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The publication of several editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM), beginning in 1952 by the American Psychiatric Association, revolutionized the practice of psychiatry by standardizing the diagnosis of mental disorders and, as a result, improving the quality of treatments afforded persons with mental illness. Throughout its major revisions, the DSM has expanded our understanding of mental illness by adding newly recognized conditions, removing conditions that are no longer considered valid, and realigning those remaining conditions into cohesive groupings.

With respect to people who have intellectual and other developmental disabilities, the validity of the DSM has been challenged because of concerns that it is culturally biased or that it cannot be used accurately in persons with limited cognitive abilities or those with problems in communication. Mikkelson and McKenna (1999) argued that DSM becomes less useful as the level of intelligence decreases due to an inability to elicit verbal communication that reflects the patient’s inner life. In addition, Szynanski et al. (1998) stated that, “Some people with severe mental retardation...show patterns of symptoms and aberrant behaviors that cannot easily fit into DSM-IV criteria for a specific mental disorder” (p. 5).

In the mid-1980s, Sovner and Hurley (1986) first questioned the value of the DSM in making accurate psychiatric diagnoses in persons with what was then termed “mental retardation.” Sovner and Hurley also published a series of articles in Psychiatric Aspects of Mental Retardation Reviews (now Mental Health Aspects of Developmental Disabilities) in which they modified existing DSM criteria for use in persons with “mental retardation,” taking into account the deficits in communication skills and cognitive function associated with low intelligence. The work of Sovner and his colleagues was significant in changing the general perception of the time that people with “mental retardation” and mental illness were primarily affected by thought disorders such as psychosis and should be treated with neuroleptic medications. Coincidentally, the field recognized that persons diagnosed with “mental retardation” experienced high rates of tardive dyskinesia and that the long-term use of such medications should be avoided. Throughout the 1980s and 1990s, the standard of care evolved to incorporate these perspectives and to recognize that persons with developmental disabilities experience a full range of mental disorders.

The late 1990s saw a further advancement in the tools used to make psychiatric diagnoses in persons who came to be referred to as dually diagnosed (individuals considered to have intellectual disabilities and concurrent mental illness). Reiss and Aman edited Psychotropic Medication and Developmental Disabilities: The International Consensus Handbook (1998), which was a manual that offered practitioners the first comprehensive look at how mental health and diagnostic and treatment guidelines could be modified for use in persons with developmental disabilities. Our contribution to the manual focused on the fact that there was a significant paucity of scientific evidence and that the handbook could only, at best, be considered a clinical practice guideline from which deviation in practice would be expected (Kalachnik et al., 1998). This shortcoming aside, the book was an extremely useful and practical document that helped shape mental health practices over the next decade.

With this background in mind, we are now presented with the Diagnostic Manual–Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (hereafter referred to as DM-ID). DM-ID is another milestone in the diagnosis of mental disorders in this population. The premise of DM-ID is simple: to modify the current version of the standard diagnostic manual, DSM-IV-TR (American Psychiatric Association, 2000), to accommodate the intellectual impairments associated with individuals who are now considered as having intellectual disabilities. In the words of the editors, “A major potential
advantage of the DM-ID is that it may enhance the reliability of psychiatric diagnoses in persons with ID which could ultimately improve treatment outcomes” (p. 2). In this respect, DM-ID is similar to the earlier work of Sovner and Hurley, with the chief difference being that DM-ID is exhaustive. The diagnostic criteria for every diagnosis in DSM have been addressed. In addition to the 580-page textbook that we review here, the publishers have produced a more compact, 360-page Clinical Guide (Fletcher, Loschen, Stavrakaki, & First, 2007), although this review does not cover that volume.

Because the textbook is comprehensive, there are many similarities between the DSM and DM-ID. The most obvious is that a specific chapter in DM-ID is devoted to each of the major mental health diagnoses. However, the editors of DM-ID made a subtle difference in the organization of the chapters related to specific conditions, choosing to write separate chapters on obsessive–compulsive disorder and posttraumatic stress disorders. This was done “because of their importance in the ID population and because they are frequently underdiagnosed” (p. 6). In contrast, editors of various versions of DSM have struggled to find agreement over the years as to whether these conditions are best conceptualized as personality disorders, anxiety disorders, or thought disorders.

There are other dissimilarities between DSM and DM-ID as well. The most obvious relates to the “S” in DSM. DSM is a diagnostic and statistical manual, meaning that, in addition to aiding in the diagnostic process, it serves as a basis for standardizing clinical research and determining the reliability and validity of the manual itself. Given that the DSM has had a 50-year head start, it cannot be expected that DM-ID can achieve this goal at the present time. The proposition of creating a diagnostic manual for persons with intellectual disabilities is in its early stages and requires a degree of bootstrapping to begin to stimulate the needed research. The editors of the DM-ID wisely recognized this concern and requested that each chapter include a relatively thorough literature review and an assessment of the quality of the research or clinical findings using Cochrane Library criteria (Cochrane, 2001). The Cochrane criteria are used to assign a numerical score to evidence, with the most reliable, Type 1 evidence, being “good systemic review and meta-analysis (including at least one randomized control trial)” and the least useful, Type V evidence, being “expert opinion, influential reports, and studies” (as cited in the DM-ID textbook, p. 7). We were particularly pleased that the editors took this approach. However, the approach highlights the lack of an adequate knowledge base for this population, as most of the cited references achieve Cochrane evidence scores of only IV or V. Nonetheless, the editors state that, “This manual offers clinicians an evidence-based literature review of the existing DSM-IV-TR criteria with adaptations in a tabular format” (as cited in the DM-ID textbook, p. 7). However, at the same time they concede that the weaknesses in the knowledge base required them to rely “upon the expert consensus model in their work” (p. 6). We agree with the latter assessment; that is, as a result of the lack of scientific evidence, the DM-ID is more a set of consensus guidelines than a presentation of evidence-based standards.

This having been said, there is no clear description of how the experts achieved consensus for the disorders in the DM-ID. The editors charged workgroups, generally consisting of two to five members, to draft chapters, although it is not clear how these experts were identified or solicited. Once drafted, the chapters may or may not have been examined by any of the external peer reviewers identified at the beginning of the book. The nature of this peer review is also unclear. At some point, it appears that the draft chapters were reviewed by the editors, sent out for field testing, and perhaps modified prior to publication. It is our hope that these issues will be clarified in the future.

The ambitious goal of modifying diagnostic criteria for every DSM diagnosis resulted in somewhat uneven success. Some adapted criteria, particularly those related to mood disorders and anxiety disorders, should prove useful in clinical practice. For these conditions, there exist biological symptoms that can be objectively measured or tested (i.e., changes in weight, sleep pattern, or affect). However, diagnostic criteria, including those related to schizophrenia and other psychotic disorders, obsessive–compulsive disorder, and posttraumatic stress disorder, are more difficult to adapt because the diagnostic process relies so much on the patient’s ability to make a verbal description of internal states (e.g., of delusions or hallucinations).

In several chapters, the authors attempt to circumvent this deficiency by creating two sets of modified diagnostic criteria, one for mild to moderate disabilities and the other for severe to profound. In these situations, the modifications are
generally minor for the former group but can be significant for the latter. For example, in describing panic disorder, the authors propose no adaptations for persons with mild or moderate intellectual disabilities. However, the adapted criteria for persons with severe to profound disabilities rely almost exclusively on changes in autonomic nervous system function (pp. 260–261). The format for chapters on diagnostic categories is organized so as to present two sets of adapted criteria, one for mild–moderate and the other for severe–profound, although in some cases the adapted criteria apply to the entire range (mild to profound), as in the mood disorders chapter.

Remarkably, the authors propose no changes to the original DSM diagnostic criteria for schizophrenia. The chapter is organized so as to present two sets of adapted criteria. However, the authors do not recommend modifications in any of the criteria for either those with mild to moderate or severe to profound intellectual disabilities. Instead, the authors note that “a significant behavior change—for example, an increase in aggressive, self injurious, or bizarre behavior—should alert the clinician to the possibility of a psychotic process” (p. 260). Although in some situations this may be the case, this pattern of behavior may also reflect other problems. The presence of aggressive, self-injurious, or bizarre behavior is not necessarily specific only to mental illness. That is, there are many other underlying reasons that could give rise to these behaviors, as has been amply documented in the literature on functional behavioral analysis (Hanley, Iwata, & McCord, 2003; Iwata, Kahng, Wallace, & Lindberg, 2000). The authors’ assertion here only seems to highlight the difficulties in adapting the DSM process to persons with intellectual disability.

In reading through the chapters devoted to specific diagnoses, we had a sense that the editors were pressing a bit too hard to address all of the diagnoses contained within DSM. As a result, there is some unevenness in the quality of the diagnostic modifications proposed in Chapters 5 through 28. The editors have achieved the goal of creating a comprehensive diagnostic manual but, at the same time, and perhaps inadvertently, strengthened some of the arguments of clinicians who believe DSM may not be completely appropriate for use in this population. Thus, to some extent, like the DSM that it seeks to replace, the DM-ID fails to completely address our inability to understand the inner workings of the mind, particularly for persons with severe and profound cognitive limitations.

To their credit, the editors readily acknowledge many of these concerns at the start. They offer a cautionary statement (p. xxii) that the book is to be considered, like the DSM, as a set of “guidelines for making diagnoses of people with various mental disorders.” As a result, in clinical practice, one would expect some amount of variation in how individual practitioners use the proposed modifications of diagnostic criteria. In that regard, DM-ID does not define a standard of care.

Beyond the fact that the DM-ID represents consensus guidelines with little research to provide the statistical elements important in the DSM, we believe there is a more fundamental concern in the lack of clarity in the terminology. Admittedly, the field is changing from the term mental retardation to the term intellectual disabilities, another in a historical line of such changes that are not new to the field and for which reasons are generally accepted (e.g., the accumulation of negative referents over time for any term used to describe a socially disadvantaged population; cf. Walsh, 2002). Unfortunately, the editors of DM-ID do not examine this shift in detail despite the fact that the move to the term intellectual disabilities has important implications for the interpretation of information in the DM-ID.

Prior to 2007, the term mental retardation was used, with different meanings, by the American Psychiatric Association and the American Association on Mental Retardation (AAMR; now the American Association on Intellectual and Developmental Disabilities [AAIDD]) to describe a constellation of functional impairments that were intrinsic to the individual and may (AAMR) or may not (American Psychiatric Association) have been associated with varying needs for support. The differences between the American Psychiatric Association and AAMR definitions are important and warrant discussion in the book. Unfortunately, the editors made a decision to use the term intellectual disabilities instead of mental retardation throughout the DM-ID even in the context of citing research that was carried out prior to the use of the term intellectual disabilities. This practice creates two fundamental problems, both of which may interfere with interpretation of material in the DM-ID.

First, in our view it is inappropriate to characterize research carried out in the past, when the subjects of the research were considered as
having mental retardation by the definitions current at the time, as being representative of the field of intellectual disability. For example, one can find many examples in this volume similar to this: “Within the field of ID, several proposals have been made over the past 20 years for modifying diagnostic criteria” (p. 6) and then referencing works back to the 1980s with the term mental retardation in their titles completed at a time when “the field of ID” did not even exist.

Although there may be dissatisfaction with the term mental retardation, it does not seem appropriate in a work such as the DM-ID to simply replace the term with intellectual disabilities throughout. Bersani (2007), for example, raised the possibility of, but strongly warned against, the term intellectual disabilities being used as a linguistic substitution for mental retardation and concluded that this may simply substitute one stigmatizing label for another. It seems more important to understand the fundamental shift underlying the change from one term to another: that is, a critical reconceptualization of the construct to incorporate various external elements into the definition (Wehmeyer et al., 2008), which brings us to the second, and more critical, aspect of the terminology change for the DM-ID.

The DSM of the American Psychiatric Association includes a definition of mental retardation that significantly differs from the definition of intellectual disability offered by AAIDD. Whereas the DSM definition locates mental retardation within the person (that is, refers to defects in the person); the AAIDD definition of intellectual disability includes the fit between the person’s capacities and the context in which the person functions, typically, the availability of supports (Wehmeyer et al., 2008). Nonetheless, the DSM definition continues to be widely used in psychiatric settings and, therefore, it would likely have served as a primary definition for many, if not most, of the sources for the knowledge base presented in the DM-ID.

This disconnect between definitions comes to a head in Chapter 4, titled “Intellectual Disabilities,” in which the editors freely substitute the terminology “intellectual disability” for “mental retardation,” in citing research related to the diagnosis and management of persons with mental illness and “mental retardation,” as evidence of their opinions about the diagnosis and management of persons with mental illness and “intellectual disabilities.” The worst example of this problem occurs when the editors cite the American Psychiatric Association’s definition of “mental retardation,” as published in 2000 in DSM-IV-TR, as that association’s definition of “intellectual disability” (p. 64). The sole use of intellectual disability regardless of whether the research context was for “mental retardation” or intellectual disability has a revisionist cast to it and should have been avoided in this work. Rather than simply choosing to use the term intellectual disability regardless of the context, we believe that that the editors should have included a thoughtful discussion of the differences between the two definitions (one focusing on individual defects and the other including environmental context), how they might respectively influence diagnostic decision making, and how these two approaches may be merged going forward.

As published, it is difficult for readers to discern in the DM-ID when the cited research is referring to what the authors of that research considered to be individuals with “mental retardation” (that is, individuals for whom their disabilities and/or mental problems were considered to be located wholly within the person) or whether the cited research is from to studies conducted by researchers who thought that their subjects’ disabilities and conditions reflected both internal capacities as well as environmental contexts, that is, individuals with intellectual disabilities. It strikes us that the lack of clarity between these two definitions while research is amassed in DM-ID constitutes a serious problem in that it is more difficult to argue for consensus if the research base is, to some extent, divided on what the nature of the underlying disability actually is.

Despite the efforts in the DM-ID, there remains a certain amount of discontinuity at the boundary between the field of developmental disabilities and psychiatry as to definitions. The relevant organizations, AAIDD and the American Psychiatric Association, should be permitted to choose the language in which they conduct discourse among their members. At some time in the future, it may be that the American Psychiatric Association will determine that it prefers the newer conceptualization. However, it seems presumptive for the editors of DM-ID to have decided that already.

Throughout our reading of DM-ID, we were drawn to the comments noted at the beginning of this review by Szymanski et al., who questioned whether, in the end, DSM is an appropriate tool for
the diagnosis and management of mental illness in persons with mental retardation. Indeed, their comments make us wonder where the field currently stands and where DM-ID will take us in the future. During the past 20 years, the use of DSM in all clinical settings, including those related to persons with mental retardation, has increased dramatically. Most mental health practitioners have already recognized the need to modify DSM, although without benefit of the experience of the authors in this book. The result is not just that the frequency of diagnoses of mental disorders, such as impulse-control disorder, seems to be increasing but that the reliance on mental health interventions, including psychotropic medication, hospitalization, and admissions to mental hospitals, appears to be on the rise.

At the same time, we have witnessed in some quarters a decrease in the capacity of the service system to provide truly interdisciplinary treatments, particularly those related to applied behavioral analysis. In practical terms, what may have been previously viewed as problem behaviors related to the interaction between the person and his/her environment are now, in many settings, perceived to be symptoms of mental illness, intrinsic to the individual. The unintended consequence is that we may be returning to systems of care which are based on the medical model: building crisis mental health services rather than a behavioral infrastructure and using psychotropic medications, the exclusion of preventive interventions. One would have hoped that the introduction of a landmark tool, such as the DM-ID would have provided the groundwork for pathways out of this conundrum. Although there is a great deal of important work in the DM-ID on adapting DSM criteria, it would have been useful had it been set within a more sophisticated definitional context, one that reflects the actual state of the world in which people with intellectual disabilities exist.

Nonetheless, we believe that DM-ID will become an important tool in the management of mental illness in persons with what we now consider intellectual disabilities. However, we should exercise caution in assuming that all presenting symptoms or problem behaviors should be viewed through the narrow lenses of DSM or DM-ID. DM-ID will enhance the competency of mental health practitioners serving persons in this population. At the same time, we need a complementary approach to enhancing the quality of behavioral diagnosis and treatment services for people who exhibit problem behaviors if we are to fully maximize treatment efficacy.

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References


