

"Sticks and Stones . . . and Words CAN Hurt: Eliminating Handicapping Language"

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A number of Associated Press articles related to persons with disabilities have appeared recently in newspapers across the country. The labels used in these articles have seldom conformed to guidelines set for reporting and writing about people with disabilities (Research and Training Center on Independent Living, 1996). Even though the *American Psychological Association Publication Manual* has also outlined instructions for writing about persons with disabilities, examples of inappropriate terminology still appear in related professional journals. "To address differences, every society creates descriptors to identify people who vary significantly from the norm. This process is called "labeling" (Hardman, Drew, & Egan, 1996, p. 4). The nature of these descriptors and how they are used often infer negative implications about persons with disabilities.

Many of the terms used to describe persons with disabilities have evolved over time. The terms "mad" or "insane" were, at one time, used to describe individuals with a psychiatric disorder. The terms "moron" or "idiot" were used to depict individuals with mental retardation. We would no longer consider using these terms either professionally or informally. In the past five years, a number of other changes have occurred in the terminology used to describe music therapy clientele. It is important for music therapists to be informed regarding the evolution of disability-related terminology and the terminology that is currently correct.

Who decides what disability-related terminology is appropriate? As with any term used to describe a group of people, deference is usually given to those individuals being described (APA, 1994; Maggio, 1991). For example, the evolution of terms used to describe individuals based upon race and/or sexual orientation is well-known. This evolution was a result of public education and self-advocacy by these groups. Persons with a disability have also advocated for the use of specific terminology, though there has not always been agreement as to a specific or preferred term. For some groups of individuals, such as those with mental retardation or mental health disorders, professionals in the field have advocated for specified terminology (Blatt, 1994; Haar, 1993). For example, organizations such as the National Down Syndrome Society and the National Down Syndrome Congress advocated the change in terminology from Down's Syndrome to Down Syndrome -- the former suggesting that the syndrome belonged to the man from whom it is named. Most changes in terminology, however, have been initiated in order to avoid language that stigmatizes persons with a disability. The Research & Training Center on Independent Living (Lawrence, KS), The World Institute on Disability (Berkeley, CA), National Organization on Disability (Washington, DC), and Disabilities Research and Information Coalition (Seattle, WA) are some of the organizations that have actively advocated for the use of appropriate non-discriminatory terminology to describe persons with a disability.

Labeling is a process of creating descriptors to identify persons who differ from the norm. *Normal* is a broad relative term. Everyone is different in some way from everyone else. The type and extent of the difference, however, is the real issue in determining descriptive labels for persons with a disability. There are some positive aspects to labeling a person's disability. Labels are sometimes a prerequisite to receiving federal funding or to acknowledging accommodations that must be made for a person with a disability (Cassidy & Sims, 1990). Too often, however, disability-related labels are used unnecessarily to describe a person. A disability should not be used as the primary adjective used to identify an individual, such as "the deaf student in my class." A disability is not the most important descriptor of any individual. It is best to focus on the person first and not the disability. Defining

persons by their disability, as if the disability comprises the entirety of the person, often isolates or segregates people and more importantly, fails to recognize their humanness that goes well beyond the disability (Kailes, 1986). What words would you use to describe the individual if they did not have a disability? Interesting? Boring? Funny? Dull? The similarities between individuals with and without a disability far exceed their differences.

The fourth edition of the *Publication Manual of the American Psychological Association* (1994) provides helpful guidelines to reduce the use of biased language (pp. 44-60). The manual suggests that a writer "Use *disability* to refer to an attribute of a person and *handicap* to refer to the source of limitations, which may include attitudinal, legal, and architectural barriers as well as the disability itself." (p. 53) The term handicap originated from the phrase, "cap in hand," representing a time when persons with disabilities begged in streets in order to survive. The term, therefore, has a pejorative historical connotation (Bruce & Christiansen, 1988). Because a person has a functional limitation does not necessarily mean he or she has a handicap. Itzhak Perlman is a world famous concert violinist -- and also a person who has paraplegia; and consequently uses crutches for ambulation. He is not handicapped in performing daily living skills and certainly not in his concert career. If a recital hall is not physically accessible though, Mr. Perlman becomes handicapped. The handicap is, therefore, imposed by the environment, not by the disability.

Persons are sometimes handicapped by attitudinal barriers as well as environmental barriers. For example, persons with severe facial disfigurements are only handicapped by the social limitations sometimes placed on them by individuals who may avoid them or find it difficult to make eye contact with them during social interactions (Wright, 1986). The handicap then, rests almost entirely in the social implications of facial disfigurements, not in the physical aspects of the disability. Persons with speech fluency disabilities often experience the avoidance of others who have difficulty understanding their speech or who are just uncomfortable listening to speech that is atypical (Anderson & Antonak, 1992). If the person's speech is functional, the handicap is not the speech disability, but the lack of normal social interactions with others. Wright (1986) reported that, in social interactions between persons with and without a disability, those without a disability exhibited the following behaviors: terminated conversations more quickly, smiled less, showed more signs of discomfort or restlessness, made less eye contact, and maintained greater physical distance.

Disability is a term that is sometimes defined by the culture. Members of some African tribes use wooden disks to elongate the lower lip, a practice that results in a facial feature seen as a mark of beauty within the culture, though it may be considered a disfigurement in other cultures. Members of the deaf community, or at least those individuals who communicate manually, consider themselves to be a cultural and linguistic minority. To them, deafness is a cultural term, not a disability. In addition, many deaf adults view the term, "hearing impaired" as particularly pejorative because it implies "broken or defective" (Padden & Humphries, 1988).

There are other inappropriate disability-related terms that create negative stereotypes (Patterson & Witten, 1987); and consequently, may devalue persons with a disability. Terms such as "afflicted with . . .," "suffers from . . .," or "is a victim of . . ." create an image of helplessness and incompetence. In choosing words to describe people with a disability, the guiding principle is to put the person first and not the disability (Beninghof, 1993; East Carolina University, 1993; Milota, 1991). Use terms such as "persons with disabilities" or "a person with cerebral palsy" rather than "disabled people" or "a cerebral palsied person," or worse, "a spastic." Many government and educational agencies have already recognized the need for changes in terminology. PL 94:142, the Education for All Handicapped Children (1975), was renamed Individuals with Disabilities Education Act (IDEA) in 1990 in an effort to put "individuals first" and to change the term "handicapped" to "disabilities."

It is important that music therapists also employ these changes in their communications, particularly with other professionals in the field of disability. The use of inappropriate terminology is usually an

innocent mistake, frequently made by students as a result of lack of information, or lack of a realization regarding the often harmful impact of inappropriate terminology. Employing preferred terminology signifies acknowledgment of and respect for persons with disabilities. A number of articles regarding the appropriate terminology to use when writing, reporting, or talking about persons with a disability have appeared in music education journals (Jellison, 1990) as well as other professional journals (Blatt, 1994; Haar, 1993). There are a number of guiding principles for communicating about persons who have disabilities (APA, 1994; Beningshof, 1993; Blatt, 1994; Illinois Department of Rehabilitation Services, 1994; Research and Training Center on Independent Living, 1996).

Basic Principles for Communicating about Persons with Disabilities

1. Avoid the article "The" when referring to individuals with a specific disability, such as "The blind" or the "The disabled." Grouping all individuals together into a disability category promotes objectification and the idea that all of these individuals share common attributes.
2. Avoid terms which have negative connotations such as, "afflicted with," "suffers from," "is a victim of," "is confined to . . ." These terms promote negative stereotypes.
3. Avoid using terms that turn the disability into a personal noun such as spastic, epileptic, amputee, mongoloid, paraplegic, or quadriplegic. The preferred terms are "a person with a prosthetic arm," "person with Down Syndrome," or "a person who has epilepsy," etc.
4. Avoid comparisons between a person with disability and person without a disability. For example, "His near normal speech allowed him to communicate . . .," or "She held her own while interacting with normal children."
5. Avoid sensationalizing or patronizing the individual with a disability. For example, "She dances well for person with a prosthetic leg," or "You would never know he was blind!"
6. Don't refer to the disability at all unless it is necessary. Itzhak Perlman once said he would like, for once, to read a review of his performance that did not mention his disability, especially since it in no way affected his ability to perform.
7. Avoid self projection. For example, "I would rather die than be blind," or "I really admire you, because I don't know what I would do if I couldn't walk anymore."
8. Avoid accolades which devalue, such as describing the person with a disability as brave or courageous.
9. Avoid references which indicate an inferior status, such as "He can't talk on the phone because he is deaf." Instead, use a more positive reference such as, "He can communicate with you through the relay service for the deaf."
10. Avoid terms or references that indicate pity, even for individuals who may have recently acquired a disability. Pity references are those such as, "What a shame (what a pity, how awful) that he is losing his sight," or more subtle, "Unfortunately, he was unable to read the lyrics for himself."
11. The final and most important principle regarding terminology is, when in doubt, ask the subject matter expert, the person with a disability.
12. Avoid disability references ("Subjects were blind to the purpose of the study") when other references are applicable ("Subjects were naive as to the purpose of the study").

It is important to remember that labels only provide vague approximations of disability characteristics. While labels are often useful in communicating with other professionals and in determining services for persons with a disability, they rarely tell us much about the person. As music therapists, we can do much to promote the image of persons with a disability and to eliminate stereotypes by utilizing appropriate terminology in our practice and in our communications with others. Since most music therapists are aware of the various communication idiosyncrasies related to persons with disabilities, perhaps we can do more to educate the public by alerting responsible parties when we find examples of inappropriate terminology used in conversation or in print.

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