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Defining Mental Retardation and Ensuring Access to the General Curriculum

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Abstract: Release of the most recent edition (2002) of the American Association on Mental Retardation's terminology and classification manual provides a point in time to consider ways in which mental retardation is understood and how that understanding contributes to educational practices to promote positive outcomes for students with mental retardation. Since release of the previous edition of the manual (in 1992) much has changed about the context in which educators work and students are taught. Language in the 1997 reauthorization of IDEA with regard to providing access to the general curriculum intended to align special education practice with prevalent educational reform initiatives. The shift in the 1992 definition and classification system (continued in the 2002 manual) toward a supports paradigm and defining mental retardation as a function of the interaction between a person's independent functioning and the context in which that person lives, learns, works and plays provides a framework within which we can consider how to more effectively enable students to gain access to the general curriculum.

Defining mental retardation has always been a contentious process and it is probably the case that release of the 10th Edition of the American Association on Mental Retardation (AAMR) handbook on definition and classification (Luckasson et al., 2002) will be no different. However, based on response of the field of special education to the 1992 definition, which introduced significant changes to the definition and categorization process and placed greater emphasis on intensity of support needs instead of levels of deficits, it seems more likely that the release of the 10th edition will be greeted with silence, if not ambivalence, on the part of many special educators. The 1992 system reflected intent of the AAMR's Ad Hoc Committee on Terminology and Classification to link classification of mental retardation to a system of supports and move the diagnostic process away from it's historic reliance on levels of deficit identified by performance on an IQ test. These definitional changes mirror the field of mental retardation's shift from an emphasis on providing *programs* to people with mental retardation to an emphasis on designing and delivering individualized *supports*.

The field of special education has undergone a similar shift in emphasis toward providing supports to enable students to achieve success and gain greater access to the general curriculum. Yet too often this philosophical shift has not resulted in changes to the educational services provided to students with mental retardation. Intent of this article is to suggest that those persons who are concerned about programmatic aspects of the education of students with mental retardation can and should use release of the 10th edition of the definition system as a chance to move the field away from its historic reliance on labels and typological thinking toward models of understanding mental retardation that emphasize supports and provide a vehicle for providing greater access to the general curriculum. That is, one aspect of the 1992/2002 definitional

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frameworks that has not been adequately detailed is that it provides a more useful system within which to consider programmatic issues related to education of students with mental retardation. The following section overviews both the 9th edition (1992) of the manual and the classification system introduced in that text and the 10th edition (2002) of the manual, highlighting the changes from the previous version. This, in turn, is followed by a discussion of uses of definitions in education and, finally, of ways in which the new definition system enables us to achieve access to the general curriculum for students with mental retardation.

Defining Mental Retardation

The 1992 Definition

The 9th edition of AAMR's terminology and classification manual (Luckasson, et al., 1992) introduced a definition and classification system that "reflects a changing paradigm [in the field of mental retardation], a more *functional* [italics added] definition, and a focus on the interaction between the person, the environment, and the intensities and patterns of needed supports" (Luckasson et al., 1992, p. x). The manual stated:

> Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (p. 1)

Further, the manual stated, "the following four assumptions are essential to the application of the definition:

> Valid assessment considers cultural and linguistic diversity as well as differences in communication and behavioral factors;
> The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for supports;
> Specific adaptive limitations can often coexist with strengths in other adaptive skills or other personal capabilities; and
> With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve. (p. 1)

Readers familiar with previous AAMR definitions will note that the language in this version of the definition was not drastically different from those earlier versions. In fact, some critics of the 1992 definition identified its similarity to previous definitions as its primary weakness (Greenspan, 1997). The definition and classification process retained features of previous definitions, including using intelligence testing in the classification process, the requirement for emergence in the developmental period (e.g., prior to age 18), and the need for a concurrent deficit in adaptive behavior. The 1992 definition identified ten adaptive skill areas in which limitations in adaptive behavior need to occur.

Much of the discontent with the 1992 revisions related to issues of diagnosis (MacMillan, Gresham, & Siperstein, 1993; Reiss, 1994), particularly with regard to impact of shifting the IQ score needed for diagnosis higher or lower (Jacobson & Mulick, 1992; MacMillan et al.). This has been an ongoing debate in the field, with the IQ ceiling for classification of mental retardation ranging from one standard deviation below the mean (approximately 85) in 1961, to two standard deviations (approximately 70) in 1973.

Given obvious similarities between this version and previous definitions, one has to question if the statement by Polloway, Smith, Chamberlain, Denning, and Smith (1999) that the "manual was a significant departure from the traditional classification system" (p. 201) was warranted. After all, researchers, clinicians and practitioners have argued for years about how to measure and quantify adaptive behavior and where to place the level of IQ score for diagnostic purposes. What makes the definitional process introduced in the 9th edition a significant departure from previous versions is that it was the first step

toward forcing the field to think differently about mental retardation and how we intervene in the lives of people with that label. Polloway et al. asserted as much by commenting that:

> The publication of the ninth manual on definition, classification, and terminology in mental retardation by the American Association on Mental Retardation formally asserted the importance of supports as a paradigm in the field of mental retardation. (p. 201)

The challenge for the field of special education is to operationalize this supports paradigm, and the first step towards that is to examine how the definition challenges us to think about mental retardation in relation to design of such supports. The classification system proposed a "functional" definition of mental retardation in which mental retardation is not something that a person has or something that is a *characteristic of the person*, but is instead a *state of functioning* in which limitations in functional capacity and adaptive skills must be considered *within the context* of environments and supports. The manual's authors proposed, "mental retardation is a *state* in which functioning is impaired in certain specific ways" (p. 10). A *functional limitation* is defined as the "effect of specific impairments on the performance or performance capability of the person" while *disability* is described as the "expression of such a limitation in a social context" (p. 10). Luckasson et al. (1992) noted, accordingly, "mental retardation is a disability *only* as a result of this interaction" (p. 10); that is, *only* as a result of the interaction between the functional limitation and social context, in this case the environments and communities in which people with mental retardation live, learn, work and play.

This functional model suggested that mental retardation is not something a person *has*, like a disease, nor is it something someone *is*, but is instead a state of functioning that exists based on *the interaction between the person's functional limitations and the social or environmental context in which that person exists or functions.* The idea that mental retardation does not reside within the person as a disease or characteristic of that person is not new, but it also has not been emphasized in education to a large degree. Yale University psychology emeritus professor Seymour Sarason once noted that "mental retardation is never a thing or a characteristic of an individual, but rather a social invention stemming from time-bound societal values and ideology that makes diagnosis and management seem both necessary and socially desirable" (1985, p. 233). Education's psychometric orientation has emphasized the idea that mental retardation is a characteristic of the person, but the 1992 AAMR definition moved the categorization process away from that perspective and aligned it with the supposition that mental retardation is a social construct that can only be defined within sociocultural and environmental contexts. This sense of mental retardation as being a social construct is not completely foreign to education. It was not unusual, for example, during the 1970s to hear reference to the "six-hour retarded" child as describing a student with mental retardation with limited support needs (e.g., mild mental retardation). This referred to the fact that the child functioned appropriately or adequately in contexts or environments like his or her home, neighborhood, or community, and only had difficulty during the six hours he or she was in school.

Thus the reconceptualization of mental retardation proposed by the 9th edition of the AAMR handbook placed considerable emphasis on the "powerful role that social-ecological variables play in human functioning" (Schalock, 2002, p. 53). Quoting Ramey, Dosset, and Echols (1996), Schalock noted that social ecology's "primary axiom is that to understand one's behavior, the individual's environment must be taken into account" (p. 53). Why is this important for consideration by educators? By defining the *disability* as a function of the reciprocal interaction between the environment and the person's functional limitations, the focal point of the 'problem' we must solve (e.g., ensuring that students are better able to succeed in life) shifts from being a deficit within the student to being the relationship between the student's functioning and the environment and, subsequently, to identification and design of supports to

address the individual's functioning within that context, with a primary focus on adaptations, accommodations and modifications to the context.

Intensities of Supports

Viewing mental retardation as a function of the interaction between capacity and environments or contexts places greater emphasis on need to provide supports and accommodations to enable persons to function within that environment. This is reflected in what may have been the most obvious change in the 1992 definition and classification system, the abandonment of the "levels of mental retardation" classification scheme. Previous manuals identified four levels of mental retardation (mild, moderate, severe, profound), determined by performance on standardized measures of intelligence. The 1992 classification system eliminated these levels and identified four intensities of needed supports:

> *Intermittent*: Supports on an "as needed" basis." Characterized by episodic nature, person not always needing support(s), or short-term supports needed during life-span transitions (e.g., job loss or an acute medical crisis). Intermittent supports may be high or low intensity when provided.
> *Limited*: An intensity of supports characterized by consistency over time, time-limited but not of an intermittent nature, may require fewer staff members and less cost than more intense levels of support (e.g., time-limited employment training or transitional supports during the school to adult provided period).
> *Extensive*: Supports characterized by regular involvement (e.g., daily) in at least some environments (such as work or home) and not time-limited (e.g., long-term support and long-term home living support).
> *Pervasive*: Supports characterized by their constancy, high intensity; provided across environments; potential life-sustaining nature. Pervasive supports typically involve more staff members and intrusiveness than do extensive or time-limited supports. (Luckasson et al., 1992; p. 26)

Defining Supports

Since the idea of supports, the process of providing those supports, and categorization of levels of supports are at the heart of the 1992 definition, it is important to understand what is intended by the use of this term. The 1992 AAMR manual defined supports as:

> Resources and strategies that promote the interests and causes of individuals with or without disabilities; that enable them to access resources, information and relationships inherent within integrated work and living environments; and that result in their enhanced interdependence, productivity, community integration, and satisfaction. (Luckasson et al., 1992; p. 101)

Luckasson and Spitalnik (1994) suggested, "supports refer to an array, not a continuum, of services, individuals, and settings that match the person's needs" (p. 88). These authors refer to a 'constellation' of supports needed by people with mental retardation where, as depicted in Figure 1, the person is at the center. This figure depicts types of supports, radiating outward from self-directed and self-mediated supports, like the person, his or her family and friends and non-paid supports (e.g., coworkers or neighbors) to generic supports (those that everyone uses) and specialized supports like those provided in a mental retardation service system.

When is a support not a support? That is, what characteristics of 'providing supports' differentiate this intervention strategy from traditional models of service delivery? There are several aspects of a supports model that differentiate it from other models. First, there are the three 'key aspects of supports' identified in the 1992 AAMR manual: (1) they pertain to resources and strategies; (2) they enable individuals to access other resources, information, and relationships within integrated environments; and (3) their use results in increased integration and enhanced personal growth and development (Luckasson et al., 1992, p. 102). In other words, supports have the unambiguous intent to enhance community integration and inclusion by enabling people to access a wide array of resources, information, and relationships. Sec-

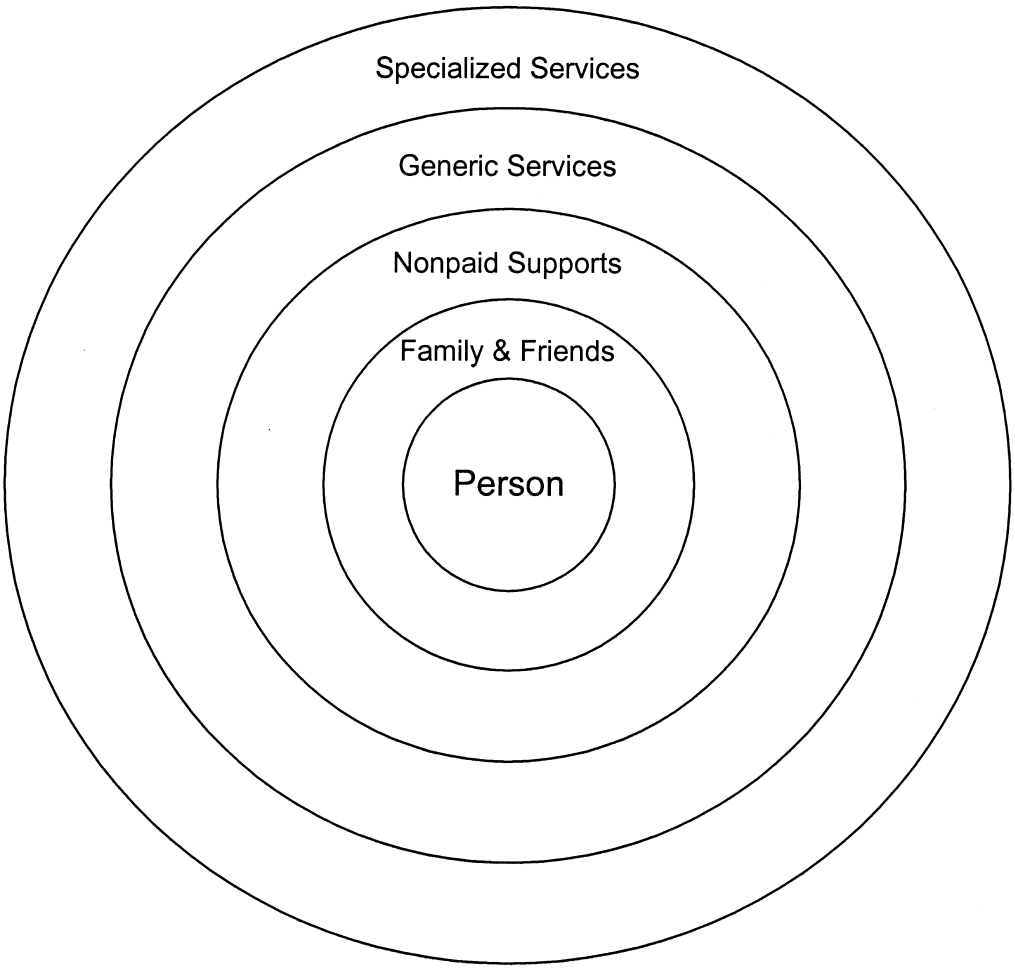

Figure 1. Constellation of supports (from Luckasson & Spitalnick, 1998).

ond, supports are individually designed and determined with the active involvement of key stakeholders in the process, particularly the person benefiting from that support. Traditional service delivery models, be they in education or adult services, have been designed primarily in a top-down process. Services were delivered in the form of 'programs' that were, at least initially, designed to meet as wide an array of needs of the population as possible. Financial and other resource restraints typically resulted in eligibility standards, which, in turn, often resulted in waiting lists to access a given program. Such models typically become paradigm-bound and driven as much by needs of the provider as by the person accessing those services.

One cannot adequately define supports by listing a limited set of resources, services or strategies. As Figure 1 illustrates, one can conceptualize more traditional generic mental retardation services as supports if that service meets two criteria. First, it is the individual and his or her family or allies who identify that particular service as a means to achieving self-determined goals pertaining to intervention. Second, the unambiguous intent of the service must be to promote community inclusion and participation and enhance personal growth. There are current models of service

delivery, including sheltered employment and congregate living facilities that simply do not meet that criteria and cannot be seen as viable support strategies.

The final factor differentiating supports from traditional models is that, as has been emphasized throughout this article, a supports model requires an active and ongoing evaluation of the ecological aspects of the 'disability' (because the 'disability' can only be defined within the context of the functional limitation and the social context) and efforts to design supports focus heavily on changing aspects of the environment or social context or providing individuals with additional skills or strategies to overcome barriers in those environments.

The 2002 Definition

The 2002 manual defines mental retardation as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18." (Luckasson et al., 2002, p. 1). The manual then stated five assumptions that are essential to the application of the definition:

> Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
> Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
> Within an individual, limitations often coexist with strengths.
> An important purpose of describing limitations is to develop a profile of needed supports.
> With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve. (Luckasson et al., 2002, p. 1)

The manual notes that this definition retains the three elements of the mental retardation definition; limitations in intellectual functioning, concomitant limitations in adaptive behavior, and occurrence in the developmental period. The 2002 definition system also retains the focus on mental retardation as a *function* of the relationship among individual functioning, supports, and contexts. This iteration of the manual emphasizes five dimensions that filtered through a system of supports, impact individual functioning (depicted in Figure 2). These five dimensions are intellectual abilities; adaptive behavior; participation, interactions, social roles; health; and context. Context is operationalized as the "interrelated conditions within which people live their everyday lives. Context as used here represents an ecological perspective that involves at least three different levels: (a) the immediate social setting, (b) the neighborhood, community or organizations providing education or habilitation services or supports, and (c) the overarching patterns of culture, society, larger populations, country or sociopolitical influences" (p. 15).

The 2002 manual extends discussion about supports and their application to people with mental retardation. Authors of the manual propose a supports model depicted in Figure 3. The manual identifies key aspects of the model as including the fact that intensity of a person's needed supports is to be determined for each of the nine support areas depicted in the figure. AAMR is currently pilot-testing an assessment, the Support Intensity Scale (Thompson et al., 2002) intended to quantify support needs and a student version of this measure will be under development in the future. With regard to education, then, one support function is teaching and representative activities of this function include training, evaluating, instructing, collecting data, individualizing instruction, and organizing the learning environment.

Education's Need for and Use of Definitions

One defines a construct for a variety of reasons, and definitions can be either operational or constitutive. Constitutive definitions tie or link a construct with other, typically related, constructs while operational definitions assign meaning to a construct or variable by specifying the operations necessary to mea-

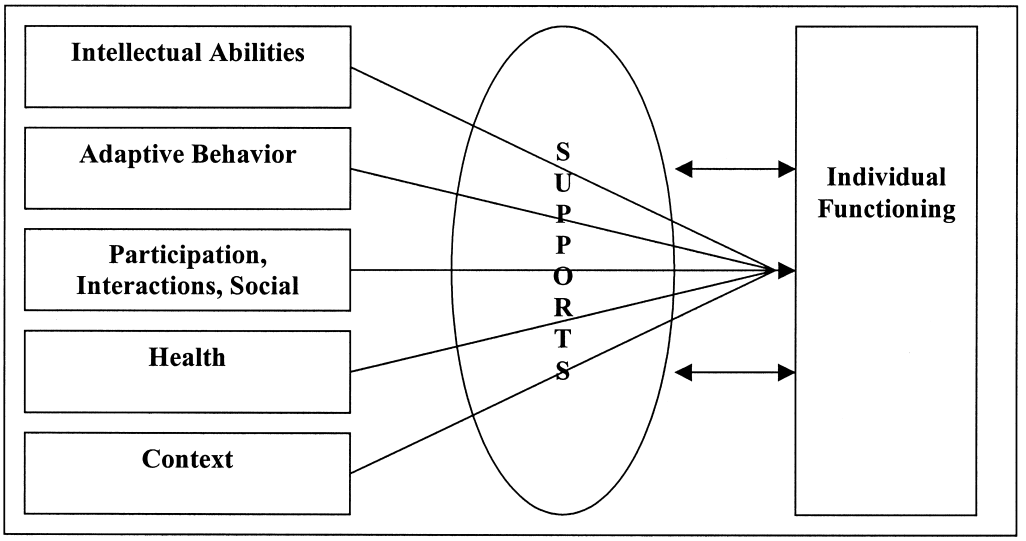

Figure 2. Theoretical model of mental retardation (from Luckasson et al., 2002).

sure, observe, or promote it. Constitutive definitions are valuable for theory development while operational definitions are necessary for designing interventions or making diagnostic decisions. The AAMR definition has both constitutive and operational elements. Linking the construct *mental retardation* with the constructs of *adaptive behavior, developmental period* or *intelligence* is a way of constitutively defining the construct and places our "understanding" of the construct in relation to our understanding of these related constructs. Identifying the developmental period as through the age of 18 or a specific IQ score as the cutoff for qualifying under the label of mental retardation are, alternatively, ways of operationally defining the construct.

Educators are tasked with providing instruction that promotes learning and development. As such, the educational process has often emphasized operational aspects of the mental retardation definition over the constitutive. Thus, the definition and classification process was paramount in making diagnoses (largely the responsibility of the field of psychology, not education) and, subsequently, placement decisions. Typical special education services created "programs" for students with mild, moderate or severe/profound mental retardation, and students were placed in those programs based on their diagnosis. By and large, there was little impact of the definition and classification system on the *ways* in which teachers taught students with mental retardation, although one could argue that the placement decision in essence determined the instructional program (e.g., students with such-and-such a level of mental retardation should receive this particular or specific instructional program).

The 1992 and 2002 AAMR definitions require, however, that we pay more attention to constitutive aspects of the definition, with particular emphasis on the functional relationship between environment and social context and the person's functional limitations. While the 1992 revisions made the diagnostic process more complex, I would argue that it, and the 2002 refinements, made the definition and classification process *more relevant* to instruction and the educational process than previous versions, particularly in the context of promoting access to the general curriculum.

Defining Mental Retardation and Promoting Access to the General Curriculum

Before examining the benefit of the current definitional focus on educational practice, it is

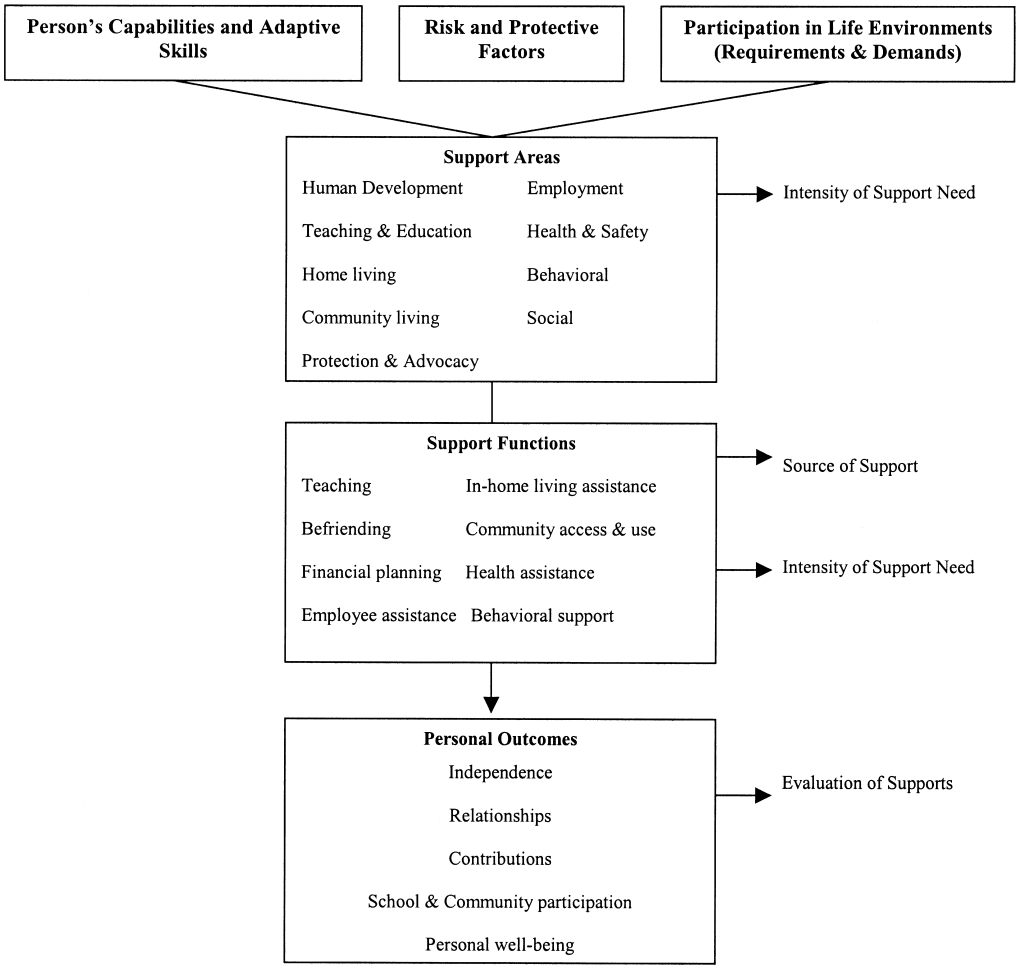

Figure 3. Supports model (from Luckasson et al., 2002).

worth briefly reviewing access to the general curriculum mandates. The 1997 amendments to the Individuals with Disabilities Education Act included statutory and regulatory language pertaining to ensuring that students with disabilities had 'access' to the general curriculum. Section 300.347(a)(3) in the IDEA requires that the IEP of students with disabilities include:

> A statement of the special education and related services and supplementary aids and services to be provided to the child, or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided for the child
> to advance appropriately toward attaining the annual goals;
> to be involved and progress in the general curriculum;
> to be educated and participate with disabled and non-disabled children.

The general curriculum was defined in the IDEA regulations as referring to "the same curriculum as for nondisabled children" (Federal Register, 1999, p. 12592). Such student access was to be provided "as appropriate" while ensuring that IDEA's requirements of

an individualized, appropriate education program are met. Intent of the access provisions was threefold, as described by OSEP officials; that all students, including students with disabilities, would have access to a challenging curriculum; that all students, including students with disabilities, would be held to high expectations; and to align special education practice with accountability mechanisms emerging through school reform efforts. Wehmeyer, Lattin, and Agran (2001) suggested that despite legitimate concerns with regard to the impact of high-stakes testing on students with mental retardation, it was critically important that educators working with students with mental retardation provide access to the general curriculum and that, in fact, this would improve quality of educational programs for students with mental retardation (Wehmeyer, Lance, & Bashinski, 2002a; Wehmeyer, Sands, Knowlton, & Kozleski, 2002b).

Harkening back to the relative lack of attention that the 1992 AAMR definition received in education (Polloway et al., 1999), access mandates have received too little attention as applied to students with mental retardation. Agran, Alper, and Wehmeyer (2002) surveyed teachers working with students with mental retardation and severe disabilities about their perceptions of the access requirements. When asked if students with cognitive disabilities with more intense support needs should be held accountable to the same performance standards as nondisabled students, 93% of the 60 teachers responding indicated they disagreed or strongly disagreed. Nevertheless, when asked if ensuring students' access to the general curriculum would help *increase educational expectations* for students with extensive or pervasive support needs, 68% either agreed or strongly agreed. In other words, teachers agreed that the expectations held of students with cognitive disabilities should be raised, but did not think holding these students accountable to the general curriculum could do this.

How then, does moving toward the 1992/2002 definitional frameworks promote greater access? In several important ways, I would argue. First, when mental retardation is understood as a condition that reflects the interaction between a person's functioning and the context, the focal point for attempts to intervene shifts from being exclusively on the student to being on the context and the student's functioning in that context. In schools, the general curriculum becomes one of the *contexts* that we must consider in intervening on behalf of students with mental retardation, and efforts to promote more positive outcomes will focus on curriculum design (e.g., planning and developing the curriculum), curriculum decision-making (making decisions about an individual student's educational program) and instructional implementation, instead of focusing exclusively on changing the student. Sands, Kozleski, and French (1999) noted that:

> Curriculum reform across both general and special education provides a unique opportunity for collaboration between school professionals, support personnel, students, families, and community members. In fact, *curriculum deficits, not student deficits, can become the common ground from which representatives of these groups can hold conversations and work collaboratively* (pp. 19-20, italics added).

This distinction is important in the education of students with mental retardation in that the focus shifts from the student with a deficit to the curriculum, its design, and implementation. We have suggested (Wehmeyer et al., 2002a, b) that a focus on principles of universal design as applied to curriculum development and instruction are needed to ensure access to the general curriculum for students with mental retardation. Orkwis and McLane (1998) defined 'universal design for learning' as "the design of instructional materials and activities that allows the learning goals to be achievable by individuals with wide differences in their abilities to see, hear, speak, move, read, write, understand English, attend, organize, engage, and remember" (p. 9). The onus is on curriculum planners and developers to employ principles of universal design to ensure that students with a wide range of capacities can access, advance, and succeed in the curriculum, just as the onus under a functional model of mental retardation is on the context and not the person. As Pugach and Warger (1996) put it:

> Different students will learn the curriculum to different degrees. They will do so in different ways and use their learning for different purposes. Not everyone (so the saying goes) is going to become a rocket scientist, so why design all curriculum around the needs of budding rocketeers? The challenge for educators is to facilitate a learning environment that teaches students fundamental learning-how-to-learn skills and encourages thinking, social, and communication skills, so that students can tackle new content in ways that better their current or future lives. (p. 228)

Writing standards to be open ended so that all students can show evidence of progress, adapting textbooks by using digitized text and graphic/audio output, or having a student show his or her knowledge by dressing in a civil war period costume and presenting information on how a soldier may have cleaned a Model 1855 U.S. Percussion Rifle-Musket; these are all illustrations of universal design and stress value of focusing on the context, in this case the curriculum, as the focal point for change. Second, as noted previously, a definition looking at disability as a function of interaction between the person and his or her environment moves away from a deficits focus in which the person, himself or herself, is the problem. This has the potential to change how we view students with mental retardation and, in turn, to raise expectations for these students . . . one of the intents of the access mandates. The first and most fundamental step in ensuring success in education for students with mental retardation is to ensure that general and special educators approach this task with high expectations for students. Feldman, Saletsky, Sullivan, and Theiss (1983) noted, "one of the best supported findings in recent years demonstrates that the expectations that teachers hold about student performance are related to subsequent student outcomes" (p. 27). What do many educators expect of and from students with mental retardation? That is not a question that is easy to answer from a data-driven perspective due to lack of such research. We do know, however, that teachers form expectations for student learning and progress according to special education labels *independent* of other information about student capacity, and that students with the label mental retardation are associated with the lowest expectations (Rolison & Medway, 1985). Moreover, students' expectations for their own performance are strongly correlated, in essence determined by, teachers' expectations for them (Wigfield & Harold, 1992).

The low expectations often associated with the mental retardation label are due, probably in large part, to the fact that students with mental retardation are among the lowest performing students in the school and are, by definition, performing below grade-aged norms. To hold high expectations for students with mental retardation does not mean that one should expect an 18-year old student with limited or extensive support needs to pass grade-normed tests in trigonometry or calculus. By advocating for high expectations and access to a challenging curriculum, I am not suggesting that educators ignore the student's functional limitations. Students with mental retardation have unique learning needs that require curriculum modifications and alterations, primarily as a function of student's age and intensity of support needs.

Stating that students with mental retardation should be held to high expectations suggests, instead, that educators not make *a priori* assumptions about student capacity based on stereotypes formed by their understanding of the label. Historically, educational labels have emphasized deficits and deficiency - educable, trainable, profound. These labels were scarlet letters attached on to the student himself or herself. It was the student who was "profound" or "trainable." When approached from a deficits model, it is almost inevitable that expectations for student achievement and progress be lowered, often for well-intended reasons. The outcome is that some students are provided educational experiences that match their label and not their personalized needs.

Only when the focus moves from the student as the 'problem' to considerations of the interaction between the student's functional limitations and the environment in which he or she lives, learns or works can we remove the barriers raised by labels and low expectations. The curriculum and the classroom (whether

school or community-based) are the social contexts in which students with mental retardation learn. The first step in achieving progress in the general curriculum, then, is to examine those contexts.

Conclusion

The 10th edition of the AAMR mental retardation definition and classification manual does not make the dramatic changes to understanding mental retardation that occurred in the 9th edition. However, in the time between the release of the 9th and 10th editions, the context of special education has changed dramatically as special education attempts to align with standards-based reform and to ensure that students with disabilities are not left behind. This realignment, in the form of access to the general curriculum mandates, provides a compelling reason that special educators pay more attention to the 10th edition than they did to the 9th. That is, these versions of the definition and classification system alter the ways we think about mental retardation and challenge us to consider more seriously the types and intensities of supports people will need to succeed in a variety of contexts. It is just such a focus that is needed if we are to achieve access to the general curriculum for students with mental retardation.

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