

## CHAPTER ELEVEN

# *Mental Retardation in the Real World: Why the AAMR Definition Is Not There Yet*

STEPHEN GREENSPAN

### INTRODUCTION

The subtitle of this chapter was inspired by William E. Kiernan's AAMR presidential address in 1996. He asked a question about the mental retardation field, quoting the children's car-riding refrain: "Are we there yet?" With respect to the last two AAMR classification manuals, my reluctant reply is: "Unfortunately, in spite of some progress, we are still not there yet." My response may surprise some readers, when my ideas (especially about a tripartite model) were heavily cited in the theoretical section of the 2002 manual and, to a lesser extent, in the 1992 manual. This citing of my work has caused some to think, wrongly, that I played a major part in developing the definitions in both manuals. I am honored to have my work so recognized, but feel obligated to point out that the definitions of MR, in both the 2002 and 1992 manuals, do not fully reflect what I had been proposing, more or less consistently, in all of the works that were cited in support of those definitions.

My passion on this subject is driven less by abstract theoretical argument, or personal pique, than by practical considerations. While I have tried to ground my ideas on solid empirical work (mostly by others), and believe that my proposed definition has a fair amount of theoretical coherence, the main influence on my formulation and refinement of a definition of MR has always been my personal experience with people with MR—as a family member, as an advocate, and as a clinical consultant. I sincerely believe that my view best describes the real-world phenomenon of MR as I and others have experienced it. My recent experience in carrying out *Atkins* death-penalty exemption assessments (see Greenspan & Switzky, "Lessons from the Atkins Decision," elsewhere in this book), has greatly strengthened my belief that the 2002 AAMR definition, by moving in an even more formulaic direction, by suggesting the need for numerical adaptive-behavior scores; and by continuing to support the use of adaptive instruments, such as the Vineland-II and the ABAS, that emphasize tooth brushing far more than social vulnerability, still does not

provide an adequate basis for determining whether a "marginally competent" person does or does not have MR.

The balance of this paper is divided into four sections. In the first section I discuss the question, "Is it better to use a cookbook formula or a natural intuitive 'taxon' to diagnose MR?" In the second section I describe the "tripartite model," both as it was proposed by me, and as it actually was used in the 1992 and 2002 AAMR manuals, as a search for a better and more adequate artificial cookbook formula. In the third section I discuss some reasons, particularly the hang-up with numbers, why the AAMR cannot come up with a better artificial cookbook. Finally, in the fourth section, I discuss why maybe it is time to abandon the artificial cookbook approach altogether and to get real.

### A NATURAL TAXON VERSUS AN ARTIFICIAL FORMULA

According to the online version of the OED, a "taxon" is a unique species or classificatory group. Derived from biology, particularly botany, a taxon refers to what the psycho-diagnostician Paul Meehl (1973) referred to as "nature carved at the joints." While one taxonomic category may overlap somewhat with another, one or more essential qualities enable a knowledgeable observer, often intuitively, to rule a particular plant, animal, or disease in or out as belonging to a particular taxon. The notion that MR is a natural taxon—that is, that there are one or more essential qualities that a person with MR either has or does not have—seems to differ in fundamental ways from the formulaic approach reflected in the past few manuals, and especially the 1992 and 2002 AAMR manuals. That is not to say that we do not carry around inside our heads an intuitive sense of what the MR taxon is, such as the one that might cause you to think that the man depicted in the following example does not have MR, but the recent AAMR manuals, in spite of some loosening on the subject of clinical judgment, say basically, "Trust the formula, not your own gut."

Here is an example of what I am talking about. Let's say you are a new board member at a DD agency and you have a conversation at the annual holiday party with a well-groomed man whose name tag reads "Eric Jones." He is very articulate and talks with insight about current events and his own life. Mr. Jones strikes you as a little odd but is "normal" enough that you assume that he is a staff member. Later on, however, you find out that he is actually a client of the agency and has a diagnosis of mild MR. Your first reaction is to say, "No way. That is a misdiagnosis."

When you have a chance to find out more about Eric, you learn that he has several IQ scores below 70, his problems developed at an early age, and his adaptive behavior profile has sufficient deficit areas to qualify him as having MR under both the 1992 and 2002 manuals. Which is correct in this situation: your gut impression that Mr. Jones does not have MR, or the psychological evaluations that suggest that he does? If Eric's adaptive behavior scores were higher, then one could say, "This is a case where a low IQ score results in a 'false positive.'" However, in the current situation, the only basis for dismissing the test scores would be your clinical judgment, and that judgment is based only on a brief meeting and conversation in a party setting.

What if I told you, however, that Eric has a long history of being tricked and manipulated sexually, financially, and in every other way, and that his seeming social skills reflect a kind of superficial cocktail party patter that he can call upon with the same words when

meeting people there may be a ing, Eric either his depth. The impression was

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meeting people for the first time? In less conventional interpersonal situations, where there may be a hidden manipulative agenda or where a complex social narrative is unfolding, Eric either runs out of things to say or else gives clear evidence of being totally out of his depth. Then you might decide that Eric might have MR after all and that your first impression was mistaken.

You might think this is a totally hypothetical situation, although we all have wondered at one time or another about some of our colleagues, but I have seen some clinical reports recently in *Atkins* death-penalty exemption cases, in which an expert witness will conduct a one- two- or four-hour clinical interview with an individual and conclude, even in the face of significant test scores to the contrary, with words along the lines of "X's verbal skills and insights are really good, and on that basis I cannot concur with Dr.Y's judgment that he has MR." Is that good enough, or is it an inappropriate thing for a clinician to do in diagnosing a disorder that is officially to be defined according to a precise set of numerical specifications, and in which information about adaptive functioning is supposed to come mainly from others who know the individual well? I think most of us would say that a clinician's sense regarding whether a person fits the natural taxon should play a role when considering the differential diagnosis "MR" or "not-MR." The relevant question is: "What exactly is the natural taxon of MR?" One will look through the AAMR manual in vain, however, for an answer to that question.

The 1992 and 2002 AAMR manuals emphasize repeatedly that MR is a condition defined by weaknesses, and not ruled out by strengths. In fact, the manuals indicate that a person can have strengths in many areas (eight out of ten adaptive skill areas in 1992, two out of three adaptive skill domains in 2002) and still qualify as having MR. Other than an IQ score below a certain level, there are no behavioral (i.e., adaptive skill) domains in which normal or near-normal functioning would rule out a diagnosis of MR. In other words, it doesn't matter how brilliant a speaker Eric Jones is at a cocktail party or on a lecture stage, for that matter; neither verbal ability, nor any other isolated ability, justifies deciding that someone cannot have MR. This position may seem an exaggeration of what the 1992 and 2002 manuals say, but if it so, it is not much of one. By being tied to an artificial formula based on theory rather than reality, and since nothing is less natural than a standard deviation unit, there is the danger that one can classify a person as having MR or not having MR, without even having to look at the person in a holistic manner as a living, breathing entity.

An example from *Blink*, Malcolm Gladwell's best-seller about automatic cognitive processing (2005), involves a nearly too-perfect ancient Greek statue that a museum was considering buying for \$10 million. To determine if it was a fake, the museum brought in chemists and x-ray specialists, who conducted a half-dozen sophisticated tests. They concluded it was for real, and the museum shelled out the cash. Then they asked an expert on Greek statues to look at it, and after a 10-second evaluation based solely on aesthetic impressions, he pronounced it fake. This expert, relying solely on his knowledge of hundreds of such statues, decided it did not fit the taxon for statues of this type. It turns out he was right.

To understand why the AAMR has moved toward the use of artificial formulas, and away from the use of intuitive judgments, one has to know something about the sad and

sordid history of the MR field in the United States and other western countries. Seymour Sarason once told me a story about a woman working for the state of Connecticut whose job was to drive around to various towns and make snap judgments, based solely on eyeballing, about whether a child or adolescent should immediately be placed in one of the state's large residential institutions. As part of a research project (Dunaway, Granfield, Norton Greenspan, 1992), my colleagues and I once interviewed a few of these people finally deinstitutionalized after decades, some after being sterilized, and we found several cases where the person, based on today's cookbook formula, would not even come close to a diagnosis of MR. In fact, in the Connecticut Department of Mental Retardation database, a sizeable percentage of these now deinstitutionalized, but still-served, individuals have the diagnostic code "Non-MR." Similarly, in a quasi-scientific but highly cited study that contributed to the policy decision around 1920 to shut down the flow of immigration into the United States from eastern and southern Europe, allegedly because a large percentage of these immigrants had MR, psychologist Henry Goddard hired poorly trained "moron detectors" whose job was to scan the tired and disoriented and non-English-speaking immigrants debarking at Ellis island and decide, based on how they looked and acted, which of them had MR (Smith, 1985).

Ironically, although the use of today's artificial diagnostic formulas is an effort in part to avoid the misguided at best, evil at worst, past misuses of clinical judgment, it also owes its origins in part to the efforts of Henry Goddard and other eugenics-oriented psychologists to devise a more reliable method for rooting out hidden "morons" who were lurking unidentified in the general population (Trent, 1994). Goddard enthusiastically seized on the newly invented Stanford-Binet Intelligence Scales, because he had doubts about the ability of "eyeball methods" to reliably identify sufficient numbers of people who have what today would be called mild MR, in that such individuals may look or act in ways that on the surface are relatively normal. Thus, the use of intelligence test scores was promoted by early 20th-century psychologists such as Binet as a more scientific and valid basis for diagnosing MR. Guess what, folks? That same attitude still prevails today.

According to the late Stephen Jay Gould (1983), Henry Goddard began to suspect, toward the end of his life, that he may have grossly overestimated the prevalence of mild MR in the population. Specifically, he acknowledged that he produced many false positives when interpreting the results of intelligence test performance. A major reason was that in the early days of intelligence testing, psychologists relied on mental age (MA), and it was not yet understood that MA scores, a composite of knowledge and raw computing power, seems to reach an asymptotic value in early adolescence and does not continue to rise with chronological age. Thus, a 30-year-old man with a MA of 15 might look mentally deficient but in fact is probably functioning in the normal intellectual range. The same criticism, of course, can be made of the early-devised ratio IQ method, which is why today we use the deviation method, which employs percentile ranks derived from norms for persons of the same age when calculating IQ scores.

The raising or lowering of the IQ ceiling, along with the invention of the adaptive behavior criterion and its more "scientific" grounding in adaptive behavior standard scores, is an attempt to eliminate some of the mistakes that flow both from unfettered reliance on

clinical judgments. However

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clinical judgment and also from sole reliance on an IQ ceiling to define the MR populations. However, it still involves implicit acceptance of the following twin notions:

1. Mild MR is a hidden condition that cannot be reliably diagnosed from a judgment that a person's observed behaviors conform to the natural taxon.
2. The best way to discover if a person actually has mild MR is through the use of a scientific numeric formula that supposedly measures capacities residing inside the person.

A major reason why MR is defined in terms of an artificial numeric formula rather than an intuitively-based natural taxon is something that is not generally understood, namely that MR, particularly mild MR, is a socially constructed disability category rather than a naturally constructed quasi-medical category. Although MR, like any disability, often is caused by a medical disease, evidence of such a disease is not necessary to be diagnosed as having MR, and in most cases of especially mild MR a cause may be suspected but is not known. The taxon for most medical diseases is found not in observed symptoms/ behaviors, which can vary widely across and within diseases, but in the presence or absence of critical etiological agents. Thus, tuberculosis (TB) is defined by the presence of the TB bacillus, and before the identification of that microorganism, TB was as difficult to diagnose as is mild MR today.

The term "disability" originated in the vocational rehabilitation field and is used to indicate that a person needs significant short- or long-term supports in order to be able to hold down a job, if he can at all. It is, thus, a bureaucratic category, usually defined by a committee, which may be influenced by political and economic considerations as much as by "science," and the decision as to where to draw the line between disability and nondisability, based on an estimate of the amount of supports needed to function normally, is relatively arbitrary. Given that MR is a socially constructed disability/bureaucratic category, is it any wonder that efforts to define it have mainly been based on theoretically elegant formulas, rather than on complex and messy reality?

So here is the \$64,000 question: "Does the fact that MR is a socially constructed bureaucratic category mean that there is no point even talking about trying to find its natural taxon?" A related big question flowing from the above discussion is: "Since MR is a socially rather than naturally defined category, should we just drop use of the category altogether?" As an eternal optimist, I answer both of these questions with a qualified "No." To take the last question first, I believe that some people are much less competent than others in coping with the demands of life, and a point exists beyond which such incompetence places these individuals at dire and potentially dangerous risk of catastrophic social or physical failure. I also believe that in some individuals, those whose primary impairment is not mental illness, a high potential vulnerability to catastrophic failure can be traced to serious abnormalities in brain development which limits their ability to think and to learn.

The fact that there have always been some individuals who have developmental limitations in their ability to master and effectively apply cognitive schemas to challenges of everyday life is reflected in the use in every society of descriptors and epithets such as "stupid" or "retarded." So it is useful to maintain some category, whether or not one calls it

"MR," to identify and bring needed supports and protections to those people who are viewed in such a light. Whether it will be possible to construct a definition of that class of people which is close to the category's natural taxon will hinge on the extent to which the definition/formula taps into the behavioral profile which laypeople use in deciding that some people have such a disorder. A practical implication for individual diagnosis, rather than defining the taxon, is that the best and maybe only way to establish whether a person qualifies as having MR is not how the person is viewed by a psychologist or other mental health professional in an artificial mental health setting, but in how he has been seen by peers and adults in his ecological world.

### THE TRIPARTITE MODEL OF ADAPTIVE INTELLIGENCE

Something that I termed the "tripartite model" (Greenspan, 1979, 1981; Greenspan & Driscoll, 1997; Greenspan & Love, 1997; Greenspan, Switzky & Granfield, 1996), and which I borrowed and modified from an earlier formulation by E. L. Thorndike (1920), has been cited as a theoretical justification by both the 1992 and 2002 AAMR manuals. In fact, it was incorporated into the 2002 manual as the basis for its model of adaptive behavior. The tripartite model has been used by the T&C Committee as a foundation for devising a better, more valid, and thus more widely used formula for adaptive behavior and, thus, for devising a better cookbook recipe for defining and diagnosing MR. However, without using the term "natural taxon" (because this term has only recently entered into my vocabulary), I have argued that the model is useful mainly as a way of bringing awareness of the central importance of a critical aspect of "MR-ness" that has been overlooked, namely "social intelligence." Thus, the tripartite model has served both to tinker with the artificial formula and to bring that formula closer to the natural taxon.

To the extent that there has been tension between myself and the authors of the 2002 AAMR manual, it is that they have not gone nearly as far as I would have liked, although they have taken some welcome baby steps, toward stating that low social intelligence and its most dramatic expression, gullibility, is the universal and most important aspect of MR's natural taxon.

A point that I have been making over the past 25 years, hopefully with increasing clarity as my own understanding has deepened, is that MR is a condition characterized by deficits in three types of intelligence. The problem with the way that MR has typically been approached, however, is that one of those types of intelligence, conceptual (or academic) intelligence, measured by IQ tests, has received all of the emphasis. The construct of "adaptive behavior" was an attempt to loosen the overreliance on a single IQ score as the sole basis for definition and diagnosis. The adaptive behavior construct has muddied the waters, however, because of the failure to ground it solely in the other two types of intelligence.

Using Thorndike's tripartite model of multiple intelligences, I have suggested (Greenspan, 1979, 1997, 1999a, 1999b) that the best way to think of adaptive behavior, given that the term that was invented and used before it was defined or understood, is in terms of the two nonacademic domains in Thorndike's tripartite model. These are "social intelligence" (e.g., understanding of people and social processes) and "practical intelligence" (e.g., understanding of mechanical objects and processes). These two nonacademic domains of intelligence have been described (Greenspan, Switzky, & Granfield, 1996;

Sternberg, 1985). The definition of intelligence is the cation of intelligence.

Given the likelihood that the measure of adaptive behavior is a measure of a person's ability to function in the real world, the definition of MR is based on the measure of adaptive behavior. The advantage of this approach is that we think of adaptive behavior as encompassing the totality of a person's behavior, as opposed to focusing on a specific measure of intelligence. This approach also allows us to fuse the definition of MR with the definition of adaptive behavior, thus reflecting the reality that MR is a condition of adaptive behavior.

It is probably not connected to intelligence, but it has been ignored in the current literature, as has been the case with the model of adaptive behavior (AAMR) Adaptive Behavior Checklist (ABC), which is a summary of adaptive behavior. II, have provided a summary of the two sub-

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On the surface, the social and social deficits in MR consisted of a lack of social-emotional skills against one's environment.

Anyone who has clearly had substantial psychological problems almost always has a history of social culture. This is a problem that is worked in the culture of a mentor or a teacher. One could argue that the

Sternberg, 1984) as comprising "everyday intelligence," which has to do with the application of intelligence to real-world settings and problems.

Given that the purpose of inventing the adaptive behavior construct was to reduce the likelihood that someone might be diagnosed as having MR solely on the basis on a single measure of academic intelligence (IQ), there is a major advantage in broadening the definition of MR to include the two aspects (social and practical) of everyday intelligence. The advantage is that, historically and logically, when we think of someone who has MR we think of someone who has low intelligence, and redefining adaptive behavior to encompass everyday intelligence keeps that historical and logical connection while weakening the tendency to think of low intelligence solely in IQ terms. Defining adaptive behavior, as has been done in all of the AAMR manuals since 1961, in ways that are not specifically tied to the notion of low but broadened intelligence, threatens to further confuse the definition of MR by bringing into the equation aspects of human competence/incompetence such as mental illness or antisocial behaviors other than those specifically reflecting low intelligence.

It is probably because adaptive behavior measures have not been clearly enough connected to intelligence, broadly defined, and thus to the historical construct of MR, that they have been ignored more than they have been used. In the field of adaptive behavior measurement, as with other constructs (including intelligence), current instruments have largely been modeled on the first widely used measure, which in this case was the AAMD (later AAMR) Adaptive Behavior Scale, widely known as the "ABS." In addition to providing a summary or overall index, the ABS, and its successors such as the Vineland-I and Vineland-II, have provided two subordinate scores, in addition to an overall adaptive behavior score. The two subordinate domains tapped by these instruments have both of the following:

1. Competence in dealing with practical aspects of life, what have been termed "self-help" and "community use" skills such as dressing and feeding oneself and using public transportation.
2. Competence in dealing with social-emotional aspects of life.

On the surface, these seem to have some logical connection with the everyday practical and social domains in Thorndike's tripartite model. A major problem, however, is that the social-emotional domain of adaptive behavior was termed "maladaptive behavior" and consisted of such things as the presence or absence of incompetent behaviors directed against oneself (e.g., anxiety, self-abuse) or others (e.g., aggression, noncompliance).

Anyone with deep experience in the MR field knows individuals whom they consider to clearly have MR but who have few if any maladaptive behaviors (i.e., they lack substantial psychopathology). Such individuals, however, if they are correctly diagnosed, almost always demonstrate deficits in social intelligence (i.e., they lack the ability to pick up social cues or anticipate reactions of others). A case that I have previously used to illustrate this point concerns "Bob," an adult man with Down syndrome who lived and worked in Omaha, Nebraska (Greenspan & Shoultz, 1981). The late Frank Menolascino, a mentor of mine who was one of the leading psychiatrists specializing in MR, actually used a videotape of an interview he did with Bob to show new psychiatry residents that one could have MR and yet be mentally healthy (i.e., lack maladaptive behaviors). Bob



indeed was a very well-adjusted person, who possessed many positive qualities. However, he did have serious social intelligence deficits and, thus, was appropriately given the diagnosis of MR.

One example involved a time when Bob was at a going-away party for a female social worker and started telling the woman's mother that he had long wanted to have sex with her daughter and then elaborated on this story, even after the mother showed obvious signs of discomfort. Another example involved a meeting in which several self-advocates were complaining about a state legislator who opposed funding a program which they supported. Bob made the serious suggestion that the group send a letter to this politician threatening to shoot him if did not change his position, and had a hard time understanding why sending such a letter was not a good idea.

The use in adaptive behavior measures of maladaptive behavior (i.e., acting-out or self-abuse), rather than social intelligence items, to tap the "social" aspect of adaptive behavior, had the effect of muddying the distinction between two disorders, MR and mental illness, that historically and conceptually have been seen as distinct. Furthermore, it missed an aspect of incompetence that, much more than maladaptive behavior (which may or may not be present in persons with MR), goes to the heart (as in the case of Bob) of what it means to be viewed as having MR.

This failure to frame adaptive behavior mainly in terms of low everyday intelligence was also seen in the fact that many of the items on the ABS and other instruments tapped whether a person habitually did a certain activity, such as being nice, rather than on whether he or she possessed an adequate understanding of why such an activity is desirable. This problem of confusing understanding with outcome behavior (which could reflect personality and motivation as much or more than understanding) is one that still afflicts adaptive behavior measures.

### ADAPTIVE SKILLS IN THE 1992 MANUAL

The T&C Committee that wrote the 1992 AAMR manual was somewhat taken with my early writings about the connection between adaptive behavior and nonacademic aspects of intelligence, as reflected in the fact that the manual's second and theoretical chapter cited me quite a lot, and used the tripartite model as the theoretical justification for the way they approached that aspect of the definition. Given the emphasis on the notion of competence and incompetence in the 1992 manual, the T&C Committee apparently liked my suggestion that adaptive behavior should be conceptualized in ability rather than adjustment terms. However, in a foreshadowing of 2002, the model of adaptive behavior adopted in the final 1992 manual diverged significantly from what I had been suggesting.

What happened is that the next-to-last draft of the manual did base the definition of MR and of adaptive behavior on the tripartite model, but at a brief meeting when the final draft of the manual was being planned, the committee backed away from the tripartite model and took a very different tack. However, because of time constraints or the fact that the approach they finally took lacked an adequate theoretical justification, the tripartite model was kept in as the theoretical framework for a definition that now bore no resemblance to it. The reason why the tripartite model was dropped at the last minute, according to personal communications to me from committee members, was concern

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about the lack of empirical support and the lack of valid measures for the domain of social intelligence. So, with relatively little discussion, the committee took an adult community skills curriculum which possessed far less empirical support off the shelf and used it as the basis for a model of "adaptive skills" with nine dimensions. Later, after pressure from AAMR's recreation division, this was expanded to ten dimensions with the addition of leisure skills, as if more advertising were needed that science had little to do with the selection of this model.

In another arbitrary decision, the T&C Committee adopted a polythetic, so-called Chinese menu, approach to meeting the adaptive skills criterion, noting that in order to be eligible for a diagnosis of MR, a person had to show deficits in at least two out of the ten adaptive skills. Why two and not three, four, or five? The only answer given in the manual is that the committee wanted to make the criterion a fairly easy one to meet.

My biggest concern about the 1992 manual was its failure to recognize the importance and centrality of social intelligence deficit—which I have consistently argued is the most important, and most overlooked, domain—as the key to capturing the essence of the MR taxon. As already noted, skepticism about the importance of social intelligence framed mainly in terms of measures, but also reflecting doubts about the construct itself, was responsible for the decision to reject the tripartite model—except in the unchanged theoretical chapter—in the first place. Lack of appreciation for the importance of social intelligence was also reflected in the ten-domain model itself, in two ways:

1. Only one out of ten as opposed to my proposed one out of three domains dealt with social aspects of competence.
2. The construct of "social skills" is different, in very profound ways, from "social intelligence."

The term *social skills* is widely used by behaviorists and refers to the extent to which an individual engages in behaviors that are socially valued (Matson & Fee, 1991). In seeking to make people with MR more socially accepted, behaviorists have emphasized such isolated skills as eye contact, greeting verbalizations, and a range of other positive behaviors. There has been a consistent lack of emphasis in the behaviorist social skills literature on the cognitive underpinnings of socially competent behavior, which may explain why there is so much bemoaning of the lack of "generalizability" of acquired social skills from one situation to another. (I shall never forget a young woman with moderate MR who was trained to emit greetings, and then said "hello" so frequently and indiscriminately that her greeting verbalizations had to be extinguished, as they were driving the staff crazy.)

The Adaptive Behavior Assessment System (ABAS; Harrison & Oakland, 2000) was the first major adaptive behavior measure to base itself on the 1992 manual. In line with the 1992 manual, it had one subscale, termed "social," that mainly listed positive behaviors as "says 'thank you' when receiving a gift," "offers assistance to others," and "congratulates others." Such behaviors are more a function of what I have previously termed "character" (e.g., niceness toward others) than of social intelligence (e.g., understanding of others). The only other of the 10 adaptive skills in the 1992 manual that touched indirectly on the socio-emotional realm was "self-direction." On the ABAS, this domain was captured by a few other character items (i.e., "routinely arrives at places on time" and

"stops a fun activity . . . when time is up"), but mainly contained items such as "controls anger," "controls disappointment," and "controls frustration" that reflect mostly what I have termed "temperament," which is the ability to control emotions and attention.

In the 2003 revision, now termed the ABAS-II, the authors recombined the original subscales, such that "self-direction" is now part of the "conceptual" domain, a combination that to me makes no sense. To have more than one subscale in the new "social" domain, the authors combined the "social" subscale with the "leisure" subscale, which contains mostly nonsocial items such as "plays alone with toys, games or other fun activities." In other words, in the ABAS-II—and, I can assure you, in other adaptive behavior scales such as the Vineland-II—we have a quantitative index that is conceptually and methodologically a mess. (See also Greenspan & Switzky, "Lessons from the Atkins Decision," this book.)

Thus, the construct of social skills, as defined by the 1992 manual and as operationalized on measures such as the ABAS, is not that different from what pre-1992 AB measures termed "maladaptive behavior" (i.e., the presence or absence of psychopathology), as good character is the absence of beating up on others, while good temperament is the absence of beating up on oneself. All of such information likely is useful in devising a service plan but is irrelevant to the main function of adaptive behavior assessment, namely the diagnosis of MR.

As Herman Spitz (1988) has pointed out, and I have also said repeatedly, MR is in essence a "thinking disorder." In contrast, behaviorists—and the 1992 adaptive skills model was essentially a behaviorist checklist—have tended to think of MR as a "learning disorder." To paraphrase Spitz, a learning disorder is characterized by a paucity of behavioral schemas, while a thinking disorder is characterized by an inability to apply those schemas flexibly and appropriately in novel and complex situations. People with MR likely have a greater ability than previously appreciated to learn new schemas (skills), but there are still real structural limitations, likely reflecting brain abnormalities, in the ability to apply those schemas/skills effectively, especially in complex and challenging situations. The term "intelligence" implies thinking, while "skill" implies learning. The essence of MR, from the standpoint of definition and diagnosis, is thus found not in the relative absence of especially routine skills but in the relative inability, especially under conditions of ambiguity or stress, to figure out when and how to apply those skills.

### ADAPTIVE SKILLS IN THE 2002 MANUAL

On the surface, the 2002 manual appears to have incorporated the tripartite model into the definition of MR, but in fact it is not the tripartite model of "adaptive intelligence" that I had proposed but rather a transformed version of "adaptive skills" proposed by Robert Schalock (1997). He was a member of both the 1992 and 2002 T&C Committees and played a very influential role in coming up with the adaptive behavior component in the 2002 manual. I know that firsthand, as I served briefly during the early stages of that committee. The 2002 committee recognized early on that the ten-domain model of adaptive skills in the 1992 manual had been a mistake, as reflected in the widespread reluctance of clinicians and agencies to use the 1992 definition. The committee's solution was to restore into the definition of MR the term "adaptive behavior," thus defining MR as a

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disorder marked by deficits in both intelligence and adaptive behavior, but to now further define adaptive behavior as comprising three adaptive skill areas: "conceptual adaptive skills," "practical adaptive skills," and "social adaptive skills."

One can see that this differs fundamentally from my repeated insistence that MR is a disorder marked by deficits in three areas of intelligence. Specifically, the 2002 definition continued the practice, established in 1961, of viewing adaptive behavior as something different from intelligence and thus of less centrality to the diagnosis, given that persons with MR have historically been described mainly in terms of their low intelligence. If the committee had instead used, as I recommended, the tripartite model of intelligence, there would no longer be any need for this artificial invented construct of adaptive behavior. Or, if one wanted to continue using the term, perhaps because of some unwillingness to put other aspects of intelligence on quite the same level as IQ, then one could say that "MR is a disorder marked by deficits in academic intelligence (i.e., IQ) and adaptive behavior, with adaptive behavior operationally defined as everyday (i.e., practical and social) intelligence."

This last formulation would have been a slightly less direct and therefore less desirable way of saying "MR is a disorder marked by deficits in academic, practical and social intelligence," but it would have at least acknowledged an obvious and very simple truth, namely that MR is a disorder characterized by low intelligence, broadly defined. Instead, the solution adopted by the 2002 T&C Committee allowed continuation of the convoluted, artificial and, in my opinion, mistaken argument that intelligence equals IQ scores plus some set of behaviors other than intelligence.

The idea of morphing the tripartite model of adaptive intelligence into a tripartite model of adaptive skills was proposed in the chapter that Schalock (2003) wrote for the first e-book version of this volume. (A draft of the book was substantially completed well before the manual was completed, even if the e-book was published a year later in 2003.) That chapter built on an even earlier formulation of the same ideas, contained in a chapter written by Schalock (1999) for a book on adaptive behavior that he edited and in which I (Greenspan, 1999b) was also a contributor. In my chapter I argued that adaptive behavior should be viewed in terms of one's ability to negotiate challenging microsituations, such as a deceitful and manipulative interpersonal interaction. Schalock characterized his proposed solution as a way of "integrating" intelligence and adaptive behavior, by transforming the tripartite model of intelligence into a tripartite model of adaptive behavior/skills. On the contrary, I saw it as a way, whether intended or not, to continue to support the primacy of IQ scores in the diagnosis and definition of MR, by maintaining the shaky notion that "conceptual skills" is something other than conceptual or academic intelligence.

Schalock (2004) has acknowledged to me that the tripartite model has not been fully implemented, and he sees both the 1992 and 2002 as transitional documents that may, eventually, evolve into a fuller implementation of the model. I have no reason to doubt his sincerity and optimism, but 100 years of the field's infatuation with the twin notions that IQ scores = intelligence and MR = low intelligence leads me to question his estimate of that endpoint's being reached in the foreseeable future. Maintaining the idea that "adaptive skills" are anything other than "intelligence applied in various settings" is likely

to perpetuate the idea that intelligence (i.e., IQ test scores) is central to what MR is all about, while adaptive behavior is still peripheral.

The compromise by which a tripartite model of adaptive intelligence morphed into a tripartite model of adaptive behavior may seem elegant in a Hegelian sense, and may make its adoption more politically attainable, given how resistant most psychologists are to any effort to suggest that IQ test scores no longer rule, but it does not, in my opinion, solve the problem of establishing a more valid basis for deciding if someone does or does not have MR. One reason it does not is that it contributes to the development and acceptance of measures such as the ABAS-II, on which an item such as "has pleasant breath" is taken seriously as a basis for diagnosing MR.

In the 2002 manual, a diagnosis of MR is now based on deficits in intelligence still defined as below minus two standard deviations on a measure of full-scale IQ, taking into account standard error of approximately five points and significant deficits in one out of the three adaptive skill domains of "conceptual skills," "practical skills," or "social skills." As was the case in 1992, the 2002 criterion was made fairly easy, in order that adaptive behavior not be too great an impediment to allowing someone with low-enough IQ to qualify as having MR.

A new step in making the definition more "scientific" is the strong indication for the first time in the various AAMR manuals that the adaptive behavior criterion should be derived from use of a formal instrument with population norms, and that a diagnostic decision be based on the same minus-two-standard-deviations equation that has been applied to IQ. The notion that use of a numerical index makes a definition more scientific is discussed later on, but one obvious problem with this notion is that if the number is based on a conceptual and methodological muddle (e.g., measures such as the ABAS-II and the Vineland-II), then what we have is a clear case not of science but of pseudoscience. That is not surprising, since the entire history of MR, starting with Goddard's bogus claim to have uncovered the menace of hidden mental defectives, is the history of a pseudoscience trying to pass as or turn itself into a real one, by using methods (MA or IQ cutting scores) whose main claim to scientific respectability is the fact that they produce a number.

Ranting aside, and aside also from the metatheoretical issues raised earlier, here is the main problem I have with the new formula. As indicated, a consequence of having the tripartite model become a model of "adaptive skills" rather than of "adaptive intelligence" is that it became necessary that the "conceptual skills" component of adaptive behavior be portrayed as something other than "conceptual intelligence" (i.e., IQ scores). Otherwise, using the formula  $MR = \text{low IQ} + \text{low (one-out-of-three) adaptive skills}$ , one would have a situation where an individual could be diagnosed as having MR on the basis of having deficits in IQ and academic incompetence only. In such a scenario, the idea that a diagnosis of MR must be based on more than academic incompetence somehow gets lost.

In order to avoid that problem, and to placate publishers who had invested heavily in the 1992 model, the approach taken by authors of the 2002 manual was to plug scales from the 1992 list into the three skill areas, including conceptual skill, in a relatively arbitrary manner. Thus, as depicted in Table 5.2 on page 82 of the 2002 manual, "Social Skills" was constituted by combining "social" and "leisure" from AAMR 1992, "Practical Skills" was constituted by combining "Self-Care," "Home Living," "Community Use," "Health and

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Safety," and "Work" from AAMR 1992, and "Conceptual Skills" was constituted by combining "Communication," "Functional Academics," "Self-Direction," and "Health and Safety" from AAMR 1992.

This may have nicely solved a practical problem for the 2002 T&C Committee, but does it make sense, either theoretically or practically? I don't think so. Conceptual Intelligence has now morphed into a "Conceptual Skills" domain having only two subscales ("communication" and "functional academics") that have any connection to the conceptual intelligence piece of the original tripartite model, and it adds one subscale ("self-direction") that is really a measure of temperament which has nothing to do with the taxon of MR and another subscale ("health and safety") that really belongs in the practical skills domain.

If we are to remain saddled, as I am afraid we are, with the notion that adaptive behavior involves "skills" rather than "intelligences", then here is my own proposed Hegelian synthesis, which I believe is more acceptable both theoretically and practically than the one that the authors of the 2002 manual came up with (under, I suspect, very hasty circumstances). Simply drop "conceptual skills" from the right side of the plus sign, thus integrating it more into the notion of "intellectual processes" on the left side of the plus sign. Adaptive behavior would be redefined as significant deficits in "practical" and "social" skills in meeting everyday challenges, and these skills would, hopefully, be defined operationally more in terms of cognitive processing than in terms of personality styles. Thus, one would still have the tripartite model, but the conceptual piece would be moved over to the left side of the plus sign, as in the revised formula: MR = deficits in intellectual functioning (e.g., IQ, language, academics) + deficits in everyday functioning (e.g., practical and social skills).

This notion that adaptive behavior should be grounded in the idea of "everyday competence" (e.g., social plus practical deficits) was actually something that Robert Sternberg (1985) proposed in one of his few forays into the MR field, and that I proposed (Greenspan & Driscoll, 1997) in a revision of my model of personal competence a few years ago. One could still use a polythetic (one-out-of-two) decision criterion, if one wanted to stay with an artificial cookbook formula. Personally, I prefer an approach more grounded in the notion of requisite aspects of the MR taxon (e.g., all people with MR are practically and socially incompetent, defined in terms of "stupidity" rather than preference), as I discuss in the last section of this chapter.

### WHY THE AAMR SEEMS UNABLE TO DEVISE A BETTER COOKBOOK

I have already vented enough spleen, and there is no need to beat a dead—or, in this case, sick—horse. So I shall keep this section brief. There are lots of reasons why the AAMR keeps coming up with a flawed manual, two of them being the inevitable difficulty of getting a committee to agree on anything, and another being my own and others' failure to present a clear enough rationale or to come up with acceptable alternative measures, particularly for the "social" piece of the equation. Also, the "truth" is not always easy to figure out, especially in a situation where there are conflicting pressures from numerous constituencies.

In an obituary for the 1992 manual (Greenspan, 1997), I pointed out, without any pejorative intention, that the process of producing an AAMR manual is inherently "political."

Among the many conflicting political pressures faced by the T&C Committee were: the AAMR wanting the manual out fast (it is a major money maker for a financially strapped organization), psychologists threatening to bolt if their beloved IQ test was disrespected, researchers screaming "science," advocates wanting something respectful (i.e., the notion that one can have MR and still have normal talents), the international faction wanting the WHO to be honored, the DSM-IV threatening to go off in its own direction, internal factions on the T&C Committee, and various AAMR divisions wanting their own interests accommodated. In light of these pressures, it is a wonder that the 1992 and 2002 manuals turned out as well as they did.

In the most insightful analysis ever written about the political nature of any diagnostic manual, sociologists Stuart Kirk and Herb Kutchins (1992) described the writing of the path-breaking DSM-3, which has remained fundamentally unchanged in subsequent revisions, as the result of a tremendous internal battle within the psychiatric community between old-guard psychoanalysts and new-guard biological and descriptive psychiatrists. The new guard won this battle, not on the basis of their superior rhetoric—it is hard to beat psychoanalysts at that game—but on the basis of their superior claim to being "scientific," a notable weakness of psychoanalysts. They did this by demonstrating—debatably, it turns out—that the new diagnostic scheme was more reliable, using a newly invented statistic: Cohen's kappa. Thus, a diagnostic manual that was really grounded on a different kind of theory, was successfully sold on the basis that it was more reliable, and therefore more scientific (i.e., based on a number). Whether or not it did a better job of making true discriminations among people was another matter than was never really resolved.

A basic belief of most psychologists, perhaps reflecting a neurotic need to be seen as "real" scientists, is that high reliability leads inevitably to high validity. That is not always the case. J.P. Guilford (1965), using intelligence as an example, argued that while many constructs are multifaceted, the most internally reliable measures are reliable because they are narrow, which means that they hardly have adequate content validity. Thus, the best way to attain validity is to base it on the construct of interest, even if it may be a little hard, perhaps because of its fuzziness, to measure it reliably.

Assuming, as I argue, that "gullibility" is a hundredfold more important as an index of the MR taxon than brushing one's teeth daily, then a valid adaptive behavior scale is one which contains many gullibility items, even if one has to word these items in a way that can't be rated as reliably as "wipes up spills at home" (an item on the ABAS-II). This has important implications for the diagnosis of MR, as probably the most valid index that one has MR is also not completely reliable (which is why one should always use many raters), namely whether or not others in a person's community view him or her as having MR.

I have already indicated that probably the biggest obstacle to the full adoption of the tripartite model for defining MR is the idea that IQ is somehow more "scientific" than adaptive behavior, especially given that IQ measures are highly reliable (i.e., they produce roughly the same score from one time to another and regardless of who is administering the test, and the scales are fairly internally consistent). The need to be seen as more scientific is reflected in the debatable decision of the 2002 committee (debatable given the inadequate measures currently in use) to apply a statistical formula to the adaptive behavior criterion as well.

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My main argument against sole reliance on the IQ score as a basis for diagnosing MR is that an IQ score does not provide a sufficiently valid basis for diagnosing a disorder that historically (i.e., before invention of the IQ test, and even before universal schooling) has been viewed mainly in terms of inability to function independently and safely in the social and practical world. The biggest myth in the intelligence field is that IQ scores equal intelligence. In fact, the first and all subsequent IQ measures assess academic potential, precisely because they were compiled by taking tasks from different grades within the school curriculum. If intelligence refers to the ability to apply "thinking" to challenges in the world, then it should be obvious that there are challenges in the world that people, whether children or, especially, adults, face that have nothing to do with what they learn at school. This brings me back to the point that falls at the heart of this chapter, and which I shall expand on in the final section: An artificial cookbook formula (i.e., minus two standard deviations in X and Y psychological tests) may look more scientific, and may be more reliable (which remains to be proven), but does not necessarily lead to a diagnosis that is true.

#### CAN WE DEVISE A DEFINITION OF MR BASED ON ITS TRUE NATURAL TAXON?

No one is more aware than I that people with mild MR can have a mixed profile of abilities and deficits, and that there may even be areas of near or actual normal functioning. The question is: Are there behavioral competencies which, if present, should rule out automatically any eligibility for a diagnosis of MR? The fact that Mr. Jones, in the example at the beginning of this chapter, can talk adequately in a conventional social setting does not, in my opinion, rule out such a diagnosis, even if some laypeople or clinicians—some of who are essentially laypeople when it comes to MR—might disagree. On the other hand, if Mr. Jones never gave any sign of being easily fooled or tricked in complex and deceitful social settings, then I would think it likely that the diagnosis of MR was a mistaken one, regardless of what score he may have received on one of the adaptive behavior scales in use. However Eric did, as described, have a history of frequent and dramatic gullibility, so that requirement of the universal natural taxon was met.

In the 2002 AAMR manual, there is only one absolute requirement, namely that an IQ be below 70 (75 if one takes into account standard error). In terms of the adaptive behavior criterion, one can be substantially average or even above average in two of the three areas in the tripartite model of adaptive skills and still have MR. To me that seems somehow wrong, based both upon theory and, more importantly, upon how people whom we believe to have MR actually function in the world. If the cookbook says that one can be normal in one's ability to see through deceptive manipulation, forgetting for a minute that no gullibility items are on the ABAS-II (and only one on the Vineland-II), then I say "Better ditch the cookbook." Fortunately, mention of the word "gullibility" finally made it into the 2002 manual, but hardly in a major way.

In the earlier (Greenspan, 2003) but now totally rewritten version of this chapter that was in the electronic edition of this book, I argued that essence of the MR taxon, which I then termed "prototype" or "behavioral phenotype," had three components:



1. It is grounded in the implicit, even if not always established, notion that a person has developmentally based abnormal brain structure or functioning.
2. It is grounded in the notion that a person has limitations in "thinking"—that is, he will be seen as "dumb" in coming up with solutions to real-world problems, particularly when these are novel, complex, or anxiety producing.
3. It is grounded in concern that, because of these brain-based limitations in thinking ability, a person will be vulnerable to catastrophic failure, academically, practically, socially, unless formal or informal supports and protections are put in place.

An obvious implication of this formulation of MR's natural taxon is that any definition of MR should emphasize clearly the idea of organicity, the idea that incompetence is solely based on thinking limitations, and the idea of vulnerability and need for supports. In fact, none of these three core components of the natural taxon are emphasized clearly in the 2002 model. With respect to organicity, the 2002 definition makes no real mention of etiology, and it is only very indirectly tied in with the idea of origination in the developmental period (because that is interpreted temporally and not etiologically). With respect to vulnerability and supports, there is no mention of vulnerability in the definition and only very indirectly is there mention of supports, in that the term "disability" implies need for supports. However, the notion of thinking limitations is partly satisfied in discussion of intellectual processes, but is undercut by the failure to specify that limitations in adaptive behavior must be considered only in regard to the application of thinking skills and not in terms of a grab-bag of behaviors reflecting inclination more than thinking applied to the everyday world.

Another major problem with the wording of the 2002 definition and previous ones is that by putting intelligence first (i.e., MR is "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior"), the definition encourages the tendency (documented in the Greenspan & Switzky chapter, "Lessons from the Atkins Decision," in this book), where adaptive behavior is considered only if a low-enough IQ score is attained, and not if IQ score is not low enough. In other words, an implication of the current cookbook formula is that adaptive behavior can be used only to rule out a false positive where low IQ gives a wrong diagnosis that a person has MR, but cannot be used to rule out a false negative where too-high IQ gives a wrong diagnosis that a person does not have MR. That seems to me to be fundamentally wrong, and if the cookbook formula is to be valid (i.e., to result in diagnoses that are in line with the natural taxon), then adaptive behavior needs to be able to rule out false negatives as well as false positives.

One way of doing this is to reverse the order of the wording and place adaptive behavior first in the equation. Here is one formulation of a definition in which this is done (this is also formulated in slightly different form in our *Atkins* chapter): MR (preferably called something else, perhaps Intellectual Disability) is "a form of disability, first suspected in childhood or adolescence, that is characterized by significant deficits in adaptive (social, academic, and practical) functioning that are attributable to significant brain-based limitations in the ability to think and process information adequately. These limitations in thinking make a person very vulnerable to catastrophic failure in various aspects of every-

day life, and minimize the risk of harm. It also be expected that a person with MR will have given infinite interaction. The fact that in the past o

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day life, and require the use of formal and informal supports and protections in order to minimize the occurrence and consequences of this vulnerability." This definition should also be expanded to indicate that MR is a condition inferred from how a person is viewed in his or her natural ecology, such that opinions by knowledgeable laypeople should be given infinitely more weight than opinions by a clinician based on a brief and limited interaction. Thus, in a very real sense, the best evidence that a person actually has MR is the fact that almost everyone who knows him thinks he has MR, and has given evidence in the past of using that or some similar term to describe him.

By placing the notion of adaptive functioning in front of "the ability to think," it is established both that the condition is defined first and foremost by actual behaviors, rather than by IQ scores, and that measures of adaptive functioning will always be needed in making a diagnosis of MR or not-MR. Furthermore, by indicating that these limitations are attributable to limitations in thinking, it is hoped that measures of adaptive behavior will contain many items such as "is vulnerable to trickery and deceit" or "cannot cook without producing an inedible mess or burning down the house" and very few items such as "has clean hair" or "has pleasant breath."

To get back to the example of Eric Jones with which I started this chapter, I want to delve a little bit into the fundamental question which needs to be answered if an adequate manual is to be devised, and that is: "Are there certain abilities or inabilities, derived from MR's natural taxon, which will universally need to be present or absent in deciding whether a person actually has or does not have MR?" The relativistic cookbook formula contained in the 2002 manual does not, as I have indicated, do this. It is my belief, however, that there are some universal aspects of the MR phenotype that must be in the definition if it is to be considered adequate.

At the risk of seeming somewhat crazed on the subject—it is hard to keep quiet when one feels one has made a major discovery—I think that a key to the universal natural prototype of MR is unusual gullibility (Greenspan, Loughlin, & Black, 2001). This is an aspect of the MR taxon that was mentioned in early textbooks (Ireland, 1877; Morrison, 1824), but has been almost absent from the recent research or clinical literatures. However, it is central to the MR taxon as it manifests in the real world, as seen in a story that appeared in my local newspaper.

It involved a woman, Sherri Bramer, who became lost at sprawling Denver International Airport when her plane was diverted to a gate other than the one posted. The main concern her frantic waiting family members felt, as they searched for the 52-year-old woman (described as having mild MR), was over a topic that is rarely even addressed in the scholarly literature: the possibility that her extreme gullibility made her vulnerable to being exploited if she fell into the wrong hands. As described by journalist Lynn Bartels (2004), Sherri's 57-year-old brother Keith said that the first thing that occurred to him and his 81-year-old mother, when they realized that Sherri was lost, was that "Sherri is very vulnerable. She'll do whatever you say, go wherever you want her to." In other words, their concern was fueled by a type of incompetence that is addressed in only a single item on one the leading adaptive behavior measure, namely Sherri's extreme gullibility and her tendency to believe anyone and trustingly do whatever was asked of her, even by strangers.

Similar evidence that gullibility is a major issue for cognitively impaired individuals can be found in fiction, as in the story of the gullible puppet Pinocchio (Greenspan, 2004), and more importantly in many other real-life examples. One such example can be found in the recent award-winning documentary *The Collector of Bedford Street*, by film maker Alice Eliot (2001). This film has won wide acclaim as the story of how neighbors in New York's Greenwich Village banded together to set up a trust fund to enable an unrelated man with mild MR, Larry Selman, to continue to live in their midst. The media emphasized that this act of caring was a form of thank-you to Mr. Selman for being such a kind person himself (he gets his nickname of "collector" from his having raised hundreds of thousands of dollars for charity in the neighborhood over the years). In fact, the main impetus for setting up the fund was that Larry's extreme gullibility had placed him and the other tenants in danger from repeated acts of exploitation by homeless people (e.g., taking his keys and ripping off his possessions, damaging the building, and terrorizing the residents). Yes, the neighbors are to be commended for caring about Mr. Selman, but they cared about him (and their own interests) not just because he was good but because he was extraordinarily socially vulnerable. This social vulnerability is not a collateral aspect to Mr. Selman's MR, similar to having pleasant breath. Larry's *extreme gullibility* was the central thing, far more than his IQ score (which most of the neighbors didn't even know), that caused all of the people who loved him to see him as having MR. Unless the next AAMR manual comes up with a definition that taps into such a universal aspect of the MR natural taxon, then the process of diagnosis and of fiddling around with the cookbook formula will be an artificial game with little relevance to the real world and the real people living in it.

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