

TRANSCRIPT: Fred Nisen
Interview in 6 segments
Disability Rights Education and Defense Fund (DREDF)
Ed Roberts Campus
3075 Adeline Street
Berkeley, CA 94703
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Segment 1

I'm Fred Nisen. I live in Berkeley, California. I'm an attorney at Disability Rights California, a nonprofit, a statewide nonprofit that, that helps people with disabilities with their legal issues and I'm in the Bay Area office. I have cerebral palsy. My kind of cerebral palsy affects my fine motor control as well as my speech. And also I have involuntary movements often. Back in 2005 I had some serious, bad neck pain and I was seeing a doctor who recommended that I go for a CAT scan so they could see what was going on. I get to the radiology department at the time of my CAT scan. I brought my attendant to help with the transfer and the table is very narrow, so narrow that I don't know how anybody would get on. And the radiology tech says that they want me on my belly. And we look at each other -- and say "that's not going to happen" because there's no way anybody's getting me on my stomach on that narrow of a surface. At that time I was pretty good at rolling over but not on that surface. So the radiologist said "okay, we can do it on your back," but my attendant somehow manages to get me on the table without dropping me, which was a feat. I get the results, and the result is that it's arthritis and it's scar tissue. I didn't know where I got the scar tissue from. So they told me don't worry about it, take ibuprofen when you have pain. At the end of 2006 in the middle -- end of the summer, I still had the pain. It was actually worse and I realized slowly that I couldn't bend at my waist to do some of the things that I used to do like read and get a drink from a straw on the table. But I was trying to ignore that (laughter). But then when I got numbness in my feet I got concerned. I called my neurologist. He said, "Oh, it must be that you are taking too much Zanaflex." After a minute, I said, remember I told you how numb my feet are. He said, "Then you should take more Zanaflex, that should help." I said, "No, then I'll be out of it all the time. What's going on?" He said all it is is the effects of the aging process on people with CP and I was 35! I said, I don't know. That can't be right. He said that is what is it. You have two options. He said take more Xanax or Valium daily or get a Baclofen pump, which is something that I wasn't willing to do. I told him I wanted a second opinion. He told me that might be a good idea. So I went to my neurologist at the teaching hospital and told him my situation.

Segment 2

I went to a second neurologist. He said I needed an MRI. I said okay. You, but I need to be under anesthesia for that. He said "Yeah, I know", but obviously because I have to stay still and I can't stay still for 30 seconds let alone 45 minutes. So I scheduled the MRI as I was instructed. Before I was about to leave my house I got a phone call from the hospital saying, "We just wanted to let you know that your insurance hasn't approved it yet. You can come and we can do it, but you might have to pay for it." So, I had to postpone it. This must have been March of '07 or February. So I have to go to-- I have to go through all this fighting with my insurance, which tells me to go back to the place that does the MRIs in the network. I said okay, I don't care who does it as long as it gets done and I get what I need. I go back to -- I call up the MRI facility that's in the network and I remember I've been there once and I had an MRI but under anesthesia but that was years before. I called to make an appointment. But, because they wanted to do sedation, I'm like, sedation won't do it, it has to be anesthesia. "Oh, we don't do it here. I've been here a long time, but we don't do it here anymore." Where do I go? You have to go to the teaching hospital where I originally scheduled it for. But I have to get my primary doctor to request it. Then they fight me about it. By the time I got it, it was June.

Segment 3

So I finally get the MRI but by that time the numbness in my feet went all the way up to my waist. And so I brought my attendant. He put me on the table and they hooked me up with IVs and they did the MRI. Then that night my phone rings. From a doctor from the hospital-- he said, "You need to make an appointment in neurology ASAP." I'm like, does that mean that you found something? He said, "Yes." And I asked "Can you give me a clue what it is?" He said, "Oh, spinal stenosis -- narrowing of the spinal column and pressure on the spinal cord." So, I'm not nervous yet. I go back to the teaching hospital, not knowing that that visit was not covered by my insurance. I assumed that the doctor that ordered the MRI would actually read the results. I had to pay for that visit. But (laughter) in the visit he said you need surgery. There was something about how bad it was, he couldn't even see my spinal cord, it was that bad at C5 to C7. He told me to call a surgeon at that hospital. So I made an appointment and asked my primary doctor's to refer me to him. They denied my visit to the neurosurgeon. They didn't realize what they were doing to me. My primary doctor called up the insurance. This is in July--and said, "What's going on?" They said, "Oh, there's a neurosurgeon in the network," and the doctor asked them, "OK, who is it?" And my insurance said, "You have to find out." So they did find out. I went and I brought the MRI. He pulled out the MRI, said, "Oh my God, this is bad," but basically after he looked at my fingers and realized that there was a problem because they were bent, which was why I wasn't able to type, which is how I make my money. It took three weeks to get approval. Then the fun starts [laughter].

Segment 4

I asked him about his experience with cerebral palsy. He said, "Well not much but some." That scared me. I go to the hospital. I'm scared out of my mind already and the doctor sits down and says, "Oh by the way you might wake up paralyzed." If I could have escaped, I would have at that point. I got so dizzy. Then I got the surgery. Then after the surgery, I'm in a lot of pain and I had a flimsy collar. A collar you could buy at Walgreens. I'm basically--I'm a little bit in a fog, or a lot in a fog from the medications. I was having problems opening my mouth with the collar, but my doctor said you don't need that collar all the time. He said because we did it from both sides you could wear the collar only when you want. The therapist comes in to get me up like they do every other patient who has surgery. My attendant happened to be visiting me. He said look, I know how I did it before surgery so let me help you. No. We don't want help. They never get me up. Then they come back again. The first time they got me into a sitting position my wound started to open up really bad-- They said, "Oh no," and then they had to wipe the blood up. The doctor said to take the collar off to eat. They didn't know, -- the nurses were in such shock that that was the case. Every time the nurses changed they called the doctor. Then he finds out I'm not getting up. It wasn't my fault [laughter]. They don't know how but they said I refused, but what they were doing it was not working the way they were doing it. So he said you're going to get pneumonia and die. You're not ready for the rehab hospital unless you can get up. I'm like, you guys don't know what you're doing. It's not my fault. I know from my professional experience that nursing homes don't do much. And my co-workers were ready to help me advocate and file a lawsuit if I had to to avoid the nursing home. But as the surgeon later pointed out, I got lucky and got pneumonia so they still don't get me up five days out. I have pneumonia, I'm having a hard time breathing then my mom -- I have a friend who used to be my orthopedist. He came to visit me the day after. He gave my mom a call and apparently my mom called him and told him what was going on. He came on Sunday, I believe it was a Sunday with three kids on his way to wherever and he sat on the bottom of my bed and sat me up, not voluntarily. He said, "I don't care if it hurts, you're sitting up." Then as luck would have it the hospitalist came and my friend said, " You guys better get him up, I don't care what you do." OW. So I made it an hour. Because I was sitting up they let me eat something and drink something for the first time in a week. But the one issue that nobody resolved was when they did the surgery they put a catheter in me. Two days later the surgeon said I could have it taken out but the doctor, the hospitalist said no, leave it in. It's getting painful basically when they move me and people thought I was making it up. They would say, "He says it hurts." But then the last day the doctor had the nerve to order that they leave it in and to put cream on the area. The nurses looked at me like why am I doing this? I'm like, can't you take it out, I'm leaving? No, let them take it out. And when I got to the rehab. hospital they were appalled that I still had it and then I ended up having a lot of trouble urinating for like a month after.

Segment 5

I had some function back in my legs, my arms, thank god, my fingers. I could type again. I could tell that I had some positive effect from the surgery but after three years I still had neck pain. I asked my new neurologist [laughter] is that normal? And he finally said, "Not really." I said, "Don't you think I need another MRI?" So I go for the MRI, and they have my attendant put me on the MRI table before they knock me out and oh my God it was like the last time. But it took like three people. My attendant who knew what he was doing and the nurses who had no idea what they were doing. My attendant had to direct them. You get out of my way [laughter], you get his feet so he doesn't fall. So I have the MRI. The doctor read the report--severe stenosis in C4 and C5 so he said you'll probably need surgery again. He sent me back to the same neurosurgeon where I went the first time. I went and got a neurosurgeon at the teaching hospital and I knew a way that I could change my HMO but I could go there, but I wanted to see what this guy says. He said, "Oh, it's not that bad. It's not urgent. All we'll do this time is go through the front, it will take an hour. Normally people will be out of the hospital--hospital the same day, as an outpatient. It might mean that you would stay overnight because of your situation. You'll be back like new in a week. I'm not convinced that that's the best thing to do. So I went to the teaching hospital. Basically, I told them what the other doctor said. Normally, they said, well that's not a bad idea--but this idea ... yeah, I guess you could do that if you didn't have CP. It would be really, really risky. This is the same surgery you had last time. It would be even more painful than last time. At that time, I couldn't imagine ... it would be hard, but I think I can do it. I've done a lot. I've done it with people with CP. I said well how long can I wait? I don't know exactly but people in other surgeries and are back home working, he said. But if you didn't have CP I'd say wait until it gets worse, but because you have CP I'd say do it ASAP. Otherwise you might not be able to use your arms. I went, oh, okay. I had to change all my doctors so I could have it done at their hospital. My doctor said, "Oh by the way, we decided to keep you intubated for an extra day and to keep you sedated with Propofol. The drug that killed Michael Jackson--to basically put me in a coma for a day to prevent the pneumonia, so that's what happened. When he opened me up, he found a mess. The plate was corroded, and he had to replace--he had to take all the hardware out, then he had to do the surgery. So my guess is that's why I've got movement in my legs.

Segment 6

Another problem is that because of my accent, speech disability, a lot of the medical staff do not understand me because--they don't try. They assume they won't understand me so they don't try and some people don't think I'm intelligent enough to communicate with just because of the way I talk. That's why I always have somebody with me. At the rehab hospital the neuropsychologist, evaluator--like I needed a neuropsychologist anyway--came into my room for my evaluation said, sat there for a while, said, "Oh, what do you do?" I said, "I'm an attorney."

He said, "Really?" He said, "Oh, I was just doing that to see how your pain would be when you got upset." I wasn't upset. But whatever. If that makes an evaluation complete, so be it. My advice to medical professionals is to just take a step back. OK, what does a person need because of his disability, maybe even talk to other people like them and most importantly don't assume that that person doesn't know what they're talking about even if they have a speech disability. They've been through a lot with their disability. They might know a little bit more than medical professionals. Medical providers need to think before they do what they normally do when they treat a person with a disability. And something needs to be done about the insurance. They took so long to approve the MRI, the diagnostic tests. That's because I needed to be put to sleep. The other problem is the diagnostic tables so need to be a lot more accessible. A lot wider, go up and down, be more friendly to people with disabilities. Have some padding because somebody like me--I can't tell you how many times I've banged my elbows on those tables. And another issue -- I don't know if this is the right forum but I'll say it anyway -- the DME caps -- the Durable Medical Equipment caps are at most \$5,000. I'm lucky mine is \$5,000. Most of them are \$2,000. Even at \$5,000 I need to pay like \$10,000 for a new wheelchair and then if I get other pieces of equipment then I pay more. I'm lucky I've got a job but I hate to say this, but there's no way I'd be able to pay the co-pays.