

THE LANGUAGE OF DISABILITY

In the field of disability, language has often caused considerable controversy, and terminology has undergone numerous changes over the years. When people hear the terms “mental retardation” and “developmental disabilities,” and, more recently, “intellectual disabilities,” they sometimes wonder if these expressions mean the same thing or not. They are also concerned about which term to use.

Mental Retardation

Until a few years ago, “mental retardation” was the term used by the American Association on Mental Retardation (AAMR), the national professional organization in the field. In May, 2006, the organization’s membership voted to change the name to the American Association on Intellectual and Developmental Disabilities (AAIDD). As you may still come across “mental retardation” in some literature, a little history might help to reduce the confusion.

When first adopted in the early part of the twentieth century, the term “mental retardation” was considered an improvement over earlier expressions such as “idiot,” “imbecile,” “moron” and “feeble-minded.” AAMR used definitions and degrees of mental retardation that closely paralleled the development of intelligence quotient (IQ) testing. Those who ran the public institutions where people with disabilities lived and

Six superintendents of state institutions in which people with mental retardation were housed started the first professional organization in 1876. In keeping with the medical and custodial model of care, they named their group the American Association of Medical Officers of American Institutions for Idiots and Feeble-minded Persons. The name was changed to the American Association on Mental Deficiency (AAMD) in 1933, to the American Association on Mental Retardation (AAMR) in 1987, and to the American Association on Intellectual and Developmental Disabilities (AAIDD) in 2006.

founded AAMR thought that IQ tests represented a scientific advancement. A person’s IQ score, coupled with his so-called “mental age,” was thought to explain comprehensively and conclusively what that person was capable of learning. (This deeply flawed assumption was gradually subjected to challenge.) Over the next several decades, AAMR made several adjustments in the specific criteria used to define mental retardation.

By 1961 the organization defined mental retardation as “significantly subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behavior.” “Subaverage intellectual functioning” referred to people with IQ test scores more than one standard deviation below the mean score of 100. The categories, or degrees, of mental retardation were borderline, mild, moderate,

severe and profound. In 1973 the definition was changed to “significantly subaverage general intellectual functioning resulting in or associated with concurrent impairments in adaptive behavior and manifested during the developmental period.” “Significantly subaverage general intellectual functioning” referred to people with IQ test scores more than two standard deviations below the mean (an IQ of 70 or below). Consequently, the category of borderline mental retardation, which encompassed the majority of individuals with mental retardation, was dropped entirely. In 1983, AAMR’s criteria for mental retardation remained essentially the same, except that the IQ limit could be extended upward to 75.

The category of “borderline mental retardation” was dropped in 1973.

In 1992 AAMR made two further adjustments. Although an IQ test score as low as 70-75 (two standard deviations below the mean) was still required for a determination of mental retardation, adaptive skills were given more importance than in the 1973 and 1983 definitions. For the first time ten specific areas of adaptive skills were delineated: communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics (reading, writing, basic mathematics), community use and work. To be classified as mentally retarded, an individual had to have “significant limitations” in at least two of the adaptive areas along with a sufficiently low IQ score. In addition, the categories of mild, moderate, severe and profound mental retardation were officially dropped.

The 10 areas of adaptive skills in the 1992 AAMR definition of mental retardation:

- *communication*
- *self-care*
- *home living*
- *social skills*
- *leisure*
- *health and safety*
- *self-direction*
- *functional academics*
- *community use*
- *work*

In 2002, the organization adopted a more simplified definition, which stated: "Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills." Furthermore, "this disability originates before age 18." AAMR also enumerated five assumptions essential to the application of the definition:

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

Developmental Disabilities

The term "developmental disabilities" was used for an important piece of federal legislation in 1970, the Developmental Disabilities Services and Construction Amendments (PL 91-517). At the time the term was used by Congress as a qualifier for funding rather than as a term for clinical practice. The new law provided funding for individuals in several different, but occasionally overlapping, groups—mental retardation, cerebral palsy, epilepsy and other neurologically handicapping conditions. The premise was that these groups of people, whose condition had originated during the developmental period (defined as occurring before the age of 18), would have similar service needs and thus be similarly benefited by the appropriations made under the law. When the law was re-enacted in 1975, the category of autism was added. Then, in 1988, amendments to the federal developmental disabilities legislation dropped the specific categories of handicapping conditions in favor of a functionally oriented definition. The new definition required three or more substantial limitations in seven areas of daily living: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. These new categories were to be used to qualify individuals for services under the law.

The 7 areas of daily living in the 1988 Developmental Disabilities amendments:

- *self-care*
- *receptive and expressive language*
- *learning*
- *mobility*
- *self-direction*
- *capacity for independent living*
- *economic self-sufficiency*

Intellectual Disabilities

As we have seen, the origins of the terms "mental retardation" and "developmental disabilities" were quite different. "Mental retardation" came out of the then emergent field of psychology in the beginning of the twentieth century. The term "developmental disabilities" was born in the halls of Congress many decades later. Technically speaking, the terms "mental retardation" and "developmental disabilities", although closely related, never meant exactly the same thing, but they began to be used somewhat interchangeably. Members of advocacy

organizations and some professionals gravitated to "developmental disabilities" as a substitute for "mental retardation" because "developmental disabilities" did not have the negative connotations associated with the term "mental retardation." The word "retarded," long ago thought to be an improvement over "idiot," "imbecile," and "moron," had become one of the most noxious epithets in our society. Its sting could be felt in playgrounds across the country, and it was used with equal harshness in television programs and in the media. Continued adherence to terminology containing the "R" word became increasingly indefensible. Consequently, the national advocacy organization, which in 1980 had become the

Association for Retarded Citizens of the United States, dropped the word “retarded” in 1991 by becoming simply The Arc. State and local advocacy organizations followed suit. For example, Massachusetts Association for Retarded Citizens (MARC) became The Arc of Massachusetts, and Greater Boston Association for Retarded Citizens (GBARC) became The Arc of Greater Boston. As time passed, self-advocates became fully committed to getting rid of the “R” word completely.

Two major organizations led the way to a new term, “intellectual disabilities.” The first was Special Olympics, and the second was Best Buddies International. Both organizations originated through the Kennedy family. President John F. Kennedy, whose sister Rosemary had been born with mental retardation, was instrumental in the promotion of new research, the training of professionals, and the development of services in the field. In the first twenty years after he had appointed the first President’s Committee on Mental Retardation in 1961, there were 116 new federal acts or amendments providing support to people with mental retardation. President Kennedy’s sister, Eunice Kennedy Shriver, began an informal summer camp for children with mental retardation on the spacious lawn of her Maryland home, and Special Olympics came about from these private efforts to enhance the children’s lives. In turn, Eunice’s son, Anthony Kennedy Shriver, began Best Buddies International, a program that promotes friendship between people with and without disabilities, in the 1980s. In the mid-1990s both organizations eliminated the term “mental retardation” and embraced the term “intellectual disabilities” instead.

Eventually the professional organization, the American Association on Mental Retardation (AAMR) began to question its own continuing use of the term “mental retardation.” A tense and often heated debate ensued at conferences and in the pages of the organization’s professional journals. Some questioned the wisdom of changing terminology because they claimed that any new term, such as “developmental disabilities,” would eventually acquire the notoriety of the term “mental retardation.” Others quibbled over which new term to adopt. Several terms, including “cognitive disabilities,” “developmental disabilities,” and “intellectual disabilities,” were discussed. Finally, in May, 2006, the membership of the organization voted on changing its name to the American Association on Intellectual and Developmental Disabilities (AAIDD), effective January, 2007. In describing the change, then AAMR President Valerie Bradley wrote to the membership, “This is a positive step and we should all feel very good about what it portends for the future...[P]lease spread the word to our friends in the self advocacy community for whom the [AAMR] name was a bone of contention.” The 11th edition of the AAIDD definition manual, published in 2010, gives the following definition: “Intellectual disability is 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.”

Current Thinking

In the winter of 2010, Special Olympics began a campaign to get rid of the “R” word forever. This effort was spurred by the use of the term by presidential advisor and former Congressman Rahm Emanuel, now mayor of Chicago. March 3, 2010 was designated a day of awareness, and the goal was to get 100,000 people to sign a pledge not to use the “R” word. The continuing campaign can be followed at www.r-word.org.

No one can absolutely predict that getting rid of the “R” word will quash the negative attitudes that it has conveyed, but one can also hope that no term will ever become so offensive as the word “retarded” did. Best Buddies International is now using the hybrid term, “intellectual and developmental disabilities,” that was adopted by AAIDD in 2006, so the organizations are clearly keeping track of one another. The Best Buddies web site also includes an explanation of “intellectual disabilities” and “developmental disabilities” and how they differ: “According to the AAIDD, intellectual disabilities fall under the umbrella of developmental disabilities, but the boundaries often blur as many individuals fall into both categories to differing degrees and for different reasons.” (See www.bestbuddies.org.)

Until very recently, the term “mental retardation” could still be found in federal legislation that benefits this population; anyone classified as having an “intellectual disability” under the new terminology was considered eligible for services and programs designated for people with “mental retardation.” A new law

called “Rosa’s Law” was filed in 2009 by Senators Barbara A. Mikulski (D-MD) and Michael B. Enzi (R-WY). If passed, all federal laws using the term “mental retardation” would use “intellectual disability” instead.

The words of the two senators in 2009 were eloquent.

Senator Mikulski said: “This (federal) bill is driven by a passion for social justice and compassion for the human condition. We’ve done a lot to come out of the dark ages of institutionalization and exclusion when it comes to people with intellectual disabilities. I urge my colleagues to join me to take a step further. The disability community deserves it. Rosa deserves it.”

Senator Enzi said: “We know now that words have meaning, sometimes far beyond what we intend. Therefore, we must be very careful about the way we describe the people we see every day, including those with disabilities, or those who are undergoing treatment for a variety of health issues. Unfortunately, the federal government has not dropped this term [“mental retardation”] from our laws and it still appears in the regulations and statutes that come before our legislative bodies and our courts.”

Rosa’s Law, S. 2781, was passed by Congress and signed by President Obama on October 5, 2010. Under the new law, the term “mental retardation” has been replaced with “intellectual disability” and “individual with an intellectual disability.” Thus U.S. federal legislative language is finally consistent with the following organizations: American Association on Intellectual and Developmental Disabilities (AAIDD), The Arc, Best Buddies International, Special Olympics, the President’s Committee for People with Intellectual Disabilities and the World Health Organization (WHO).

Some people are concerned that it will be only a matter of time before “intellectual disability” acquires the negative connotations of the word “retarded.” This remains a debatable issue. There is no guarantee that it will not, but the profound changes since the early 1970s in how people with intellectual disabilities are treated in our society may help to prevent negative connotations from being associated with the new terminology. “People First” language is the best policy, and it will not go out of style.

People First Language

The most important question is: What attitude do you demonstrate toward a person when you use a particular word? When using any one of the currently acceptable terms, it is essential to employ the “people first” principle. “People first” language emphasizes the person, not the disability. “People first” language understands that no person wants to be considered solely in terms of a label and that no label can adequately express what that person is like or what that person can or cannot do. Therefore expressions such as “people with intellectual disabilities” and “people who have intellectual disabilities” are strongly encouraged. If you are referring to someone, you can always simply say “my neighbor” or “my friend” unless the person’s disability is relevant to the context of your conversation. In addition, you can write letters-to-the-editor or call TV stations when newspapers and TV stations do not use “people first” language.

“People First”	Not “People First”
I work with people who have disabilities.	I work with the disabled.
She has diabetes.	She’s a diabetic.
He uses a wheelchair.	He’s confined to a wheelchair.
There’s my next-door neighbor.	There’s my autistic neighbor.