

GCPD Brenda Interview Transcript

Testimonials from People with Disabilities and Caregivers. Sponsored by GCPD.

Brenda, Mother and caregiver.

Total Run Time:22:45.

Brenda Sunderdance:

My name is Brenda Sunderdance, and I'm from Platteville, Wisconsin.

Interviewer (off screen):

OK, first question is, are you a person with a disability? And what is the nature of that disability or what brought you into the health care system, I guess?

Brenda Sunderdance:

What brought me into the health care system? My wife has MS and my sons both have autism. So, I have been in a caretaking role for some time. I went to the emergency room with my one son who needed medical care. We didn't know what was going on. And he was scared. I was scared. And we were told that due to COVID, that because he was an adult, that nobody could go in with him to the emergency room.

That didn't sit well with me. And I told them that he had autism and that he needed a support person to go with him. He was not in a good mental state at the time and agreed that he wanted me to come with him. The health care workers that we spoke to kept insisting that he would need to go into the emergency room alone. So, I asked to talk with their supervisor. They disappeared for a while and came back and again told me that they talked to the supervising supervisor of nurses or something like that.

And that unfortunately I would not be allowed to go back in the E.R. They came back a short time later and said, well, you can come to this first session, because I had insisted that David would not be able to provide his medical history, which was true that you can come in while we get him set up.

But when he goes back in the emergency room, you will have to go back out to the waiting room. When they came back, I again insisted that David needed a support person and that it was my understanding that under the ADA that they could not deny him his right to have a support person with him, at which point they did allow me to go back with him.

But it was a whole lot of stress for both of us. And at one point they did separate me from him. I'm not sure why they did that. And I think it did impact the medical care he received. It was a very stressful time for us.

Interviewer (off screen):

I can only imagine as a parent. Can you describe knowing that you need to be there with your son and what is that like to not be there to know that he needs that support and you're not able to help?

Brenda Sunderdance:

Well, I was very, very anxious for him, for, you know, worried that he would not get the medical care that he needed. That, and thinking about, well, where else can we go? Because we were at the UW and, you know, they're some of the best in the state. So, if we receive that kind of treatment, there, you know, across the state, I wonder what other hospitals, other organizations are doing.

And our family clinic, we don't have a problem, but they know our family and they know my son has a disability. And so, they have experience. They know that if I'm not with him, that they're not going to be able to provide the same level of care. He's not going to be able to follow up because he doesn't remember what they tell him in terms of what he needs to do after an appointment.

If he needs to schedule anything, he relies on me to help him with scheduling. So, there are lots of reasons why somebody might need a support person present to help in a medical setting. And then you put on top of that, if somebody is not feeling well, if they're, you know, they're there for a reason, they're not at their best either to gather information.

And for those of us who don't have a significant disability, sometimes it's helpful to have another person present especially when we have something serious going on.

Interviewer (off screen):

So, you kind of said that someone at the clinic did separate you two. What kind of reasons were they telling you? What were they telling you for these things?

Brenda Sunderdance:

They asked me to wait. And they had taken us both back to this room and they asked me to wait there. They said that they were going to take him for some tests, but then he did not come back for a long period of time.

I'm not even sure what tests they were referring to. They did do a, you know, blood workup and things of that nature. But, and then a doctor came and talked to me without him. And eventually they reunited us, brought me back to where he was in the emergency room.

Interviewer (off screen):

And at the end of this, did you get to tell somebody from the hospital about your experience? Has there been any more movement on it? Did you talk to anybody about it, to kind of let them know that this happened or was there was there anything since this?

Brenda Sunderdance:

I did not, you know, at the time, I was more concerned about my son getting the medical care that he needs. And my days are busy, and I guess I didn't want to expend the time and energy to call the hospital. Who do I call, you know, to talk to? I just at the time, I was more focused on making sure that he got the care that he needed and getting him healthy and taking care of the rest of my family.

Interviewer (off screen):

And is there anything, like, could you describe what, I guess, the ideal situation? How could a hospital, you know, from the time you pull up into the driveway that they can properly accommodate somebody with special needs?

Brenda Sunderdance:

I you know, I think that there has to be a process for which individuals with disabilities, if they request a support person with them, that even though they're you know, we're in the midst of a pandemic they need to be allowed that support person so that they can get the care that they need. In our case, we're a family unit. You know, \ he's already exposed to me. There's got to be a process by which they can keep everybody safe. I told them that I had been at that point in time, I have been vaccinated, you know, none of that seemed to matter. It was this is our policy. And, you know, I really didn't feel like they were listening to me.

But I think in an ideal setting, there would be a process by which individuals can request a support person and the staff know when it's appropriate and when it's not appropriate for a support person to stay with that person. And if you're going to error, I would say error on the side of providing you know, allowing for that support person. You know, there's going to be, I imagine, some exceptions.

I've heard that the emergency rooms are very, very busy at this point. You know, I would hate to have to seek medical care for some other reason at this point in time, you know? And that probably makes it harder for hospital personnel to think outside the box or think of a way to manage allowing safely allowing a support person to come back. If the clinic can allow me to go with my son to his appointments, then why can't the emergency room figure out a way to do that safely?

Interviewer (off screen):

Do you feel that this was because of the pandemic? Was this not as much of an issue in the past?

Brenda Sunderdance:

We've had some questions since he became an adult. When he was younger, that was not as much of an issue, I think primarily because he requested that I be allowed to go with him which is only right. I do think the pandemic has made it harder you know; I don't know if this would have happened the way that it did if there wasn't a pandemic. I can't tell you that because I

haven't had the experience of needing to go to the, thankfully to the emergency room with him prior to that.

Interviewer (off screen):

So, yeah, he's unfortunately, he's not the only one that's experienced these problems. You're fighting for your son or people fighting for other family members or loved ones or people that they just care about or themselves. What, pretending you're talking to the system, as it were. You know what? What do you have to say? You talked about how what could be better, but maybe you've got something to say, you know, here's let's make this better for everyone.

Brenda Sunderland:

Well, you know, there are laws that protect individuals with disabilities. Unfortunately, not every individual with disabilities knows their rights. And I think they shouldn't have to always fight to access the rights that are afforded to them under the law. The reason those laws are in place are because people who have come before us have had difficulties accessing health care, education you know, just being in their community for one reason or another related to their disabilities.

So, I think, you know, if I could tell the system one thing is, you know, individuals with disabilities don't want anything special. They just want to be included just like everybody else. They want to have the opportunities and access that everybody else has. And sometimes that means doing things a little bit different to allow them that access.

Interviewer (off screen):

Is there anything that we didn't touch on that you think is incredibly important about what happened that you'd like to say?

Brenda Sunderland:

I think having my spouse has M.S., and that is very apparent disability, you know, she has physical limitations that are obvious. Uses a wheelchair at times, uses a walker most of the time for mobility. And people will sometimes bend over backwards to be helpful because the disability is so visible and so obvious. But individuals like my son, who has autism but looks normal, oftentimes they act as if you're trying to take advantage of the system without realizing or understanding what day-to-day life is like for him, you know? He struggles. And I wish that there was a little bit more compassion and empathy for individuals who may have invisible disabilities or not so, disabilities that aren't as visible or obvious what their needs are, and that people would listen and just be kind.

Interviewer (off screen):

What's his attitude like? Obviously, most people don't want to let these things get them down. Has he talked about it? Does he have anything to say about it?

Brenda Sunderdance:

He has. He's pretty insightful about his limitations and where he has difficulties and he will voice that, you know. He will talk about, you know, talk to my mom because I have a hard time remembering things or if they're giving directions, they want he wants them to tell me because he has a hard time following multi-step directions, he loses track or forgets pieces of the information, you know?

So, in some ways, he is able to, you know, express what he needs. He doesn't always know what to anticipate. And, you know, will sometimes feel bad or get nervous because he feels like he should be able to do whatever it is that they're asking him to do. And so, I guess sometimes he is able to talk about what he needs and sometimes he isn't. Did I answer that question?

Interviewer (off screen):

Yeah. I was just kind of curious if he's ever made a comment, you know, that made you think, you know, did he ever say, I never want to go back to that place again or anything like that?

Brenda Sunderdance:

No, but he gets really nervous when he has medical appointments because it's very stressful for him. He knows they're going to ask lots of questions, and he knows that he's not always going to be the best reporter or have the best ability to answer all of the questions that they may ask.

Interviewer (off screen):

To get proper care you need to be able to answer questions.

Brenda Sunderdance:

Right. Right. And, you know, we continue to work on ways for him to be more independent, you know, but you don't always have your entire health history in your back pocket.

Interviewer (off screen):

Has there been a time where he's expressed that that went easy, or he's felt great about his medical appointments or anything like that? Has there ever been a time where he's been at ease?

Brenda Sunderdance:

Yeah, Due to changes in our insurance we had to change our primary care doctors. And I asked him to look over, you know, look over the bios. You got to choose somebody, you know, and he was very nervous about that first appointment. But I remember after the appointment, the doctor was great. He set him at ease.

And after the appointment, he said that went a lot better than I thought it would. So, you know, I think, you know, when doctors take time, you know, and are patient with a patient, our you know, he didn't make him feel silly for having his mom with when I think he was 20 then at that point in time.

You know it's he just accepted that this was how it was and went with it and asked David the questions directly and anything David wasn't able to answer I helped respond too. Or if David asked for help in answering something, I would respond to it. But the doctor was you know, very respectful and took time to get to know David.

So that appointment went well. I think that's really important, especially, you know, in establishing care with a new doctor, that they take a little bit more time with individuals with disabilities.

Interviewer (off screen):

I guess just out of curiosity, how many clinic options do you have in your area? I'm not very familiar with Platteville.

Brenda Sunderdane:

Given our insurance, we have one choice in Platteville at this point in time. There are two medical clinics, and otherwise you have to there are some smaller communities that do have clinics that would be covered. You know, you could stretch out of Platteville, but we come to Madison for almost all of our primary care, or not primary care, our specialty care.

So, when you think about being a person with a disability and needing specialists frequently, you know, oftentimes we can't access that care in our home community.

Interviewer (off screen):

We need better access to health care. But is there anything else that could make it easier for rural communities?

Brenda Sunderdane:

Oh, transportation.

Interviewer (off screen):

Like what? What does that look like?

Brenda Sunderdane:

Well, Platteville has a small shuttle bus system, but it is very, very limited. They have what they call a taxi service. But we live five miles outside of Platteville. And most of the time they will not come that far out. So, for my son, who is unable to drive because of his disability, he pretty much depends on me to get him to any appointments, anywhere he wants to go.

So, it really limits independence. Right now, he is in school up in Minneapolis. And as I said, he's working you know, he has more access to public transportation and options and the ability to, you know, things are closer together, more condensed. And so, he's able to walk from his apartment to work and back again, you know, but just more opportunities for him.

I think transportation is a huge barrier for people with disabilities in rural communities.

Voiceover (off screen): Thank you for watching. This video is sponsored by the Governor's Committee for People with Disabilities. Visit www.dhs.wisconsin.gov/gcpd to learn more.