Our Fight for Disability Rights -- and Why We're Not Done Yet

Judith Heumann

I was born in 1947, a long time ago, and when I was 18 months old, I had polio. I was in an iron lung for three months and in and out of the hospital for three years. Now, we had lots of neighbors in our Brooklyn neighborhood, and some of them were really very helpful for my parents. Some of them were really afraid of contagion, and they wouldn't even walk in front of our house. They would literally walk across the street. I think this was a time when my family really began to realize what disability meant to some people: fear.

And it wasn't even a sure thing that I would live at home, although I didn't learn about this until I was 36 years old. I was having a discussion with my father one night, and he said, "You know, when you were two years old, one of the doctors suggested to your mom and I that you live in an institution, that they could just go ahead with their lives and raise their kids and kind of be done with having to deal with all the disability-related things. I didn't believe my father, not because he was a liar, but I'd never heard this story, and my mother in fact validated that. She never wanted to tell me.

But in reality, I don't know why I was really surprised by this story, because when I was five years old, and my mother, like mothers and fathers all across the United States, was taking me to school to enroll, she pushed my wheelchair to the school in walking distance to our house, pulled the wheelchair up the steps into the school, and we were greeted by the principal. Not really greeted. But the principal said, no, I couldn't come to that school because it wasn't accessible. But he told us not to worry, because the Board of Education in fact would send a teacher to my house. And they did for a total of two and a half hours a week.

But for good behavior, they threw in an occupational therapist who taught me that very essential skill of cross-stitching.

I don't cross-stitch today.

I didn't actually get to go to school in a real building until I was nine years old, and then I was in classes only with disabled children in a school that had mainly nondisabled children. And in my classes, there were students up to the age of 21. And then, after 21, they went to something called sheltered workshops with menial work and earning either nothing or below minimum wage. So I understood discrimination. My parents understood discrimination.

My parents came from Germany. They were German Jews who left in the 1930s, escaping the Holocaust. My parents lost family and they lost parents. Both my parents lost their parents in the Holocaust. And so they realized that they could not be silent as things were going wrong for me in my life. Not me personally, but what was going on around me.

They learned that because I used a wheelchair, none of the high schools in New York City, in the entire city, were wheelchair accessible, so what was supposed to happen is I was supposed to go back onto home instruction along with many other students. So my parents banded together with other parents. They went to the Board of Education and they demanded that the Board of Ed make some of the high schools accessible. And they did. And so I and many others were finally able to go to high school, a regular high school, and take regular classes.

So what happened next? I was learning more and more about what discrimination was, and equally important, I was learning that I needed to become my own advocate. I was entering college, Long Island University, and I had always wanted to be a teacher, and so I minored in education and I took all the appropriate courses, and then when it was time for me to go for my license, I had to take a written exam, an oral exam and a medical exam. At that time, all three of those exams were given in completely inaccessible buildings, so I had friends who carried me up and down the steps for these exams, not in a motorized wheelchair.

In a manual wheelchair. But I passed my oral exam. I passed my written exam.

My medical exam was something completely different. One of the first questions the doctor asked me was, could I please show her how I went to the bathroom. I was 22 years old and you know when you go for any kind of an interview, you think about all the kinds of questions that people could ask you?

That was not one of them. And I was freaked out in the first place because I had heard that there were actually no disabled people using wheelchairs who were teachers in New York, so each step along the way I was expecting something bad. So I said to her, is it a requirement that teachers show their students how to go to the bathroom? If it is, I can do that.

So no surprise, I was failed because I didn't pass the medical. The official reason that I was denied my job was paralysis of poliomyelitis sequelae of -- I'm sorry. Paralysis of both lower limbs, sequelae of poliomyelitis. Honestly, I didn't know what the word "sequelae" meant, so I went to the dictionary, and it meant "because of." So I'd been denied my license because I couldn't walk.

So what was I going to do? This is a really important time in my life, because it would be the first time that I really would be challenging the system, me, and although I was working with a lot of other friends who had disabilities who were encouraging me to move forward with this, it was nonetheless quite frightening. But I was really very lucky. I had a friend who was a disabled student at Long Island University and was also a stringer at the "New York Times," and he was able to get a reporter to write a really good piece about what had happened and why he thought what had happened was wrong. The next day there was an editorial in the "New York Times" with the title of "Heumann v. The Board of Education" and the "New York Times" came out in support of my getting my teaching license.

And then the same day, I got a call from an attorney who was writing a book about civil rights. And he was calling me to interview me, and I was interviewing him. He didn't know that. And at the end of our discussion, I said, "Would you be willing to represent me? I want to sue the Board of Education." And he said yes. Now, sometimes I say that the stars were aligned around this court case, because we had an amazing judge: the first African American female federal judge --

Constance Baker Motley.

And she knew discrimination when she saw it.

So she strongly encouraged the Board of Ed to give me another medical exam, which they did. And then I got my license, and while it took a number of months for me to actually get a principal to offer me a job, I finally did get a job and I started teaching that fall in the same school that I had gone to, second grade. So --

That's a whole other TED Talk.

But I was learning as my friends were, and people I didn't know around the country, that we had to be our own advocates, that we needed to fight back people's view that if you had a disability, you needed to be cured, that equality was not part of the equation. And we were learning from the Civil Rights Movement and from the Women's Rights Movement. We were learning from them about their activism and their ability to come together, not only to discuss problems but to discuss solutions. And what was born is what we call today the Disability Rights Movement.

So I'd like to tell you a couple of riddles. How many people do you think it takes to stop traffic on Madison Avenue during rush hour in New York City? Do you have a guess? How many?

Fifty. One would be too little. Fifty people. And there were no accessible paddy wagons, so they had to just kind of deal with us.

But let me tell you another riddle. How many people does it take to stop a bus in New York City when they refuse to let you on because you're in a wheelchair? One. That is the right answer. So what you have to do though is take your wheelchair --

Sidle in the right place right in front of the steps and give it a little push underneath, and then their bus can't move.

Any of you who want to learn how to do that, talk to me after this.

In 1972, President Nixon vetoed the Rehabilitation Act. We protested. He signed it. Then the regulations that needed to be promulgated to implement that law had not in fact been signed. We demonstrated. They were signed. And when the Americans With Disabilities Act, the ADA, our Emancipation Proclamation Act, looked as though it might not in fact be passed in the House or Senate, disabled people from all across the United States came together and they crawled up the Capitol steps. That was an amazing day, and the House and Senate passed the ADA. And then President Bush signed the ADA. It's a great picture. President Bush signed the ADA on the lawn of the White House. It was an amazing day, and there are about 2,000 people there. It was July 26, 1990. And one of the most famous statements he had in his speech was, "Let the shameful walls of exclusion finally come tumbling down."

For any of you in the room who are 50 or older, or maybe or even 40 or older, you remember a time when there were no ramps on the streets, when buses were not accessible, when trains were not accessible, where there were no wheelchair-accessible bathrooms in shopping malls, where you certainly did not have a sign language interpreter, or captioning, or braille or other kinds of supports. These things have changed, and they have inspired the world. And disabled people around the world want laws like we have, and they want those laws enforced.

And so what we've seen is something called the Convention on the Rights of Persons with Disabilities. It is a treaty that was adopted in 2006. It's celebrating is 10-year anniversary. More than 165 countries have joined this treaty. It is the first international human rights treaty fully focused on disabled people. But I am sad to say that our US Senate has failed to recommend to our president that we ratify the treaty. We signed it in 2009, but it doesn't come into force until ratification, and the president -- no president can ratify a treaty without the consent of the Senate. So we feel really strongly that our US Senate needs to do its job, that our Senate needs to enable us as Americans not only to be able to assist disabled people and governments around the world to learn about the good work that we've been doing, but it's equally important that disabled people have the same opportunities to travel, study and work abroad as anyone else in our country. And as long as many countries don't have the same laws as we do and don't enforce them if they have them, opportunities for disabled people are more limited.

When I travel abroad, I am always meeting with disabled women, and those women tell me stories about how they experience violence and rape and how in many cases these forms of violence occur from family members and people that they know, who in fact may be working for them. And frequently these cases are not adjudicated. I meet disabled people who have been offered jobs by businesses because they live in a country where there's a quota system, and in order to avoid a fine, they will hire you and then tell you, "You don't need to come to work because we really don't need you in the facility." I have visited institutions where the stench of urine is so strong that before you open the door of your vehicle, you're kind of pushed back, and then gone into those institutions where people should be living in the community with appropriate supports and seen people almost naked, people who are chemically drugged and people who are living lives of despair. These are some of the things that the US needs to be doing more to correct. We know discrimination when we see it, and we need to be fighting it together.

So what is it that we can be doing together? I encourage you all to recognize that disability is a family you can join at any point in your life. I'd like to see by a show of hands how many of you have ever broken a bone? And then, when you leave today, I'd like you to maybe write a couple of sentences about what that period of time has been like for you, because frequently I hear from people, "You know, I couldn't do this, I couldn't do that. People talked to me differently. They acted differently towards me." And that's what I see and other disabled people see in flashing letters.

But we -- you in this room, people listening and watching this TED Talk -- together we can make a difference. Together we can speak up for justice. Together we can help change the world.

Thank you. I have to go catch my bus.