



Voices
OF OUR REGION
THE DISABILITY CONNECTION

Interviewee: **Jeffry Parker**

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Interviewers: **Athena Aardweg, Judy Barricella**
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Jeff Parker

I'm Jeff Parker and I'm from a suburb of Philadelphia called Phoenixville and that's really kind of near Valley Forge Park. It's kind of rural because it's out of the way from Philadelphia. It's very interesting. I'm from a very, very medical family. I'm the one non-medical person. My father, who has passed away, was a surgeon. My mother was a directress of nurses. I have one sister who is a veterinarian; another sister who is a physical therapist. So it's all medical. We grew up reading medical magazines and watching films of medical operations my father would bring home. So that just had an effect on us. I actually studied science. I'm a psycho-biologist myself but I've done everything for the last 30 years other than psycho-biology. I came out here to go to college and so that was 1971 and I knew Pittsburgh a little bit because my grandparents had been out here. You know, to go to college I wanted to be away from my parents but not far enough away that I couldn't get back. So Pittsburgh seemed like a good choice. And I actually, Pitt was the only college I even applied to. I just applied to that one and just decided this where it was going to work out and did it. And that was like 1971, so now I've been here more than half my life. Well I have a pseudo-dystrophy. And it's called the Kugelberg Welander Syndrome. I usually don't tell people cause it just sounds like it's some kind of special dinner as opposed to a disability. The Kugelberg Welander platter is coming out now. And the story is that it's pseudo in the sense that is a muscular disability that plateaus and doesn't get worse and so that would differentiate it. But for me I mean ultimately Kugelberg Welander might not get worse but with aging things get harder. It's something that developed. u notice it about 3. When I was 3 years old and I was actually walking and started using a scooter in 7th grade and that was before there really were scooters. The scooters that we see people using now, they were just being used in warehouses. Warehouse guys would go through the big warehouses on a stand up scooter and he had a seat installed on one and I used that through junior high school and high school. And also me coming out here to Pitt, Everest & Jennings had this non-wheelchair wheelchair that looked like a fiberglass boat and I actually rode that around the University of Pittsburgh. You and I were talking about what are some things that you're proud of. I'm riding down 5th Avenue in 1977 and this crazy guy comes up to me and he turned out to be a really a visionary but he comes up to me and says, "I have this idea. I want to divide the campus into quadrants. And in quadrants we're going to find out what is accessible and what isn't accessible and we're going to map it out, and we're gonna do it!" and this fellow's name was Jack Hayes and he was the Director of the Office of Veterans Affairs. "Come to my office and we'll talk about it." So I went to his office and this started what I kind of see as my first big project, my first successful thing. Where this guy picks me off the street and says we're going to do this and really what this was, this was 1977, so it's a couple of years after the Rehab Act of 1973 and universities, places with public funding, federal funding had to start looking at what was accessible. You know in 1971 when I went to Pitt they didn't have the campus buses like you could get on. I literally would follow the snowplow going up 5th Avenue to get to- I'm trying to think of what my building was... Langley or Clapp Hall or... And I was there at Pitt the year that they exploded. Remember when those three building exploded?

And the interesting thing about that was I had all my classes planned in those three buildings combined together so I wouldn't have to go back out. I cut class that day and I had never cut class because to me cutting class was like a slippery slope, once you realized how easy it is, why do it again. So my rule was I was never going to cut class even though it was wintertime, even though I had to go through 6 inches of snow to get there I wasn't going to cut class. And that day I just decided not to go and that was the day that the lower level lab had exploded and it exploded right – this is one of these psychic things I think – it was right underneath where I usually sat at lunchtime.

Back then, Jeff, did you need assistance? Did you need any kind of assistance and was there any available?

There wasn't any. I was lucky that I didn't need it then. Again, I think about things that I pulled off back then versus now like how did I get from the wheelchair to the side of the bathtub to a bench in the bathtub, how did I get in and out of that boat everyday? But I managed to do it then. And there wasn't anything really available. So the interesting thing about this is, I'm going through high school not knowing whether I can pull college off or not, physically. I had it totally under control what I needed to do academically. But physically I didn't know. My parents, they don't know what's going to happen. They're worried, I'm worried. It just was this gray area and I threw myself into my studies in high school because that's one thing I could control. And literally went to Pitt not knowing whether I could pull it off or not. I had an admissions interview at Pitt with Rich Smith and which meant I had to go see the doctors at Pitt, the medical staff. They had to decide physically whether I could be a student at Pitt or not and my story about that is I'm there and of course my whole idea of being at Pitt was to be able to be on my own, the independence thing then and I'm there at this interview with my parents and then the doctor is saying to me, "Well, do you realize your parents aren't going to be there to take care of you?" And I told him, I said that's why I'm coming here to Pitt, so my parents won't be there! I studied really hard through high school and I had really good grades. I was valedictorian, but not because it came easy because I really studied hard because I didn't want any college to have any kind of academic reason not to accept me. And then you go through an interview where someone – you're thinking you're this adult, you're out there, you're in the world – and they're asking do you know your parents aren't going to be there to take care of you. I was 17 and of course I'm also going there with the idea in my mind that I don't know whether I can pull it off or not. I'd never tell them that. I didn't know what was going to happen. I literally didn't know what kind of shower, what kind of tub, what kind of bathroom, what kind of dorm room. What was going to happen? I didn't know. But everything there was just good enough that it worked. I lived in Tower C. Tower C. And Tower C was the single rooms and if you had a disability you were in Tower C. Don't know why. Guess if you had a disability you wouldn't want a roommate or a roommate wouldn't want you. I don't know what it was. But it was okay because I had a single room and that was nice.

What other things have happened in your life that you might consider pivotal?

Running into this Jack Hayes I told you about. I had moved to Gateway Towers. Gateway Towers was a lot of big executives and then Jeff Parker with his hair down to his shoulders and a moustache and things; it was still, my Pitt Look. But I met people there. This was this person named Dori and she was very nice and she said "I want you to meet the president of Joy, you could be doing something and I want you to meet him." So there's my in, there's my gatekeeper, there's my interview. I started out in a credit department at Joy, and ultimately I was overseeing the managers of millions of dollars in pension benefits but I worked my way through there for 15 years. The late 70's, early 80's, Radio Shack had one of the new kind of personal computers out that we were playing with at Joy. We had one there but nobody knew what to do with it in the office so I was playing with it, writing up a program that would come up with a credit limit for companies because that's what I did. I set credit limits on companies we sold to. And one of the managers that was over the credit area, Ron, he saw me doing this and he said "I'm taking you to this class we're going to." So he took me to this class and it was the class for the predecessor of Excel, it was called Lotus. So I knew Lotus inside out and ultimately showed Joy how they could use it. Joy got personal computers for everybody and I taught a Fortune 500 company how to use Lotus, how to do spreadsheets. But again, it was like one guy there seeing me working on something and said "I'm going to take you to this class" and I saw some other way that I could distinguish myself.

What I find interesting, Jeff, is that you were fortunate to find these people who took an interest and said hey, let's do this or let's do that. And the disability didn't seem to play into it.

No, it wasn't like working through an OVR or a counselor or of things. It was just like going through work. And my idea back then was this disability was a very low profile thing for me. The idea was that I'm out there in the business world now, I'm at a Fortune 500 company just wanting to be any other employee there. We're not talking about disability and we're not looking at disability. I'm just trying to show that I could do anything else. It was very, very low profile. It was in my latter years where I even got involved in the community of people with disabilities here in Pittsburgh. So it wasn't an element. It didn't have an effect on the interviews because at Pitt a fellow off the street brings me to the office; at Joy somebody refers me to the president of the company. So who knows what somebody would have thought through a regular interview process, what would have happened? But I kind of went around the barriers at that time. My whole goal there was to really show it that it didn't really have anything to do with anything, I'm just working. People handle disabilities different ways. But for me it displays like a really very personal thing. I can't just say well that's my disability and this is me.

Do you still see yourself that way?

It's still like to me a very personal thing. What had to happen with me was somebody had to appeal to my business side and recognize that and incorporate more ideas. What happened with me was, it was Lucy and Paul O'Hanlon, the two of them invited me to part of this group they were getting together to work on the transportation crisis. And I'm going in there as Jeff Parker the businessman where I'm used to doing these 100 page reports and used to calling and getting this information and that information. So we're going there and we're at a meeting and we're trying to find out how are other cities coping with this. I said, "Well, it's obvious. I'll call 15 other cities, I'll put a report together. I'll bring it to the next meeting." That was my showing Lucy and Paul that what I could do. And they realized though that this guy isn't just a businessman, he can do this, too. And they started incorporating me in their projects and in their ideas and I'm seeing this whole other side of what's going on as far as disability issues were. But I approached it as a businessman. It wasn't Jeff Parker with a disability. I'm here on this committee to help solve a problem, create a report, get the good information. So that's how I got into it. Of course, things with disability, they were really a very gray area to me. So I'm a person with a disability not really knowing about the concepts of independence or inter-dependence or gatekeepers. But as I was getting more involved in more disability related issues and you start having them defined what it is, it gave me a different way of looking at things. You're living through years thinking like "I have to be independent. I have to be able to do this by myself. If I can't, there's something wrong." Then you find out, well, but there's the idea of interdependence. I mean, what does it mean if somebody's helping with my grocery shopping if I'm helping them with their taxes? What does that mean? Are they not independent because they can't do their taxes? Am I not independent because I can't do the grocery shopping? But up to then I would say no, my goal is I'm supposed to be here, I'm supposed to be able to do things by myself. It's a different way of looking at things. So how is the fact that a person with a disability receiving services and receiving help any different than anybody else? Because who else is out there growing their own food or who else is doing everything they need themselves.

Have there been any people in your life, I know you mentioned Jack Hayes and Ron, but have there been other people that really have been a big influence on you?

Well, you know, when I talk about Lucy and Paul, I mean Lucy, Lucy- you know the fact that- and of course I always have to throw my wife Katie in, that's just kind of a given- the influence of a spouse, of my wife. I met Katie through Lucy, from meeting who my wife is or where we went on our honeymoon or working, Lucy has been a big influence in my life actually. She'll- She'd be surprised that I'm saying this but she actually has been.

Any words of wisdom?

Well you know I think about this as I think about Pittsburgh, too. And I think about what we will be seeing in Pittsburgh and what I've seen in Pittsburgh since 1971 to now.

We've seen a lot of different things, but the 1970's there weren't curb cuts in Pittsburgh. I literally came to Pitt because Pitt was its own terrarium. Everything was there. Your food was there, your movies were there, your stores were there. It didn't matter whether there were curb cuts because you could be there. And what you see in Pittsburgh developing is, well Pittsburgh like opened up. It opened up with this gets me back to my transportation side - lifts on the buses, with the Access system. Allegheny County became the terrarium instead because in the early 2000's before we had these most recent cutbacks you could literally get anywhere in Allegheny County. And to be able to get anywhere you could do that to get a job, you could get out, to do whatever you want. So Pittsburgh, it's been big what's changed here.

You said something about this particular type of muscular dystrophy that it plateaus. At what age does it plateau?

Well, I'm not sure when it was, you know, when it really did plateau. What I'm feeling and seeing are the effects of aging and I got to about 1990. So about 1990 and I just started falling more often. I was getting up earlier and earlier every morning because it was taking me that much longer to get ready. I'd start getting ready at 4:00 in the morning. I got up one morning and I'm sitting in my wheelchair and I'm pulling my pants on and I literally fell asleep while I was putting my pants on and I fell out of my wheelchair. That day I broke my leg falling and that's where attendant care became a part of my life. Your life changes altogether once attendant care starts because you never have a day by yourself again. But I can think of one other time that I had fallen out of my wheelchair too. And you know over the years you develop different methods to get back up. I mean I could crawl on the floor and get to a couch and just kind of get up to the couch and get from the couch back into the wheelchair. I had one other day I couldn't do it. This was a Saturday night I had fallen and what I did was I made it to my door in the apartment, waited all night till the newspaper delivery man came the next morning. I got him to help me get back up in my wheelchair. So I'm seeing the 90's, like I'm getting up at 4:00 in the morning just to get ready, I'm falling out of my wheelchair, I'm doing this and I'm doing that and that was before I really knew about an organized attendant care program.

What would you said about having an attendant was interesting? The fact that you never have any time alone?

One day you're off- you can be- you can have the whole weekend to yourself. It can be wintertime, you can just decide to stay in, watch movies, you can come home when you want to, you go out when you want to, it's a Saturday and you don't want to get up until noon, why you stay in bed until noon. The next day you have an attendant. You're on a schedule and you never have your place totally to yourself again and you never have things to yourself again. It changes everything. It's the biggest help in the world. But it does change things because you can never really say this is the day that I just want to stay in bed and not get up. You just can't do that again. This goes back to the independence

versus the interdependence. So the idea is that you see that you have an attendant but you still have control. That's where you have to get your mind to. That this isn't a failing, this isn't a flaw, this is like there's somebody else and maybe you need to help them with their income taxes. Does this mean they are a failure, that there's something wrong with them? But it's not easy getting your mind to that. But that's the analytical side of me that can say that. The hard part is there is something inside that makes you feel differently though.

What, Jeff, are you most proud of in your life?

My idea of coming to Pittsburgh, each step was advancing along the way. My idea was coming to Pittsburgh, getting into college, getting a job after getting out of college, and ultimately being married, having a relationship. I don't know whether it's something you should be saying it's proud of, but you know, it's just something- that meeting someone and meeting the absolutely the right person, I met my wife Katie in my 40's and a lot of time had passed and I really thought, "Well, I don't think relationships are really going to be my thing." My whole life I'm growing up I'm wondering "Am I ever going to have a relationship?" and is that the one obstacle with a disability you can't overcome, and how do you work that out, and how do you make that happen. So, I don't know, the fact that it happened and I have a very, very, very wonderful person that I'm married to, too.