



Voices
OF OUR REGION
THE DISABILITY CONNECTION

Interviewee: **Sarah Stewart**

Interviewee Number: **17**

Interviewers: **Athena Aardweg & Tony Buba**

Date of Interview: **May 14, 2008**

Interviewers: Today is Wednesday, May...

Sarah: 14th.

Interviewers: 14th. And we'll just start off...just with you saying your name and some information about where you were born, your family, who you grew up with...maybe kind of how you got here.

Sarah: Oh boy. OK. My name is Sarah Elizabeth Stewart and there's five Sarah Stewarts in Pittsburgh. So I have to use my middle name. I grew up in Brentwood, Pennsylvania, near Pittsburgh. When I was born, there was nothing wrong and about three months old; our mother, who was a practitioner, who died on May 4 of this year, noticed some things that were going wrong. I started walking at about nine months old, but she still noticed some things that were going kind of askew. And even though I wore a dress, she always made sure I wore pants because it was easier for me to crawl than to walk. So, about the age of three is when the surgeries all started on the eyes, legs and hips, and...

Interviewers: Eyes, legs, and hips?

Sarah: Um hmm. Yeah.

Interviewers: OK.

Sarah: So and then there was a big operation when I was about five, and I went to Easter Seals then because that was the only accessible school at that point. My mother, who had severe diabetes at the time, had four kids in four different schools. Two with learning disabilities, one with physical disabilities and one with severe allergies. So she opted for surgery. My understanding is she assisted in the surgery also; and I was in a body cast for the summer. Until about the age of six, I walked with wooden crutches because the legs had to get stronger to be able to...and she bought a swing set so I could swing because that would strengthen the legs. Learned to ride a bike. Didn't like it too much, but I can ride a bike. Swimming, I did that a lot. I was mainstreamed by the age of six because she refused to let me stay at Easter Seals. There was no reason for me to...mentally...mentally there was nothing wrong.

Interviewers: So how long were you at Easter Seals?

Sarah: From about the age of 2-1/2 to 5. She made mention that I... she had me take my entrance exam to school early, because she was busy with two jobs and all these kids, and she didn't want to waste time taking each child separately so, she took me with my brother. I missed all...I...I answered correctly all but two questions and the one question I missed, I don't know, I forget. I think it was one or two questions. The one question I did miss was how many pennies were in a nickel, but I was only like 2-1/2, 3 at the time I took it. But I knew all my colors, all my fruits and vegetables, all my...my address, my

phone number, my all that. So I stayed at Easter Seals until about five. I cut my hair there, too. They got mad at me. One day I was there in class and I cut my hair.

Interviewers: Is that a day school or just a...

Sarah: It's...It's a...It was a kindergarten school and they had physical therapists there and you would take time to go to physical therapy and do that. They have a speech therapist there. They had occupational therapists there. Depending on what you needed, you know, they had you go. So and there's a picture in the paper of me with Mrs. Moody, who's the head...was like the kindergarten teacher. And so then from there, I went to St. Sylvester School, and that was just a basic school. The teachers were always kind of...they were to adjust the games and told the kids to be extra careful around me because, I think, they were more concerned with liability than anything. But I was on the cheerleading squad there. I played basketball there. Then when I was in...fifth grade, my aunt took me down to the Y where I learned to swim very well. So, I started swimming for the Goal Getters, which, I don't know if you knew about them, but they're with the city and it's specific for people with disabilities. I tested out to be a high 7. Actually they want to keep me at 7 because I could compete better at 7. Because if you were an 8, it was the highest and that's you have noticed...no physical impairment. It was more for...I guess, more of the mentally impaired would be because there are no physical arms or legs involved with impairment. That was when I was about 10 and I won trophies and all that kind of stuff there. So when I got to high school, they had a swim team. We had like a big seven people on our swim team, so I competed there and did OK. I mean, we didn't do much because there were only seven of us and we would be against much larger schools that had like 25 people. But we were encouraged to compete against the clock for ourselves because we still could get scholarships and so forth to colleges with our times. We did win a couple heats because sometimes the other schools would just put in kids that didn't qualify for the heat; and if you're...if you're in seventh or eighth grade, you could be on the team and just practice with the team. But you...your...If you swam in a meet, it didn't count so, you know, we won one or two of those just because we were...we were able to count; and they had a person on their team that didn't count, and didn't matter in the whole thing anyway. So then I lifted weights and all that kind of stuff as well. In college, I started in Pharmacy; and I was on the swim team there for a couple years. You can only be on there for four years. I think I stayed on for three. So, Duquesne University...Then I finally switched my major around and graduated in Psychology, Social Work, and Criminal Justice. I did some volunteer work with the city for the Goal Getters and people with disabilities and I got a part-time job there. I moved out of my family's home my second semester in college.

Interviewers: Did you live in Brentwood that entire...was home Brentwood the entire time?

Sarah: When I... I graduated from Brentwood High School.

Interviewers: OK.

Sarah: But then after I graduated, my parents moved into a ranch house out this way. And then I moved into an apartment because I needed a city address to work for the city. And I had done some volunteer work in hospitals and so forth in high school. I was taking computers and people needed help in the summer time with billing and computer keyboard entry things, so I would do that as well as volunteer at my mother's hospital. And so then I graduated college. I worked three jobs while I went to undergraduate, and then I worked for a while. Decided the field that I was in didn't pay a heck of a lot of money. I had to get a master's or something. Because it was a lot of physical labor if you wanted the high paying jobs and people were always telling me because I was only...I'm only 5 feet 2 inches and I did some CNA work. The guy I last worked with was 7 feet tall and had a size 14 shoe. Luckily, he could stand by himself. My boss said "You have to...you have to, you know, catch him if he falls." If I catch him when he falls, I'll be a pancake on the floor. So that just wasn't a job for me. So, anyway, I went back to school to, you know, because I played around in college and worked three jobs, the QPA wasn't that great. So I convinced...Duquesne University had a program, it was called Liberal Studies, and you paid...It was a discount that you paid. Because they gave you the discount...so I worked two jobs. I worked as an elevator operator, in one of those manual elevator at IUP--not IUP--Art Institute of Pittsburgh, AIP. And did that; got my school loans paid down. Paid for school; worked the night shift as well.

Interviewers: When did you do schoolwork?

Sarah: I worked at night.

Interviewers: Yeah, but when'd you sleep?

Sarah: Probably about every three days.

Interviewers: Wow!

Sarah: Maybe in the afternoon.

Interviewers: That's what I'm saying. There's not much free time.

Sarah: No, so I haven't had really a social life from that point on. But, you know, the one day I had worked, because the elevator job was union. That's the only way they could be fair with people; because once you learned it, it was not a hard job to do. It was just repetitive and boring; and the kids got on your nerves. They were just ignorant teenage kids that were let loose by their parents because they were over 18, you know. So they weren't mature enough yet, so you had trouble with that. So that was your biggest issue was that. I did supervise there for a while because it went by union; and if somebody who was full-time called off, I was called in. And if I didn't go in, I would lose my spot. So I

didn't want to do that either. There were times where I worked around the clock basically; and I can tell you one time I was, I just felt really extremely tired because I just worked a whole bunch of hours on both jobs. And the night shift job, at night, you had to stay awake so, they said "You have to do something. So you can use the computer and, you know, save stuff on a disc and do your school work if you're done with your other work." You know, because basically once you count the medications, and people are in bed and it's a quiet night, then you have to do something to keep yourself awake. So that's how I studied. But I'd come home after like a whirlwind of working both jobs, lay down in bed. Got woke up by a neighbor knocking on the door. I couldn't get out of bed. She had a key to the door...to open the door and I said, 'I would come open the door for you, but I can't get out of bed.' Well, it turned out my whole body was swollen. It was sort of like carpal tunnel...you know you get carpal tunnel in your arm from doing too much repetitive work. My whole entire body was swollen. Because when you do the elevator, it's like you're using your arm to manipulate the thing and then you have to open a gate, and then a heavy door, and then you have to close it, then you switch sides. And you're like basically either sitting on a high metal stool or standing the entire time. So you think your whole body is in a repetitive moment...movement for that. So, and the doctor said, 'You're just not getting your correct sleep.' So anyway, I went and worked for Civil Service for Child Protective Services and intake with Allegheny County. Did that for six years.

Interviewers: Six?

Sarah: Six. And that's when I started getting the prejudice point. One of workers came to me and said he was told by our supervisor that she was told by the administration to find a way to fire me because they realized I had a disability, which is why I'm here trying to do this with you. Because it's not...

Interviewers: When was that? Like a time frame.

Sarah: That was like back in 19...My tenure was like 1995 to 2001. So, and my disability had just passed a few years earlier because I had...when I worked for the city I had written some letters with Senator Heinz and the United Cerebral Palsy Group in Oakland at the time to get that passed. It doesn't really help me. It does help me, but not to the extent it helps someone who is not, um, as able as me. So...because, you know, some employers say, 'What kind of adaptations do you need?' Well, I don't really know. Because I do basically everything you do. I might do it a little slower. I might do it a little differently. A lot of times, I talk to my coworkers and they're having the same issue I am so it's really not due to my disability. There's really not anything you can do to change that and I got my eyes checked recently and the doctor said this year and last year they have improved in eye sight, not gotten worse. I'm like completely backwards from everybody else.

So, you know, you know, the hip situation is something that happens with the boys in their knees when they're too active in football and start football too soon, so how it ended in my hip and I'm a girl and all that kind of stuff. It doesn't make sense. So, where was I?

Interviewers: You were at the Civil Service. You worked there six years.

Sarah: OK. I worked there six years. And it's just the nature of the beast. It's very hard to keep your case load to the mandate of the state mandate of 30. Everyone has trouble with that. I went to...I got in trouble with that. I contacted an attorney. I got a job within a week of leaving...of being let go from that one. Because I saw...You can see the axe coming; so I started looking, and I had interviewed at least once and they offered me the job. So this one let me go, and that one picked me up. So, they basically, the attorney was able to make them see that they were...there was an issue here and they were incorrect. So that I have regular shows with Civil Service and I can be rehired at any time, and they've actually looked at rehiring me for that position. And they really want me back, but they want to make sure I'm in the right position with all my skills, because when I...when I...

Interviewers: They you mean? They're looking at rehiring you or they were?

Sarah: They are.

Interviewers: Oh, OK.

Sarah: So you're not supposed to say anything bad about them, but basically anytime you read an article about any type of child care service or any type of services, the state mandate is 30. Every agency I've interviewed with or researched has that same problem. I just had an interview about a year ago down here for the Department of Aging, and it was a supervisor. She didn't want me or something. She started talking about how she can't keep people in her unit, how no one can stay under 30 cases, how they're not computer literate there. They have to do everything by hand. You know, and she's like, 'You don't really want this, do you?' You know that kind of thing so it's just that way throughout the state, and it probably is throughout the country. But I haven't checked that far into that. Anyway, so when I got this other job, I was able to go back to school, because with CYS, it's...it's a...They're a very good agency. They do a very good job. They have a very, very hard job but it is very time consuming. And I can't say that if I ever go back, that I'd be able to keep my case load under 30. But I have more skills now and I'd probably be able to do that better now than before. But I will never say I can definitely do it. Don't ever say 'definite,' not in social work.

Interviewers: I had Social Work for undergrad and grad so...

Sarah: So, I was able to go back and finish my degrees. I have a degree in Community Mental Health and in School Counseling. And when I did the School Counseling piece, I

had to quit work because you had to be at school 40 hours a week doing your internship. And it was unpaid. But it was like, that was my future, so I took off. I had worked for UPMC for a while and I used those hours for my first internship. So, again, people saw me and they started raising questions. "Is she going to be safe here?" This kind of thing. I had to call the same attorney. We wa...

Interviewers: Before you started working or after?

Sarah: Well, I had worked there for a year and a half without any problems. I've never been written up by them or anything and they started asking questions. So I contacted the same attorney I used, and we wound up taking it all the way to federal court, and won.

Interviewers: Wow. That was a big success.

Sarah: So. Yeah. But, it's very hard because now my job career looks very choppy. So, it's very hard to get rehired into a position that I'm qualified for because, like, why did she only work here two...there's what. Why this, why that? You know, what was going on here and so it makes it look bad. You know. Now they want to rehire me, too, and it's like...and I'm not blaming one person and they're big agencies and most attorneys won't take them on. I was lucky to find an attorney that would, and they would listen to, and he would at least go and try to speak with them. And it can be one person that starts the ball rolling and it's really hard to get it stopped. Most often, that one person moves on to another agency and, you know, things get straightened out; but it's a long haul and it's a long process. I don't blame just one person either, you know. And, you know, things happen for a reason and it certainly, you know, leaving CYF provided me with the opportunity of getting my other degrees and finishing that which I had put on hold. And now I can have my own contracted business which I'm trying to start. I just got called today that I do have my last and final reference; and tomorrow I'm upgrading some of my other things I need for that, and I'll be ready to roll.

Interviewers: What kind of...?

Sarah: It... They hire counselors, psychiatrics, psychologists, social workers, nurses. And basically they contract with different agencies such as Step by Step, Mercy Behavioral Health, other agencies that, they'll call in and say well somebody's going on maybe maternity leave, so you will go step in with them for a while. Or, you know, we can't have this space vacant, but we're looking for a candidate who's able to do this job. So while they're looking, you might do that job; and then you might get hired by them as well. But, you know, you can be a proprietor or you can be an incorporated. So I'm trying to be incorporated because that protects you a little bit as far as taxes; and if there is a liability issue, it protects you as well. So...

Interviewers: What is it, for profit or nonprofit?

Sarah: It doesn't matter. This would be for profit actually. But it's basically, I mean, they give...they call me up; they say can you do this. I say yes or no. So I can work as much as I want or as little as I want; but if I don't work, I don't get paid. Mercy Behavioral was one of the three jobs I had as an undergraduate and I was on their casual pool, which I could work when I wanted to work. So it was like fill in. And I learned things. Like, now that I know the field very well, like, I know that if I work certain holidays I get paid extra. So if I have two jobs like that, I'll work. Like, the one year my mother said, well I said, "What time are you having dinner?" She said, "Four o'clock." And I said, "OK, fine." So I worked the night shift for the one job. Got my double, time and half, you know two and half time pay. And then I worked the other job, 7:00 to 3:30 and got the other one. And then I got to my mother's house by like 4:30 for dinner.

Interviewers: And then crashed.

Sarah: Basically. But I...No. I mean you plan stuff. You sleep during the day and I like took all my Christmas presents and during the night shift. Like, there's only one client there, because everyone else went home or went to a friend's house for the holiday. And they had a stepping stone and this person, I don't know if he had anywhere to go or if he was so new he couldn't go anywhere for an overnight. So I just used their big dining room table and I wrapped our Christmas presents, you know. So, you know, you just find things to do. And now after all this time, I had a lot of trouble with my school loans when I was going...having the issue with unemployment and courts and the house was a big...This house that I just bought was a big deal because I had been looking for a while and couldn't find something; or because of credit issues, something wouldn't come through. So I had a good job with UPMC, and I...There was no problems at that point, when I started looking; and right as I found this house, and was ready to close on papers, that when all the... job break and issues started. So, the guy who was handling the mortgage papers calls, and finds out I lost my job or I'm not there anymore and wants to know where I'm employed, because they don't let you sign on the closing papers unless you're employed. And it doesn't...It has nothing to do with disability. That's just the way it is. So somehow or other we kind of finagled it that I was still OK to sign the papers, and we got the papers signed. So at least, you know, with this house I'm... My money is going towards an investment. It's not going toward a landlord who could kick me out at any time they please. They have certain rules they have to follow, but a lot of landlords don't follow those rules, so it becomes an issue. And I didn't think a lot of it...the seller had a lot to do with it because she wanted to sell to a certain person, and she wanted to sell to me. And she wasn't willing to sell to anybody else, and I talked with her about a few months ago. I saw her down at her job down there at the Giant Eagle and I told her about how I'm renovating the house. She goes, 'I can't wait to see it. I haven't been up there since I moved out. I can't wait to see it.' The bench you're sitting on was actually hers. This chair was actually hers. She left all the furniture here, all the lawn equipment, everything. Because her husband had passed away and she was downsizing to an apartment. She didn't know what to do with half the stuff. I said, 'Just leave it here.' So

I've kept a few things which might be tossed out later on by...a few things, because otherwise we would be sitting on the floor right now.

Interviewers: How long have you owned this house?

Sarah: Since 2004. I signed June 30, 2004. That's how I got here, and...

Interviewers: When did you graduate from Duquesne?

Sarah: I graduated...The first time I graduated was 1992 that was with two bachelor's degrees. The second time I graduated was, I think it was December 2002, for the first one and then I finished my school...my schooling for school counselor in 2005. And from 2004 until about last year of June 17, 2007, I was looking all over the place for jobs and just couldn't get that start anywhere. I worked for Step By Step for a while, but it had nothing to do with what we're here today for. It had to do with, a lot of the jobs are salaried. I had a lot of bills and it took a lot of time. And it just wasn't covering the bills, and I couldn't pick up something extra because of the time it required. So I left there and continued to look for employment. In the meantime, my father took ill, so I took care of him; and my aunt had some issues, so I took care of her. My mother was in the hospital and she, like I said earlier, she just died last week. We had the funeral Monday, which I arranged and everything that. My aunt was in the hospital this year, again. She just got back and I put in services in with her through the Department of Aging, so I haven't left the field. I'm still doing my thing. I just don't get paid for it. But I've had...Mercy Behavioral is a very good employer and they have gotten...looks like I'm going to get two places. I'm going to have to choose. Because my current supervisor told me she has a full-time position opened up. Am I still interest in it? And I said, of course, yes; but, at least, it's full-time.

Interviewers: Where's it at?

Sarah: It would be in Baldwin.

Interviewers: So how far is that?

Sarah: About half an hour. Its supportive housing where people come out of Mayview or other facilities need support; and learning how to live in communities and keep their medications...take their medications. The other job is with the same employer, because now I've been there six months I'm able to interview in-house. I'm also interviewing with Civil Service. I have two interviews with them lined up for next week, which I cancelled this past week because of my family issues.

Interviewers: For what type of positions?

Sarah: For the Civil Service?

Interviewers: Yeah.

Sarah: The Civil Service would be a MH/MR case worker, and the other one is actually working as a counselor in the state prison system.

Interviewers: Wow!

Sarah: So I get to use a gun and a rifle and all those fun things.

Interviewers: How would you use it?

Sarah: I have actually the equivalent of two bachelors; almost three masters because, actually, there's three legs at Duquesne. There's family and marriage, community mental health, and school counseling: The latter two I have completed all the academics for. The family and marriage, I can do that with community counseling. I just wouldn't get the license. There's like two Saturday courses for like, you know, two Saturdays and you're done, and then an internship which I could probably do through my current employer. Carlow College has a link-up with Mercy and then sent me my PsyD applications. That's for a doctorate. They want me to apply. So I could take those. They have the same program there as Duquesne has. I could probably take those three courses at Carlow and still get a license. I did apply to Capella and they just didn't have the seat for me; but they did say I have advance standing and a strong application. I could probably go and reapply, but depending on the school you go to, it's a whole different venue of people that apply. Kaplan because they are an online program, you've got a lot of people from like internationally that are applying. And Carlow's a little bit... There have some classes online, but not as many; and because of the link-up with my employer, they tend to take us sooner. The departments at Duquesne, the Learning Center is a supportive department for people with disabilities. I got to know them in my sophomore year for my undergraduate. And Laben and Sherry Goldman had reviewed my transcripts and said, 'There are actually mistakes on your transcript.' And she...she rattled off numbers and basically said that I actually have a 3.9 grade point average not a 3.2 like it says on the paper. It's actually comical, because when I left schooling to work for CYS, I had signed up for a course and I realized it's impossible for me to get with the mandates of my job. So I said I want to do this job and I'll just skip the class because really taking those classes was just to decide, do I want to be a lawyer? Do I want to be a counselor? How do I want to work this thing and then transfer those credits in to another program, which is what I eventually did do. But when I did that, I called my advisor and she said, 'Don't worry you don't have to come in. I'll make sure, you know, you get withdrawn from the course.' Well, an 'I' grade for that course shows up in my transcripts and so, I go and inquire about how to remove this 'I' grade from my transcript. And they said, 'Well, we have to talk to the professor.' They tracked down the professor. The professor doesn't even remember what the course is about let alone what the project was about. Because I said, at this point, I'm willing to do a small project independently to get this 'I' grade

removed from my transcript. You know. And he couldn't remember what he did or what the class was about for me. I...So it just sits there. And they said...They wrote a note in my general...my file about it and just said, 'It doesn't affect your overall QPA and doesn't affect your overall graduations, so don't worry about it.' And so it just sits there and it will be there for eternity.

Interviewers: Like I want to go back a little bit and talk about...when you were six, you were in the body casts or when...

Sarah: The casts were like between the ages of 3 and 5.

Interviewers: So, and when did...At two you realized and did everyone know it was cerebral palsy then?

Sarah: I don't know exactly when the diagnosis came about as cerebral palsy, but I know that my mother noticed I was walking on my toes. And they usually say that some kids, that straightens itself out and mine didn't. And there was other issues going on. And walking on your toes is also characteristic of autism. So, you know, she was very concerned at that point. When the other point was, they were feeding me my bottle when I was very young, my lips would turn blue and they all had to know CPR. So, and, you know. I recently learned, like I said, things happen for a reason, and my short stint was Step By Step. I had to take a client. Step By Step deals with a lot of individuals who have a lot of physical disabilities and mental disabilities, and they're difficult clients and consumers. And I had to take specific consumer to the doctors, and for neurological work up. And I wound up talking to the neurologists, and obviously, and we're talk...And I didn't let her know what I was diagnosed, but she might have recognized something. But I didn't let her know what I was diagnosed with and he happened to be...At least his record showed he happened to be diagnosed with the same thing that I have. So we were talking about what the diagnosis was, and it was then I learned that it's neurological. It has to do with the synaptic connections in the brain. And that it's a, what she termed as a garbage can disorder, in that they know something neurological is going on, but they don't know what. So they give you a diagnosis of cerebral palsy. That's why you see people in wheelchairs, walking and all over the gamut like that. Because they don't know what's going on. Now, they didn't know what was going on with this particular person. But as they watched and things either progress or don't progress, they can make other, you know, neurological determinations. And I said, 'Does cerebral palsy usually progress?' And she said, 'No.' I took some schooling. I did take some classes for disabilities for the title but it was called by inclusion classes, talking about no child left behind and including children with disabilities in regular schools, and teaching the teachers how to teach them. It was brought up in that class for different things, that when people have brain injuries, they complain often of headaches, especially when they have to use the...when...whenever they're trying to do is using the injured part of their brain. Another thing that I read in someone's neurological report in another part of my tenure and this particular person the neurologist wrote down that there was sort of a like a dead

spot in the brain and through therapy and so forth, the brain rerouted. And he delayed in responding to that certain activity, or those activities that the dead part of the brain dealt with. Not because he couldn't do it, but because the wiring had to reroute and it was a longer route for the message to get from what he wanted to do to the muscles and things that would do that activity. So, you know, through that, I learned about myself and, you know, I look at other people and I'm like, you know, at least I'm not like in a wheelchair and I have my own house.

Interviewers: So basically it has been the like the same most of your life? Or has it gotten necessarily worse but different?

Sarah: It's...It's gotten better, but I can say like, you know, there are days...When I heard about the brain injuries and the headaches and things, and I, you know, the more I learned about that and what I'm dealing with, OK, that's where that comes from. So I can figure out how to deal with it, like biorhythm therapy helps me a lot, you know.

Interviewers: What is that?

Sarah: Relaxation tapes. The biorhythm more is...there are certain alpha and beta rhythms in your brain and those tapes will make those, to help you relax. And sometimes it doesn't work for people...I've fallen asleep twice during trainings when they've done those tapes. The one time, I was actually snoring on the floor and they had to wake me up. And I woke up and I was like, there's no headache on, there's no backache, you know. And then I'm driving home and saying, 'Oh gosh, I got to do this paper for class. I've got to do this and that. And my pains are coming back. So I also have to learn about stressors and my stress happens to be in my lower back, so it's a learning process for me. The biggest issue, I think I mentioned this to you, Athena, but the biggest issue for me was especially high school. In grade school we were a very close knit group. We had grown up together. With dances, I went with somebody on a date. In college, there were some kids that, you know, weren't mature. But the other kids that were more adult, young adults, would step in and say something. So I got to a lot of nice dances there; but, in high school, I ran into a bunch of idiots. It's interesting to find out that, now that I've gone the path that I have, that a lot of those, quote, unquote, idiots have mental health issues. And other issues that weren't present at the time they were being very cruel. You know, the one guy I kind of liked and wanted to go out with him. Everybody knew it. He wouldn't go out with me. He would leave me alone; and when I started dating other people from other neighborhoods, and I actually dated a guy from another state, he literally said if I brought him to a dance or anything, that he would beat him up.

Interviewers: Was this in high school?

Sarah: Yeah.

Interviewers: What year was that?

Sarah: That would have been '83 and '84 that he did that, and when I went to class reunions, which a lot of the guys came to me and said, 'When you were younger I was thinking of asking you out, but you liked so and so.' Well, you should have asked me out, because so and so wasn't going to, you know... And his excuse was because I was handicapped, but he's the one who's on SSI. He's the one who takes his Haldol injections every Thursday. He's the one who has the hallucinations about World War II. He's the one that takes the, you know, G down and has the case worker. And, you know, and here I am, although I'm working three jobs, you know, or, you know, that kind of thing. I have a house. I have a car. I have a family that sometimes doesn't really understand or get it because they have their own issues. But sometimes they do, like, after my brother for the first time came this week and I shared with him and returned the tape; you know, he's seen what I'm doing here and he wants to come in and save some labor and do some of this for me.

Interviewers: What was it like when you finally got out then?

Sarah: I'm basically, yeah, OK. I'm basically the youngest of five.

Interviewers: Basically, how are you basically?

Sarah: Well, my one sister died when she was just born. My mother counted her, so five. And my oldest brother was more of... more there... My parents had some financial issues and the way they had to solve them was that dad had to move out of the house; but he always showed up around dinner time and, you know, I didn't recog... I didn't know about any of this stuff until I got older and I didn't like... it wasn't like, you know, I haven't seen dad for months. I saw him every day, and I saw him at work every day. I saw him at home every day so, to me, he was never really out of the house. But, he was out of the house legally. He lived somewhere else, and that was because he had a proprietorship. We talked about a proprietorship versus the... and he had a proprietorship of a business and his partner, and other things happened and he ran into taxes problems. They wanted to take the business and put liens against the house; and we were about to lose the house, so that... they talked with attorneys and it was the best way to handle it--to kind of protect the house and the family, not to split up the marriage. So, my brother was... And another thing I can remember is like, they would always say, 'Let's see what she can do,' you know.

Interviewers: So your oldest brother was how much older than you?

Sarah: Eleven years.

Interviewers: And then did you have another brother?

Sarah: I have another brother that's about 18 months older than me. Now see, like, my two...two of my siblings have dyslexia; and so like, my one brother who's closest to me, he's close but he doesn't realize the impact of the problems and it takes him more time to get it. He's very good with math. It kind of reminds you of like, one of those scientific geeks that, socially they're like out the window. So like, you know, I tease my one friend. She's very intelligent. She has two doctorates, and I tell her, "But you're socially inept and your disability is like common sense," you know. She doesn't have any, and so, you know, he...and he does say, you know, like when he was little he would write his name backwards. And so he...he does say to this day, that when he tries to do too many things at once; he gets confused. Like once he reaches nine things, it's enough; he can't do anymore. Or, you know, I don't know really what the number is, but it depends on the complexity of the issue. You know, and you know, he called me in distress a few times now because he's...he was...Initially, he was the power of attorney and he had to do the taxes. He had trouble with that. So who does he call? He calls me. I got a frantic call from him last night; and I haven't got back to him yet because he's at work right now. But his frantic call was he's now the executor, but the...he's having trouble with the bank, again, with that stuff. So, he...who does he call, he calls me. You know. But, you know, to me...I don't know anything about a car. When I have trouble with my car, it's like, you know. You see the grass is so high outside. But he said, 'I don't cut grass.' He can show me how to cut grass as much as he wants. He can give me the easiest lawn mower on the planet. I can't cut grass. It just...It...I can't; and a lot of it's not necessarily the physical part. I mean the hill side is difficult; but it's like, I just...forget it, you know. It's one of those mentally things I can't do.

Interviewers: Do you brothers and sisters live nearby then?

Sarah: My one brother, well, he lives over at my parent's house, you know; and so he's still there. My other brother has moved around. My sister has moved around, but their home base right now. My brother is in Massachusetts, and my sister is in New Mexico. They were just in this weekend for our family situation, and I planned the whole thing from start to finish. I was the one going to the hospital. My brother, who was the initial power of attorney, I had to switch over to get on there also with him because he could not be at the hospital when she needed him; and it looks like I might have to do something for the executor thing, and...

Interviewers: It seems like you're the glue that holds this family together.

Sarah: Yeah. And I...That's the hard part because like, you know, I told him, I said, 'If we don't get the car paid off and mom passes away, the car's in her name.'--the car that sitting in my driveway. I said, 'So we're responsible for the taxes and so forth.' He goes, 'No, that's your problem. That's your problem.' Well, he found out from the attorney when he got sworn in as executor, that it is his problem, because if I wreck, it's on him. It's not on me. He...it's like he's very difficult in that you tell him something and he'll like na na na na. And then when he slams up against the wall or, you know, somebody

else says something, 'Oh, really?' But we recently found out, my cousin who's a doctor has ADD. His son has ADD. My brother has issues of ADHD because you'll say something to him and he's like bluh, right over top of you. I'm trying to talk and he's talking right over top of me. And my family finally recognized it last...over the weekend. And that's a part why he's having trouble, too. But he's good at his job because he's a machinist, and he's on his feet, and he's like, 'Oh, I was real busy today. I was over at this machine, over at that machine.' And he's bouncing all over this machine shop and getting all this stuff done. And...but...that...it works for him. And he's good...He's not a good teacher. Like my oldest brother, he's a good teacher. Like he and I can put this floor in...and he could teach me. If I asked my other brother to teach me, he's like, 'I'll just do it.' So...

Interviewers: So what are you most proud of when you think back on your life so far?

Sarah: Who am I most proud of?

Interviewers: What.

Sarah: What? Oh.

Interviewers: Or who if that's easier and comes to mind.

Sarah: I don't know. I just think that...sometimes I'm sitting there, like, at work or something and I'm talking to somebody; and I just get the thought that, you know, this is...this is where I should be in life. This is what I was meant to do and it's where I should be. Even though I have...there are a lot of things I want to do that I haven't gotten to that I should, you know, and that I chose not to do. I mean, the employer I have now, I passed up a lot of positions with them in the past, because I wanted to do certain things. I passed up marriage proposals because it was like, I can't be married to him and, you know, and that kind of thing. And so, and the other thing to point out is, people think that they're being nice and helping you when they're actually hindering you. I mean, for me, well you see me. I've accomplished a lot. I'm really not as disabled as my medical records would show. I can get sick at the drop of a hat. But, I can do a lot myself and some people think, you know, helping people and being extra nice or something is going to help with me. It's like, no, it really irritates me more. A good example of that would be is I was riding on the PAT bus the one day and a lady who was blind got on the bus. She seemed very independent. She got her change purse; put herself down on the seat. She got her change purse open and she had to feel the money in order to know whether a dime, nickel, quarter, because you have to put exact change in. So the bus driver was patiently waiting and there was traffic ahead of us, so there was no reason for him to rush. I had to move. And an older man said to her, "Would you like some help?" And she's like, "No! I don't need any help!" It was just the way she does things...She had to do it that way. You know, and it wasn't that she needed help, it was the way she adapted to do her thing. And so, you know...so, you know...you know, I was white water rafting

the one time with a supervisor who had worked with me in the Department of Disabilities for the state, for not the state, the city of Pittsburgh. We went on a trip with friends from the office just because we felt like doing it. We went white water rafting and one of... One or two other people that weren't in the office that didn't know me came along. Everyone was getting out at certain points pushing our raft because the water got too shallow at certain points, and so I got out to push and the one lady... Oh, the one girl says to me, 'Why don't you get out and push?' Well, the one lady wouldn't let me get out and push. She just, 'Well, she's handicapped. She can't push.' Like, I do everything else. I can push. You know, I was... The other thing I was in Brownies and Girl Scouts when I was... I went all the way through to Cadets in 8th Grade. I was the one who carried the tents on my shoulders by myself. A lot of times, it's easier for me to do it by myself and it looks like more... like I'm having a difficult time when you look at me. But it's easier for me to do it for myself, by myself, than to have someone try to help me; because they... they do it at different pace. They do it different way and it just throws me off. I can throw a canvas... a 75-pound tent with its poles over my shoulder and carry it five miles without problems. If somebody tries to help me, I'm going to have problems, because I'm used to doing it that way. And I... and they always took me because I had to... I was the one that carried the tents, you know. The one girl she said, 'I'm just clumsy.' She, you know, skin and bone, no muscle, no muscle coordination. And the one girl says, "She's always like say... you know, helping her and then rescuing me" because this girl always knocks everything off balance. She fell in the lake about five times and they finally said she wasn't allowed to go anymore because she kept falling in the lake. So, you know... It's, you know.

Interviewers: Well, who's been the biggest influence in, you know, your life, or maybe what. Maybe it was, you know... it could, you know, a video, or an article, it could be a person.

Sarah: I don't know if there was one biggest influence, but I think that the initial... my initial family approach was like, "Okay let's see what you can do." You know. Okay. You know. Here's what going on, and... but, let's see what happens. Now sometimes they wouldn't sign certain permission slips or whatever. I think it's like, let's see what... Instead of focusing on, she can't do that; it's like, let's see what you can do. And, too, one thing that we talked about when I worked at UPMC in the program, was like, it's not that you can't do it, it's you need extra time. We had a couple people there that, one patient in particular, had one arm. Well, for him to get his stuff together, take the shower is going to take longer because he has one arm. So he has to put the wash cloth down, put the soap on it, and put the soap on it in a different way, than if you had two arms. So it takes him an extra five, ten minutes to take a shower. And the one girl said, "You know, people have no patience." He can do it. It just takes him extra time, you know. And there... and, you know, I have a girlfriend who went on a scholarship to college for basketball. She's a military policewoman. But yet she can't ride a bike or swim. I can ride a bike and swim, you know. She can't do that at all. She's tried, you know. So everybody has their thing they can't do. I think disabilities are more like, there are

invisible disabilities, and there are visible disabilities. You both wear glasses. Okay. If Benjamin Franklin did not invent glasses, where would you be today? And glasses and contacts...

Interviewers: I would be moving very, very slowly.

Sarah: Yeah. Well...

Interviewers: Yeah, exactly. I can't see, you know, hardly at all. So it would just take me a lot longer, because I can see but...

Sarah: Right. And that...and it really is your disability. But glasses and the contacts and so forth, things like that are so common that people don't see it as a disability anymore. And so, I, I can't like rob a bank or do anything like that because I...I'm too visible. People remember me. I don't remember people too often. People remember me because I stick out like a sore thumb. OVR told me I would never graduate from college. So I don't think that I shared that with you on the phone.

Interviewers: Why did they say that?

Sarah: My test scores were too low, and I was irritated that day, and that was their thing. I knew...But my aunt took me downtown when I was 10 years old to the Y and we would...I would swim and she showed me around town and the different eateries. We would go out to eat and she would buy her groceries down at Market Square. And we would go home. So when I went to go take my OVR test, we went downtown. So I went on my own because I know how to get there. My mother knew that. I was what, 18 at the time and the atrium down at the end of Market Square had great...had great fruit yogurt at the time that that park closed. But I like going down there. I wrote a paper on that building once for an architecture class. And, you know, they said, "Well, there's McDonalds and that here, there." And so the two people who were administering the test saw me going down toward the atrium. They're like, "No, McDonalds is up here." I don't want to go there. I know downtown. I will be back at 1:00. I don't want to go there. I want to go somewhere else where I can get good...I hate McDonalds, you know. I don't want to go there. It's not that I don't know, I didn't hear what you said. I don't want to go there, you know. And so...and the one guy kept smoking cigars during the test and all that kind of stuff, and some people just aren't good test takers. And, you know, I started in pharmacy and that's a rough degree to get. That's...You're taking like 17, 19 credits a semester. And they're heavy; they're chemistry. They're organic chemistry. It's biology. They're rough courses. And it's, you know, it's a three-days-a-week lecture. It's two days a week in the lab for each class, you know. So, it... They're rough classes. And so, and it takes a lot out...of you. And the books are not easy to carry. You know. They so you're only to have so much weight in your backpack. Well, the backpacks didn't have wheels at the time. I had to carry it on my shoulder. I was carrying a thick chemistry book, thick biology book; and then along with all those, you had to get those big, thick publisher's

notebooks for each class. OK. And that's, you're talking just your sophomore year. Wait until you get to your senior year, and so forth. So they're heavy duty. So part of that was, you know, learning that I can do those classes. But pharmacy maybe wasn't the right niche for me.

Interviewers: Um hmm. Right.

Sarah: And I still work with pills. I still count pills. I still have to read prescriptions. I still have to fill...get prescriptions filled for people and know those things as counselor and teach them how to take their meds. The other thing I didn't like about pharmacy, was like "Okay, here's your meds, go away." You know. And I did work in a pharmacy for a while and one of the girls was a couple years ahead in the Pharmacy School. And I got special privileges because my mother was a nurse in the hospital, so I got to go early. To the...work in the pharmacy early but, she came down from doing a med delivery. Because the chutes, you'd send it to the third floor and it would wind up on six. You know, so we just hand delivered them. She came down and said, "I saw this...this person's dead today. I saw the person yesterday. They're green." Well, you could be a little bit more sympathetic, you know, about it. Because, you know, part of life is dying. The minute you are born you start to die, and that's the philosophy of the whole thing. So, you know, and you don't know when the end is coming. And when my mother first got sick and she was having her open heart surgery, I was talking to my boss on my cell phone at the hospital and he says, "It sounds like a fight with the grim reaper." And I said, "The grim reaper wins the last battle all the time, but he...and wins the war." But it just wasn't today. So, you know.

Interviewers: Yeah.

Sarah: And the other thing that one of the nuns at school told us, and she passed away recently, maybe a year or more ago. Maybe it was more than a year ago. But anyways, she said, "We're all temporarily abled." And the definition for social security disability is, what you couldn't do...you can't do now but you could do before, is basically the general definition. Well, there's no baseline of what I could do before. So, they really can't...There's nothing I can think of that severely inhibits me to doing what I need to do except for people and their preconceptions, you know.

Interviewers: Where are you working now?

Sarah: Mercy Behavioral Health. And they teach crisis intervention and I do that. They do have a crisis team and I was on the team when the...they had the flood in Homestead and I think the airplane crash that was near Pittsburgh and Homestead or something like that. But I wasn't able to go because I was actually on shift and they didn't call me in. They had enough people with...who weren't on shift. So...And they were also looking for master level people at the time, but I snuck in there. And, so...

Interviewers: Well, do you have a hero or anyone of that type of...?

Sarah: No, not really.

Interviewers: No. It's just a question I have asked a lot of interviewees just to see. We'll let ... Do you have any other questions? No. Is there anything else that you just wanted to make sure gets on the...the oral history we talked about quite a bit.

Sarah: Yeah. I...

Interviewers: Or any words of wisdom on how to live your life. How, you know, a good way to end it.

Sarah: I don't know. It's just...I guess the point of everyone has their problems and I think we focus too much on people's problems than, "Let's just see what she can do." If you...If you can't do that, then there's something you can do. You know, and it's not, you know, it's... They have certain ways, "Well this is the way you do this." And if you don't do it that way, people, like kind of look at you funny. The...it's not... You do your thing in your own way and, you know, don't let people...I found out when people were kind of against me or trying, you know... "Don't talk to her." That kind of thing. They found out they were jealous for some reason. I had a group of kids that were jealous of me because they thought I was getting special attention because of my situation, medical situations.

Interviewers: You mean in school?

Sarah: Yeah. And I think in a way that was true because there's that liability issue there for the school. And I'm mainstreamed in a regular gym class with kids that are rough and tumble and they're like...they don't want, you know, me getting hurt, because I can...I'm already compromised to them and to get hurt again, you know. So, then I had the other group of kids, there were two, at least two others that I'm aware of that had or diagnosed with cerebral palsy like myself, and one was more...One would test out lower than me and one actually tested out higher than me. But, their doctors signed for them to be in a special gym class where they could deal with their disabilities more so and do exercises around their disabilities. My doctor felt that was not in my best interest, so he didn't do that. So they thought I was getting special...special privileges because they weren't getting them. They were against me that way. So I was like in the middle. And then I found, you know, found people that were not against me at all. But, you know, they would be friends with me in this situation, and then they would go into other things with their friends but I wouldn't necessarily...I never would ...belonged to one particular clique in school.

Interviewers: Does this, you know, where you envisioned...What did you envision yourself at this age in your life?

Sarah: I envisioned myself married with kids. Which is way far from what I have. So, and because it, and a lot of the successful dates that I've had, they've asked to talk to my doctor about different things. And I let them. Because they weren't doing it out of, out of...

Interviewers: What are they...Do you know what they're asking?

Sarah: They...They want to know what's going on, you know. And, you know, does it affect having children. No, it doesn't. It doesn't affect having children at all; and so, but they don't understand that and they don't know that, so they want to talk to the doctor. And they also, you know, just want to know to be there to be able to help. So, and, you know people say, "I hear this about her." And, you know, well my one boyfriend I had in college, a friend of his from high school came and said, "Well, I heard that she falls a lot," because there's ataxia involved with cerebral palsy. We some...some...it's called a special disorder in so...you know, so, ataxia which is where you fall a lot. And I think that part of the weight lifting and strengthening the muscles and keeping them loose helps with that. Because there are times, I feel dizzy and I'm not sure what's up, because I'm sick, or is that because of the situation. But then he goes, "She doesn't do that anymore than anybody else does." That's what his answer was, you know. And so, and I think nowadays, too, I have some friends that were growing up in divorced homes. So they didn't want to wind up in a divorce and wind up with their kids, and be fighting so severely like their parents did, so they don't want to get married. So it's a whole different... from when we grew up and were told we're going to get married and this and that and the next thing. It's a whole different venue now. The marriage laws are different. I would not get married at this point unless I had a prenuptial agreement. Because if you do get married without a prenuptial agreement, you wind up in a predicament like my brother is where if his wife signs something, then he can be financially responsible for it. And he wouldn't even know about it...and...

Interviewers: You bring up finances. What, it seems to be a running theme with the...sort of all through your conversations, but a lot about finances and financial stuff.

Sarah: Yeah. It's been difficult because I never got SSI. They tell me I'm medically qualified, but even when I didn't have this house, I had to sell my car. I had to give up my IRA to get SSI and live basically only owning \$2,000 of my own stuff. So my car would have to go into someone else's name. I couldn't live here because the bus service is not adequate for someone who doesn't have a car. I couldn't have the job I have or the career I have because, for example the job that I'll be shadowing for...some of the jobs in civil...in social work they don't let you have until you shadow someone, because they want to make sure you want to...you want to do that. Which I think is a good idea, because you really don't know until you get in there as to whether or not you can do it. So you better...you might still not have a good idea whether or not you can do it, but at least it gives you a visual of what you're going to be doing. And you talk to the worker

who has been doing it and why they like it and why they don't like it and that kind of thing. And you can't do that without a car. We...my boss...the potential boss, who actually hired me, he worked for the agency that I worked for previously, and he hired me. So it's a good chance I'll get hired on his team here, but they have company cars, and he said if a company car isn't available, because there are 11 on the team and there's only eight cars. So we tried to disseminate them evenly depending on who needs to take someone somewhere, but you do wind up using your own car. So, no way could I have done civil service, CYF, if I didn't have my own car, you know. There's no way I could go to the Bell SEI or house to SEI next week if I don't have a car. They're like an hour away, two hours away. So, this career that I seem to have latched into and do great at and enjoy, I can't do without a car.

Interviewers: Right.

Sarah: So, on the one hand, you want to be employed as best I can; but yet on the other hand, you don't want me to have a car so I can get the benefits that the state, or federal government allows me to have. And my mortgage could be paid by SSI but, you know, and that's a choice people make; but yet it curtails your freedom, because you can't own stuff. You wouldn't be able to save money to like go, my nephew's going to China to teach English. I can't go visit him because...unless he paid for a ticket for me because I wouldn't be able to save any money. Because soon as my bank account went over \$3,000 or \$2,000, they would take away the SSI. My one nephew has Down Syndrome. He does great, too. We mainstreamed him. He, you know, he's in special classes for reading and math, but he can...he can basically... he got the skills basically to do his bank account and the basic things that you would do on a regular basis, you know, that works with a do pay our bills. He's on the high school wrestling team. He'll be 18 in September. I hope he graduates with his diploma. When he was born, they told us we should put him in an institution because he won't be able to contribute to society. But he is. He's on his Special Olympics Olympian and does all those things. So, I mean, I think more pointing out not just don't look at the disability and this is what it is and this is what they can't do. Look at what they can do, you know.

Interviewers: Yeah. Well, thank you very much.