

Models of Disability: Removing the Barriers to Full Inclusion

by Patricia K. Keul- 2008

What's in a name? Maybe a rose by any other name would smell as sweet. Does changing the label assigned to all roses change how we think of roses? Probably not, roses can be clearly defined changing their name or moving roses under a label other than flowers would have little or no affect on how we identify and experience roses. But does the same principle apply to people? How do name and, specifically labels, shape the way we think about a person? Given the often-negative impact of labeling, it is easy to forget that assigning labels serves a useful purpose. Labeling disabilities is a convenience that society uses to facilitate communication.

A recent experiment, conducted by Dr. Gary Lupyan, suggests that language clearly affects some thinking as a special device added to an ancient mental skill set. In his study, Dr Lupyan asked students to identify and group some odd shaped clay creatures on the basis of those that were friendly aliens, versus unfriendly aliens. The students were not told which aliens fell into either group and the differences in the clay creatures were subtle and not easy to describe. After completing the task, students were told that the friendly creatures had smooth heads, but the unfriendly ones had bumpy heads. One group of students was given one additional important piece of information before they started the grouping assignment. They were given labels (fake names) to assign to the two groups. While all the students eventually learned to group the clay creatures correctly, in subsequent trials, the students who had the labels learned to assign clay creatures into the correct groups much faster than the students who did not have labels for the two groups.

Defining disability groups can lead to better service delivery, treatment or other interventions designed to support the specific needs of a defined disability group. Labeling groups of people can also be restrictive and can create negative perceptions of the individuals grouped under a specific label. For individuals with disabilities labels are highly charged words whose meaning can affect every aspect of life in society. Labels are the component parts of over arching models of thinking. Historically the labels we use to describe disability groups and has changed as society has evolved in our thinking about the experience of disability.

According to scholars of disability history there are four distinct historical/social models of disability. These are as follows:

1. The Moral Model
2. The Medical Model
3. The Rehabilitation Model
4. The Disability Model

The Moral Model: The moral model is the oldest of the four and by far, the most damaging. The moral model asserts that disability is a defect of character, or the soul. Ancient cultures such as the Spartans, placed infants with disabilities on the hillside outside of the city to die because they were deemed to be of no benefit to society. Today there are still communities in the world that believe people with disabilities should be shunned because they sinned in another lifetime and their bad karma caused them to suffer in this lifetime. In cultures where the moral model prevails, people with disabilities are hidden by their families and excluded from any social role in the community.

The Medical Model: The medical model views disability as a defect, sickness or impairment requiring medical intervention or therapy to cure or treat. This model emerged in the 19th century when physicians were gaining prominence in society. Under this model, disability rests with the individual who must be "cured or treated" to recover or be improved via medical intervention. Society does not have a responsibility to include people with disabilities, society's role is to support medical intervention on behalf of the person with disabilities.

The Rehabilitation Model: Coincidentally, the rehabilitation model gained a foothold after World Wars I & II when soldiers returning from war needed services from rehabilitation professionals to re-enter society after acquiring their disability on the battlefield. The current Vocational Rehabilitation system is modeled

from this concept. The rehabilitation model is a subtle improvement over the medical model in that services such as job training and counseling are added to the medical therapies and interventions. However it still focuses on the mentality that the person with disabilities is sick or injured and needs treatment to overcome the situation.

The Disability Model: The disability model asserts that disability is one of many normal aspects of human life that many of us will experience over a lifetime. Born from the disability rights and independent living movements, the disability model forces us to look at the experience of having a disability as just one facet of adapting to the human condition. At the heart of the disability model is the notion that none of us is perfect, we all have (or will have some day) diminished capacity of one sort or another (due to age, temporary injury, or emerging disability) and we will all have to make adaptations to accommodate our disabilities. The disability model also suggests that how we view adaptations for disability is informed by the ease by which society can accommodate it via equipment or accessibility solutions.

For example, most of us do not view even severe nearsightedness as a disability in modern life. At best, it can be cured via laser surgery. Even the low cost solutions, wearing glasses can a fashion statement while providing adaptive equipment to help us see clearly! Early humans with moderate nearsightedness would have been severely impaired in hunting and in seeing dangerous predators before it was too late to react. Without glasses these individuals might have been viewed as a liability to the early human tribes as they made poor hunters and needed others to watch over them to keep them safe.

The disability model asserts that society has a role to play in creating an environment that is accessible to all of its citizens (those with disabilities and those who do not have a disability). Furthermore, when the environment is made more accessible for citizens experiencing disability today, it makes the community more welcoming to people as they age or when they are sick or injured and have temporary disabilities.

In the modern world it is increasingly difficult to separate the experience of disability from the social factors that disability presents. In fact, in some ways the medical and social advances raise interesting questions about who is and who is not disabled. For example, considering the following list of people, whom would you define as disabled?

- A person with a heart transplant
- A person with a cochlear implant
- A person with Chron's disease (a severe digestive disorder that severely limits one's food choices)
- A person who is very short
- A person who is allergic to the sun
- A person who was extremely poor at math
- A person with an extremely scarred face
- A person who was obese
- A person with arthritis

Different readers will have different responses to the question of whom they would consider to be disabled in the list above. In the examples above, disability presents functional limitations in some cases and not in others. Some may consider that the person received a cochlear implant was "cured" of being deaf. However, without the implant, the disability remains. A person with arthritis may have to curtail his activities, and may not be able to lift heavy objects that some jobs require. However the person with a facial scar will not have any functional limitations but may still be viewed by some people as someone with a disability because his appearance deviates from society's concept of what is normal appearance. The person with the facial scar may be passed over (wrongly and in violation of the ADA) for a job as a register clerk in a store, if the employer assumes that his appearance will be a distraction that negatively affects his customers even though the person is otherwise qualified to perform the duties of a store clerk.

The problem with models of disability and the labeling that results from these models is that they serve to separate the person with a disability from the rest of us in unique and often isolating ways. Rather than seeing the experience of disability as just one facet of being human, disability labels define a difference that

is considered “abnormal.” The notion that disability is aberrant (not just different) but abnormal from the rest of so-called normal human experiences is what creates the isolation. Consider that many people with visible disabilities live their entire lives with their ‘difference’ going before them whenever they interact with another person. In affect, society meets the wheelchair, before it meets the person using the wheelchair and sees the cane and guide dog before they meet the individual who is blind. Is it any wonder that people with disabilities continue to have difficulty becoming fully included in society when their first impression is preceded by the disability and all the associated perceptions the disability incites for others meeting them? Is it any wonder that people with hidden disabilities such as cognitive impairments, mental illness and others will often hide their disability from others?

There is reason to be hopeful that the evolution in our thinking about disability will result in a new model of thought that accepts all facets of human capacity as part of the rich tapestry of being human. Given the recent medical advances that have extended our capabilities beyond what is biologically restricted (heart transplants, cochlear implants, laser eye surgery) we already see that the lines that demark those with disability and those without have blurred. Today adaptive equipment and assistive devices have made it possible for people to overcome even severe disabilities to drive digitally controlled, lift equipped vans and use computers. In the future, medicine will bring us advances that will cure spinal cord injury, and will use advanced gene transfer methods to regenerate amputated limbs. Certainly these individuals will not consider themselves to be disabled in the classic sense of the definition and will instead view their situation as a temporary one.

But medical cures will not enable everyone to escape the experience of disability and adaptive equipment and devices will still have their limits (not the least of which is cost to purchase them). There is another social change that is coming to help level the playing field that will influence how we think about disability in the future. The advancing age of the population and the natural deterioration and disability that comes with age will force virtually all of us lucky enough to grow old to join the ranks of people with disabilities in the not too distant future.

Today on the Internet, people using handicapped accessible computers with voice or eye blink commands are invisible to able-bodied Internet surfers, creating a totally equal playing field for human interaction and social connection. Through the Internet people with disabilities meet others who are not disabled and they meet as people first, the disability does get out in front of the person. Imagine the conversations and friendships that result when people meet people as equals!

Hopefully as more and more of us, live longer lives we will be faced with making the “normal” adaptations that come with the natural consequence of richer lives. More of us will experience temporary and more permanent disabilities. More of us will have family members and close friends or co-workers who experience these life events. More of us will become more familiar with human differences, and as a result these “differences” will not seem so different after all.

Is the Disability Model the final word on how we classify and think about the experience of disability? Thankfully, no because our models of thinking about disability are evolving together with our understanding of what it means to be human.