

Reflections on Inclusion: Integrating the Disabled Self
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Abstract: In the following essay, I explain how my experience as an included student with cerebral palsy influenced my identity as an individual with disabilities. I also outline how my discovery of disability studies has influenced my role as a teacher, educator, and researcher in special education.

Key Words: disability, identity, inclusion

Since the age of two, I have been in some type of educational setting. Like countless other parents of children with cerebral palsy, doctors told my parents that I likely had severe mental retardation, that I would never walk, talk, or write my name, and they should consider an institutional placement. Thankfully, my parents rejected this negative approach. However, they did believe that getting as much therapy as possible was best, and the best place to receive therapy at that time was in a preschool for children with disabilities. Therefore, my first stop on the “road of knowledge” was a preschool for “crippled” children.

Not Like “Them”

Most of the other preschoolers had mental retardation, and even at that young age, I recognized that I was different from them. Somehow, I also recognized the negative stigma attached to mental retardation and did everything I could to distinguish myself from “those” kids. With the speech and physical impairments of cerebral palsy (CP), this was not an easy endeavor.

My preschool days were spent in hours of occupational, physical, and speech therapies, all in an effort to “fix” me, or at least make me as normal as possible. The therapists’ attempts to have me put my tongue behind my teeth to make a perfect “t” sound or scoop food to my mouth without spilling it sent the message that I was not acceptable as I was. The more I could do things in a typical fashion, I subliminally learned, the better my life would be.

Not “Handicapped”

In the summer of 1975, just months before the passage of PL.94-142 (a U.S. special education law now known as the Individuals with Disabilities Education Act), my parents faced a critical decision. I was too old for preschool, and they had to determine where I would continue my education. The most recommended placement for me was a school in the center of a large Midwestern city, an hour bus ride each way from our home. My mother approached the superintendent and asked him to educate me within the district, asserting that she would go to jail before letting me go to the special school.

My parents were not advocating that I be mainstreamed, as it was called then. They simply wanted me to have an education. A district counselor visited our house several times that summer, assessing me, and negotiating my placement.

My first public educational placement was a class for students with learning disabilities and mental retardation, but I only stayed two days. When my mother received a call from the counselor saying I could not stay in that class, she was horrified, her mind racing to think what I had done to be expelled so soon. The problem was that I answered all the questions and would not let the other students have a chance.

Not knowing what to do with me, they gave me a homebound teacher in the morning, and then I joined a regular first-grade classroom in the afternoon. I was fully included with a full-time aide

from second grade until I graduated from high school.

I owe a great deal to my parents for following their instincts and going against the grain. I never regretted being included. Considering the accounts of other included students, I fared well socially. I was very lucky because my peers were rarely cruel or made fun of me. Since I was included from first grade, my peers just got used to me. But the great thing was that I wasn't tolerated; I was truly included. I had a best friend in every grade and was invited to birthday and slumber parties. When we went to middle school, kids from other schools came together in one school. There were many kids who did not know me and a few seemed unsure, but they got used to me just like the peers I had known for five years.

I think my biggest struggle for acceptance was in Junior High, but that is when everyone feels left out and does not know to which group he or she should belong. It was the mid-1980s and the key to acceptance was designer clothes. So, Mom bought me a couple of pairs of Calvin Klein jeans and I was "in."

Despite the early messages that my disability made me less worthy, my parents encouraged me to believe in myself and did not place limits on their expectations of me. I knew from my preschool experiences that others might not recognize my intelligence right away. As a result, I often felt I had to prove I belonged in public school by making good grades.

Although I am grateful to have been included, in retrospect, I realize that striving to be "just like everyone else" had some negative consequences. My attempts to distance myself from children with mental retardation left me with a cognitive abled stance and prevented me from embracing my identity as an individual with a disability. In eighth grade, I recall proudly telling a newspaper reporter who wrote an article about me that I "did not consider myself handicapped." I fought efforts to connect me with other people with disabilities. I did not interact with many other students with disabilities in school, and I was the only included student with CP. Therefore, when I met a young man with CP in college, it took some time for me to feel at ease with him.

Not Able Enough

My first semester of college brought about a realization that my physical limitations threatened my ability to achieve academically. I had three courses that required a great deal of writing. Typing eight words per minute on a typewriter with a stylus, keeping up was tough. I could not type as fast as thoughts came, and there were not enough hours to do all the typing. At the end of the first semester, physically and emotionally drained, I gave in. For the first time in my life, I felt disabled!

Returning to the "panacea of rehabilitation," I sought more therapy that would help me do more for myself. In other words, I wanted them to "fix me" so I could continue my life.

Six months of speech and occupational therapy did little to increase the stamina I needed for academic work. I learned to dress and feed myself, but for the price of time. With the amount of typing finishing college would require, time was not something I could expend haphazardly. I realized there was little point in spending three hours dressing myself if I was too tired to do anything else the rest of the day. I made a decision that it was better to have people help me, saving my time and energy for academics and fun.

With nothing to make typing easier, I still decided to return to college. Even if it came to taking one class at a time, it was better than doing nothing at all. I completed two more years of school with the typing stick. The summer before my junior year, my father purchased a computer for me, not really knowing how I would access it. When we brought the computer home I told Dad to put the keyboard on the floor. I had always used my feet to dial the phone and push buttons on my

stereo, so it was just a natural progression to type with my toes. I also discovered the miracle of abbreviation-expansion, software that allowed me to create abbreviations for the words I used most.

My life changed completely when I got the computer and assistive technology. I increased my typing speed from eight to 20 words per minute (still slow, but manageable). Work did not take as long, and I had more time for fun. I completed my B. A. with a double major, English and Psychology, in two more years, graduating with honors.

Toe-typing not only gave me a means to demonstrate academic ability, but it also became means by which to celebrate my differences and begin to embrace and celebrate my identity as an individual with disabilities. I made greeting cards called "Toe-Typed cards by GDL," complete with a custom logo depicting feet on the keyboard.

Graduate School

At the end of my undergraduate career, I faced two possible areas for graduate study, English, my true passion, or special education, which would fulfill my desire to use my experiences to help others gain access to assistive technology and make their inclusion easier.

I believed that studying special education would be easier, in that the stigma of disability would be easier to overcome. Furthermore, I believed that my opportunities to teach English with a speech impairment would be extremely limited. I had never let others' perceptions of my abilities stop me before; I cannot explain why I allowed them to curb my ambitions this time.

As a graduate student in special education, I always felt something was amiss, but I was not sure what it was. I assumed my disability would be more understood by my professors and fellow scholars. They, of all people, would see my experiences could have an impact on the education of children with disabilities. I was an asset, not a threat.

Although I was never mistreated, I felt like an insider forced to look at special education as an outsider. I was trying to understand special education from the perspective of a person with cerebral palsy and to integrate the content with my own experience as an included student. When I attempted to use my personal knowledge to illustrate points in class, I did not feel validated. Many implied that my education was an entirety unique event, never to be replicated again. Someone implied that my success was based on luck, fate, or Divine intervention, having nothing to do with "best practices." Of course, I realized not all students had the family support and exceptional teachers I had, but I felt I still shared much with the current generation of students who have disabilities that would be useful to improving current educational methods.

My area of expertise was assistive technology. When I attended exhibits at conferences, vendors always assumed I was looking for technology to help myself. The concept I looked for ways to help others was beyond their comprehension.

I was discouraged from taking a workshop in augmentative communication because I had physical impairments requiring slight modifications to the computer (putting the keyboard on the floor). The organizers admitted afterward it would have been no problem to accommodate me, but just the idea I was not wanted made me hesitant about viewing them as trusted colleagues.

After reading Linton's *Claiming Disability* (1998), I realized what special education lacked was a disability studies perspective. Linton points out that special education ignores subjective views of disability, failing to see people with disabilities as having power over their own lives, or as important to culture in general. Next, Linton criticizes special education and related disciplines for objectifying people with disabilities, ignoring how personal accounts of individuals with disabilities

contribute to an overall body of knowledge, favoring instead scientifically collected data.

Although my classes denounced the medical model and promoted student-centered approaches, there was little talk of the social construction of disability or encouragement for students to celebrate their differences. In trying to make the education of students with disabilities as typical as possible, the uniqueness of the disability experience and recognition of disability culture became lost.

Integrated Identity

My identity as a person with disabilities evolved as I progressed from preschool to public school to college and to graduate school. While my misdiagnosis and survival in public school forced me to separate myself from my disability as much as possible, my college years required me to recognize my disability, and my use of assistive technology gave me a means through which to celebrate it. I now consider myself a member of the culture of disability, along with people with cognitive and all other disabilities. I am a fellow soldier in the battle for accommodations, respect, and the freedom to celebrate our differences.

Inclusion has come full-circle for me, progressing from the viewpoint of student to teacher. I now instruct general educators in ways of including students with disabilities, integrating my own experiences into my online course.

As I delve further into the disability studies literature, I continually reconfigure my class to reflect even broader perspectives of disability. Together, I hope that my students and I can discover ways to accommodate disabilities in a manner that honors students' differences, supporting celebration rather than compelling disdain. Students should not have to wait until adulthood to learn disability pride!

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References

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