

# Disability Finds a Voice

Carol Gilson

**Abstract:** The U.S. Developmental Disabilities Act states, "Disability is a natural part of the human experience...One American in five is a person with a disability, making people with disabilities the largest minority group in our nation, and it's the only group that anyone can join at any time: at birth or through an accident, illness, or the aging process." When I discovered that my fellow social work students were not required to take courses on the topic of disability, despite the fact that within The University of Texas Austin School of Social Work (UT-SSW) there is a Center for Disability Studies, I knew I had to do something. This narrative reflects my personal experience with disability, my return to school, and the help I received while I attempted to create change within the curriculum.

**Keywords:** disability, Developmental Disabilities Act, University of Texas, social work, advocacy.

## **The Journey Begins:** *"Hope at last"*

At the age of 25, life as I knew it stopped. I was diagnosed with rheumatoid arthritis, a crippling auto-immune disease that resulted in more than a decade of pain primarily caused by isolation and a greatly diminished capacity to accomplish even the simplest tasks. Within that first year, I was completely homebound and unable to work or support myself. My mind and spirit were slow to adjust to these new realities. I still saw my body as strong and capable, but anyone who took one look at me knew this was no longer true. I had trouble bridging the sense of freedom, strength and vigor that I had always known with the realities of my diseased body; a body that suddenly struggled to stand up, walk, or perform basic activities of life and self-care. I slept my way through the next several years. During that time most of my peers graduated from college, began new lives; many married, started families, or moved away. I felt as though the world was passing me by.

Within two years of diagnosis, I had lost mobility. I spent the next four years attempting to reclaim the ability to walk through physical therapy and other modalities. While in a physical therapy session at a local rehabilitation hospital, I met someone who helped prepare me for the next phase of recovery - a social worker. She created a safe time and place each week where I could talk about my fears for the future, fear of what was happening to my once healthy body. During those sessions I could hear myself voicing issues I had not yet confronted which helped

to reduce the anxiety I was experiencing and enabled me to make tough choices about my medical care.

The choice I faced was to become a person who navigates the world in a motorized wheelchair or endure several invasive surgeries that would require countless months of intensive rehabilitation. I chose surgery. Within six months I was hospitalized twice, and had a total of four surgeries to replace both hips and both knees. I had to relearn how to walk two times that year, once with new hips and again with new knees.

While in the hospital recovering from the first surgery, I began thinking about my future. For the first time in almost six years I had hope, and I began to understand how to live a rich and fulfilling life despite chronic pain and a disability. It was in that hospital bed that I reconnected with my childhood dream of becoming a therapist. It struck me that my personal journey had given me the experiences with illness, disability, and rehabilitation that could enable me to work empathically with people whose bodies are in crisis. I wanted to help other newly-disabled adults on their path to wholeness as they struggle with their own fear. My illness gave me a second chance at life. I have gained a deeper insight and understanding of the human experience and have a strong desire to share what I have learned. I decided that a Master's degree in social work could be the vehicle for developing the skills I need to be effective in helping other adults who have become disabled through illness or injury.

### **In Pursuit**

My pursuit of a Master's in Social Work began as an undergrad at Austin Community College where I gained enough credits to transfer in as a junior at The University of Texas Austin School of Social Work (UT-SSW). I looked forward to taking classes relating to disability. However, I quickly learned that issues of disability were only briefly included in the social work (SW) core curriculum. In a university-wide search for disability related courses I found web-based classes offered by the Center for Disability Studies. To my surprise, although these classes are sponsored by the UT-SSW, the academic advisor did not know about them. I took the opportunity to register for my first disability studies class, which satisfied an upper division elective requirement and steered me in the direction of viewing human experience through the lens of disability. Although I personally got a lot out of the disability course, I still found myself frustrated. I knew it wasn't enough. The curriculum needed to reflect that disability does not discriminate based on gender, race, age, and socioeconomic status. The fact is everyone's life will inevitably be impacted by disability, whether it affects us or someone we love.

Before long, I was speaking up in a social welfare class about poverty. The textbook only spoke about the risk of poverty to people with mental illness. I felt it was important for my fellow students to understand that medical expenses are the primary reason people file for bankruptcy in the U.S., as a way to highlight the fact that people with any type of disability are at a higher risk for living in poverty than other members of our society. In policy class when students shared personal accounts concerning social justice issues, I listened from the perspective of a person who doesn't live in a typical body, and made connections between my experience and theirs. Seeing these differences in experience, and some of the resonances with issues of race, class, and gender, I began to question.

I created an online survey where I asked my fellow students how they viewed disability, and what, if anything, they wanted to learn about working with people with disabilities (PWD's). I was surprised by the fact that most of them had never considered disability to be a social justice issue until completing the survey and, 76% of those who responded felt the curriculum did not prepare them for working with PWD's. From the data, I chose to focus on the top three topics that students were most concerned with learning. They wanted specific techniques and resources that could help them work with PWD's, as well as tips on how to advocate for their clients with disabilities. This information helped confirm my desire to better integrate disability into the academic curriculum, but it was still unclear to me how I could accomplish that.

### **Finding My Voice**

“We've GOT to make noises in greater amounts!

So, open your mouth, lad! For every voice counts!”

– *Horton Hears a Who*, Dr. Seuss.

Though I was not the only student in my cohort with a visible disability, my fellow classmates and even professors looked to me as the voice of disability in class. Being asked to take on this responsibility left me feeling angry and frustrated and I was keenly aware of the burden of representation. When these situations arise I speak from my experience and needs related to my experience of disability, pointing out that each person has different needs and unique perspectives of what it is to live with disability. As I listened, in class or in the hallways, to questions posed by fellow classmates and I did the best I could to amplify the voices of all people with disabilities. However, I became a student to find out the answers to many of the same questions that were being asked of me. By seeking my own answers I found there was growing interest among my peers to learn more about disabilities so that they could better serve their future clients.

I knew that I wanted more from my educational experience and I felt that change was needed within the curriculum itself. I requested an appointment to speak with the Associate Dean for Undergraduate Programs, hoping to generate a conversation about my experience. She received me warmly, and although I felt nervous pointing out what I saw to be a flaw in the way disability issues were addressed, thanks to her generous spirit I quickly felt at home in the discussion. She encouraged me to share my concerns, and even asked for ideas about how to improve the curriculum as it related to disability issues.

During that meeting, I made the argument that disability can be considered a culture of its own, and warrants inclusion in the SW curriculum, alongside critical race theory and issues of gender and sexuality. Disability needed its own lecture courses that could be taken as electives and also meet multicultural course requirements. The Associate Dean became very excited by my ideas, and she was in complete agreement. By the end of the day, disability courses were reclassified as both electives and multicultural components, thereby making them more available to students. Little did I know that meeting would have a profound effect on more than just the curriculum.

As a result of our meeting, the Associate Dean suggested that I create a disability initiative. It was decided that we should form a committee comprised of students, faculty, and community advisors to help us create more disability awareness at the UT-SSW. In May of 2011, she helped to assemble a dynamic team to form a Disability Visibility Initiative Committee (DVIC) at the UT-SSW that could formulate concrete goals for implementing the desired change.

In the fall of 2011, the DVIC presented the first ever symposium at the school of Social Work focused on disability, entitled "Making Systems Work for People with Disabilities." The symposium, held on October 21, 2011, was made possible through the help and support of the School of Social Work

administration, faculty, and leaders from the Center for Disability Studies. The symposium featured two panel discussions. The first was comprised of five people who live with their own disabilities every day, who in my opinion are the true experts in the field. The second panel highlighted the contributions of professionals who work with people who have disabilities, all of whom were disabled themselves. The speakers represented an eclectic mix of organizations, and I did my best to reflect the diversity within the disabled population by including people with a variety of disabilities. One speaker, a local journalist who lives with a psychiatric diagnosis, spoke about the challenges she faces juggling her symptoms and medications, while maintaining a fulfilling family and work life. Another panelist, a member of President Obama's Access Committee and Director of the Texas Independent Living Council, whose injury was the result of a gunshot wound at the age of twelve, spoke about the importance of supports that help PWD's live in the community. While another who was an Olympic hopeful until injured one day in practice at the age of seventeen, talked about coming to terms with an acquired disability that changed the trajectory of his life and led him to become a lobbyist for disability rights.

Each of them brought a unique perspective to the discussion, and gave examples of individualized supports they have needed as a result of their disability, although commonalities could be seen among the panelists. They all wanted more from their lives than society expected or even thought they could accomplish based on their diagnosis. For me, this highlighted what I had been saying in my classes all along, and it was empowering for me to hear my words echoed by my peers. The panelists conveyed the desire to be seen as individuals, instead of being perceived primarily as disabled and in need of support. People with disabilities want the same things that everyone else does: opportunities to become active members of society and have fulfilling relationships with others, while finding meaning and purpose for their lives.

There were close to 200 people in attendance. CEUs were offered to alumni of The UT-SSW. A printed program for the symposium was given to all attendees, and it contained a resource list to help attendees in the future when working with PWD's. Many of the agencies listed were on hand as part of a resource fair created in conjunction with the event. I consider the symposium a huge success not only because it was so well attended but we also received much positive feedback from a post-conference survey completed by each attendee. They identified changes in perceptions of disability and most felt that their attendance would help them better serve PWD's.

A pivotal moment of the symposium occurred during the Q and A portion at the end, when a student asked the panel how to best serve people with disabilities. ADAPT founder Bob Kafka responded, by asking us as social workers to remember that PWD's are more than a file on our case load. They are unique individuals with hopes and dreams of living a fulfilling and meaningful life. For some that may mean marriage and a family, for others it may mean a career or hobby that brings purpose to their lives. He also pointed out that it is important to remember that PWD's often rely on social services to meet their basic needs, including funds to help pay for living expenses and programs that provide medical care. Therefore, it's important for social workers to take the time to understand their clients' needs. It was that interaction with Bob Khafka that really drove home for the audience the importance of looking at disability and the supports available to PWD's as a social justice issue. Here are a few selected quotes from attendees, revealing the insights they gained through attending the symposium.

Figure 1. Disability Visibility Symposium Making Systems Work for People with Disabilities attendees' comments:

*I think a course on disability in our society should be a required core class in the social work program*

*A very interesting symposium; it definitely increased my knowledge, awareness and interest*

*We need to confront stigmas, stereotypes and myths but shifting the focus to what works – not just what doesn't*

*Social workers need to work with not for people with disabilities by listening to them as unique individuals– Thanks Bob Kafka!*

*Thanks to this symposium I now see disability as a social justice issue*

The symposium continues to affect the campus climate concerning disability issues and was the catalyst that opened a dialogue for addressing disability issues campus-wide. The semester following the symposium, I, along with several other students, created a campus-wide disability advocacy committee that is sponsored by the Office of Services for Students with Disabilities, where the dialog concerning advocacy work has continued throughout campus. Readers may view the entire symposium on the Center for Disability Studies website: <http://tinyurl.com/q6ahgty>

### **Onward**

*“Don't Mourn – Organize” – Bob Kafka, ADAPT*

Through work with DVIC, I have been given the opportunity to work closely with other organizations throughout the university to help ensure that the voice of students with disabilities is heard throughout campus. I served with the Office of Services for Students with Disabilities (SSD) to develop a university wide disabled student's organization, and I serve as the SSD representative on the Division of Diversity and Community Engagement Student Advisory Committee, which works to increase diversity awareness and tolerance at the university.

I have been working with SSD to help improve accessibility throughout campus, focusing

primarily on the SW building. To date, improvements to the SW building have included the instillation of automatic door openers and even removal of some doors altogether. Additionally, there are plans underway to increase the number of wheelchair accessible parking spots available to SW students with disabilities.

I hope that the changes made to our building will encourage other schools throughout campus to review and improve their buildings accessibility. Although I have accomplished much in a short period of time, the work is far from over, and I plan to continue being a campus disability advocate throughout my time at UT-SSW.

### **Finally**

The University of Texas at Austin's motto is, "What starts here changes the world", and I hope that in some small way I have begun to change the world by simply speaking up. It is my greatest hope that through sharing this story of advocacy that other students and helping professionals will be inspired to find their voice, and create the change that they would like to see in the world.

***About the Author:*** Carol Gilson, LMSW wrote this as an undergraduate student. She is currently working towards clinical licensure, as a therapist in an intensive outpatient program, using dialectical behavioral therapy (carolgilson@gmail.com).