

Don't Fence Me In

Karen Stallings

Too often people see individuals with disabilities not as people, but as freaks. They don't realize that people with disabilities have a lot to contribute to society by educating people about disabilities or how to advocate for one's rights to live, work, and play in society against the odds. Whether people are disabled or not, everyone can contribute to their community and to society. If individuals would just stop and listen to people with disabilities, then they would realize that we have something to say.

They would see us in a different light. We are a people. We are different in a way. We may walk and talk differently, but we are just like everyone else in society. We have a body and soul, we have minds, and we know what we want to do with our lives. Some people with disabilities know what they would like to do with their lives. They would like to have real jobs with good pay. Some would like to live on their own or maybe with a roommate in their communities. People with disabilities are going to school. We are graduating from high schools and colleges to fulfill our dreams for our lives. Some may be doctors, attorneys, computer/software designers, actors, or actresses. We can be anything that we want to be in life, as long as we put our minds to the tasks at hand. This is true for anyone.

Take my job, for instance. I am an executive director of the Association of Self Advocates of North Carolina (ASANC) based in Raleigh. I have held that position for 12 years. ASANC works for self-advocacy and self-determination.

We have a board of directors consisting of people with and without disabilities. We have a contract with the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services that we are governed by. As in any organization, we have board meetings to determine what decisions need to be made for the Association. Although there are some individuals who may think—or have thought—that we couldn't make decisions for our organization, nevertheless, we have made them.

I never thought I would become an executive director of a state organization, but it was a job that I believed in. So, I took a chance, and I was hired as the executive director. Just because I have 25% cerebral palsy with my speaking,

walking, and fine motor skills, being affected doesn't mean that I can't work, live, or play in my community. I am active by being on other boards of directors now and in the past. I am a writer. I love to write. By writing and applying for a grant with the assistance of two friends, I created a newsletter for people with disabilities. My newsletter, *Disability Express, Inc.*, has been in existence for 14 years, and it is still going strong. I am still proud of *Disability Express, Inc.* My husband and I have our own television show, "Speak Up, Speak Out, Voices in the Community" on Cable 10 through the Public Access Channel in Raleigh, North Carolina, which has been running for 10 years. The show is geared towards people with disabilities and topics that deal with legislative issues such as the People First Language Bill, that was passed, to emergency preparedness for people with disabilities.

My husband and I both act with the Raleigh Ensemble Players. I have run for city council four times, and even

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though I didn't win, I did have a runoff. Some people recognized me as a candidate and some didn't. Some people thought that my disability would interfere with my ability to hold a position in the city council. They saw my disability and not my ability to serve on the city council.

I graduated from Irmo High School on June 3, 1975. While I was in high school, I didn't let my disability get in the way of my learning, even though there were some people who believed that I shouldn't have been in regular classes. They believed that I couldn't keep up with the work or changing classes, but I showed them that I was capable of doing anything that I put my mind to doing. Of course, there were accommodations that had to be made for me in school such

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as note taking, locker opening, and taking tests, but once those accommodations were made, everything else was fine. I was voted "Miss Congeniality" by the senior class. Sure, some of the students made fun of me at school, but I tried to ignore them. If they didn't know me or didn't want to understand my disability, they weren't my true friends; my true friends knew me and understood me as a person. They saw me as their friend. Some of the students wanted to label me as "retarded" or "stupid," but I'm not a jar. Labels belong on jars, not people. After graduation from Irmo High, I attended the University of South Carolina in Columbia. My major was Early Childhood Development, and I graduated on May 13, 1978.

You would think that people with disabilities have certain privileges, receiving help with daily activities without difficulties. However, what if services such as Medicaid, SSI, and SSD were taken away? By taking supports and services away from people with disabilities, life for them wouldn't be so simple and easy. It would be rough for some, especially if they were dependent on those services to help with their financial needs on a regular basis. How would it be for people without disabilities to live that way? I imagine that they wouldn't prefer living with little or no money. Also, I bet many people without disabilities do live in some kind of daily financial struggle, but some won't let others know what trouble they are going through in their lives. It is hard with our economy as it is today. And it affects everyone whether they have disabilities or not.

Now, I would like to tell the story of my SSI check. I began receiving an SSI check when I started working in the late 1970s. My mom and I went to the Social Security office in Decatur, Georgia. We were told by a Social Security representative that as long as I didn't go over the amount of my current salary, I could keep receiving my SSI check for my entire working career. We were very happy and excited about hearing that news. Well, as life would have it, over the years my jobs changed and my salary changed. That was the good news. My salary was pretty decent, and I was still receiving SSI checks to help make ends meet. I thought things were fine, but Social Security saw things differently. I began having long disputes with Social Security over many years. It has been an uphill battle. Social Security wouldn't bother me for years then, suddenly, they would pop up out of nowhere and mail letters telling me that my SSI check would be taken away because of my salary being high, or saying I had to pay the money that I was receiving back to Social Security.

My dad, my husband, and I would have to go back to the Social Security office in Raleigh and speak with representatives about my SSI checks. It was often frustrating because some of the Social Security representatives wouldn't listen; but some would listen and they would try to be of assistance. It was as if I was going to a new drawing board every time I had to do battle with Social Security. It seemed like when my case was reviewed and discussed by the representative and myself, we could get the kinks worked out and get back on track with me receiving my checks. To say the least, once more I was happy and relieved that the battle with Social Security was finished for the moment. I could continue living my life with some ease due to my Social Security checks. I was paying my bills without really worrying about not having enough money for my living expenses.

Even though everything worked out with Social Security for a period of time, a monkey wrench was thrown into the works once again. In 2003, the battle started again with Social Security. As hard as I tried, I couldn't win that battle. Social Security finally took my checks in 2003 because my gross income was too high. It wasn't quite fair. I realize that the government needs money to be paid back by citizens, but I am trying to contribute to the community by working just like everyone else. However, Social Security doesn't see it that way. All they are concerned about is their money and how people are going to pay them back.

I have known friends and coworkers who have lost their benefits along with services just because they wanted to get married and live in the community of their choice. They would like to contribute to communities as taxpayers, but it's especially hard when Social Security won't work with people with disabilities and let them receive their checks. It could make their lives simple. People with disabilities face living without assistance to help them live their daily lives. Their services are being cut due to not enough money in the state's budget. I'm asking you, is this fair? No, it isn't fair. People with disabilities shouldn't be penalized because they want to live, work, and play in society.

We will keep fighting for our rights until our voices are heard throughout the community. When you see people with disabilities out and about in the community, remember, we are people, and we are enjoying life as well. If you stop and listen, we may learn from one another. Please don't let our voices be silenced any longer. Hear what we are saying to our communities. **NCMJ**