



**Voices**  
**OF OUR REGION**  
**THE DISABILITY CONNECTION**

Interviewee: **Dave Scott**

Interviewee Number: **04**

Interviewers: **Athena Aardweg, Judy Barricella**  
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**Give us your name, where you were born, when you were born and anything about your family.**

My name is Dave Scott. I was born, I'm originally from Butler. I was born on November 14, 1973. I'm the youngest one in the family and the only one with a disability. Of course, I prefer to call it a birth defect. I moved down to Allegheny County in '92, right out of high school.

**What is your disability?**

Spina Bifida.

**Why did you move down?**

Because where I grew up was actually a mile and a half out of the city and I didn't have the, uh, transportation that I do in Allegheny County. We had a bus service but I would have had, first of all, to be in the city of Butler. Second of all I would have had to make arrangements a week in advance of anywhere I wanted to go. Instead of here it's 24 hours in advance. I've got no problem with that. But it's... I have a lot more opportunities down here and that's the main reason I'm no longer up there.

**So you came down here in '92? And what did you do when you came down here?**

Well, I started here... I really came down here for the Gatehouse Program which is an independent living center and they taught me how to, you know, the things I was going to have to do to live on my own.

**That was run by the Spina Bifida Association?**

Yes. I was there for a year and a half. That was also because I had my name on a waiting list for an apartment. That was the other reason. Because a lot of the other residents were only there for 6 months but that extra time was only because of the waiting list because it was only a 6 month program. And thankfully the one list I was on was only 3 to 6 months, because I put my name on one list that was 5 to 7 years. I knot, it's... And the only frustration I really felt with that was that some places were for senior citizens. Places for seniors. I said I called them they were like "You don't sound old enough". And I'm thinking "Okay, fine". But the place I did find was mainly seniors. It was down in Coraopolis.

**What was the name of it?**

State Avenue apartments. Or State Manor Apartments. I was there for 7 years. So I was living on my own for quite awhile before I ended up in Cain Regional. But the problem with that was I didn't... I thought I could live on my own but I'm maybe too independent minded because I didn't have aides or anything. I thought I could do everything on my own. Well I started having skin problems (**5 MIN**) and it wasn't until I got up here that I realized maybe a little bit of help isn't so bad. At that point I was 22 and at that point I was ready to get out on my own. You know, thinking I could do these things.

**But you lived there for 7 years without any assistance?**

Yea but 5 of those years I had nurses coming in because of skin problems. I was up at Cain one time for 7 months until one of them went away and then I went back to my apartment. So at that point I did keep my apartment. This time no. We just figured it may not be the best thing for me.

**So you went back to your apartment and you got skin breakdowns again?**

Again, yes.

**Did you have any attendants coming in?**

No.

**Okay. You didn't learn the first time huh?**

No, see that's the problem. Independent minded or hard headed, I think a little bit of both. I know I'm stubborn. But that's been my goal ever since I moved up here because I've been up here 6 years. Just to get out on my own. And now I realize that I don't want to do anything until I have attendants in place. But I do want to get out on my own but I do realize it's probably not going to happen. That's why my father told me it wasn't going to happen. He didn't think I could do it on my own. I want to prove the man wrong. But I do agree with one thing, I don't know that it's going to happen unless I have attendants this time.

**Are you ready to leave?**

Yes, and the sooner the better – like the day I moved in. I mean, I'm going to be 35 in November. Too young to be up there for so long. I was up there, like I told you, back in 2001 for 7 months because of... And that... I had the help and I didn't mind that, but 6 years of this, it's not the life for me right now.

**What do you do on a daily basis? And what did you do when you had your own apartment?**

I use the computer room right now that they have. I'm not on my floor right now unless I'm eating my meals or going to bed. Just to keep myself sane. And when I was at my apartment I had volunteer positions. And that's another thing, I want to go back to school. Because every interview I've ever been on, I've been on job interviews, everybody always says they're looking for people with a little more experience, so I'm just trying to make sure people don't have the excuse anymore. Plus I also say "You look in the mirror you're looking at this." I've got to think that too. Are they worried about the wheelchair? Cause it seems like that's the attitude I get with every interview.

**What can you do to change that?**

Like I said, I want to go back to school and get the experience. I admit I graduated high school and then I had one semester of college. College didn't go too well. So I want to be able to get **(10 MIN)** to the point where they're not going to use that excuse. So I'm figuring it this a problem, let them say it.

**So you said you weren't ready for college.**

What I said was I didn't do well. I had one semester and I flunked out. It didn't go too well. Maybe that came from not knowing at that time specifically what I wanted to major in. I had general studies at that point.

**Where did you go?**

Butler County Community. This was all before I moved down to Allegheny County. I graduated in June and my college started in August. And after my first semester I got into the Gatehouse down here in Wexford and I've been here ever since.

**What did your family think about you moving down to the Gatehouse? Your mother and father still alive?**

My father is. Unfortunately not even a year after I moved in there she passed away. That was a bad New Year's Eve weekend to be home.

**Oh, you were home?**

Yea. See that year and the year before I had a friend at the time that lived over in Murrysville so I spent those two New Year's weekends with him. But that weekend, I was home when it happened.

**Had she been sick?**

No, it was a heart attack.

**Very sudden.**

Yes, extremely sudden. Stubborn, stubborn, stubborn. No, I get home and she's having chest pains all day but wouldn't go to the hospital. The doctor says does it hurt when you pushed on it because she called him. When she said yes he said "Oh, you just pulled something." That was all it took for her to hear, so wouldn't go anywhere.

**How old was she?**

55 going on 56.

**Young.**

Extremely. She would have been 56 in September and this was the morning of January 2<sup>nd</sup> that this happened.

**You lived at home?**

At that point, yes. I was still down here, getting ready to go down here to Gatehouse.

**How old were you then?**

At this point I was 22 going on 23. Actually, no, I was in the middle of Gatehouse because I was there for like a year and a half. I moved to my apartment in '96. And that was another thing, she really didn't want to let go and see me move in. She wasn't protective, or terribly. I went to a public school and stuff. Maybe it was because I was her last out of the house. She didn't want to see me go but she probably knew it was time. I know I did. But yeah, I'd have a, uh...I was in public school.

**And what about your dad?**

I've been fighting that man tooth and nail since I moved into Cain this time. **(15 MIN)**

**Why's that?**

Well, at least that's the way it feels. 'Cause ever since she passed away it seems like he's becoming more protective of me. Now they were both married before and I am his only child, her fifth but his first. I don't know. I've had people say maybe it is the disability, in a sense maybe since he's seen how much problems as far as skin problems I've had in the past. Because he's flat out told me he doesn't know if I could live on my own again. I'm bound and determined to prove the man wrong.

**Yes.**

Because I know I had problems the first time, but like I told you, I didn't... The problem was I didn't do it right. I thought I could do everything on my own without the assistance of aides. But I truly believe if I have somebody there, even if it's just a couple hours or a couple times a day, just to keep an eye on things. I'm sure I could... that I'm sure. (unintelligible) I know now that if I have the little bit of help that I am more than capable of doing this. I mean, you know, I probably shouldn't say I'm gonna prove the man wrong. I don't want to sound like I'm against him or anything but I do want to show him that "Okay things didn't go well the first time but things can change."

**How are you planning differently this time?**

Like I said if I get the attendants I think that might be my biggest hurdle.

**So now you have to find a place to live again?**

Well, I am working with somebody through TRCIL. I have a peer counselor that comes up to Cain to see me once a week. I do have applications; I work with Eduardo through the nursing home transition. And right now, I'm only in this right now on days I have to go down here. I'm on a prone cart otherwise just to keep myself closed. Cause I do, I did have a tendency to want to be in here a little too much, a little too much sitting.

**Do you have the right kind of cushion?**

I have a Roho.

**Okay.**

And everybody told me they were the best kind. But the problem is, it is my skin and just the amount of hours, over time. Today isn't going to hurt. I'm going to be here until the 7:00. So I'll get home, get out of this, get in bed and be on the prone cart the rest of the month until I have to come down here again.

**Do you ever change your position in the chair? I mean pick yourself up and move around?**

Well, Yes. This has... This has a tilt and recline if I want it to. But the nurses down there didn't like the fact that they wanted me (**20 MIN**) to be able to tilt the whole thing up more than recline. So the place I got this from, the guy said to come up and readjust this. So now I can no longer lay myself flat.

**I'm not understanding why they didn't want you to lay flat?**

The P.T. up there, the therapist thought I would do better if had more... again, I'm gonna move, but I'm gonna be careful. She thought it probably would, um... If I had more movement this way I would take more pressure off here. But, see... There came a time when I first got this that I could lay my head all the way into a bed, practically.

**But that headrest isn't doing you much good; it's not touching your head.**

That's because of the way I have the back. I don't... Another thing I do, you can see, now they got it that that's as far back as it's going to go. Like I was saying, and that's another thing I was thinking also, it's just that mainly I don't always sit up straight with my head. Plus I also worry that, I allow it back a little bit so I also worry that the straighter I was the more pressure I had downward.

**Dave, I'm going to ask you a question. About, um, when you were growing up, what did you imagine your life would be like when you became a man?**

I really didn't have any expectations, in all honesty. And to this day I always said that I was going to live as normal a life as I could. I mean I had times when I was really young that I wondered "why me" because of disability. But that changed. You know, that just kind of turned into "Well this is what I am, I'm going to do what I can, and I'm going to do the best with it." But I really didn't have any expectations. I just figured, you know, I could do anything anyone else "normal" could. I just learned that I've got to do them in different ways. So there really weren't any specific expectations. I honestly believe that if I put my mind to it I can do anything anybody walking can do.

**Did you think you would get a job? Get married? What did you think?**

I'm engaged right now to be honest.

**Are you really?**

Oh, yeah. Yes. She has Spina Bifida also. That's the only thing I found a little bit different (**25 MIN**) is it seems that people walking around that I'm friends with but otherwise they've shied away from me. That anybody in a wheelchair I have gotten that close to. And that's probably because I understand what they're going through as much as she does, as much as the next person. But I am engaged and I do plan on getting married some day. And right now because of where I'm at I've got that on hold. 'Cause I'll tell you right now, I mean, Cain is not the place for that right now. I've got to find myself in a better situation before I do that.

**How did you meet her?**

At a camp that we both attend up in North Hills through the Spina Bifida Association. As a matter of fact, she's previously from my area. She's from Clarion, originally. And

that's like, a little up I 80 and like, I forget, like an hour and a half north of me. We're from the same area practically.

**So where is she now?**

She's over on Babcock Blvd; the area is considered, um, Allison Park. It's like 2 miles from me right behind Passavant Hospital. It's an apartment; it's called the Villa Riviera.

**I know exactly where it is. So are you able to get Access and go visit her?**

I haven't, in all honesty because of the way things are going here. I mean I'm close right now but I have been limiting myself. I've taken the day to come down here about three times a month but I haven't taken a day to go in the wheelchair to visit her yet in those three years.

**Does she come see you?**

Not very often. Well, first of all, we're dealing together with her depression and I realize how hard that is on her. Plus the fact that she does not like to see me where I'm at, at all, meaning Cain.

**Does she work?**

Unfortunately, she volunteered but like me she has had a lot of skin problems. She used to stand with braces but now we have a heel that we're trying to keep closed. 'Cause it seems like... She's possibly going through some kind of procedure that they are going to inject some type of medication and then they're going to send her to a nursing facility or something for about six weeks. She's not supposed to be on it whatsoever. 'Cause she, she can... I have no control from my hips down, my waist down. But her knees, even though she has Spina Bifida, her knees lock and she can stand as long as she is holding on to something. And this is how she transfers to the toilet, to the shower, to bed and that's what keeps giving her problems. She stands on that long enough just to do this, no longer than that, but several times a day and things open right back up.

**Dave, who has been the biggest influence on your life? (30 MIN) So far, your only 35.**

Yeah. 34. (Unintelligible) You know, I really don't know. I would like to say both parents. I would have to say parents. But I really can't tell you... But if you're looking for the most influence I really can't single the one out. They way they worked at times, I was on my own until they got home. I was independent from a fairly early age, preteens probably. She was a secretary. She was in real estate where she was the secretary for them. And my dad works shifts in a steel mill. So, you know, I was on my own quite a bit. But as far as influence, I would have to say them. 'Cause, um, I really... My

brothers and my sister all grew up with their father. Well, my brothers grew up with my mother but my youngest is 12 years older than I am. So they were out of the house and gone when I was still fairly young.

**I've got a funny feeling I know how you're going to answer this question but I'm going to ask you. What's the most important lesson you have learned in your life so far?**

I would say so far not to really worry about how other people are going to react to me. I mean... I try to be friendly with everybody. You worry about how they're going to react to some point but I meant as far as not thinking are they prejudging me for what I can and cannot do. Because that's the part that still irritates me. To this day, I swear, that's why I even told you I hate interviews and the way they respond me. I start to wonder are you looking at me or are you looking at this.

**Dave, is there anything you want us to have on this tape that you want to say?**

For whoever hears this, don't let whatever disability you have or how bad it is, because when I went to school a lot of my homeroom, see my homeroom was for physically disabled but we were mainstreamed out into "normal classes". So I've seen people with disabilities even before I came here, with disabilities worse than mine. But like I said, whatever I went through there was one thing I would tell anybody. "Use what you do have in any way possible and don't let whatever you have stop you, if you believe in yourself."

**Good. 35 MIN) That's good.**

I mean, I've learned... The way I look at it, I'm going to do whatever anyone else can. I just may have to do it in different ways. I've walked with braces and crutches until I was 10. Unfortunately I kept going this way and this way and this way. And the hip joint kept breaking on my braces. And there are days now that I'll go to places where there are steps and as I was growing up even, even before the ADA law and I would start wondering why I was not still in them. Plus, where I was living in Coraopolis, and I didn't mind it, I've got the power of my arms, I've only got this because of my skin problems, but I had a manual one until about 2 years ago. So we went all over the place, no problem. But when you go to buildings where they have one step that on the manual wheelchair would be up to about here and a doorway big enough for you to walk into and that's it. It gets a little frustrating. When I moved it was around '96, when I moved out into the community. So everything was in place. You would have thought that because of it there would have been some things done; but there wasn't. I mean I did have curb cuts, I did have that. I've got no problem there but as far as the buildings go. I had to wheel about two blocks or maybe a block and a half to go get my hair cut and even they had a step that was like that. I had enough arm strength that it was nothing for me to get up. The only building I saw... I did get into my bank with no problem. But the only

buildings around there that had a ramp were the post office and the back of my apartment building. As a matter of fact, when I moved in I was told the building was 20 years old and I was the first one to use that ramp.

**If you go back to school what are you thinking of doing? What would you like to major in? I was like 26 or 27 before I started college. It took me that long to figure it was time to do it. It's not the same as when you're 18 years old.**

I'm 34 and I'm just... At this point, I've been talking about it for years. I would like to maybe get into business administration or something like that. As long as it has something to do with computers, because I love computers. I've been working with them since I was 8 years old, third grade. I'm thinking business administration and really, to be honest with you, I'm trying to put things on hold because I'm trying to get out of the nursing home first. I'm trying to prioritize what needs to be done. Right now I would also like to do something online. It would save me a lot of traveling. **(40 MIN)** Make it easier on me.

**You have a computer I take it.**

Unfortunately... You see, I do, but I don't have my own. I have a computer room for the residence, okay? But I don't have my own.

**Do you have a computer somewhere?**

No.

**So you need a laptop.**

I need the money. Well that's another thing. I'm getting my SSI but all I'm getting is \$35.00 a month to live on. Everything else is going to Cain for my treatments, food, you know, and to be taken care of. So really, no, I don't have... Because one of the cheapest I've seen is about \$500.00 - between \$500 and \$1100 to be honest with you. I would love one; I would love to get a laptop. Because I would love to go back to school online but I have a computer room that, you know, it is set up computer wise but not with the programs I would probably need.

**Can you push the cart and stuff?**

Oh yes. Oh yes. Like I keep telling everybody from the waist down don't work, the legs don't work but everything else is fine. And that is the attitude I've always taken. That's why it gets so frustrating when I'm trying to find a job because I know what I'm capable of. I may just have to do it in different ways. I have to make sure the building is accessible but otherwise I'm fine.

**Well David, I really appreciate you coming in and being interviewed and we're going to make sure you get a copy of the CD and are invited to the premier.**