

What's Your POSITION?

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

Like the patchwork of a quilt, we all fit together somehow. We all touch one another; sometimes directly, sometimes indirectly. And our positions—our personal philosophies and actions—have an impact on the children and adults with disabilities who are in our lives.

Have you thought about your position lately? Some people do; they try to continually learn more, and then revise their positions. This may be an easy change or a soul-searching struggle. There are others who seldom or never examine their positions; they wear them day in and day out, like a comfortable pair of shoes: things are fine just the way they are, thank you very much. Employees of a bureaucracy must usually follow the position dictated by the policies and procedures of their employer: one's personal position may be irrelevant. In this case, some folks may embrace the bureaucratic position; others tolerate it and grumble often; others chafe under it, try to change it, and/or move on to another job that more closely matches their personal position.

There are, it seems, people whose positions are truly moral; that is, their personal philosophy and actions toward people with disabilities and disability issues are born out of a passionate belief about "right and wrong." The position of others may have nothing to do with morals. Instead, their philosophy (if you can call it that) and/or their actions represent "indifferent efficiency"—do what's easiest and in the shortest amount of time. If these actions don't represent the "best" for people with disabilities, "So what?" they think. And there are still others who don't really have a personal position in which they're grounded; they blow in the wind, often swinging back and forth between extremes, as they follow the lead of physicians, educators, bureaucrats, family members, or others, in search of the latest treatment, cure, or quick fix.

Regardless of your relationship with a person who has a disability—whether you're a parent, other family member, service provider, educator, physician, or have some other role—*your position matters!* Your personal philosophy and your actions make a huge difference, for better or worse, in someone's life.

There are probably as many positions as there are individuals. So an attempt to define them all is impossible. It seems, however, they run the gamut from "pity" to "equality" and everything in between. An exploration of these two extremes may inspire us to closely examine our own positions, and see where we fit on the continuum.

The "pity" position is, unfortunately, common and widespread. Being the object of pity is, of course, an anathema—a curse—to most people with disabilities and family members. Unfortunately, some people may not even recognize they operate from this position because they don't associate the word "pity" with their personal philosophy about individuals with disabilities. Instead they may feel sympathy, sadness, or sorrow. It's not uncommon for family members, friends, and even strangers to say, "Oh, I'm sorry..." to parents when they learn a child has been diagnosed with a disability. My response to this "apology" has always been, "Why are you sorry? We don't feel sorry for my son and we certainly don't want you to, either!"

Another component of the pity position reflects the ideal of: "I want to change the world by helping people with disabilities." Again, a person who holds this position may not *feel* she's operating from the pity position. Instead, she may feel she's responding to a noble calling. When asked why they chose their careers, many special ed teachers, service coordinators, and others often give the "change the world" answer. Further questioning, however, gets to the meat of the issue. Using one set of words or another, many

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describe that they want to “help,” since people with disabilities are needy, unable to help themselves, and so forth. And parents, family members, friends, and associates of people with disabilities may also share these sentiments.

Is it possible a person chooses the pity position because he genuinely believes he's superior to people with disabilities? Or could there be a hidden agenda at work? Did John adopt a “helping” role to help *others* or to help himself? Some people may choose the pity/helping position because it boosts their own self-esteem. Perhaps John can only feel good about himself if he is surrounded by people who are (in his opinion) more “needy” or “worse off” than himself.

The dangers of the pity position are many. If we feel a person is unable, needy, incompetent, etc., we may have low expectations, try to keep him in a child-like state, behave in a patronizing manner, do too much—or too little—to or for him, segregate or isolate him, or take other actions that have negative and harmful outcomes.

All of these are exacerbated by the inherent inequality of the relationship when one person is always the “provider” of help and the other is always the “recipient.” This provider/recipient relationship is common in the service system, in schools, and even in many homes.

Contrast the *constancy* of the official “provider/recipient” relationship with the ebb and flow in the relationships of people who don't have disabilities. I am sometimes the “provider” of help to my son, daughter, or husband (the “recipients”). An hour later, however, one of them may help me. Because the pendulum constantly swings back and forth, the equality of our relationships is maintained.

We often “talk the talk” of promoting equality for people with disabilities, but we don't “walk the walk” if we operate from the pity position. For if you're always the “provider” of help, do you have an equal relationship with the “receiver”? In the best case scenario, you may feel you *do* have an equal relationship with a person with a disability, but here's

the acid test: *does the person with a disability also perceive equality in the relationship?*

If you agree it's time to move beyond the pity position, the first step is to *examine* your personal philosophy. None of us wants to believe we operate from the pity position, but it's so pervasive and has been with us for so long, that it may be masked—but active—behind some other position.

The second step is to *change* your personal philosophy—your position—about people with disabilities. This will be easy for some, harder for others. But if you spend time thoroughly examining your current philosophy, change will come. Check your assumptions. Ponder where some of your beliefs came from. Were they valid at the time? Are they still valid? Each of us developed our positions by adopting the beliefs of others and/or acquiring beliefs through personal experience. We can do the same again. Our attitudes are infinitely changeable. When we adopt a

new position, new actions will follow.

We may still provide help or assistance to a person with a disability, but with a difference. When

respect and equality replace pity, we'll *ask* what a person wants help with, instead of assuming we know best. Instead of seeing a person as helpless, needy, or pitiful, we will see him as an equal, recognizing that his differences are just that—differences that should be respected, not “fixed” or “cured.” We'll work diligently to ensure the person has the supports, accommodations, and assistive technology devices she needs for success. We'll work toward equality within relationships, so the “recipient” of help also becomes the “provider” of help to us or to others. And we'll focus on the similarities shared by people with and without disabilities, to find common ground.

Opposite the pity position is the equality position. This is the position which can best lead us to an inclusive society. In general, people who operate from this position tend to believe that people with disabilities are more like people without disabilities than different, are equals, and should be included in all aspects of society. The equality position also leads us to believe that people with disabilities are able and competent, and—like everyone else—their abilities

The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.

William James

are enhanced when they have the tools, assistance, supports, and/or modifications needed for success.

But even people who *think* they operate from this position aren't necessarily home free. They, too, may benefit from regularly examining their personal philosophies to ensure they're "talking the talk" and "walking the walk." It's easy to say words; it's harder to do/not do the deeds that truly reflect our positions.

For example, Sue, the mother of a young child with a disability, operated from the equality position and believed in inclusion. But she also supported a "Walk" event for children with disabilities, which is partially sponsored by a big store chain. This seemed somewhat incongruous. The TV ad for the Walk (in the eyes of many people with disabilities and family members) reinforces the pity position. In one scene, a mother, on the verge of tears and with a quivering voice, says something like, "They [the store employees] really *l-i-k-e* our kids!"

But Sue didn't feel her support of the Walk was in conflict with her equality/inclusion position. During a discussion on the subject, Sean, a person with a disability, commented, "The store might 'like' cute kids with disabilities, but does it routinely hire adults with disabilities? Maybe the store's support evaporates when the kids are all grown up and not so cute!" Sean also expressed his dismay at disability-specific events which, at first glance, seem benevolent and helpful. But on further examination, the outcomes of these events often have the opposite effect: the focus on a group of people *because of their disabilities* maintains or even increases negative stereotypes. Sean added that programs which attempt to "create friendships" for individuals with disabilities reinforce the notion that people with disabilities are so different or needy that "friends" have to be recruited!

During this discussion, Sue realized she wasn't seeing The Big Picture. She came to the opinion that the Walk did not promote the equality, dignity, or inclusion of people with disabilities, then decided she could no longer support it.

Whatever our current positions, we can evaluate ourselves on a regular basis. If pity, sorrow, and/or sadness are part of your personal philosophy, do what it takes to eliminate those—they're not helpful to people with disabilities. Even if we hold the equality position, we can explore every nook and cranny in our noggins to make sure some form of pity is not lurking in a dark corner of our minds.

I check my position on a regular basis, and others help me maintain a steady course. A resident expert—my son who has a disability—keeps me on my toes, as do the many parents, people with disabilities, and professionals I meet during presentations who ask questions and share comments.

When I discover conflicts between my personal philosophy and my words or actions, I do a lot of internal wrangling and often talk it out with someone until I reach the point where I'm sure my "walk" matches my "talk." None of us is perfect, and I try to own up to the errors of my ways and correct them!

It's important to do this for my own sake: internal conflicts can generate stress, lethargy, tension, and a nagging feeling of "something's not right." Examining my position and making adjustments is just as important for my son and others with disabilities in my life, *for my actions and attitudes will have an effect on them*. And if I'm unaware of my true position, I could unintentionally hurt my son and others!

Try tuning up your position on a regular basis—just as you perform other habits and routines—and watch for some great outcomes. If you're employed in the field, you might influence the position of your organization, change the way you do your job, and/or create positive outcomes for those with disabilities. Or you may decide to change jobs! If you're an educator, you could change the direction of a child's life. If you're a family member, you may permanently—and positively—alter the direction of your whole family's life. Consider the awesome possibilities!