I'm Denise Sherer Jacobson. I live in Oakland, California. I have cerebral palsy, and I've had it all my life. I am a writer and disability educator and I'm married and have an adult son who's 25. I was asked to participate in a disability education program for a local school of optometry and the session included having the students give me an eye exam and a screening for glaucoma. So we go through the exam and went on to the screening using a standard glaucoma testing machine -- I forgot what it's called. But what they had me do was look into a cone and they put on a laser beam, a red laser beam and every time I would see it, they asked me to click--to indicate when I saw the little dot of light. Because I have CP it slows down my reflexes and the doctor realized that my response time was slower than usual, but they also caught that it might not have been due to the reflex time, it might be due to the fact that I might be a glaucoma suspect. So they recommended that I call my own doctor and get a referral to an ophthalmologist, and so I did.

I went to the ophthalmologist and he understood the problem of using the standard machine and so he wanted me to have a different kind of test, which also involved me looking at a screen and seeing a dot of light but instead of having to click a mechanism, that machine was able to take pictures of my eyes and the back of my eye to see how my eye responded. And the results were that there was the possibility of--that I would eventually get glaucoma and the doctor and I talked about using eye drops twice a day and my hesitation was that because I do all my ADL--that I don't have an attendant coming in every day, my ophthalmologist suggested that instead of using the eyedrops that he would monitor me every six to nine months and see if the problem progressed. He--so we did that for a number of years until I, I changed my health plan, which no longer covered him. And I went to a different ophthalmologist. When I went to the new ophthalmologist, I brought all my records from my former ophthalmologist. I tried to explain I was a glaucoma suspect. The new doctor really didn't take me seriously, which I kind of expected because I know that in the medical profession, um, doctors don't have a lot of experience with people with disabilities and also people with speech impairments, which is one of the reasons I was so diligent about bringing along my records, but I don't think that he looked at the records and instead he ordered a glaucoma screening. and when I called up to confirm the appointment I tried to make sure that they understood that I couldn't be tested
with the standard machine, but of course when I got there they said all they had was the standard machine. And so I--my son came along with me and the way the technician dealt with the issue was that when I saw the red dot I would tell my son who would then click the button [laughter] which delayed my response time even more, but they seemed to think that since I saw the dot, everything was okay. They didn't take into account my reflexes or my response time, so they told me everything was fine and to come back in three years. I knew in the back of my mind that one day I'd need to deal with my issue about my eyes. I just felt it was okay for that time. I was still trying to learn how to navigate that new health care plan and so it was just another issue on the plate. My experience with a lot of people in the medical profession is I freak them out as soon as I roll in the door because here I am a grown woman with cerebral palsy with a speech impairment and they seem to look at me and think, "Oh, why isn't this woman in an institution?" You know, or "Why is nobody with her?" I used to go alone to my appointments but now that I'm older and I don't have the energy, um, to deal with all their misperceptions, now I take along a friend or an attendant to help me deal with these stupid people [laughter].

Segment 2

I caught my hand on the elevator door as I'm going out with my hand on my joystick. The edge of my hand hit the doorway and it hurt, it really hurt but, you know being stoic, I just got on the train and I got myself home and then it started to swell up (laughter) and turn all different shades of black and blue and purple and, and I got up the next day and it was twice the size so I went to the doctor. She wasn't on call that day so I saw someone else who wrote a prescription. I went to get x-rays and they told me I'd fractured (laughter) the fifth metacarpal. So, I'd never had a broken bone, I was like fifty-seven years and I'd never had a broken bone. It was my dominant hand. The more coordinated hand. It's the hand I do everything with from feeding myself to wiping my ass [laughter]. The person who does referrals at my doctor's office frantically called around for, you know, a specialist and the only one she could find was this really old pediatric orthopedist. So my neighbor drove me to the office and this was about three o'clock on a Friday and so I went in and he looks at the hand and he says we have to cast it and I said "No, I can't have a cast," and the stupid doctor listened to me and took out one of those wrist/arm braces that they give people for carpal tunnel and he said "Okay, wear that," and I thought, okay, I'll go home and so I went home with it and it didn't seem right, but... so I called back my friend and said well, it's broken and he said, "You really got to get it casted -- they've got to come up with something." My friend worked at the disabled health clinic and I arranged to come down and see him. I didn't trust my doctor's office to send me to anybody who really knew. I was racing around in my house a couple weeks later and I caught my foot between the kitchen cabinet and the front wheel of my wheelchair, and guess what! I broke my ankle, my left ankle. So now I had two
things going on. So, I thought that is a lot more serious because I do all my transfers—I stand up to pull on my pants and so with a broken ankle you can't stand up so I did call my doctor's office and I really said I need somebody good because this was about two months after I broke my hand. They said my ankle would take about three months but at three months it still wasn't all healed. So I talked to my doctor and thought that maybe something was going on with my bones. So I couldn't do a test for osteoporosis because I couldn't lay still enough and they would have had to knock me out and they didn't want to do it. So my doctor suggested that I go to an endocrinologist. I went with my attendant and this doctor came in. He was about 90 years old, you know, and I'm not looking my best. I've got my leg in a boot, my arm in a cast thing. I'm dressed in clothes that go on and off easily. And so the guy comes in and I see on the wall that he went to NYU medical school and I went to NYU graduate school so I tried to make conversation, "Are you from New York?" I, I tried to let him know I have a brain, you know. This guy, he wanted to get down to business. He started asking me questions that I would get out a word or two and then he would cut me off and go on to the next question. And after about twenty minutes, "Okay, let's take some blood work and we'll have the results next week. We'll call you." So, Okay, well, he was so patronizing that my attendant who went with me just couldn't believe the way he treated me. Um, like he treated me like I was a dog or a cat you know I wasn't a human being. So I waited a week for the results, no call. I waited….no call. I finally called that office and the woman said, "Oh, we sent your report to your doctor," which didn't get read to me either. And the woman said would you like us to send you the report. I go, "Yes," and I got the report.

Segment 3

Here's the letter that accompanied the lab results that went to my doctor from the specialist of endocrinology and metabolism. Okay.

"We saw this unfortunate 57 year old woman in our office on March 10, 2008. My [chuckle] impression is she is far more intelligent than she looks to be. It is really hard to get a history from her. It appears that she has cerebral palsy and she tells me that she has not walked, even with crutches for four years." Let me just read one last sentence. "No surprise that she has bone demineralization and weakness since she has not been weight bearing or in the upright posture for so long." Which is not true since, number one is I do have upright posture as you can see and the other thing is I weight bear all the time. When I got the letter I felt like I was punched in the stomach or maybe rolled over by a Mack truck because not only was I having to deal with health issues and pain but then to get a letter like that on top of everything, I felt like a piece of crap. And, you know, I wasn't going to respond because I thought no matter what I say he was such an ignorant SOB that it wouldn't even register.
Segment 4

So this is available on disability awareness and they need to talk to real disabled people not read about us, not just watch a video. Videos are great, but they need to really experience to overcome their own biases and prejudices. And, and it's not enough to ask one person with a disability to come in and do it. There needs to be people who have different disabilities coming in and talking about their issues. When we are faced with medical issues, many of us are faced with bias and prejudice so when we go to get our health needs addressed, we've got to overcome the misconceptions and when you look at my story you can see there were a lot of assumptions made by medical people that weren't true. You need to question whether you are not part of the problem.