.130, and very similar language as found in SB 151 in describing "a disorder… that substantially impairs judgment, behavior, capacity to recognize reality, or ability to cope with the ordinary demands of life."

Conclusion: Seeking the ID Behavioral Phenotype

The move to devise ID-Equivalency pathways for service eligibility reflects a belief that direct real-world functioning (e.g., observed need for supports) should be given more weight than indirect performance on a measure (e.g., IQ score) that imperfectly predicts real-world functioning. In this concluding section, we suggest the parameters of what such a behavioral phenotype might involve and provide some suggestions for a DD services eligibility scheme that would better benefit people with FASD and other brain-based disorders. To some extent this involves a revisiting of some issues addressed in the Introduction, but with a consideration of lessons learned from a review of the diverse formulae that have been devised to get around the excessive reliance on IQ cut-offs.

A Broader Approach to Cognitive Impairment

A mistake made in some eligibility solutions is to assume that to eliminate excessive reliance on IQ and IQ ceilings requires one to get rid of an emphasis on cognition as a central feature of ID and ID-Equivalence. In fact, deficits in thinking, reasoning, learning and "intelligence" (broadly defined) are central to understanding ID, FASD and the pathway to ID Equivalence. What needs to be done, however, is to find a key to the cognitive essence of DD that is not grounded solely in IQ or an IQ ceiling. In fact, as discussed in the Introduction, full-scale IQ is an outmoded concept that is still taken seriously by very few leading cognitive psychology scholars, even if, because of simplicity and ease of decision-making, it is still central to judicial and administrative approaches to disability determination. Intelligence is just too broad-based a construct to be adequately summarized by a single score from a single test. Furthermore, critical aspects (such as

social intelligence) are not covered at all by existing tests. As well, the idea that one can identify a specific ceiling score on a single test (or more than one test, for that matter) which can reliably discriminate between those who qualify or do not qualify for service eligibility is questionable to say the least. So, at a minimum, one should rely on a cross-battery approach, where information is integrated in a profile rather than in single-number manner, combining sub-scale scores from multiple measures of intelligence. Such an approach puts greater demands on an evaluator but certainly will provide a richer and fuller picture of the individual being evaluated.

A growing consensus is emerging in the field of ID, and also in the FASD field, that the quality of cognitive impairment that most contributes to everyday functioning difficulties in people with brain-based disorders, involves skills captured by models and measures of "executive functioning." This term refers to a set of skills that are controlled primarily by the prefrontal cortex, with numerous neuronal connections to other brain regions, and involves "a set of interrelated supervisory attention and control processes in the brain that are involved in the selection, planning, initiation, execution, monitoring, and troubleshooting of goal-directed behavior in non-routine situations" (Brown and Connor 2014). According to Shallice (1982), the primary role of the executive system is to respond effectively to novel situations that are poorly served by automatic and habitual responses. Such situations include those where planning and decision-making are required, those that are not well rehearsed, and those that contain sequences of actions that have not been performed previously. Executive functioning is particularly important in situations that require error detection and correction, such as dangerous or technically difficult situations (Brown and Connor 2014), and also plays an important role in resisting the temptation—often stemming from pressure or inducements from manipulative others—to engage in foolish, dangerous or illegal behaviors.

Executive functioning differs from what is typically thought of as intelligence, because it involves taking what one knows (intelligence) and translating it into action (adaptive behavior). Thus, the concept of executive functioning does a better job than intelligence in explaining why it is that people with ID and ID-Equivalence (i.e., most people with FASD) get into serious trouble in ambiguous or novel situations. People with FASD are by definition deficient in many areas of executive functioning, and the same is true of all individuals with ID. It is because people with FASD and other brain-based disorders inevitably have more serious limitations in executive functioning than might be inferred from their sometimes "borderline" IQ scores that knowledgeable scholars and professionals argue for a more inclusive approach to DD eligibility. Such an inclusive approach would provide a path to services for people with brain-based cognitive disorders who do not quite make the artificial and arbitrary IQ ceilings mentioned in too many eligibility statements.

Quality of Behavioral Incompetence

The behavioral essence of ID then, which flows directly from the above cognitive limitations especially in executive functioning, is a tendency to show very bad judgment in situations that are novel, ambiguous or anxiety-producing. As first stated by Spitz (1988), it is now understood that ID is less a disorder of learning (i.e. acquisition of rote schemas) and more a disorder of thinking (i.e. flexible adjustment of schemas to adapt to changing situations where habitual schemas no longer work). Such flexibility in solving novel problems, so central to "thinking," is in fact exactly what is tapped by measures of executive functioning. Because poor judgment in approaching novel problems will place a person at risk for some undesired outcome—ranging from task or role failure to a catastrophic physical or social event—it has been argued (Greenspan et al. 2011) that ID is a "common sense deficit disorder" in which common sense is defined as awareness of physical or social risk. In fact, it is to reduce, eliminate or provide a buffer against risk and its consequences that DD services are provided, whether to protect people from physical consequences (e.g., starvation, burning down the house, medical emergencies, getting run over) or social consequences (e.g., financial or sexual exploitation, imprisonment, loss of employment, severe harassment or abuse) stemming from a failure to appreciate danger and how to avoid it.

As mentioned by Tassé (2009) and by us earlier in this paper, adaptive behavior has been poorly defined, and measures that attempted to assess it often: (a) involve skills that are too low level (e.g., toileting, feeding) to apply to people with mild ID; (b) involve skills (e.g., self-direction, friendliness) that are not specific to ID or even to disability per se; (c)) fail to involve or give sufficient emphasis to skills such as social judgment that are particularly central to the ID behavioral phenotype, and (d) were developed more with service programming in mind and not for the purpose of diagnostic determination. Two problems with existing measures of adaptive behavior are: (a) there is almost no mention of risk-awareness or risk-vulnerability, and (b) the items or subscale scores do not translate directly into need for services, supports or funding levels Greenspan (2009).

In line with the fixation in the ID field on academic deficits and outcomes, social functioning is given very short shrift as it is only one out of 10 sub-scales on the ABAS-2. Further, it is conceptualized more in terms of "niceness" (which, however important for popularity and success, is not specific to ID) than in terms of "social judgment" (which also is important for success but is very specific to ID and ID-equivalence). Needless to say, poor social judgment is one of the main defining features of FASD. However, an aspect of poor social judgment that is particularly important diagnostically, and which is especially connected to poor executive functioning, is judgment about the likely bad outcomes flowing from particular courses of action. Measures of intelligence, and cognitive measures in general, ask subjects to come up the best solution to a problem, while the real challenge in terms of adaptive survival, is being able to avoid choosing the worst (i.e., most risky) solution to a problem. The construct of executive functioning,

because it taps the ability to systematically foresee the future consequences of a course of action, has great explanatory and predictive value in identifying people likely to need supports to protect them from risk. Such a determination should not be based solely on scores on tests, whether cognitive or adaptive, but should involve qualitative information about episodes involving bad consequences reflecting social and practical judgment deficits. In the case of most people with FASD, such information is easy to obtain, as their lives have generally been a long litany of poor decisions and disastrous outcomes. The key to obtaining DD services through the ID-equivalence route is to help to convince a gate-keeping agency (such as the regional center that granted fifth category status for "Lisa" in spite of a relatively high IQ) that the person's history of behavioral mistakes reflects a cognitively-based unawareness of risk rather than a character-based lack of acceptance of social norms.

That is not always an easy thing to establish, however, as people with FASD often present with a complicated mixture of ability and inability, with maladaptive behaviors that give the misleading impression of being psychiatric rather than cognitive or neurodevelopmental in origin. Among other frequent misconceptions of FASD are that: (a) it is a temporary state that can be overcome, and (b) that persons with FASD (who because of modularity of brain lesions appear smarter than they are) are malingering their cognitive limitations.

Rediscovering the Neurological Basis of ID/DD

A curiosity of the definitional and diagnostic manuals on ID and DD is that the words "brain" or "neurological" are generally nowhere to be found, except to a limited extent in chapters devoted to possible biological causes. Thus, if one peruses the various AAMR/AAIDD classification manuals, the definitional criteria are completely functional i.e. emphasizing deficits in various skill domains. One will not see mention of the word "brain" anywhere. This is somewhat puzzling, as the skill deficits found in people with ID are clearly a sign of subnormal brain functioning. This absence of emphasis has been rectified to some extent in the ID section in DSM-5, which: (a) contains some mention of the role of the brain in ID, (b) locates ID within a new super-category termed "Neurodevelopmental Disorders" (previously it was located in a section dealing with disorders of childhood and adolescence), and (c) has added a parenthetical second name to the disorder, by replacing DSM-IV-TR's term "Mental Retardation" with the two-part name "Intellectual Disability (Intellectual Developmental Disorder)."

The addition of the parenthetical second name reflects a wish to eventually join ICD-11, which has signaled its intent to change the category name to "Intellectual Developmental Disorder" (Salvador-Carulla et al. 2011).This is much more than merely a semantic change, as it reflects a paradigm shift from a "disability" approach which emphasizes arbitrary psychometric (especially IQ) cut-offs, to a more clinical and qualitative "disorder" approach which emphasizes the medical,

etiological and neurodevelopmental nature of the condition. This approach is reflected in a general disavowal of rigid IQ cutoffs and a suggestion that executive functioning is generally a more important indicator of ID than IQ. It is also reflected in a disavowal of a particular age-of-onset (such as 18), and replacement with a more general mention of slowed development including a failure to ever attain adult levels of functioning.

The failure in state DD statutes to mention the brain abnormality basis of ID is particularly notable in light of the fact that all of the developmental syndromes mentioned to illustrate the need for ID-equivalence—whether Prader-Willi, cerebral palsy, traumatic brain injury, or FASD—are diseases that affect brain processes and structures. A small number of statutes, however, after mentioning a few syndromes, do insert words along the lines of "[and] other neurological conditions" (State of Washington), or "…other neurologically disabling conditions closely related to mental retardation and requiring similar…" (Montana). In fact, such language is a holdover from the 1970 Federal DD legislation, which first introduced the term "Developmental Disabilities" (DD), and by operationally defining it as "mental retardation, epilepsy, cerebral palsy, and other neurological conditions originating before the age of 18," strongly implied a brain basis for ID. However, the 1975 revision of the Act added autism and dyslexia. This was curious, as dyslexia typically does not affect everyday adaptive functioning. Yet, the revision dropped "and other neurological conditions." Probably, the dropping of "other neurological conditions" was motivated by bureaucratic and economic concern about opening the floodgates to hordes of applicants, and possibly also by overly concrete equating of the term with "traumatic brain injury." However, this change (which has been modeled in virtually all state DD statutes) was unfortunate not only because it made it more difficult to take an expansive view of DD, but also because it removed an important (if obvious) statement, namely that ID is a disorder of brain development.

A Formula for DD Eligibility that Would Include Many with FASD

The ID section in DSM-5 represents a shift from a "disability" (numbers-based) to a "disorder" (clinical/medical) approach to the definition and diagnosis of ID (Greenspan and Woods 2014a, b). Central to the disorder approach is the notion that IQ and other test scores, while useful as a window into a person's level and profile of cognitive functioning, cannot be used rigidly as a make-or-break basis for ruling ID in or out. That is because ID is viewed as a reflection of underlying brain pathology, and such pathology usually manifests in a complex and variegated manner that cannot be captured by a single test score, especially one with limited content validity.

Here is our attempt at a definition of Intellectual Disability/Developmental Disability: "ID/DD is a developmental condition that involves incomplete development of brain functioning and which is reflected in significant deficiencies relative to peers in the acquisition of intellectual, cognitive and executive skills needed to succeed in various age-relevant community roles and to cope with everyday as well as unique challenges and dangers in physical, academic and social realms."

We believe that this definition is in the spirit of existing expanded DD eligibility formulae, but is superior in that it provides considerable flexibility by eschewing score ceilings. It also takes a broader approach to cognitive impairment than IQ, for example, by emphasizing executive functioning. It also links adaptive behavior (without using that poorly-defined term) to cognitive impairments, emphasizes the brain basis of the disorder (without limiting itself to a few causes such as Prader-Willi or even FASD), and indicates that what makes ID a disability are the dangers resulting from failure to recognize or avoid risk, including social risk. A much larger percentage of people with FASD would, we believe, be able to justly achieve DD eligibility using this formula. That assertion should be testable by applying the formulation to individuals discussed in this chapter or others who might be known to readers.

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