**Book Reviews**


Since its founding in 1876, the American Association on Mental Retardation (AAMR) has served a central role in understanding, defining, and classifying the condition known as mental retardation. The AAMR first published a manual on definition and classification in 1921. Updated editions have appeared periodically and have mirrored evolving perspectives on the nature, etiology, and functional consequences of mental retardation over the past 81 years. The most recent 10th edition of the Manual builds on this historical foundation and reflects an integration of commentary offered at numerous public forums with key findings in the literature on mental retardation since 1992 as well as input from AAMR members and advocates. The new Manual is the product of the careful synthesis of this information by the AAMR Ad Hoc Committee on Terminology and Classification.

The authors note that people who are labeled as having mental retardation and those who work with and advocate for this population are struggling to identify a new, less stigmatizing term for this disability. However, at this time no consensus has emerged among stakeholder groups for an acceptable alternative term that means the same thing. Consequently, the term mental retardation has been retained in the current 10th edition, although the authors do note that the term will likely change in the near future. Despite this caveat the current Manual reflects a synthesis of the state of our knowledge about mental retardation and provides both a definition and a wide ranging discussion of the implications of current understanding in relation to defining, classifying, and providing services to this population.

The 2002 AAMR definition of mental retardation is as follows:

Mental retardation is a disability characterized by significant limitations in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

According to the AAMR, five assumptions are essential to the application of the definition for the purposes of naming, defining, and classifying mental retardation:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

The three prongs of this definition—significant limitations in intellectual functioning and in adaptive behavior, with onset before age 18—are retained from earlier AAMR definitions. The 9th edition of the AAMR Manual (1992) represented a significant paradigm shift in the conceptualization of mental retardation, from an absolute trait expressed solely by the individual to a mutable condition that results from on-going interactions between a person with limited intellectual functioning and the environment. The 1992 Manual also maintained that the meaning of mental retardation is functional and interactionist rather than statistical and proposed that classification be based on the intensity of needed supports rather than on the severity of impairment (i.e., mild, moderate, severe, and profound categories based on IQ scores). The current 2002 Manual maintains this strong commitment to a person-centered, ecological approach to definition and classification.

The AAMR 10th edition extends the functional approach to defining mental retardation and proposes an explicit, contextualist model to denote the relationships among individual functioning, supports, and social outcomes. According to the AAMR model, five dimensions of functioning are
central to defining the impact of mental retardation on social outcomes: intellectual abilities; adaptive behavior; participation, interactions, and social roles; health; and context (e.g., environments, culture), and each of these dimensions is mediated through the supports available to the person. Thus, mental retardation is a "particular state of functioning in a particular context of time and place that results from interactions between individuals and their environments and interactions among risk factors across a lifetime" (p. 139).

The authors note that, from the earliest formal conceptualization of mental retardation to the present time, adaptive behavior deficits were the distinguishing feature of this disability. Despite this, the assessment of intellectual functioning has dominated the diagnosis of mental retardation, with a measured IQ being the primary and essential criterion. The AAMR 10th edition attempts to correct this imbalance by encouraging practitioners to focus on both intellectual functioning and adaptive behavior skills in the diagnosis and classification of this disability. The new Manual retains the perspective adopted in the 9th edition that adaptive behavior skills are particular and specific to domains of functioning rather than global and general. At the same time, the AAMR 10th edition eliminates reference to 10 adaptive behavior skill domains and adopts a tripartite model of adaptive behavior as a collection of conceptual, social, and practical skills. The 10th edition also eliminates the reference to problem or maladaptive behavior that was included as a dimension of adaptive behavior in previous editions. The authors note that the assessment of adaptive behavior skills should refer to an individual's performance of conceptual, social, and practical skills during daily routines, in typical environments, and under changing circumstances.

The AAMR 10th edition is divided into five sections that address the theoretical model, diagnosis, classification, supports, and implications. The first section of the Manual presents the new definition and the model that serves as its foundation. In chapter 1 the new definition is introduced and explicit operational definitions for key terms are provided (e.g., adaptive behavior, supports). Chapter 2 contains a detailed historical review of previous AAMR definitions as well as research-based findings published in the professional literature since 1992 and recent critiques of the 1992 definition. Chapter 3 includes a thorough discussion of the ecological model.

In the second section of the Manual, the authors address assessment issues in the diagnosis of mental retardation. It includes chapters on assessment of intellectual functioning (chapter 4) and adaptive behavior (chapter 5), as well as a discussion of the role of clinical judgment in the diagnostic process (chapter 6). This section also includes a review of the technical adequacy of contemporary instruments and key considerations for assessment of intellectual functioning and adaptive behavior. The third section of the Manual, in which issues related to classification of persons with mental retardation are addressed, includes chapters on the similarities and differences in various contemporary disability classification schemes (chapter 7), as well as etiology and prevention strategies and the relationship of these to supports (chapter 8). The fourth section of the Manual integrates current perspectives on support-based service provision with the focus on supports in the current AAMR definition. It includes chapters on the application of person-centered support strategies in the planning and provision of services (chapter 9), physical and mental health issues (chapter 10), and a discussion of public responsibility in the provision of supports (chapter 11). In the final section of the Manual (chapter 12), implications of the 2002 System for current practices in education and habilitation are discussed.

The AAMR 10th edition is a curious mixture of old and new perspectives on the disability of mental retardation. The authors retain the centrality of standardized intelligence tests in the diagnosis of mental retardation and note that intellectual functioning is "best represented by IQ scores that are obtained from appropriate assessment instruments" (p. 41). At the same time, they rightly acknowledge that even the best contemporary intelligence tests are generally more accurate for individuals who score closer to the mean score and are less accurate in classifying individuals who have extreme scores. Because all scores below the cutoff score of 70 can be considered extreme scores (i.e., at least two standard deviations below the mean) for which standardized intelligence tests have limited sensitivity, the authors of the 10th edition also emphasize the role of clinical judgment in the use of standardized assessments of intellectual functioning and adaptive behavior for the purpose of classifying individuals. At the same time, the new definition strongly reflects an ecological approach to disability that stresses the power of person–environ-
The field of mental retardation continues to be in a state of flux, with spirited disagreements on numerous issues that are relevant to the AAMR goal of establishing an acceptable definition of this disability. For example, consensus remains illusive in regard to (a) the nature of intelligence, (b) the relationship between intelligence and adaptive behavior, (c) how to implement the person-centered support model, (d) the best way to characterize disabling conditions, and (e) the effects of terminology upon individual lives. Thus, the AAMR 10th edition is best understood as a work in progress that honestly reflects the present consensus of the field and discusses the issues around which consensus has yet to crystallize. The Manual makes an important contribution in its integration of contemporary perspectives and its adoption of a supports-based approach to diagnosis, classification, and service provision. The authors also perform an important service to the field through the thorough and comprehensive discussion of the theoretical foundation and practical implications of the new definition for understanding the condition of mental retardation and providing services to persons with this disability.

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We have seen some far-reaching advances in employment services in recent years. The authors of Self-Directed Employment build upon and extend those advances in an important way by explicitly defining a process by which individuals with significant disabilities are clearly in charge of making career choices and decisions.

The book is primarily designed as a workbook for practitioners. Most of the material is presented in two major sections, comprising chapters 3 to 9. Section One is divided into four topics: making (initial) choices; exploring choices (through job shadows and a novel process called “situational interviewing,” which represents a cross between job shadowing and traditional informational interviewing); testing choices (through job try-outs and internships); and final choices. Section Two is divided...
into job-matching, satisfaction appraisal, and solving on-the-job problems. Each topic consists of several objectives, with specific activities and assessment procedures embedded in each objective, leading to a consumer choice. Each activity is spelled out in detail. Sample worksheets are provided within the body of the text, and blank worksheets are provided as appendices. The book is spiral-bound for ease in photocopying the worksheets.

The authors’ work is deeply rooted in the ideology of self-determination, described in the first two introductory chapters. The historical introduction and conceptual overview of the concept is illuminating but possibly a little dense for a practitioner workbook. I found the distinction in chapter 2 between what the question is and who asks the question to be a particularly useful way to shift thinking. One might ask, for example, “What job best matches this individual’s characteristics?” But then one can also ask the question, “Who is it who needs to figure this out?” In this book the authors provide a method for assisting consumers to ask and answer questions for themselves.

The book is rich with insights and suggestions to guide the process of career development. The process is fully individualized. For example, it is inconceivable that individuals from the same employment service agency using this process would wind up working together as a group. Perhaps this goes without saying, but I mention it because too many people still appear to sincerely believe that group employment represents an expansion, rather than a restriction, of vocational options.

A major strength of the book is the authors’ insistence that meaningful choices must be based on direct experience of a job, “seeing it, feeling it, smelling it, and hearing it” (p. 32), not merely on a one-shot exposure, but multiple exposures to job situations and multiple opportunities to process information and make choices that add up to a career decision. Thus, the method involves a connected series of experiences that build on one another and lead to stable paid employment. Staff members act as a guide through the process, sometimes making strong suggestions perhaps, but never usurping the individual’s autonomy as the final decision-maker. To begin the process, the individual is even provided with two different versions of a form to collect information about initial preferences and asked to select which form he or she would prefer to complete.

“What if?” sections are provided for each objective, and I found these extremely useful. They give a range of options in situations where the standard process might not match a particular individual’s circumstances. At one point or another readers are reminded that they should add items, skip items, draw pictures to clarify something, or to skip whole objectives, as needed. These “What if?” sections also provide down-to-earth tips regarding how to think about various circumstances that might be encountered and how to interact with the consumer as a guide and facilitator.

The process is based on the authors’ substantial direct experience in assisting people with employment over an 11-year period of model development and refinement. Following the presentation of the approach, additional chapters relate a series of stories of individuals who have gone through the process (chapter 10), and summary statistics documenting the outcomes of the demonstration project upon which the approach is based (chapter 11). The stories are rich in detail and, along with the “What if” sections, show the vast range and flexibility that is possible using what might at first glance look like a rigid “recipe” approach. So the process should be useful for both staff who need or expect a great deal of structure and those looking for a process they can adapt in individualized and creative ways.

In self-determination, the “rubber meets the road” at the point where an individual chooses something that his or her service providers do not agree with. So I looked carefully for how the authors deal with this issue, and I was not disappointed. A good example of the recommended approach can be found on p. 116:

Do not modify an individual’s plan, even if the plan does not seem like a reasonable way to achieve the goal. What may not seem to be a good plan to you may be a good plan for the individual, or at least a necessary step in his or her reasoning process.

I was a little disappointed because of the scant attention paid to job search methods. Readers are advised to “sell your unique employment program” (p. 167) and to consult the “many good books that explain how to do marketing” (p. 72). Much supported employment marketing literature is mired in staff-controlled and agency-centered practices. My experience has been that mapping these practices onto a self-directed approach must be done with extreme care. As one notorious example, some job developers “market” their program by promising to reduce an employer’s turnover rate. Once this con-
cept is “sold” to an employer, the employment support agency has an incentive to make sure an individual who is placed there stays on the job, and consumer choice can easily take a back seat. Because the authors recommend working with the consumers to develop resumes, and many of the stories clearly describe normative job search activities, what is implicitly being recommended appears to be, rather than traditional supported employment job development, a hybrid process involving some elements that look like a typical job search and some elements that look more like program marketing. This seems to call for a fuller explanation. One issue in particular—how to establish consumer control over the disclosure of disability—needs a full account of a self-directed job development process.

A second weakness, in my view, is the lack of information on how to appropriately involve members of an individual’s personal support network in career planning and job development. In relation to career planning, for example, mainstream career theorists are largely abandoning the notion of the self-contained rational utility maximizer as the model for understanding the decision-making process, and now talk about career development as a socially constructed activity involving conversations with family (Young et al., 1997), consultative approaches to decisions (Phillips, 1997), and “collective social value” as a legitimate decision-making orientation (Brown, 2002, p. 50). To be sure, the authors direct staff members to suggest that consumers “talk to friends and relatives” (p. 42) in thinking about career preferences, but a lot more could be said about how to do this in a way that maximizes positive input while minimizing the potential for undue influence.

Finally, the process promises to serve as a vehicle not only for obtaining a job, but also for ongoing career advancement. This may turn out to be a somewhat exaggerated claim. If one examines the postemployment process carefully, once a job is secure, job change is driven only by the express dissatisfaction of the consumer in relation to his or her current job situation. There is no provision for the continuing exploration of new options to increase career satisfaction. A discrepancy-based process alone is unlikely to advance many consumers into the primary sector of the labor market. A demonstration program job-type profile for participants—including some who have been in the program for many years—that “reflects the . . . entry-level job market” (p. 268) seems to bear this out.

None of these weaknesses diminish the value of Self-Directed Employment as a major contribution to our understanding of how to incorporate consumer choice and self-determination more explicitly into the employment process. As the authors point out, advances in employment services have occurred in a series of phases, and this process is likely to continue. The core process described in the book can easily incorporate new elements. For example, it would be a straightforward matter to assist an employed and satisfied consumer to cycle back through the process of exploring and testing potential new choices. Anyone interested in employment services will find that this book provides a wealth of practical service strategies and represents a challenging new way of thinking to guide the future development of services.

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References


In the early 1990s, a new degree course in learning difficulties (which, in the United States is called mental retardation) was developed at Stockport College in the United Kingdom. Editor David Race, in the introduction to this book, describes the connection of the book’s development to that course: first it was necessary to (a) create a textbook that would be useful for undergraduates and (b) transmit the kind of energy the authors perceived to arise from active engagement in the practical as-

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pects of the field. Thus, Race reasons, the book embodies an inevitable tension between academic acceptability and a teaching approach relying heavily upon students and people with learning difficulties for its values and direction. In particular, the course at Stockport was designed to take advantage of the life experience of people with learning difficulties.

This book is a collected volume, with chapters by authors who were associated, in one way or another, with the Stockport course. The different chapters meet the aims described by Race to varying degrees, and I can imagine the response of students using this as a textbook might be similar to mine in that regard. Some chapters (e.g., “Advocacy and Parents With Learning Difficulties,” by Kathy Boxall, Michaela Jones, and Shaun Smith or “The ‘Normalisation’ Debate—Time to Move On,” by Race) would seem to provide the kind of introduction to ideas or movements that might be particularly helpful for students. Others would appear less useful for that purpose. Some chapters, for example, provide a dense litany of British legal, bureaucratic, and organizational history that would be excellent reference material, but would, perhaps, be less than fully accessible from the perspective of a student. This sense of uneven chapter development prevents achievement of the kind of natural flow one would hope to see in a well-crafted textbook.

On the other hand, the book has much to commend it as a source of thought-provoking philosophical perspective, not only for British readers (despite the heavy emphasis on British governmental movements and the ebb and flow of politics in the U.K.), but for others as well. A couple of chapters would, for instance, make good reading for American thinkers at a time when our leaders are heavily engaged in reworking the language of the field. Thus, although it has been considered progressive here to use such phraseology as “person with developmental disabilities,” rather than “disabled person,” it is argued in this book (by Kathy Boxall) that people are, in fact, “disabled” by the organization of society—that the problem lies in the inability of our cultural institutions to remove the barriers that disable or impair individuals. This, of course, is a social construction of the concept of disability and stands in contrast to the more typical individual construction that defines disability in terms of characteristics of the person. Put another way, according to Boxall, the individual model locates the “problem” in the person; the social model locates the problem in the system (e.g., school, community).

The social construction of disability is articulated slightly differently by Joe Whittaker and John Kenworthy in their chapter “Education Services: Why Segregated Special Schools Must Close.” These authors alert readers at the outset that they do not accept the phrase people “with learning difficulties” and instead choose to use people “described as having learning difficulties.” This too, of course, is a construction intended to place responsibility on social institutions to integrate and support individuals whose needs and characteristics may be unlike those of the majority of students. To schools that would claim not to have the resources to serve children with special needs, Whittaker and Kenworthy point out that if children were truly turned away due to lack of appropriate resources, the schools would reject a much wider range of children—with and without learning difficulties.

For readers interested in history, whether recent or longer-term, this book offers several chapters of note. Although much of the history is described in the context of the U.K., there are occasional references to American developments, and much of the evolution of ideology runs parallel to events in the United States and other European countries. Near the end of the book, Race describes the influence of movements associated with Wolf Wolfensberger and with John O’Brien on recent history in the United Kingdom, attempting to sort out the relationships among Wolfensberger’s versions of normalization and social role valorization, and O’Brien’s “community of practice.”

Finally, and perhaps most important to the authors of this volume, the voices of individuals with learning difficulties are respected and presented at various points in the book. These include a number of people who became involved in teaching, as guest speakers in the Stockport course (e.g., David Barron and Kevin Chettle), and parents with learning difficulties (Michaela Jones and Shaun Smith), who have advocated on their own behalf with governmental agencies, among others.

This book prompted me to think differently about learning difficulties as a concept, and the relationship of those “described as people with learning difficulties” to the broader culture. For that reason alone, it was well worth the reading.

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