The Issue Is

The Fine Line

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About 20 of us who use wheelchairs were drinking coffee and enjoying a perfect fall morning on the University of Illinois campus in Champaign. Thirty years had passed since we had visited 35 cities in South Africa and Rhodesia—in 6 weeks—to demonstrate that people with severe disabilities shot archery, swam and played basketball all day, gave speeches all evening, and raised hell most of the night. All of the athletes were on leave from middle management and professional jobs in the United States. After 5 weeks in southern Africa, we flew to London, spent a couple of days disrupting that city with our antics, and went to the International Wheelchair Games at Stoke-Mandeville, England, to key waste to the gold medal hopes of the German, Italian, French, and British teams.

Thirty years later, we found that we were still going strong. A number of the group had retired, which was normal, considering that a number of the guys had picked up their disabilities in World War II, and we had all had at least 40 years of being wheelchair jockeys. The snapshots passed around of homes, children and grandchildren, vacation property, boats, and other accomplishments of success certainly did not present the picture of persons with disabilities living in poverty that is frequently painted by one group or another.

"You know," said one of our group, "it looks like we did pretty well for a bunch of cripples."

"We were pretty rugged individuals to start," said another, "but then, when we first got disabled, there were no rehab programs to teach us what we couldn't do. The docs told us we'd live a couple of years—then let us alone to do our thing."

The point of this illustration is neither to belittle rehabilitation medicine nor to ignore the wonderful advances made in the field in the past 40 years. Rather, this article explores the fine line between rehabilitation medicine being a supportive environment that facilitates restoration of function, or being a highly structured institution that, probably inadvertently, fosters dependency and low self-esteem.

In 40 years, rehabilitation medicine has grown to be a widely recognized specialty. In 40 years, the ideas have been accepted that people will live lives of normal length despite severe disabilities, that people with disabilities deserve equal education opportunities, and that people with disabilities can work. In 40 years, occupational therapy has grown from a service by ladies who taught crafts and other leisure pursuits in asylums, sanitoria, and hospitals for the chronically ill into a field encompassing kinesiology, psychology, clinical reasoning, and other highly technical skills.

The asylums, sanitoria, and hospitals for the chronically ill are gone. The Americans With Disabilities Act of 1990 and disability activism are here. Why, then, don't more people with disabilities, who have the benefits of new, highly sophisticated treatment modalities, go forth from the rehabilitation institutions and pick up their lives at the point where disability interrupted it?

I often meet people with disabilities who are convinced that they are now members of a suppressed minority, subjected to negative attitudes ranging from pity through paternalism to fear. How can they succeed, they ask, when insurmountable attitudinal barriers exist? In reading the newly emerging disability press, I sometimes think that, as a person with a severe disability, I was not tuned in enough to recognize the barriers. In reading the rehabilitation professional press, I often have the faint feeling that a patient with a disability is a collection of parts, unrelated to one another and each part most definitely the responsibility of a specific discipline.

Let us assume the rehabilitation team is not going to push the "jackal theory" (each member of the team grabs a piece of the patient and goes to his or her territory to chew on it). Let us assume that the disability press has a significant percentage of valid points. Let us assume some validity in the anecdotal evidence that children who go to special schools, segregated from children without disability, graduate to nursing homes—that some monstrous percentage of persons with disabilities remain unemployed despite advanced rehabilitation.

So what! What can you or I do? There are many factors that could lead to people with disabilities occupying a societal role of dependency, and, therefore, having less individual potential for success. Dependency could be rising because the number of persons disabled from birth is increasing and these persons do not have the experience of becoming independent from authority figures during their formative years. Disabilities incurred by people who have drug or alcohol dependence could affect successful
adjustment to and coping with a disability.

Is dependency rising because the disabilities incurred by people are more severe and more limiting than they were in previous years? Is it because our social and welfare system encourages reliance on public and private programs? Is there a possibility that our rehabilitation programs are fostering—or at least supporting—a belief on the part of people with disabilities that they must depend on others? If so, is that dependency preventing self-responsibility and personal choices?

Who cares what the reasons are? The important thing is that every person with a disability must make the choice at some time to take control of his or her own life. No parent, physician, or therapist can make that choice. The most profitable use we can make of this space is to explore how you, as occupational therapists, can prod people with disabilities into making that choice—and making it early in their experience with disability.

Lacking training in health care and clinical procedures, I fall back on common sense to create a list of possibly outrageous suggestions about how you can become an expert problem solver.

- You will never treat another patient. You will cooperate with a person who needs to work out solutions to situations that need fixing, such as eating alone, feeding oneself in the presence of others with a modicum of dignity, getting into clothing to go out in public, and taking care of daily tasks.
- You will listen more than you talk and force the person with whom you are cooperating to tell you what he or she is going to do. Occupational therapists are clever people—they can listen even if the other person's verbal capacity would not qualify him or her to anchor the 6 o'clock news.
- You will have social or recreational experience with people with disabilities who function well in life. Then you can insert remarks into conversations with newly disabled people like: "It's no big deal to go out to dinner at a restaurant—grab a friend and go!" Or "Yeah, it takes more effort to put on makeup and get duded up, but you'll attract a better class of people that way. Being mistaken for an over-aged hippie doesn't cut it in the job market."
- You approach the use of anything new by presenting the biggest collection of options (including the use of no devices), then force the person with whom you are cooperating to think what this addition means in his or her life. For example, therapists tell me I would benefit from a custom seating system... a power wheelchair... the latest gadgets. I know that. For heaven's sake, I've made my living selling the stuff. However, I don't want to benefit from this stuff. Part of my personal charm happens to be my stubbornness.

Can people with severe disabilities have full, productive lives? Of course. We have been doing it for years.

Can you, as one overworked, burdened-down-by-administrative-tasks occupational therapist, point every person with a disability toward full reentry into the mainstream? Of course not. Can you point some of them in that direction despite all the negative factors on which we are so fond of dwelling? Yes, if you always keep in mind that you are cooperating with a person—not treating a patient.

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