

The World of Disabilities

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It is estimated that 43 million children and adults in this country have disabilities; eight million are children, birth to 21 years of age. Strong advocacy for this group of individuals has been especially evident over the last 25 years. Yet, in the 13th Annual Report to Congress on the Implementation of the Individuals with Disabilities Act for fiscal year 1990-91, only five of the eight million children with disabilities were able to receive services on some level throughout the States. Program cutbacks, insufficient number of specialists to meet the needs, underserved populations in rural communities, inner cities, or within communities of color including Native American and Hispanic, have created gaps in basic services that continue to bring pressures on families and professionals that remain critical.

In 1972, two landmark cases (Pennsylvania Association for Retarded Children (PARC) v. Pennsylvania; Mills v. Board of education) recognized in a substantial way the basic constitutional right to public education for all children, including those with mental retardation. These court battles, multiplied by countless more just throughout the last 20 years, have shaped a new world for people with disabilities.

That historical perspective is important to understand. Individuals with disabilities, their families and advocates, have been forced to do "battle" over the years to gain access just to basic rights in education, housing, jobs, transportation, recreation, and information; to protection from harm or from aversive treatments; and even to guarantee freedom of speech. **Advocacy** is the rule of operating when you enter the world of disabilities at any level. Legislation resulting from these efforts (e.g. Individuals with Disabilities Education Act and the Americans with Disabilities Act) has increased services and accessibility to services for people with disabilities.

These laws have also helped create a world of specialized "jargon." This has made communication difficult, even for those individuals "in the know"! It can become impossible, especially when you cross over areas, within disabilities and beyond (e.g. deaf to DD; or OHI to SED; or special education to child welfare). Many people speak of the "alphabet soup syndrome" that has infected most professionals in this business, with no cure in sight!

One of the most important goals of a strong disability advocacy movement is to challenge everyone to people-first language and orientation, i.e. e., "This is John, who is 14 yrs. old, loves Star Trek, hates math and happens to be blind."; or "Martha, a young woman who has cerebral palsy" or "who has a disability," rather than the blind boy or the mentally retarded. The goal is to remember there is a person behind the label who may not be handicapped because of his/her disability. Even the use of the word "handicap," which is often used synonymously with disability, is less acceptable these days. One of its origins is from the phrase "cap in hand" (begging). This often carries with it a negative perception that can become a barrier to seeing the person and the real problem.

Whether it be "physically challenged, differently abled, handi-capable," people with disabilities do not agree on the best term to use in describing themselves. Similar to other minorities throughout history, the press, legislation and philosophies tend to dictate the usage. The real answer to correct usage, however, is to **ask the person or significant other what is their personal preference**. The key lies in respecting individual differences and giving each person their personal dignity and respect. On many levels, it's that simple!

Perhaps the most difficult aspect of this entire area, however, is the vastness of the information available, and the variety of disabling conditions that exist. Separate agencies, systems, resources, training and support networks have been built around each type of disability with limited vehicles in place to allow for networking or the time to accomplish that! Even within smaller fields such as deafness or blindness, agencies or professionals may target only sub-groups of each population, i.e. e. work only with individuals

who are hearing impaired rather than profoundly deaf, or who have low vision versus being congenitally blind, those who meet legal definitions of a disability, or who have a disability which is "educationally significant," rather than everyone who comes in with a specific need. Each of these distinctions suggest specific techniques, training and resources which have been developed, complicating the issues and sometimes even leaving children and families unserved... lost "between the cracks" of a profession that was designed to provide them with support! It is an ongoing, challenging problem.

So, what are some guidelines upon entering the world of disabilities:

1. **Remember the person, he/she, adult or child.** Behind every brace, gesture, confusing sentence, lack of eye contact or missing limb there is someone there who is the same as you if you keep your focus. Find that connection.
2. **Don't be intimidated or "fooled" by the jargon in this world.** It is only as useful as it can be explained to another individual. Don't hesitate to ask the question: "What do you mean that this person has a developmental disability, or is blind?" Without that question, it is merely alphabet soup!
3. **Embrace the total world of disabilities** which is composed of many specialists who represent multiple philosophies and orientations, who themselves are consumers or family members or child advocates. Recognize that one person alone, no matter how accomplished, cannot speak for the broad diversity of individuals and families the world of disabilities represents. Seek greater representation of this group in all of your efforts.
4. **Read more about it!** Did you know that under federal law, all televisions with screens 13 inches or larger sold in the U.S. after July 1, 1993, must have built-in decoders for closed captioning? And did you know that May 25, 1992 marked The Tonight Show's and Jay Leno's debut into the world of closed-captioning? There are numerous national organizations and resource centers across the country that provide basic fact sheets on all areas of disabilities and available resources. Usually, it's not that needed services don't exist; many times we just haven't discovered where to find them! Ask around. People with disabilities exist and our challenge is to make "them" a part of our world.

On many levels, it's just that simple!

Resources:

- Office on the Americans with Disabilities Act, Civil Rights Division, U. S. Department of Justice, P.O. Box 6618, Washington, D.C. 20035-6118, 202-514-0301/0381 (TDD/TT).
- The Center on Human Policy, 200 Huntington Hall, Syracuse, NY 13244-2340, 315-443-3851.
- Council for Exceptional children (CEC), 1920 Association Dr., Reston, VA 22091, 703-620-3660.
- The Disability Rag, 1962 Roanoke Avenue, Louisville, KY 40205, 502-459-5343 (\$12/6 issues).
- National Association of Protection and Advocacy Systems (NAPAS), 9000 2nd Street, NE, Suite 211, Washington, D.C., 20002-202-408-9514/9521 (TDD).
- National Information Center for Children and Youth with Disabilities (NICHCY), P.O. Box 1492, Washington, D.C., 20013, 1-800-999-5599/703-893-6061/8614 (TDD/TT).
- National Center for Youth with Disabilities, Resource Library, 1-800-333-6293/ 612-6262825.
- Sexuality and Disability Journal, Stanley Ducharme, Editor, Human Sciences Press, Inc., 233 Spring Street, New York, NY 10013-1578, 212-620-8000 (\$40/4 issues).
- Tips for Disability Awareness/Tips for Portraying People with Disabilities in the Media. Free brochure with a # 10 SASE to: Disability Awareness Tips/MM, National Easter Seal Society, 70 East lake Street, Chicago, IL 60601, 312-853-9690.