

Coping With The Transitions In Our Lives: From "Afflicted" Identity To Personal Empowerment and Pride

This narrative reflects the author's initial reaction to acquiring a disability as an adult and her eventual realization that she had internalized an inculcated shame and sense of less worth. Through becoming involved with professionals who had been disabled since childhood and with the independent living movement, she recounts how she developed an understanding of how medical model biases often routinely devalue people with disabilities and perpetuate systemic inequities in human service practice and cultural oppression.

by
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DISABLE

I know that many people gain an inner strength as they grow weaker but, though many travel this path, getting there is not easy in light of the social stigma that still surrounds disability. Perhaps writing about it will crystallize the experience.

My introduction to the world of disability was a gradual one. At age 34, after being diagnosed with MS (Multiple Sclerosis), I did not truly comprehend the realities of the disability experience for several years. I have known all along that my disability is progressive. At first, when I overdid, blurred vision, vertigo, and fatigue warned me to slow down. It wasn't too frightening in 1974. I would simply deal with it. I made sure I rested sensibly, didn't walk too far, or get overheated in order to continue doing all the things I was involved in — being a homemaker and mother who was active with her kids, being a businesswoman who successfully ran a company for her husband, and being politically involved in her suburban San Diego community.

The MS Society brochures talked about dealing with the symptoms, which vary

greatly in each person "afflicted," and holding on for a cure. There was very little written about actually living with the disability unless the individual was considered heroic, inspirational, or courageous — or was someone who became almost non-disabled. I remember wanting to shun people who thought I was a tragic victim "afflicted" with MS. That seemed like a melodramatic excuse to avoid getting on with life. But I couldn't shun them all.

Some of them made me doubt myself. As president of the local board of education, I spearheaded the move not to renew the superintendent's employment contract. He and his supporters spread a malicious rumor that MS had affected my brain. Some of their children even taunted mine at school. I didn't run for reelection in 1978. I ran for cover.

In the years that followed, my self-esteem took a few nosedives as I went through a divorce, tried unsuccessfully to get another job, then trained for another career. By the time the State Department of Rehabilitation turned down my request in 1980 for law school tuition assistance because, in their opin-

ion, a person with MS would be unable to hold down a 9-to-5-job very long, my sense of self worth was pretty low. I was being defined by my disability. So, as my rationale went at that time, if everyone else thought MS was so terrible — and I was the person with MS — I must be terrible.

When my sister suggested that I begin using a cane so I would not look tipsy when walking, then I knew the disability would no longer be invisible. The world I grew up in had devalued, excluded, and perceived disabled people as objects of pity and charity who needed to be cured. Suddenly, in 1974, that stigma had included me. I began to realize by the 1980s that non-disabled people who knew I had MS treated me differently even though I was essentially the same person. Embracing this confusing status and identity took many more years.

Because I had always worked, the rehabilitation counselor advised me to apply for Social Security Disability Insurance benefits. He said the Department of Rehabilitation's denial of services, more than my medical records, would guarantee my qualification. It wasn't until years later, when I learned how difficult it is to get disability benefits awarded, that I realized how right he was. I remember feeling apprehensive when the letter came stating that, unless I worked and earned more than \$200 a month, monthly cash benefits of \$494 had been approved effective February 1, 1982. I was officially disabled.

Never mind that I had borrowed enough money to finish a university paralegal program with honors and was about to look for a job in Los Angeles. The government believed gainful employment and MS were incompatible. I decided not to take my cane to job interviews or to use it at work. Due to fatigue, I lasted only six months in the 9-to-5 job. If the ADA (Americans with Disabilities Act) of 1990 had been law in 1982, I wonder if the law firm would have provided reasonable accommodations, such as part-time work or longer breaks and a place to lie down? I doubt it.

Looking back on those years both saddens and angers me. It was the loneliest, most unenlightened period of my life. I did not seem to fit anywhere socially. In spite of that, I began doing freelance paralegal work. It wasn't too hard to give up the cane for a wheelchair once I realized that sitting down would really conserve my energy. It was harder on my family and friends. I still remember the look on one UCLA doctor's face as I rolled into his office using what I considered to be a smart-looking wheelchair and he quipped "When did you get THAT thing?" It helped open my eyes to the stigma that is attached even to the equipment we use. No one, not my doctor, friends, or rehabilitation counselor, could get past the MS "victim" perception to help me look at and understand the bigger picture.

How can we get society to accept us if we cannot accept ourselves when our abilities

change and we are different? Why are disabled people readily disparaged and discounted instead of empowered to live with pride and dignity? Why are we not enabled to pursue all our employment options and possibilities? Why do we feel the disability experience is devalued by society instead of just being accepted as part of life's continuum? Why can't people see the "big picture" beyond the immediate image of disability?

In 1984, I was befriended by two scholars who grew up disabled and are leaders in the disability movement, Drs. Carol J. Gill and Paul K. Longmore. Through them, I learned about the negative language as well as the stereotypes and stigma that have historically been attached to people with disabilities. I realized I had internalized an inculcated shame and sense of less worth. Suddenly, pride began to replace my devalued self-worth.

At the same time, it became apparent to me that mainstream media largely ignore the real issues of disabled people and mirror society's misunderstandings. The media did not reflect new perspectives, such as the independent living and disability rights movement's way of interpreting society. To provide a forum for such issues, in 1986 I began writing a weekly newspaper column for the Long Beach *Press-Telegram*, "Living with a Disability," which was then nationally syndicated for eight years. I learned from and networked with disabled and non-disabled advocates all over the country. A major benefit of writing the column is that I

learned about and researched Independent Living Centers (ILC).

Writing the column also



made me aware that many of our human service systems have a medical model focus and treat disabled people as passive patients, "cases" to be managed, or charity recipients. In medically biased service agencies, the "patients" are not seen first as family and community members, workers, or entitled customers and consumers of services. Solutions to problems are most often approached through professional interventions, treatments, or systemic caretaking rather than through also exploring the most equitable socioeconomic, political, educational, and cultural possibilities.

For example, I learned from interviewing one of my readers, Bob Maes, that he had no options after becoming a quadriplegic in a diving accident in 1973. He needed help with personal hygiene, getting in and out of bed, and dressing. With the meager disability benefits he received, he could not afford home-based personal assistance, and his wife could not work and also handle his physical care. So the hospital's discharge planner recommended—and the government paid—to put this 37-year-old husband, father, and auto parts diemaker

in a nursing home, even though he did not need nursing care. Bob and his wife divorced; he spent 16 years mostly doing nothing at taxpayers' expense.

However, in the early 1980s, a Michigan Rehabilitation Services counselor got him to go to college. It was there that a friend told Bob about something he never knew existed: the ILC serving Oakland/Macomb counties in Michigan. Among other things, this ILC helps consumers with disabilities stay out of—or get out of—nursing homes by helping them obtain a Medicaid waiver to pay for adequate in-home support services rather than institutionalization. The ILC held classes where Bob learned self-advocacy, how to hire and manage personal service attendants, how to seek housing, and what to expect—the good and the bad—when living on your own.

At age 54, Bob felt a new world opened up when a college friend helped him get into an apartment in a subsidized housing project where he lives today. The nursing home staff predicted he would not make it on his own, but he has proven them wrong. We constantly fight society's belief that to be disabled and to need assistance is to be useless and pitiful. The belief that people with severe disabilities can live independently, have their own homes, and run their own lives is unrealistic to a lot of people, service providers included. According to the medical and charity paradigms perpetuated in many human service professional and educational training programs, the

biggest problems are located in the individual (who is broken or sick and needs to be cared for, fixed, or cured). According to the disability rights paradigm, our biggest problems lie in the inequitable socioeconomic, political, medical, and educational policies, as well as in oppressive cultural environments and practices.

Breaking free of the caretaker's mentality inherent in the system that put Bob in a nursing home was not easy. He cannot figure out why his life was put on hold for 16 years. Having the government pay for a full-time, home-based personal attendant would have been far cheaper than having a medically biased Medicaid system pay \$40,000 a year to keep him in a nursing home.

But medical bias is still rampant in the 1990s. My feisty and independent 70-year-old friend, Sylvia, never dreamed she could lose the personal freedom she had worked so hard to maintain. When she was hospitalized for an injured leg, this tough lady, who also has MS and uses a wheelchair, had no idea she would be up against a system that treated her like an object instead of a person entitled to make choices about herself. She certainly did not expect to end up in a nursing home.

I am convinced a combination of circumstances worked against Sylvia initially: her unquestioning trust of the medical profession, her slurred speech caused by the MS, and her blurred thinking from the medications she was being given. As a result, she was unaware that

she needed to call someone for help.

During her stay, the doctor at the hospital told her that he did not think she was capable of taking care of her affairs and that he had called a conservator. When she asked to go home, she was told a court-appointed attorney would come to talk with her about it. When he did, Sylvia told the attorney she wanted to contest the conservatorship. However, without Sylvia being present, a court found she was incompetent to provide for her personal needs, unable to manage her financial resources, and unable to resist undue influence. A temporary conservator was appointed, and she was put in a nursing home.

At the nursing home, Sylvia learned the conservator had closed her bank account. She had no money and no power, and she began to realize they were planning to keep her there a long time. The fact that Sylvia was tenacious is probably what saved her. She started asking questions about what was going on and learned her home was going to be sold to pay the conservator's fees. The conservator had spent her meager savings; all the money from Sylvia's monthly Social Security check and a small pension was being spent to keep her in the nursing home.

Desperate, she started calling all sorts of agencies. No one would get involved until she called the people who had helped her install wheelchair ramps at her home, the Westside Center for Independent Living in Los Angeles. They under-

stood that slurred speech did not invalidate her as a capable human being, and they listened. Sylvia's call set off a team effort that put together a detailed plan to get her all the help she needed at home from a personal services attendant. When the plan was presented to the conservatorship firm, however, it was rejected as unrealistic. Next, the ILC advocates located an attorney who donated her services and contested the conservatorship. A temporary conservator was then found who would donate his services.

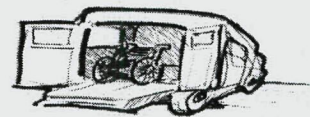
Ten months after she was put in the nursing home, Sylvia returned to her own home. The Attendant Registry at the ILC helped her find a live-in attendant who provides all the assistance she needs. But finances are tight. The original conservator put a \$10,750 lien on Sylvia's house, as did the court-appointed attorney for \$5,000. My friend was irreversibly traumatized by a series of events that never should have happened.

Could it happen to me? It is my biggest fear. At one time, I thought to be independent meant doing absolutely everything myself. Using that definition to prove I was a worthy, independent, disabled person, I would spend most of my time and energy doing daily tasks that a personal assistant does 10 times faster. People who have cooks, housekeepers, and chauffeurs are not thought of as "uselessly dependent." Living independently does not necessarily mean living alone or doing everything for yourself. It has more to do with

having options and making choices, like everyone else, about how and where you live. So far, I still have options from which to choose.

Since 1990, my hands have gotten weaker, and I no longer drive. I need help with household chores, meal preparation, personal hygiene, getting in and out of bed, and dressing. But, after moving to Long Beach (as a recognized disability-issues newspaper columnist), the local Department of Rehabilitation reversed the original denial of services and provided me with a lift-equipped van so I could get around to research and do interviews using my power wheelchair! My mother left me enough money to buy a house in 1992 and make it wheelchair accessible. After using up my savings to pay for the increased personal assistance I now need, I have qualified for In-Home Support Services through the county — and life goes on.

In 1995, I was asked to use my writing experience and



resources to increase awareness of disability rights, culture, and pride at the university level. As a result of becoming involved with California State University, Long Beach (CSULB) and its disability faculty interest group in an effort to establish a Disability Studies program on campus, I taught a course titled "Disabil-

ity, Culture, and Society: Issues and Intervention." It is a course that conceptualizes disability as a social construct utilizing an oppressed, minority group model. The course examines society's laws, policies, and practices to understand the experience of disability from the inside out.

I dread additional physical limitation and the unknown challenges it will bring. But, after 25 years of slow MS progression, I know it will probably come. And, though I will find a resourceful way to deal with the changes, it is sometimes scary. Still, I like the individual I have become, and disability is an essential and prideful part of my identity. Life and friendships seem more meaningful and honest, and I am involved and active in things that matter to me. No one ever said life's transitions would be easy.

Freedom of choice, self-determination, and independence are the corner-stones of American life. Choosing how we live and where are basic rights that are not yet a reality for many disabled people. ILCs are publicly and privately funded agencies designed to provide the support services, information, and referrals to resources that disabled individuals will need in order to live on their own. The basic idea is that disabled individuals who have successfully established independent/interdependent, productive, and satisfying lives know best what people with disabilities need. In my experience, effective centers have a majority of disabled people on their paid

staff as well as on their volunteer board of directors. As of March 1999, there were 470 ILCs nationwide, each of which offer a variety of services. Services can include peer counseling, self-advocacy training, systems advocacy, benefits advocacy, mobility training, attendant registry, housing assistance, and workshops to help consumers with disabilities acquire independent living skills in order to establish and/or maintain lifestyles that are self-directed.

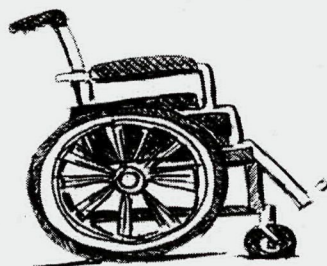
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INFORMATION RESOURCES

California Foundation of Independent Living Centers, (916) 325-1690, www.cfilc.org

Independent Living Resources Project, (713) 520-0232, www.ilru.org.

National Council on Independent Living, (703) 525-3406.



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