Like many who care about disability issues, I'm always concerned about the public perception of individuals who happen to have disabilities. Inaccurate fictional depictions in the movies and on TV; pitiful or heroic portrayals in news stories; and stereotypical perceptions held by many in the general public leave much to be desired. Through the work of some activists, glimmers of change are emerging.

Perhaps, however, we should be even more concerned about the attitudes and actions of *ourselves*—those *within* the disability arena: individuals with disabilities, family members, activists, and those employed in the field. During many years as a public speaker and host of a website, I've met and communicated with thousands who care about disability issues, and I've seen negative attitudes that equal, and sometimes surpass, the harmful perceptions of the general public. How can change occur if *our* words and actions perpetuate the negative attitudes we say we're trying to eliminate?

It's time to examine this "enemy within," and I'll start with myself. Many years ago, when my infant son was diagnosed with "moderate" cerebral palsy, I reacted the only way I knew *at the time,* and in a way that was "accepted"—I was sad about the diagnosis and negative prognosis, but was also glad that my son "only" had "moderate" CP, instead of a "severe" form of CP.

I didn't know it at the time, but I was guilty of embracing the DISABILITY HIERARCHY, in which one type and/or severity of disability is perceived as "better" or "worse" than others. But this HIERARCHY isn't limited to the *condition;* it extends to the person and the family, too. Not only did I feel my *son* wasn't as "bad off" as children who had a "worse" disability, I also felt our *family* was "better" than families where a "worse" disability was present.

In society, this stratification may reinforce pity, and the *level* of pity is equivalent to where a particular disability sits on the HIERARCHY. In the disability arena, it can result in physical segregation, social isolation, and other negative outcomes for people with disabilities. And the "severity" of these *outcomes* also corresponds to where a person's diagnosis sits on the HIERARCHY—and a variety of different HIERARCHIES exist!

I was fortunate, however. Within a few months, I rejected many societal and professional notions that reflect the DISABILITY HIERARCHY. This transition

THE DISABILITY HIERARCHY

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

was enhanced by my participation in the Partners in Policymaking leadership development program (www.partnersinpolicymaking.com) when my son was three. The wisdom I gained from the training and my classmates (including adults with developmental disabilities) helped me adopt new ways of thinking.

I learned that a disability is a disability is a disability—one is no better or worse than another—and the greatest barrier facing individuals with disabilities is not the disability itself, but attitudes about disability and the resulting social policies that dictate the treatment of people with disabilities. Now, let's move on to some other examples.

During one of my presentations about attitudes, "Sabrina" shared the following about her twin sister, "Kristina," who uses a wheelchair: "People talk about Kris like she's not even there," she exclaimed. "I mean, she's not *retarded*—she just uses a chair!" The unspoken message seemed to indicate it would be acceptable for Kristina to be presumed incompetent if she *did* have a cognitive disability, but it was *not okay* since she "just" had a physical disability. Was Sabrina aware she was promoting the DISABILITY HIERARCHY? Her next comment was even more disturbing: "My sister moved into her own apartment for the first time, and it's really scary for my mom and me—I mean, *Krissy is our baby!*" I was stunned! These 20-something young women are twin sisters, yet Sabrina sees her sister as a baby. Would this occur if Kristina did *not* have a disability? Again, it seemed Sabrina was unaware that she held the patronizing attitude that she so resented in others. How could others see Kristina as a competent adult if her twin sister and her parents didn't?

At another conference, a group of adults (who happened to have cognitive disabilities) said they liked the stories I shared about my son, Benjamin. But I was surprised when one of the leaders sympathetically said, "Benjamin sounds like a neat kid, but it's really too bad he can't walk." For years, I had heard similar comments from people who knew nothing about disabilities, who felt this was the "right" response. This same sentiment was now being uttered by a leader of a self-advocacy group! He evidently embraced a HIERARCHY in which physical disabilities are "worse" than cognitive disabilities—which is the opposite version Sabrina embraced!

"Suzanne," the leader of a parent organization, told

me about helping "Marcia" with special ed issues. Marcia's child had a part of his brain removed to control seizures. Suzanne said, "When I think of Marcia's son, I realize how blessed I am—my son *just* has autism, and he's *very high-functioning."* Shocked that a "leader" held such an attitude, I asked, "If you're *blessed,* what does that make Marcia? *Cursed?"* She sputtered that she didn't "mean anything by it." Then why did she say it to me, and *would she have shared this opinion with Marcia?*

We also promote the HIERARCHY when we make a diagnosis the defining characteristic of ourselves and/or a family member. This occurs during an introduction like, "I'm the parent of a 'Down syndrome child';" with an Email address such as "c5para@xyz.com;" or an Email signature like "Mary Lou, mother of Stephen, severe MR and uncontrolled seizures." In her Email to me, Mary Lou complained that no one could see past Stephen's disabilities. *Duh*—how can they when her signature makes his diagnoses the most important things about him? And how does Stephen feel about this? The *intent* of this practice is to "share information," but few consider what unintended negative outcomes may occur.

At a meeting of parents of children with disabilities, a "contest" erupted. Several adoptive parents introduced themselves by sharing their children's diagnoses and "problems." Then some of the birth parents "gave the prize" to the adoptive parents, saying: "Wow—you've got us beat! You *chose* to adopt kids with all these problems!" The adoptive parents upped the ante with, "Yeah, we *knew* about *our* kids' problems, *but you didn't,* and you still kept your children, so *you're more special."* Gag! This patronizing "special, heroic parent" myth will never die as long as we continue to feed it.

It seems no population in the disability arena is exempt from the stratification of the DISABILITY HIERARCHY. John, a friend who was a Voc-Rehab counselor, said his coworkers often ridiculed people with developmental disabilities who had come to them for employment help. They spoke freely in front of John, who uses a wheelchair because of an acquired disability. He resigned his position in disgust.

Some organizations tout "their" disability as "worse" or "more challenging" than others—using a va-

riety of words and strategies, plus a dose of pity—hoping to reap more fundraising dollars. Some go beyond the HIERARCHY—essentially placing death and disability in the same category. One organization's brochure includes "Tips for Having a Healthy Baby" and also features this bold statement: "[We've] achieved a track record of advances that have saved millions of babies from death and disability." This reinforces the "disability as a fate worse than death" paradigm. And this is demonstrated by a commonly-heard exchange, in which the question, "Do you want a boy or girl," is usually followed by, "It doesn't matter, as long as the baby is healthy." Translation: "As long as the baby doesn't have a disability." Babies with disabilities are considered unhealthy or different, so they're unwanted and have no value. If this horrific mentality—better to be dead than have a disability—is present *within* the disability arena, we shouldn't be surprised that it also exists in an Academy Award winning-movie (*Million Dollar Baby).*

Finally, there are some people in specific "disability communities" who say "their" condition is "so different," or who state it isn't really a disability at all! They express vehement disdain if they (or their children) are said to be similar to others who are on the lower rungs of *their version* of the DISABILITY HIERARCHY.

Little progress in changing societal attitudes will be made if *we* endorse a DISABILITY HIERARCHY. And we shouldn't wait for consensus within the disability arena—that probably won't happen. But we can exert a positive influence, each in our own way, if we so choose.

Consider your own attitudes, words, and actions. Do they represent a hierarchical better/worse classification of developmental, acquired, cognitive, sensory, physical, mental health, and/or other types of disabilities? Do they indicate a medical diagnosis is the most important thing about a person? And do they reflect a belief that some people with disabilities and/or their family members are "so different" from you/your family?

The mantra, "If you're not part of the solution, you're part of the problem," certainly applies to this dilemma. Do your words and actions promote *positive images* of people with all types of disabilities or do they perpetuate the DISABILITY HIERARCHY? It takes courage to look within; sometimes it's painful. But out of the self-examination can come extraordinary powerful change. Perhaps we would do well to follow Gandhi's sage wisdom: "Be the change you want to see in the world."