

Natalie Novick Brown *Editor*

Evaluating Fetal Alcohol Spectrum Disorders in the Forensic Context

A Manual for Mental Health Practice

 Springer

Evaluating Fetal Alcohol Spectrum Disorders in the Forensic Context

Natalie Novick Brown
Editor

Evaluating Fetal Alcohol Spectrum Disorders in the Forensic Context

A Manual for Mental Health Practice

 Springer

Editor

Natalie Novick Brown
Federal Way, Washington, USA

ISBN 978-3-030-73627-9 ISBN 978-3-030-73628-6 (eBook)
<https://doi.org/10.1007/978-3-030-73628-6>

© The Editor(s) (if applicable) and The Author(s), under exclusive license to Springer Nature Switzerland AG 2021

This work is subject to copyright. All rights are solely and exclusively licensed by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors, and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Chapter 10

Determining Disability Severity Level for Fetal Alcohol Spectrum Disorder: Assessing the Extent of Impairment



Stephen Greenspan, Natalie Novick Brown, and William J. Edwards (Billy)

Abstract Fetal alcohol spectrum disorder (FASD) is a biomedical disorder that places an individual at high risk for intellectual disability (ID) or developmental disability (DD). Yet in some legal settings, people with FASD are denied legal protections or entitlements because of a mistaken belief that the disorder has low severity. Commonly, this misunderstanding reflects a view of FASD as the functional equivalent of attention-deficit/hyperactivity disorder (ADHD). This view also reflects the fact that FASD typically is not diagnosed in childhood and because of the near-universal co-occurrence of attentional problems, affected individuals commonly are diagnosed with ADHD, which masks the underlying FASD. In this chapter, we develop a model for establishing disability severity and compare the relative severity of FASD with other disorders, concluding that FASD is much more severe than ADHD and comparable in severity to ID. We also use this model to assess individual disability severity, finding that while ADHD as a whole is a low-severity disorder, there are a minority of people within that category who have a high-severity disability and very possibly have undiagnosed FASD. Implications of these findings for forensic practice are explored, with emphasis on the importance of basing severity determination on an evaluatee's competence profile and support needs rather than diagnostic label history.

Keywords Fetal alcohol · FASD · Intellectual disability · ID-equivalence · Attention-deficit/hyperactivity disorder · ADHD

S. Greenspan
Educational Psychology, University of Connecticut, Storrs, CT, USA

N. N. Brown (✉)
University of Washington, Seattle, WA, USA

W. J. Edwards (Billy)
Los Angeles County Office of the Public Defender, Los Angeles, CA, USA

10.1 Introduction

A major obstacle in securing services and protections for people with fetal alcohol spectrum disorder (FASD) is the frequent assumption that FASD does not meet the severity threshold for a developmental disability. The basis for this misconception often confounds FASD with attention-deficit/hyperactivity disorder (ADHD). This misconception reflects the fact that attentional problems are almost always found in people with FASD, and since FASD typically is not diagnosed in children even when facial signs are evident (May et al., 2018), ADHD is the diagnosis most evaluators are familiar with and consequently assign to many individuals who later are diagnosed with FASD (Popova, Lange, Shield, Burd, & Rehm, 2019). It is understandable, therefore, that FASD would come to be seen incorrectly as the functional equivalent of ADHD. The problem with such an assumption is that ADHD is a bifurcated disorder, containing many individuals who do not have a severe disability as well as some (many of whom actually have FASD) who have a fairly severe disorder comparable to intellectual disability (ID), for which prenatal alcohol exposure is in fact the largest known cause in the Western world (Abel & Sokol, 1986).

To best navigate this confusion, it helps to keep in mind that FASD is a medical disorder while disability is a social and bureaucratic concept, and the two are not perfectly aligned (Salvador-Carulla et al., 2011). In other words, within FASD and other disorder categories, individual disability severity varies substantially. A related issue is that severity is measured differently in a disorder (where it refers mainly to depth of impairment on a single defining ability) than it is for a disability, where it refers to the number of abilities that are impaired and their effect on overall functioning (Wehmeyer, 2013). Using both of these criteria (depth of disorder impairment and breadth of disability needs), it is argued that: (a) FASD is a very severe disorder, comparable to ID, while ADHD is a much less severe disorder, and (b) even within ADHD, there are individuals (likely, many with undiagnosed FASD) who have a very severe disability. Evidence for these assertions, both clinical and empirical, is presented in this chapter. Practical implications of this severity exploration for forensic determinations in bureaucratic criminal (but also civil) proceedings are explored. While some of these implications incorporate existing methodology (such as intelligence quotient [IQ] and adaptive behavior instruments), some lead to the development of new methods (such as qualitative and quantitative considerations in personal competence profiles). Pervading this paper is an exploration of the concept of severity, a topic with major implications for ameliorating the arbitrariness of forensic and human services diagnosis and classification.

10.2 Court Case that Inspired this Chapter

The legal case motivating us to address the severity of FASD involves Zane Floyd, a former U.S. Marine who around 5 a.m. on the third of June 1999 entered a Las Vegas supermarket with a shotgun and hunted down several store employees, killing four and critically injuring a fifth (Floyd v. Filson, 2019). In the 2000 trial, there was testimony that Floyd (a) was born to a mother who abused alcohol, (b) had been diagnosed with ADHD as a child and placed on Ritalin, (c) qualified for a diagnosis of FASD, and (d) suffered from extreme mental disturbance at the time of the crimes.

The state did not dispute the fact that Floyd had FASD but argued FASD was in the same severity ballpark as ADHD and therefore should not be given substantial weight as a mitigating factor when considered against so many aggravating factors. The jury voted to impose the death penalty, apparently buying the state's argument about the low-severity nature of FASD. In Floyd v. Baker (2019), the U.S. Court of Appeals for the Ninth Circuit agreed with the state's position.

In our opinion, the court rulings regarding the supposed equivalence of FASD and ADHD invalidly minimized the severity of FASD as a mitigating factor in a capital case. Despite nearly 50 years of research documenting the severity of FASD as a brain-based medical condition that occurs in utero and manifests in infancy and early childhood as a developmental disability, the court failed to recognize FASD as a congenital disorder that (unlike ADHD) was permanent and became worse and more complex over time (see Burd & Edwards, 2019). In 2020, the United States Supreme court denied certiorari and refused to hear an appeal from the Ninth Circuit Court of Appeals.

This judicial decision basically encouraged courts (along with prosecutors and disability organizations) to minimize the severity of this organic disorder. Not only does this ruling affect the future of FASD as a mitigating factor in sentencing and capital cases, but it also allows other entities such as state disability agencies and possibly the federal government to deny benefits, treatment, and services to people with an FASD diagnosis (e.g., fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol related neurodevelopmental disorder, and static encephalopathy-alcohol exposed).

After the Ninth Circuit denied a rehearing in Floyd v. Filson (2019), the National Organization on Fetal Alcohol Syndrome issued a position statement describing how experts in the FASD field have noted the following significant differences between FASD and ADHD (e.g., Peadon & Elliott, 2010), differences that refute the court's concept of equivalency: (a) etiology and course of the two conditions are very different; FASD has a single etiology that is known, while ADHD is etiologically multifactorial (and typically unknown); (b) FASD has greatly increased mortality risk when compared to ADHD; (c) FASD typically is far more complex and severe and requires much higher levels of care than ADHD; (d) annual cost of care is over 10 times higher for FASD compared to ADHD; (e) expression of the two conditions is dissimilar in that FASD has a similar male to female ratio, while ADHD is three times more prevalent among males; (f) although FASD is a causal

factor for ADHD, there is no evidence ADHD is a causal factor for FASD; (g) ADHD gradually decreases in severity across childhood and adolescence, while FASD becomes more complex, resulting in more deficits and greater adversity across the lifespan; and (h) FASD is equivalent to ID in terms of executive dysfunction and everyday adaptive behavior, which is not the case for ADHD. It is not our intention in this chapter to repeat the above arguments, although some repetition is unavoidable. Rather, we intend to address the nature of disability severity, using three conditions—FASD, ADHD, and ID—for illustrative purposes. Such an exercise is essential, we believe, in validating the above assertions as well as developing mechanisms for establishing the disability severity of FASD in individual defendants in future cases.

10.3 Definition of Key Terms

Four terms used throughout this chapter need definition. These terms are “disability,” “severity,” “impairment,” and “disorder.” The definitions below are kept brief for the simple reason that the balance of this chapter is an extended elaboration on these definitions, especially the first two.

10.3.1 Meaning of Disability

A disability can be defined (Cambridge University Press, 2019, *Cambridge English Dictionary*) as “an illness, injury, or condition that makes it difficult for someone to do the things that other people do.” Here is a more jargon-laden version from the U.S. Centers for Disease Control and Prevention (CDC, 2020), which essentially says the same thing: “any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).” In this last definition, there is a distinction between the contributing medical or other condition (described as an impairment) and the participation restriction (disability) that results. The three terms in parentheses were developed by the World Health Organization (WHO, 2001) in its *International Classification of Functioning, Disability and Health*.

In line with the sociological orientation that dominates the field of disability studies, the intervening variable here (activity limitation, described in earlier WHO documents by the now politically incorrect term “handicap”) was viewed as the degree to which society facilitates, or places obstacles in the way of, full participation in various social roles. Undoubtedly, there is some truth to the idea that social values and biases contribute to an impairment becoming a disability, but this view fails to give sufficient weight to personal qualities (e.g., perseverance, emotionality,

etc.) that also contribute to participation. Such a more balanced “personological” perspective undergirds this chapter.

One thing that should be kept in mind when considering the term “disability” is that it is a bureaucratic and socio-legal concept and not a medical concept. The term is believed to have originated within the vocational rehabilitation field, where it referred to someone’s inability to work without short- or long-term supports or services. Today, disability is a concept assigned and used by many gatekeeper bureaucracies (schools, residential companies, treatment agencies, etc.) to determine eligibility for disorder-based special services,

10.3.2 Meaning of Impairment

The term “impairment” refers to a state of being diminished, weakened, or damaged, especially mentally or physically. One way of comparing “impairment” to “disability” is the former is an input variable, while the latter is an outcome variable. An example of such an input is having a visual impairment, with the disability outcome involving the supports that a visually impaired person needs in order to function in a real-world social role, such as holding a job. Severity as it relates to impairment typically is viewed narrowly. For example, in the case of a visual impairment, severity refers to the relative absence or distortion of vision. Disability, almost by definition, is much broader as it incorporates both number and depth of individual impairments on more than the one defining ability domain and also incorporates personality and situational factors contributing to bad outcomes.

10.3.3 Meaning of Severity

The term “severe” refers to something bad or undesirable, and “severity” therefore refers to the degree of badness or undesirability of the thing being described. We realize that under the current value system in the disability field, many would take exception to the description of a disability as undesirable, but most affected individuals, not to mention their parents, would gratefully give up their impairments if offered the chance. Thus, one does not use the word “severe” to refer to something good or desirable. For instance, in the sentence, “John received a severe sentence for his offense,” it is unlikely John would be happy to be given such news.

Severity can be applied to an almost endless number of things (from plant ill health to boat hull decay to a child’s delayed language) for which bad or undesirable outcomes can be envisioned. The concept of severity is related to “risk” (or danger) and also to “seriousness,” but in different ways. In the case of risk, the danger involves a possibility things could get much worse (a plant with a few brown spots could suddenly become brown all over and be on the verge of dying). With regard to seriousness, the thought to always keep in mind is someone with a *mild*

impairment may in fact be quite disabled, which is why the subcategory “mild ID” is so misleading, as people with that designation often receive extensive supports and would be in danger of dying if living on their own. Conversely, it often is the case that someone with relatively severe impairments may be functioning in the world in a manner far more competent than one might have thought possible. It is for this reason, along with ethical considerations, that the infantilizing over-protectiveness, which at one time characterized ID services for adults, is no longer considered acceptable (Bannerman, Sheldon, Sherman, & Harchik, 1990). This lack of predictive fit between severity subcategory and expected functional outcome (e.g., a child with Down syndrome considered “trainable” who despite expectation learns how to read) is perhaps the strongest argument against intra-diagnostic category severity classification (Hughes, 2006) as it reduces opportunities for individual growth.

10.3.4 Meaning of Disorder

Another term used throughout this chapter that also needs defining is “disorder.” This term refers to “a state of being diminished, weakened, or damaged, especially mentally or physically” (Spitzer, Endicott, & Franchic, 2018). In contrast to the bureaucratic/legalistic construct of disability, a disorder is a biomedical construct and therefore is an input variable that increases (in part because many gatekeeper bureaucrats are concrete) the likelihood an individual will qualify for a disability designation. A disorder is related to an impairment, except the latter is dimensional (e.g., degree of visual acuity), while the former is categorical (e.g., a particular vision disease, such as *retinitis pigmentosa*).

10.4 Severity in Medicine

Severity has widespread applicability in medical and human services, even apart from the practical matter of cost estimation. Some of the relevant literature will be discussed before heading into the heart of this chapter, which is devising a method for addressing the relative severity of FASD.

10.4.1 Severity of Illness

The severity concept has attracted much interest in the health services literature, with the driving force being the need to come up with better mechanisms for validating the individualized cost of hospital and medical care. This situation reflects the fact that a medical diagnosis is not always a reliable predictor of cost and within

any given diagnostic category, there often is considerable variability in need for services. As similar funding concerns also arise in the disability field, some lessons may be gleaned from a brief look at the medical severity concept.

In medicine, severity plays a role in efforts to control costs by basing insurance reimbursement on the particular procedures needed rather than on whatever a clinician or medical group asks for. An interim method was developed for the U.S. Medicare/Medicaid system termed diagnostic-related group (DRG), which combined primary and secondary diagnoses plus required procedures to come up with a severity number. This method proved inadequate because it did not take into account such individual factors as demands on staff, recovery rate, complications, and residual impairment. An improved version, termed the severity of illness (SOI) index (Horn, Horn, & Sharkey, 1984), was constructed by looking at seven factors, each with four severity levels: state of principal diagnosis, complications, interactions (with other disorders), dependency (staff utilization), procedures (non-operative), rate of response to intervention, and residual impairment. Within-factor severity scores were assigned to each factor, with ratings of severity ranging from mild to catastrophic. The result of considering all of these ratings (with synthesis handled by highly trained persons rather than computer algorithm) was to place each patient in one of four overall severity categories: minor, moderate, major, and extreme. Considerable reliability and validity were obtained for this method, although push-back from health service providers (who preferred being reimbursed for individual services) caused it to remain more of a localized than universally adopted system.

The SOI methodology was used mainly to determine individual severity rather than to compare the severity of diseases, but it seems to us that within the developmental disability (DD) field, a comparable methodology could be used for both purposes. That is, different disorders could receive severity scores on two scales: overall comparison to other disorders (e.g., FASD compared to ADHD) but also to capture individual severity variation within each category. Such a modified use of the SOI system is, in fact, what is proposed later in this chapter for calculating severity between and within developmental conditions.

10.4.2 Risk of Death

One of the controversies in the medical severity literature is whether risk of mortality can be considered an index of illness severity. Tasker and Randolph (2016) consider mortality risk to be an indicator of illness severity, but Pollack (2016) disputes that view. Pollack's position is that severity of illness refers to "extent of physiological decompensation or organ system loss of function" (p. 583) and is a predictor of both mortality and morbidity (becoming ill), while risk of death reflects many things other than bodily health, such as the training of doctors and competence of hospitals. To us, this disagreement seems a little too much of a technical argument in that

risk of a bad outcome is central to severity, and dying is the ultimate bad outcome in medicine.

In a later section, wherein we attempt to develop a severity method for evaluating people with FASD and other disorders, risk is one of the concepts utilized, and while mortality is not an outcome associated with a chronic neurodevelopmental disorder such as FASD, it does enter indirectly into the mix. This view is because, when asking what services an individual with DD needs, one question that must be asked is, “what type and level of support is needed to keep the person from potentially fatal outcomes (e.g., starving, being assaulted, getting run over) as a result of their inability in order to anticipate or avoid physical and social risks?” A relevant statistic is people with FAS (the least prevalent subtype of FASD) live only to the age of 34 years on average (Thanh & Jonsson, 2016). The reason for this shockingly low mortality rate is primarily attributable to socially and emotionally mediated behavioral factors (especially impulsivity), such as accidents, poisoning, drug overdoses, suicide, crime victimization, and poor health maintenance rather than physiological vulnerability although that, too, can be a factor due to alcohol-related birth defects (ARBD).

10.5 Severity of Core Symptom(s)

While the severity concept is applied most meaningfully to overall degree of functional impairments or risk, a very common approach in medicine, and to a somewhat lesser extent in the DD field, is to look at severity more narrowly as it relates to depth of impairment on a core symptom. Often, such an approach is used to devise a subclassification system, which in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association [APA], 2013)*, generally is covered by the term “specifier.” A controversy in the severity literature (Mehlman & Neuhauser, 1999) has to do with whether it makes sense to convert continuous severity sum scores into discontinuous severity categories as opposed to just leaving individuals on a continuum. We are somewhat on the fence regarding this matter, recognizing the artificiality of qualitative severity subcategories but at the same time understanding the widespread preference for such categories. Part of this preference reflects the historical fact that subcategories for some disorders may in fact predate the existence of a unified disorder. This is the case with ID, as there was some historical evidence (Clemente, 2015) that what today would be considered severity score-based subtypes such as “mild,” “moderate,” and “severe” ID previously were considered distinct disorders with such (today, repugnant) names as “Idiocy” and “Imbecility.”

10.5.1 Upper Extremity as a Medical Example

An example of a core symptom viewed as the basis for severity-level determination can be found in the Fugl-Meyer Upper Extremity (FM-UE) Scale of Motor Impairment (Woytowicz, Rietschel, Goodman, Whitall, & McCombe Waller, 2013), the most widely used method for measuring arm use limitations in chronic stroke patients. The FM-UE has four subsections with 33 items scored on an ordinal impairment scale of 0 (absent), 1 (partial impairment), and 2 (no impairment), resulting in a range of possible scores from 0 to 66. Patients are placed into four severity groups: mild, mild–moderate, moderate–severe, and severe, depending on where their total scores fall in the range of possible scores. It is understood that FM-UE does not measure global functional disability, but nonetheless there is a use for such a narrow severity instrument. However, where such a rating system becomes a problem is when a narrow core symptom severity index becomes the sole basis for a global disability severity index. In fact, this is exactly what has been the historic practice in the field of ID.

10.5.2 Severity Subcategorization in Intellectual Disability

When the current three-prong definition of ID was developed six decades ago (Heber, 1961), severity subclassification was barely mentioned. In fact, the only mention of it was in a single footnote in a single table (Greenspan & Switzky, 2006). In subsequent American Association on Intellectual and Developmental Disabilities (AAIDD) (formerly American Association on Mental Retardation [AAMR]) classification manuals, severity classification became far more emphasized. The initial basis for categorical subgrouping (mild, moderate, etc.) was full-scale IQ, with groupings determined by number of standard deviation (SD) points (arbitrarily set by test publishers at 15 points) below the population mean (arbitrarily set at 100). In the earliest manual, there actually were five subcategories, with the least impaired termed, “Borderline Mental Retardation,” which was set at -1 SD (for a full-scale IQ range of 71–85). As an IQ score of 85 placed someone at the 16th percentile of the population, the bar obviously was set too high for a disorder estimated to take in the bottom 3% of the population (Mercer, 1973). Adaptive behavior (AB) was supposed to bring the incidence down, but the initial absence of a standardized AB measure meant IQ was the only basis for diagnosis for a long time. Subsequently, the “borderline” subcategory was eliminated in the 1970s, an act that has proven controversial as it prevented many deserving individuals from receiving educational or developmental services (Greenspan, 2017; MacMillan, Siperstein, & Gresham, 1996).

Setting the IQ cut-score too high (and in a subsequent rebound action, too low) reflected the impossibility of identifying an IQ cut-off that adequately captured the inflection point at which someone with a global disability was included or excluded.

This kind of approach reflects three basic problems: (a) the arbitrariness of establishing a quantitative cut-off for a qualitative category, (b) the “scientific” (illusory use of a scientific concept to justify what basically is a policy decision) nature of using standard deviation units in the first place, and (c) the limited content coverage of IQ, which mainly taps into academic potential (Anastasi, 1983) and fails to capture the full range of intellectual and other impairments and needs. For this reason, both AAIDD and *DSM* later came to devise subcategorization severity subtype mechanisms based upon indices other than IQ.

The alternative approach now is used in *DSM-5* to substitute adaptive functioning for IQ as the basis for ID severity subgroupings. This makes some sense as adaptive functioning is closer to the concept of real-world functioning in multiple contexts, which is what disability is all about. However, a problem is that adaptive functioning, as reflected in the most-used instruments, has little cognitive content (e.g., social adaptive functioning has few social judgment items). One possible way around this problem would be to combine IQ and adaptive functioning into a single index, but such an approach has never been seriously considered to our knowledge.

In AAIDD manuals, beginning in the ninth edition (Luckasson et al., 1992), the basis for severity subgrouping was to substitute “support needs” for IQ ranges. This approach continues to be used today. The proposed mechanism for operationalizing the approach is an instrument published by AAIDD termed the “Supports Intensity Scale” or SIS (Wehmeyer et al., 2009). A problem with the SIS, which reflects a general tendency in the ID field—including the behavior instruments used to measure adaptive functioning, such as the third edition of *Vineland Adaptive Behavior Scales (Vineland-3)* (Sparrow, Saulnier, Cicchetti, & Doll, 2016) and the third edition of *Adaptive Behavior Assessment System (ABAS-3)* (Harrison & Oakland, 2015)—is that social aspects of competence are grossly under-emphasized, despite the fact people with ID are most at risk because of limited ability to make friends or deal with interpersonal challenges and situations (Guralnick, 1989), a characteristic well known to most family members.

10.5.3 Lack of Severity Subcategorization in Fetal Alcohol Spectrum Disorder and Attention-Deficit Hyperactivity Disorder

Unlike ID where severity subclassification is a central (even if somewhat controversial) part of the diagnostic process, such is not the case for either FASD or ADHD. FASD obviously does have a subclassification scheme, but the main subcategories (e.g., fetal alcohol syndrome [FAS], partial fetal alcohol syndrome [pFAS], alcohol-related neurodevelopmental disorder [ARND]) are based on the presence of physical signs (FAS with three facial anomalies, pFAS with one or two, ARND with none) and are not formulated in terms of disability severity, even if it is empirically the case that individuals with full-blown FAS have somewhat lower mean IQ scores

than is seen in the other two subcategories (Kodituwakku & Kodituwakku, 2014). In fact, one challenge in seeking to have people with the pFAS and ARND subtypes receive DD classification and related accommodations is getting across the idea that people in all three FASD subcategories are equally disabled academically, socially, and adaptively.

Recent efforts to find early childhood biomarkers for FASD (considered essential for developing more reliable diagnostic procedures) may contribute inadvertently to an impairment severity protocol. An example is multinational research in Ukraine (where heavy drinking by pregnant women is commonplace), which found that plasma micro ribonucleic acid (miRNA) profiles in second and third trimester pregnant women were predictive of the severity of alcohol-induced infant impairment outcomes (Balaraman et al., 2016).

With regard to ADHD, there is no official subcategorization scheme to our knowledge. However, on occasions when someone is described as having “severe ADHD,” it likely is the case that they have co-occurring problems in addition to impulsivity or inattention and also is likely, in fact, that they have undiagnosed FASD. This latter situation tends to confound much of the research on ADHD, which rarely accounts for the possibility of prenatal alcohol exposure in subject samples.

10.6 Severity as the Implicit Basis for Developmental Disability

The concept of developmental disability (DD) was invented in the 1970s (see Gettings, 2011, for an historic overview) to identify conditions similar to ID that may not qualify for that designation because full-scale IQ was above the arbitrary ceiling score (approximately 2 SDs below the population mean, or a standard score of 70–75, which generally is used as the cut-off for ID). This term owes its origins to pioneering Kennedy-era legislation in the United States that authorized various government-funded disability-related human rights, research, training, and facility-building initiatives. The term “DD,” now widely used in many state and provincial eligibility statutes, was first used in the Developmental Disabilities Services and Facilities Construction Amendments of 1970. In that law, DD was 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 as the *Developmentally Disabled Assistance and Bill of Rights Act*, and DD remained defined categorically to include mental retardation plus conditions “closely related to mental retardation: cerebral palsy, epilepsy, autism and dyslexia” (this last item a curious inclusion, as it was not globally disabling) with a pre-18 age of onset, which were expected to “continue indefinitely” and “constitute a substantial handicap.” The term “other neurological conditions” probably was dropped because of an overly concrete tendency to equate it with Traumatic Brain

Injury. This deletion was a mistake in our opinion as it would have reinforced the idea that DD conditions are brain-based and would have left the door open for a wide range of conditions not yet known (i.e., FAS was a brand-new concept at that time) or were able to be contained in a list that did not go on for pages.

A major revision in 1978 to the Developmentally Disabled Assistance and Bill of Rights Act (1975) raised the age-of-onset ceiling from 18 to 22 years old 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 (Roman numerals dropped here) defined DD as “a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22 years; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following seven areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, [and] economic self-sufficiency.” The term also included: “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.”

Pervading the language used in the above-cited DD legislation is the idea these DD conditions are similar to ID in terms of also being brain-based, involving impaired cognition, having lifelong duration, and being very severe with respect to multiple impairments and having support needs similar to ID that are “of lifelong or extended duration and are individually planned and coordinated.” Notably, the list of seven areas of impairment in DD is (without using the term) somewhat analogous to adaptive behavior/functioning (Crocker, Vaurio, Riley, & Mattson, 2009), although it is a rather inadequate list. For example, as is often the case, there is no mention of the critical area of social functioning. In addition, the requirement for a minimum of three areas of impairment is arbitrary. The original purpose of the list was to categorize programs in terms of the population they served and was not intended for the purpose of diagnosing individuals. However, and unfortunately, this list has become an official service eligibility-determining diagnostic framework in many jurisdictions.

In an earlier publication, the three of us (Greenspan, Novick Brown, & Edwards, 2016) coined the term “ID Equivalence” to refer to various mechanisms devised to get around the barrier that rigid reliance on IQ ceilings has created for providing services, supports, and protections to severely impacted individuals otherwise deserving of being served. The DD mechanism is the most widely used such framework, but it is not the only one, nor is FASD the only disorder deserving ID Equivalence status as there are many brain-based disorders (e.g., Dandy Walker Malformation or Prader-Willi syndrome) where phenotype is similar to ID in terms of impairment pattern and overall severity, despite a mean IQ that straddles the IQ cut-point. In states that still use a categorical path to DD services, FASD generally is not mentioned by name except in Alaska and Minnesota where statutes note

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” (Minnesota, 2012).

In states that have a more functional approach to DD eligibility, people with FASD are increasingly being found eligible on an individual basis, but it remains a case-by-case struggle (often involving wrangles over whether IQ is low enough), in part because FASD is a rather hidden disorder when it is overshadowed by symptoms resembling better-known conditions (with most cases not diagnosed until right before service eligibility is requested) and also because of the persistent belief that FASD is a low-severity disorder analogous to ADHD. This belief is challenged in the next three sections, which compare FASD to ADHD and ID in terms of (a) definitional elements, (b) competence profiles, and (c) risk of bad outcomes.

10.7 Definitional Elements as Severity Indicators

Although a severity judgment typically is made as an add-on classification to a diagnosis, it is possible to gather some comparative information about severity from the elements in a condition’s definition. Following is a brief statement defining the three conditions being compared: FASD, ADHD, and ID. We include the last of these conditions, ID, because it is the yardstick against which all conditions included under the umbrella “Developmental Disability” (i.e., severe brain-based conditions comparable to ID except for not meeting an arbitrary IQ cut-off) are measured. Following a brief summary of each definition, we comment on implicit severity distinctions touched upon in the definitions.

10.7.1 *Intellectual Disability*

ID has three definitional criteria: significant deficits in intellectual functioning, impaired adaptive functioning, and onset within the developmental period (typically interpreted to mean before age 18). Prong One (intellectual impairment) is measured by a full-scale IQ score of 70–75 or below, although other measures such as executive functions can be cited. Adaptive functioning, typically measured through a rating instrument such as the ABAS or *Vineland*, has three components: Conceptual/Communication, Practical, and Social, summarized into a composite Adaptive Index. Qualitative evidence, such as for gullibility and poor risk awareness, also is important. Significant deficiency (below 2 SDs) has to be shown on standardized instruments for only one of these four indices. As a rule, ID is a lifelong status, although individuals can acquire improved adaptive skills during adulthood.

10.7.2 Attention-Deficit Hyperactivity Disorder

In *DSM-5*, ADHD is described as “a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development.” Three subtypes are identified: (a) inattention, (b) hyperactivity—impulsivity, and (c) mixed. Most individuals fall into the third, mixed, subcategory. For the first two subtypes, six or more symptoms from a list of behaviors must have persisted “for at least six months (five months for older adolescents and adults) to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities,” and are “not solely a manifestation of oppositional behavior, defiance, hostility, or failure to understand tasks or instructions” (for type 1) and “do not occur exclusively during the course of schizophrenia or another psychotic disorder” (for type 2). These symptoms must be evident before age 12. Although ADHD can be diagnosed in adults, most individuals diagnosed with the disorder in childhood cease to manifest the disorder as they enter adulthood (Newton-Howes, 2004). Although people with ADHD often do poorly in school because of inattention and interpersonal insensitivity due to impulsivity, there is no cognitive or adaptive functioning criterion for the diagnosis.

10.7.3 Fetal Alcohol Spectrum Disorder

The defining features of FASD have remained essentially the same since FAS was first described in the United States in 1973: (a) selected facial malformations, (b) growth retardation, (c) central nervous system (CNS) abnormality, and (d) evidence of drinking during pregnancy (for full-fledged FAS, this can be established solely by facial anomalies). CNS abnormality typically is established by cognitive impairments (executive dysfunction and other cognitive impairments) and impairments in adaptive functioning. For the latter, *DSM-5* requires impairments in at least two of the three domains usually included in standardized instruments (communication, daily living or practical skills, and socialization), which actually is a more stringent requirement than in ID (where only one impaired adaptive domain is required). The CNS dysfunction in FASD is diagnosed under the category “Other Specified Neurodevelopmental Disorder” in *DSM-5* as *neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE)*. However, the diagnostic criteria are included as a “condition for further study” under the rubric “Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure.” Despite *DSM-5*’s odd bifurcation of the name of the diagnosis with its criteria, diagnosing ND-PAE for the CNS dysfunction in FASD has become the standard of practice in the mental health field.

10.7.4 *Comparison of Required Definitional Elements (Diagnostic Complexity)*

One of several ways to compare disability severity in competing conditions is to add the number of required or nearly universal elements in their official definitions. In Table 10.1, we do this for the three conditions being compared. The furthest right column in the table is labeled “Number of elements,” which is calculated simply by adding the items that are checked off for each of the three conditions. FASD and ID both have many elements, while ADHD has only two, indicating ADHD is less complex a condition than either ID (which has four) or FASD (which has six). The ND-PAE definition (for what essentially is the ARND subtype of FASD) includes self-regulatory deficits as a criterion, so it is possible that if anything, we have understated the broad-based complexity of FASD.

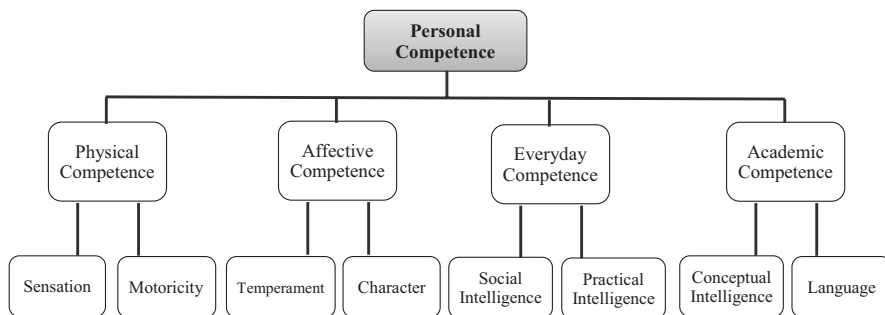
The two elements that separate ID from FASD are physical signs and causal evidence, which are both required for a diagnosis of FASD (the physical features being growth restriction and facial anomalies) but not for ID (where both are commonplace but not required). If one drops those two rows, then FASD and ID are tied for severity, with four required elements apiece. The two columns required for ADHD are “self-regulatory deficits” and “interferes with functioning.” In fact, the first item often is present in people with FASD and ID and is required in ND-PAE, while ADHD at its core is defined by two aspects of self-regulation: attention and impulse control. For all three conditions, interference with functioning is a requirement (as is the case for almost all *DSM* categories), although the interference typically is more narrow (e.g., primarily academic learning) for ADHD. In sum, if one looks only at the definitional elements, FASD is tied or even exceeds complexity scores for ID, and both are much more complex and thus more severe than ADHD. This finding is confirmed and amplified in the following pages, where we look at severity in two other ways: competence profiles and outcome risks with concomitant need for protections.

10.8 Competence Profiles as Severity Indicators

When both *DSM-IV* (American Psychiatric Association [APA], 1994) and *DSM-5* were being developed, there was some sentiment (Blashfield, 1993) in favor of shifting from categorical classification to a non-categorical “dimensional” system in which individuals were classified not by placement into distinct categories but by profiling on a number of dimensions. Such a proposal never went anywhere because of the absence of an agreed-upon dimensional taxonomy. In a book on contemporary approaches to intelligence, Greenspan and Driscoll (1997) proposed a classificatory taxonomy derived from the first author’s model of personal competence. The taxonomy (see Fig. 10.1) has not been explored previously as a severity indicator, except in one study that found it a better predictor of mainstreaming readiness than

Table 10.1 Required definitional elements for FASD, ADHD, and ID. (Source: chapter authors)

Definition elements	Physical signs	Casual evidence	Neurocognitive deficits		Adaptive functioning deficits	Self-regulatory deficits	Interferes with functioning	Lifelong condition	Number of elements
			Intelligence	Executive functions					
FASD	YES	YES	NO	YES	YES	YES	YES	YES	7
ADHD	NO	NO	NO	NO	NO	YES	YES	NO	2
ID	NO	NO	YES	NO	YES	NO	YES	YES	4



Content model of personal competence.

Fig. 10.1 Content model of personal competence. (Source: Greenspan & Driscoll, 1997)

a special education label (Javel & Greenspan, 1983). In the balance of this chapter, we illustrate how the taxonomy might be used along with other information to rank disorders in terms of where they fall on a severity continuum. In a later section, the taxonomy is used as part of a proposed method for evaluating the disability severity of individuals.

10.8.1 Model of Personal Competence Taxonomy

The taxonomy has four competence domains, each divided into two sub-domains: Physical Competence (divided into Sensation and Motoricity), Affective Competence (divided into Temperament and Character); Everyday Competence (divided into Social Intelligence and Practical Intelligence); and Academic Competence (divided into Conceptual Intelligence and Language). Two cross-domain constructs are Social Competence (a combination of Temperament, Character, and Social Intelligence) and Intellectual Competence (a combination of Social Intelligence, Practical Intelligence, and Conceptual Intelligence). We use such a model of personal competence as our severity framework because brain-based disorders are fundamentally characterized by relative incompetence in playing various age-relevant roles. The same thing is true to some extent of physical disabilities but not so much for purely psychiatric disorders, where persons are characterized more by behavioral deviance than incompetence (e.g., one can have a marked character or emotional disorder and still attain superior financial or political success). However, this distinction is not absolute as people with psychotic disorders such as schizophrenia (where a brain-lesion probably is involved) are differentiated from those with neurotic or character disorders primarily by inability to play most age-relevant social roles.

Sensation. This element refers to relative abnormality in sensory modalities and perceptions, such as touch, taste, sight, hearing, and smell. In contrast to more

conventional forms in physical disorders (e.g., lack of vision and hearing), in some developmental disorders, this element can take the form of unusual sensory symptoms, such as appearing to be deaf, being very sensitive to (and avoidant of) touch, having a very highly developed sense of smell, or finding certain visual stimuli aversive (e.g., wallpaper with busy patterns).

Motoricity. This element has to do with coordination as well as effectiveness and normality of gross and fine motor functioning. Motor movements are neurologically controlled, and as DD conditions are brain-based, it often is the case that motoricity is affected. In some developmental disorders (e.g., autism), motoricity symptoms are less in the realm of impaired limbs or motoric ability and more in the self-regulatory realm of bizarre or unusual movements.

Temperament. This element involves self-regulatory competence. The two main aspects of temperament are attention focus and emotion regulation. Attention is somewhat impaired in all brain-based disorders, but it is especially impaired (and is the defining feature) in ADHD.

Character. This element refers primarily to how empathic one is toward others. People with DD generally are not lacking in empathy, but it often appears they have no empathy because they lack role-taking ability (i.e., social intelligence). That is, it is difficult to be moved by the plight of another person if you are unable to know how they might be feeling.

Social Intelligence. This element refers to the ability to “read” people and social contexts and, consequently, exhibit adequate judgment in addressing problematic or routine social situations. As brain-based conditions often involve impairments in intelligence, broadly defined, failure in social judgment is commonplace.

Practical Intelligence. This element refers to the ability to understand and cope with physical and mechanical tasks and challenges. Examples include finding one’s way within a region or neighborhood, operating a machine, or dealing with daily living challenges such as cooking and making purchases.

Conceptual Intelligence. This element involves the ability to understand and cope with academic tasks and challenges. Examples include abstract reasoning, use of logic, doing math calculations, and problem-solving. Generally, IQ is a good measure of this ability, but there are other indicators, such as cause–effect tests of executive function and performance on school learning instruments.

Language. This element involves ability to communicate expressively and receptively. As with motoricity, language impairments in people with developmental disorders can be found in psycholinguistic inability to make speech sounds or use symbols as well as in sociolinguistic oddness or language atypicality (e.g., echolalia, nonsense, failure to understand or communicate clearly, and delays in acquiring literacy).

In Table 10.2, we repeat the severity comparison for the three conditions under consideration, with one change: we now list two subtypes for ID: Mild and Moderate–Severe. The reason we do not do this in Table 10.1 is the definitions upon which Table 10.1 is based do not discriminate between levels of ID, while the competence elements definitely do. For each of the eight competence domains, a score from 0 to 3 is assigned for each of four conditions: 0 = no incompetence is found,

Table 10.2 Personal incompetence as a basis for severity of developmental disorders. (*Source*: chapter authors)

Competence domains	Physical incompetence		Affective incompetence		Everyday incompetence		Academic incompetence		Total severity	Disability severity category
	Sensation	Motoricity	Temperament	Character	Social intelligence	Practical intelligence	Conceptual intelligence	Language		
FASD	0	0	2	2	2	1	2	0	9	Serious
ADHD	0	0	3	0	1	0	0	0	4	Mild
ID (mild)	0	0	0	0	2	2	3	1	8	Serious
ID (moderate to severe)	0	1	2	0	3	3	3	2	14	Pervasive

Domain severity ratings: None = 0; Substantial = 1; Major = 2; Extreme = 3

Total severity: 0–3 Non-disabled; 4–6 Mild disability; 7–13 Serious disability; 14–24 Pervasive disability

1 = significant incompetence, 2 = severe incompetence, and 3 = extreme incompetence. As in Table 10.1, ADHD (with a score of 4) is characterized as a mild disability, while FASD (with a score of 9) and Mild ID (with a score of 8) are serious disabilities. As might be expected, Moderate–Severe ID is a profound disability, with a score of 14. Such an analysis constitutes more support for the contention that FASD is a substantial disability comparable to Mild ID, in contrast to ADHD, which is a disorder with a much lower level of severity.

10.9 Risky Outcomes as Severity Indicators

A third way to view disability severity is in terms of outcomes, specifically the level of supports needed to enable an individual to function adequately and safely. Persons with FASD often are unable to improve adaptive functioning over time and frequently cannot live independently in society as adults (Burd & Kerbeshian, 2013). This situation is because adaptive development in FASD becomes increasingly delayed as age-related societal expectations increase, resulting in adaptive behavior that diminishes over time compared to age peers (Kambeitz, Klug, Greenmyer, Popova, & Burd, 2019).

This outcome-oriented way of looking at the matter actually is very close to the original meaning of disability in the vocational rehabilitation field, where DD referred to people who usually were unable to work without temporary supports or training. As a variation on the supports theme, we are conceptualizing outcomes in terms of risks that supports are intended to prevent or ameliorate. This is a somewhat contrarian exercise, as during the current zeitgeist, it generally is considered a sign of poor values to even mention the possibility of failure or deficiencies when discussing people with disabilities.

The outcome risk model in Fig. 10.2 is divided into four types of risk: Physical, Daily Living, Social, and Duty. These categories are further subdivided into two

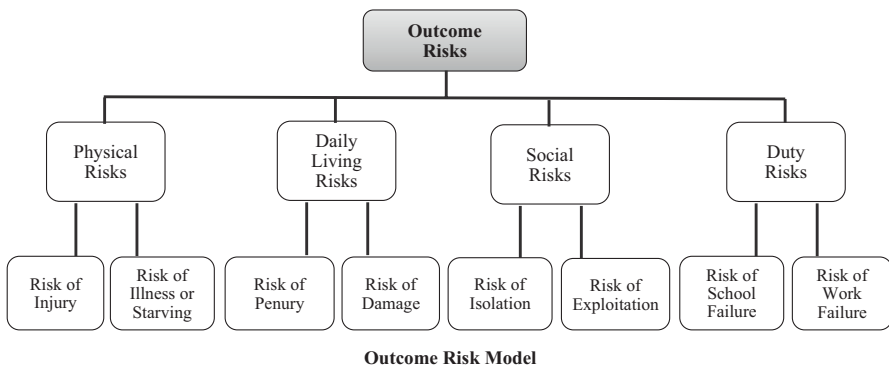


Fig. 10.2 Outcome risk model. (Source: chapter authors)

domains each, for a total of eight risk domains: Physical risk is divided into risk of injury and risk of illness or starving; Daily Living risk is divided into risk of penury and risk of damage; Social risk is divided into risk of isolation and risk of exploitation; and Duty risk is divided into risk of school failure and risk of work failure. These constructs are now described briefly:

Risk of Injury. People with cognitive disabilities tend to show poor judgment when addressing social and practical challenges. Lack of practical skill can put one at risk of injury and is one of the reasons why supported living arrangements may be indicated.

Risk of Illness or Starving. Securing food, cooking, and eating adequately also can be a challenge. The same is true for things like taking prescribed medications appropriately or getting treated for illness when necessary.

Risk of Penury. Because of inability to secure or keep a job, people with cognitive disabilities often have no financial support and are in need of financial assistance.

Risk of Damage. Living autonomously exposes one to many situations that could take a destructive turn, such as starting a fire when using a microwave oven incorrectly, leaving water running in a bathtub, and failing to close the front door.

Risk of Isolation. Making or keeping friends is difficult for many people with cognitive disorders, which can result in isolation that requires social and recreational supports.

Risk of Exploitation. Because of social isolation and impaired interpersonal skills, people with cognitive disorders are easily exploited by malign individuals who portray friendliness in order to manipulate them sexually, financially, or criminally.

Risk of School Failure. People with cognitive disorders usually have sad histories of school failure. In fact, the purpose of special education is to make it possible for those who otherwise would fail academically to feel some sense of efficacy.

Risk of Work Failure. Succeeding in work, even of a menial nature, requires some modicum of skill, along with attentional, social, and self-regulatory skills that often are missing in people with cognitive disorders.

10.9.1 Calculating Severity of Three Conditions Using the Outcome Risk Model

As we did previously with competence impairments in Table 10.2, we now depict the typical profile of outcome risks for FASD, ADHD, and ID, with this last category divided into Mild and Moderate–Severe subgroups. These profiles are depicted in Table 10.3:

Overall, the risk outcome pattern in Table 10.3 is very similar to the competence impairment pattern in Table 10.2. Again, ADHD emerges as a mild severity disability, with very few areas of support needs, and with these mainly manifesting in academic contexts. FASD and Mild ID are, again, essentially tied, with many areas

Table 10.3 Outcome risk as a basis for severity of developmental disorders. (Source: chapter authors)

Conditions	Physical outcomes		Daily living outcomes		Social outcomes		Duty outcomes		Total severity	Severity category
	Risk of injury	Rick of illness or starving	Risk of Penury	Risk of damage	Risk of isolation	Risk of exploitation	Risk of school failure	Risk of work failure		
FASD	1	1	2	1	1	2	2	2	12	Serious
ADHD	0	0	0	1	0	0	2	1	4	Mild
ID (mild)	1	2	2	1	1	2	2	2	13	Serious
ID (moderate)	3	3	3	3	3	3	3	3	24	Pervasive

Risk Outcome Ratings: Minor = 0; Substantial = 1; Major = 2; Extreme = 3
 Total Severity: 0-3 Non-disabled; 4-6 Mild disability; 7-13 Serious disability; 14-24 Pervasive disability

of risk-minimizing support needs and with a total score in the Serious Disability category. Finally, Moderate–Severe ID is rated as having very pervasive support needs, with maximum scores in every outcome risk category.

10.10 Assessing Individual Disability Severity

Thus far, we have demonstrated that FASD is a much more severe disorder than ADHD and is well-deserving of being considered a developmental disability under the rubric “ID Equivalence.” The reasons for this equivalency are that FASD is brain-based, manifests congenitally or in early childhood, is of lifelong duration, and in terms of its definitional elements, has an incompetence pattern and risk-based support needs that are essentially identical to those in Mild ID. The consequence of so many people with FASD not having their conditions diagnosed and then being misdiagnosed with ADHD is that they are prevented from qualifying as DD and becoming eligible for services and protections to which they are entitled.

But we would be remiss if we stopped with just demonstrating the underappreciated severity of FASD. It also is important to note categorical classification is an inherently unreliable process (Aboraya, 2007) because it results in people being misdiagnosed, with incorrect labels following them throughout life. In terms of severity, this situation has the unfortunate consequence that people with high-severity needs are incorrectly assigned a lower severity label and mistakenly assumed to have few needs. With respect to a large number of people with FASD, this situation means double jeopardy: (a) people with a high-severity disorder (i.e., FASD) are given a lower severity label such as ADHD, and even in the minority of cases where FASD is correctly diagnosed, (b) they are handicapped by the incorrect belief (as in the *Floyd v. Filson* [2019] ruling or DD regulations in Illinois) that FASD is itself a low-severity condition.

One solution to the above problem would be to do away with categorical classification altogether, but we are not naïve enough to think this is likely to happen in our lifetimes. An alternative would be to develop a method for assigning all labeled individuals to a disability severity category, analogous to the “specifiers” used in *DSM-5*. Then, one could make decisions about eligibility for DD bureaucratic purposes based upon a person’s severity specifier rather than label, assuming certain basic requirements (e.g., developmental and brain-based) were met. The main challenge in devising such a system is to avoid falling into the conventional trap of relying on full-scale IQ or some other arbitrary indicator of a single dimension of impairment, one that does not translate adequately to the broad-based concept of disability.

It is our opinion that the basis for an individualized developmental disability specifier index might be obtained by summing the eight incompetence (“input”) variables in Table 10.2 with the eight outcome risk (“outcome”) variables in Table 10.3. The utility of this proposed framework is demonstrated in Table 10.4. The y-axis contains 16 factors, the first eight of which are incompetence inputs, and

Table 10.4 Individual severity ratings for six young adults. (Source: chapter authors)

	Individual Characteristics	John (FASD 1)	Amy (FASD 2)	Stan (ID 1)	June (ID 2)	Alan (ADHD 1)	Mary (ADHD 2)
Input factors	Sensation	0	0	0	0	0	0
	Motoricity	0	0	0	1	0	0
	Temperament	1	1	1	3	3	3
	Character	0	1	1	1	0	1
	Social intelligence	2	2	2	3	0	2
	Practical intelligence	1	1	1	3	1	1
	Conceptual intelligence	2	2	2	3	1	2
	Language	0	0	0	2	0	0
Outcome factors	Risk of injury	1	1	1	3	1	1
	Risk of illness or starving	1	1	1	3	0	1
	Risk of penury	1	1	2	3	0	1
	Risk of damage	2	2	2	3	0	1
	Risk of isolation	1	1	1	3	0	1
	Risk of exploitation	2	2	2	3	0	1
	Risk of school failure	2	2	2	3	2	3
	Risk of work failure	2	2	2	3	1	2
Total severity		18	19	20	40	9	20

Impairment Ratings: Minor = 0; Substantial = 1; Major = 2; Extreme = 3

the next eight are risk outcomes. On the *x*-axis are six individuals who are rated on this proposed instrument, with four impairment ratings for each variable: 0 = no impairment, 1 = low impairment, 2 = high impairment, and 3 = very high impairment. Thus, individual scores can vary from 0 (score of 0 on all 16 variables) to 48 (score of 3 on the 16 variables). Two people each in the example have been given the labels, FASD, ID, or ADHD. First names are listed, with diagnosis placed in parentheses along with the number 1 or 2, indicating their order in the table. Their names are John (FASD 1), Amy (FASD 2), Stan (ID 1), June (ID 2), Alan (ADHD 1), and Mary (ADHD 2). All of these individuals are young adults between ages 21 and 28. Each person’s scores on the 16 variables, as well as the sum (disability severity) index obtained by summing across the 16 variables, are shown in Table 10.4.

At this point, we do not have an empirically derived basis for categorizing the disability severity numbers but have done so intuitively, using the ranges we proposed in Table 10.2 and then summing across them. Scores between 6 and 13 are in the “Mild Disability” category, scores between 14 and 30 are in the “Serious

Disability” category, and scores between 31 and 48 are in the “Pervasive Disability” category. Scores for all six rated individuals are depicted in Fig. 10.3.

Scores (18 and 19) for the two people with FASD (John and Amy) are comparable to the score (20) for Stan (ID 1), suggesting the three of them have “Serious Disability.” The score (40) for June (ID 2) is extremely high, in the range of “Pervasive Disability,” and shows ratings of 3 nearly across the board. June’s score indicates Moderate–Severe ID in contrast to the score Stan (ID 1) received. Thus, the severity of Stan’s ID, while substantial, is in line with the less pervasive nature of Mild ID. The severity score (9) for Alan (ADHD 1) is quite low and labeled “Mild Disability.” Alan’s score is consistent with most people with ADHD and very much in line with the demonstrations in Tables 10.1, 10.2, and 10.3, indicating the low-severity nature of ADHD.

Thus far, results for the individuals in Table 10.4 are very much in line with what one might expect from the earlier findings we have noted, specifically the equivalency of FASD with Mild ID and the much lower severity findings for ADHD. However, the sixth person in our example, Mary (ADHD 2), illustrates why automatically equating individual disability severity with the severity of the label is a mistake that could result in an unfair eligibility decision. Mary’s score (20) is very much in line with those of the three individuals who have Serious Disability stemming from FASD and Mild ID but substantially different from the low-severity score (9) obtained by Alan (ADHD 1). This situation reflects the bifurcated nature of ADHD, with basically two subgroups: one with low severity and one with high severity. A viable hypothesis concerning Mary’s high-severity score is the likelihood she has undiagnosed FASD.

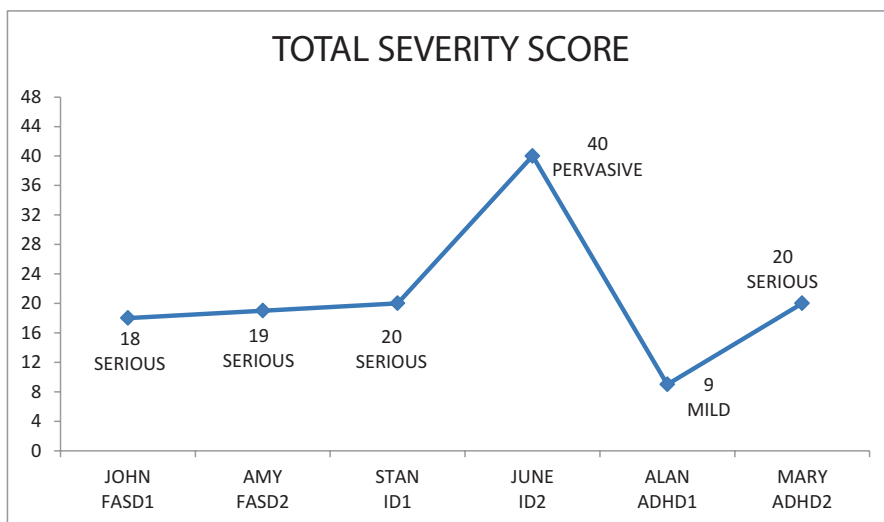


Fig. 10.3 Individual severity total scores chart. (Source: chapter authors)

10.11 Conclusion

In this chapter, we have explored the construct of disability severity and argued, as have many others, that FASD is a lifelong, globally impactful, developmental disorder deserving of the rubric “ID Equivalence.” The functional real-world implications of FASD are in stark contrast to ADHD, which is a more narrowly focused form of impairment that typically becomes less problematic after the school years and does not qualify as an ID-Equivalence disorder. Using the competence and outcome criteria we have described to evaluate and compare the relative severity of the two disorders, it is possible to apply such a system to individuals as well as categories. When one does this individualized assessment, some ADHD-labeled individuals—perhaps because they have undiagnosed FASD—manifest disabilities that are more in line with an ID-Equivalence disorder. Given this, and the fact FASD typically goes undiagnosed, it seems prudent and just to develop and apply an individual severity metric—not only for persons applying for disability benefits but also for those facing criminal charges as part of a mitigation assessment.

While a primary focus of this chapter, and of this book, is on criminal adjudication, the widespread myth that FASD is a low-severity disorder on par with ADHD rears its misleading head in the human services realm as well. As an example, consider the following statement in the manual used by the state DD agency, Illinois Department of Human Services (IDHS) (2019) to determine whether an individual “has mental retardation or a related condition ... and whether he or she requires active treatment.” Section 500.20 of that document states, “most diagnosable syndromes, such as Fetal Alcohol Syndrome, are not related conditions.” The document does not specifically equate FASD with ADHD, but it is likely such a view played a role in this inaccurate statement. The practical effect of such language is to make it almost impossible for someone with FASD to become eligible for developmental services unless they also qualify as having ID. In so doing, provisions such as this support the continued hegemony of “King IQ” (Castles, 2007) as the reason why people with FASD fail to qualify as ID when they have IQ scores a few points above the ID cut-score of 70–75 but adaptive functioning well within the ID range. This situation defeats the entire purpose of a “related condition” option in DD regulations, given there are few disorders more related to ID (both in causing that disorder and resembling it functionally) than FASD.

Without legislative changes and grass roots advocacy, other jurisdictions around the United States may follow the lead of the Ninth Circuit in *Floyd* and Illinois Department of Human Services (IDHS) (2019) by continuing to conflate ADHD with FASD. If this mistake continues to happen, many people will not receive the educational and developmental services or legal protections to which they are entitled. Further work in defining and measuring disability severity may be a key to ensuring everyone with a developmental disorder, regardless of assigned (or mis-assigned) diagnostic label, will have their conditions accurately recognized and appropriately treated.

References

- Abel, E. L., & Sokol, R. J. (1986). Fetal alcohol syndrome is now the leading cause of mental retardation. *Lancet*, 328(8517), P1222. [https://doi.org/10.1016/S0140-6736\(86\)92234-8](https://doi.org/10.1016/S0140-6736(86)92234-8)
- Aboraya, A. (2007). The reliability of psychiatric diagnoses: Our psychiatric diagnoses are still unreliable. *Psychiatry (Edmont)*, 4(1), 22–25. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2922387/pdf/PE_4_1_22.pdf.
- American Psychiatric Association (APA). (1994). *Diagnostic and statistical manual of mental disorders (DSM-IV)* (4th ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)* (5th ed.). Arlington, VA: American Psychiatric Association.
- Anastasi, A. (1983). What do intelligence tests measure? In S. B. Anderson & J. S. Hemlick (Eds.), *On educational testing: Intelligence, performance standards, test anxiety, and latent traits* (pp. 5–28). San Francisco, CA: Jossey-Bass.
- Balaraman, S., Schafer, J. J., Tseng, A. M., Wertelecki, W., Yevtushok, L., Zymak-Zakutnya, N., ... Miranda, R. C. (2016). Plasma miRNA profiles in pregnant women predict infant outcomes following prenatal alcohol exposure. *PLoS One*, 11(11), e0165081. <https://doi.org/10.1371/journal.pone.0165081>
- Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavioral Analysis*, 23(1), 79–89. <https://doi.org/10.1901/jaba.1990.23-79>
- Blashfield, R. K. (1993). Variants of categorical and dimensional models. *Psychological Inquiry*, 4(2), 95–98. https://doi.org/10.1207/s15327965pli0402_3
- Burd, L., & Edwards, W. (2019). Fetal alcohol Spectrum disorders: Implications for attorneys and the courts. *Criminal Justice*, 34, 3. https://www.americanbar.org/groups/criminal_justice/publications/criminal-justice-magazine/2019/fall/fetal-alcohol-spectrum-disorders-implications-attorneys-courts/.
- Burd, L., & Kerbeshian, J. (2013). Commentary: Fetal alcohol spectrum disorders. *International Journal of Alcohol and Drug Research*, 2(3), 3–6. <https://doi.org/10.7895/ijadr.v2i3.173>
- Cambridge University Press. (2019). *Cambridge english dictionary* (4th ed.). Cambridge: Cambridge University Press. <http://www.dictionary.cambridge.org/us/dictionary/>.
- Castles, E. E. (2007). *Inventing intelligence: How America came to worship IQ*. Santa Barbara, CA: ABC-CLIO.
- Centers for Disease Control and Prevention (CDC). (2020). Impairments, activity limitations, and participation restrictions. *Disability and Health Overview*. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>
- Clemente, M. (2015). A reassessment of common law protections for “idiots.”. *Yale Law Journal*, 124(8), 2746–2803. https://www.yalelawjournal.org/pdf/c.2746.Clemente.2803_u6x66sv8.pdf
- Crocker, N., Vaurio, L., Riley, E. P., & Mattson, S. N. (2009). Comparison of adaptive behavior in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Alcoholism: Clinical and Experimental Research*, 33(11), 2015–2023. <https://doi.org/10.1111/j.1530-0277.2009.01040.x>
- Developmental Disabilities Services and Facilities Construction Amendments*. (1970). P.L. 91-517.
- Developmentally Disabled Assistance and bill of Rights Act*. (1975). P.L. 94-103.
- Floyd v. Baker*, (2019). U.S. Court of Appeals for the Ninth Circuit, Case No. 14-99012, Opinion (940 F.3d 1082 (Oct. 11, 2019) and amended 949 F.3d 1128 (Feb. 2, 2020)).
- Floyd v. Filson*, 940 F.3d 1082 (9th Cir. 2019).
- Gettings, R. M. (2011). *Forging a federal-state partnership: A history of state and federal developmental disabilities policy*. Silver Springs, MD: American Association on Intellectual and Developmental Disabilities (AAIDD).
- Greenspan, S. (2017). Borderline intellectual functioning: An update. *Current Opinion in Psychiatry*, 30(2), 113–122. <https://doi.org/10.1097/ycp.0000000000000317>

- Greenspan, S., & Driscoll, J. (1997). The role of intelligence in a broad model of personal competence. In D. P. Flanagan, J. L. Genshaft, & P. L. Harrison (Eds.), *Contemporary intellectual assessment: Theories, tests and issues* (pp. 131–150). New York, NY: Guilford.
- Greenspan, S., Novick Brown, N., & Edwards, W. (2016). FASD and the concept of “intellectual disability equivalence”. In M. Nelson & M. Trussler (Eds.), *Fetal alcohol spectrum disorders in adults: Ethical and legal perspectives* (pp. 241–266). Amsterdam and New York, NY: Springer.
- Greenspan, S., & Switzky, H. N. (2006). Forty-four years of AAMR manuals. In H. N. Switzky & S. Greenspan (Eds.), *What is mental retardation?: Ideas for an evolving disability in the 21st century (rev. ed.)* (pp. 2–28). Washington, DC: American Association on Mental Retardation.
- Guralnick, M. J. (1989). Social competence as a future direction for early intervention programs. *Journal of Mental Deficiency Research*, 33(4), 275–281. https://depts.washington.edu/chdd/guralnick/pdfs/Guralnick_SocialCompetenceFuture_JMDR-1989.pdf
- Harrison, P., & Oakland, T. (2015). *Adaptive behavior assessment system (ABAS-3)* (3rd ed.). Toronto, ON: Pearson Assessment.
- Heber, R. A. (1961). *A manual on terminology and classification in mental retardation. Monograph supplement to the American Journal of Mental Deficiency* (2nd ed.). Springfield, IL: American Association on Mental Deficiency.
- Horn, S. D., Horn, R. A., & Sharkey, P. D. (1984). The severity of illness index as a severity adjustment to diagnosis-related groups. *Health Care Financing Review*, (Suppl), 33–45.
- Hughes, J. (2006). Teaching reading skills to children with down syndrome. *Down Syndrome News and Update*, 6(2), 62–65. <https://doi.org/10.3104/practice.349>
- Illinois Department of Human Services (IDHS). (2019). *Developmental disabilities program manual*. Chicago, IL: IDHS.
- Javel, M. E., & Greenspan, S. (1983). Influence of personal competence profiles on mainstreaming recommendations of school psychologists. *Psychology in the Schools*, 20(4), 459–465. [https://doi.org/10.1002/1520-6807\(198310\)20:4<459::AID-PITS2310200413>3.0.CO;2-2](https://doi.org/10.1002/1520-6807(198310)20:4<459::AID-PITS2310200413>3.0.CO;2-2)
- Kambertz, C., Klug, M. G., Greenmyer, J., Popova, S., & Burd, L. (2019). Association of adverse children experiences and neurodevelopmental disorders in people with fetal alcohol spectrum disorders (FASD) and non-FASD controls. *BMC Pediatrics*, 19, 498. <https://doi.org/10.1186/s12887-019-1878-8>
- Kodituwakku, P., & Kodituwakku, E. (2014). Cognitive and behavioral profiles of children with fetal alcohol spectrum disorders. *Current Developmental Disorders Reports*, 1(3), 149–160. <https://doi.org/10.1007/s40474-014-0022-6>
- Luckasson, R., Coulter, D. L., Polloway, E. A., Reiss, S., Schalock, R. L., Snell, M. E., et al. (1992). *Mental retardation: Definition, classification and systems of support* (Vol. 2, 9th ed.). Washington, DC: American Association on Mental Retardation.
- MacMillan, D. L., Siperstein, G. N., & Gresham, F. M. (1996). A challenge to the viability of mild mental retardation as a diagnostic category. *Exceptional Children*, 62(4), 356–371.
- May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, . . . Hoyme, H. E. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *Journal of the American Medical Association*, 319(5), 474–482. doi:<https://doi.org/10.1001/jama.2017.21896>
- Mehlman, M. J., & Neuhauser, D. (1999). Alternative definitions of disability: Changes in a dichotomous v continuous system. *Disability and Rehabilitation*, 21(8), 385–387.
- Mercer, J. R. (1973). *Labeling the mentally retarded: Clinical and social system perspectives on mental retardation*. Berkeley: University of California Press.
- Minnesota. (2012). 252.27. Children’s Services; Parental contribution. In Chapter 252. Services for persons with developmental disabilities. <https://www.revisor.mn.gov/statutes/cite/252.27>
- Newton-Howes, G. (2004). What happens when children with attention deficit/hyperactivity disorder grow up? *Journal of the Royal Society of Medicine*, 97(11), 531–535. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1079646/>
- Peadon, E., & Elliott, E. J. (2010). Distinguishing between attention-deficit hyperactivity and fetal alcohol spectrum disorders in children: Clinical guidelines. *Neuropsychiatric Disorders and Treatment*, 6(1), 509–515. <https://doi.org/10.2147/ndt.s7256>

- Pollack, M. M. (2016). Severity of illness confusion. *Pediatric Critical Care Medicine*, 17(6), 583. <https://doi.org/10.1097/PCC.0000000000000732>
- Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of fetal alcohol spectrum disorders among special sub-populations: A systematic review and met-analysis. *Addiction*, 114(7), 1150–1172. <https://doi.org/10.1111/add.14598>
- Salvador-Carulla, L., Reed, G. M., Vaez-Azizi, L. M., Cooper, S.-A., Martinez-Leal, R., Bertelli, M., ... Saxena, S. (2011). Intellectual developmental disorders: Towards a name, definition and framework for “mental retardation/intellectual disability” in ICD-11. *World Psychiatry*, 10(3), 175–180. <https://doi.org/10.1002/j.2051-5545.2011.tb00045.x>
- Sparrow, S. S., Saulnier, C. A., Cicchetti, D. V., & Doll, E. A. (2016). *Vineland adaptive behavior scales: Vineland-3 manual* (3rd ed.). San Antonio, TX: Pearson.
- Spitzer, R. L., Endicott, J., & Franchic, J.-A. M. (2018). Medical and mental disorder: Proposed definition and criteria. *Annales Médico-psychologiques, revue psychiatrique*, 176(7), 656–665. <https://doi.org/10.1016/j.amp.2018.07.004>
- Tasker, R. C., & Randolph, A. G. (2016). Severity-of-illness scoring in pediatric critical care: Quo vadis? *Pediatric Critical Care Medicine*, 17(1), 83–85. <https://doi.org/10.1097/PCC.0000000000000559>
- Thanh, N. X., & Jonsson, E. (2016). Life expectancy of people with fetal alcohol syndrome. *Journal of Population Therapeutics and Clinical Pharmacology*, 23(1), e53–e59. <https://jptcp.com/index.php/jptcp/article/view/240/196>
- Wehmeyer, M., Chapman, T. E., Little, T. D., Thompson, J. R., Schalock, R., Tassé, M. J., & MacLean, W. E., Jr. (2009). Efficacy of the supports intensity scale (SIS) to predict extraordinary support needs. *American Journal of Intellectual Developmental Disabilities*, 114(1), 3–14. <https://doi.org/10.1352/2009.114:3-1>
- Wehmeyer, M. L. (2013). Disability, disorder and identity. *Intellectual Developmental Disability*, 51(2), 122–126. <https://doi.org/10.1352/1934-9556-51.2.122>
- World Health Organization (WHO). (2001). *International classification of functioning, disability and health*. WHO. <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>
- Woytowicz, E. J., Rietschel, J., Goodman, R. N., Whittall, J., & McCombe Waller, S. (2013). Cluster analysis of upper extremity Fugl-Meyer Assessment defines levels of motor impairment severity. Combined Sections Meeting Neurology Section Poster Presentations; San Diego, CA.