GCPD Lawrence Interview Transcript

Testimonials from People with Disabilities and Caregivers. Sponsored by the Governor's Committee for People with Disabilities.

Lawrence, Caregiver and advocate for people with disabilities.

Total run time: 23:09.

Lawrence Brown:

My name is Lawrence Brown. I'm also known as DJ Larry Love on stage. And we live in the southeastern Wisconsin area of Milwaukee County.

Interviewer (off screen):

Very nice. Are you a person with a disability? And what is the nature of that disability?

Lawrence Brown:

Yes, I have a disability. I have multiple sclerosis. And I'm also dealing with bouts of diabetes.

Interviewer (off screen):

And so, you do you are a caregiver, do you want to talk about your relationship to the person that you care for and how that got started and share anything you can to get us into your story here?

Lawrence Brown:

Yes. Well, I am a caregiver for Mark and of course, we met each other on the wheelchair soccer team. OK. We're extended family actually. So, I found out I had new extended family after I met him in soccer. But anyway, I have been through a lot of ups and downs with Mark and stuck with him through it all, even to the point where I've sacrificed some of the things I love to do for the sake of his well-being and preference.

So, the reason I got into this is because a lot of people may not be aware of this publicly, but caregiver, there are shortages. And of course, the caregivers that are out there fail to meet a lot of expectations, even if clients don't speak up, we know something is wrong. It's very evident.

And Mark, all this time just said, I've been looking to see if I can get you on board. So, I decided why not? And so that's how our relationship began.

Interviewer (off screen):

OK, so what was your experience in seeking medical care during the pandemic? I take it you were contacted to be a part of this video because of something profound that happened?

Lawrence Brown:

Yes. So, with regards to Mark's medical treatment, he has several specialists to monitor and do his health care. And a lot of times they have the same expectations during COVID. Like, go by yourself. A lot of hospitals had no visitors' policies. And it was up to the nurse whether people like myself were even allowed into their appointments, even if it were a professional only, which in our case was. Their nurses contended they could take my spot. But when they did, they never had very good notes on their discharge notes that really helped me. Mark couldn't quite remember.

So, I had to make a round of calls. And finally, I'm like, I need to be on your appointments, period, so I can take notes and report my findings that I observe as I live with this person. Back to his doctors. Mark is unable to always recall and if something happens to Mark, like, for example, like a lot of people with epilepsy, he has once in a while seizures. Well, he can't tell what the heck time that happened. I write it down and I monitor it and measure it.

He's been all right, but my information comes in very helpful for the doctors in monitoring his medication and doing whatever is the next step medically. So, during the pandemic, we've had an uphill battle of different places have tried to, including emergency room visits, if any. I’ve had to hand Mark my iPhone and say, I'll try to talk with you guys in the background then.

But by and large, it's been very harsh. While we understand the general needs, we expect reasonable accommodations. So, in public comment at Governors Committee for Persons with Disabilities, I put that in places where that happened. And under ADA law, if they're receiving any funding and Mark's insurance is Medicare, they most definitely do, ADA accommodations apply here. So, we filed complaints with the administration, made public comment and tried to get the word out to people that, hey, you're probably not the only one.

So, person by the name of Dave Morstad started to do a project, and there were several other participants that had similar issues with caregivers. So, we looked at all the analyses, saw the graphs, and we realized, hey, there's a lot more interesting folks out there and cases out there. So, it's probably happening to relatives in the ones you love.

Interviewer (off screen):

Can you talk about like; what kind of supports does Mark need? What things does he need for these medical appointments to go smoothly and to not have to have concerns?

Lawrence Brown:

Well, he needs somebody that can accurately take notes in the appointment. He can't write. He has trouble speaking and his memory is not like some of ours. It's pretty good, but it could be better. So that's where I take my notes and my memory and play tag team, so to speak, and help him out. And then also when they have stuff that they can answer our questions, I take notes there so that's one important concept.

The other important part is since I'm administering like, meds and stuff like that, we need to ask questions on meds and any med changes. They aren't always apparent in the discharge list. If we aren't sure I would be the person to call. Well, if I were in the appointment, I could provide that one-on-one, face-to-face to make sure things are right in the first place.

And again, if something happens where Mark can't communicate, he'll need me to scribe, help him voice stuff and be his memory so to speak, to say, OK, these are the meds he's on, have a list compiled wherever possible and have a conversation where also I can understand medical jargon. Mark is like, like I said before, with a lot of people, they talk above his head a lot. So, it's not hard when you have cognitive challenges as well that go along with cerebral palsy.

And so, I think a lot of doctors, nurses make honest mistakes and say, well, we assume a lot. And then they talk to him just like he's just like your average person. And for most case that may be true, but a lot of times they use technical terms, even terms like if I said, hey, Mark, do you know the meaning of the word torpor? I highly doubt he's going to know that. But then they'll also throw medical jargon at me. So that's the thing.

So, services I provide is communication, written charting, accepting written charting. If he needs help personally in the appointment, like help him with his straps on his arm trough, helping him get his zipper out. If he decides to go to the cafeteria, he wants something to eat, we'll get it and I'll feed him.

Stuff like that. Simple stuff that make a huge difference.

Interviewer (off screen):

Did anyone from these clinics or the doctor's office give an explanation or explain?

Lawrence Brown:

Well, they said for the purposes of protecting their patients and infection control, they said they have to do that. And besides, there's nothing, I was told there's nothing that I could do for him that they can't do.

And I said, well, if he needs help, say, with his ostomy in the bathroom, hey, Dr. Khatri's a great guy, but he may not understand how ostomys work or the nurse may not. And that's part of the issue. You know, as I can help him dump bags, dump urine bags, explain stuff of his appliance, explain other things that have come up in other, say doctor Kiechle, his urologist has some plan of treatment. I can discuss this with Dr. Cronsell, his physical medicine rehabilitation doctor. So if they decide to do botox in urology, they can concur with neurology folks.

And so, it really makes things really seamless. So.

Interviewer (off screen):

And I mean during all this is this are you getting frustrated at this point?

Like, can you explain what this might feel like to people that aren't aware of these issues? What is it like to seek this care and not get it?

Lawrence Brown:

I'll be honest with you, no better than me saying now that's not the case, but I'm thinking, why are we here if we can't give good, you know, and they think that they can extract the information from Mark's mind alone in the appointment, you know, if it's not there, it's not there. They need me there to help out. Half the time when they didn’t, they would come to me and said, Mark needs help with such and such.

So, it's very frustrating. It's very like there's tons of barriers up there. And to me, that puts a barrier between him and his good health. And to me, when they talk about long term care and so-called health and safety stuff, I think part of that is comprises making sure we go to doctor's appointments.

What good are we as caregivers if the right hand doesn't know what the left hand is doing? All I'm doing is mechanistically saying, here are your pills, Mark, you know, but without working knowledge and without questions, I can be a lot better of assistance both to Mark and to physicians if I'm there.

One doctor was pretty quick to kick me out because he found my questions a little bit cumbersome. But I'm like, well, I knew they were warranted. And I was trying to advocate for Mark's best interests. On the vans I'm not always the most popular guy on the van sticking up for Mark not being loaded in the back of the van.

So, I go with him as is PCA and the driver wants to load him in the back of the van, and it's hard on his bottom end, let's say it that way. It's healed now. He's got a Roho, yes, but we don't want to start anything else or rekindle anything.

And so, I have been an advocate. And yes, I'm not always made the most popular name socially, but I know it's right because doing the right thing means you’re not always going to be popular. It means not always pleasing everybody. As the old adages say, you can please all of the people some of the time and some of the people all the time, that should be usually sufficient. But sometimes you knock your head against a brick wall, so to speak and you say, well, they won't let me in.

I can't do anything now. So, I'll put an iPhone in Mark's chair, and we'll just press send he'll call me, and I'll answer my phone and say, hey, make sure this doesn't press end so that I can at least have him on speaker. And sometimes that doesn't work. They don't like that either. So, I'm like, well, how am I supposed to participate and be a good caregiver? Part of being a good caregiver is participating in their medical appointments and helping them and doing the right thing at the right time. Otherwise, you know, being a good caregiver isn't just giving him a bath, isn't just saying, here's your lunch, it's doing the right thing all the time, as Vince Lombardi says, you don't do things right some of the time. You do them right all of the time.

And so, when we're not allowed in there, I know COVID's important, it effectively puts a block on us caregivers. And then I'll bet you dollars to donuts if something bad happens to him, well, you know that public people are going to likely be all over that sooner or later and as they should. But you know what? I'll just tell people, well, I wasn't even allowed in this guy's appointment at such and such a time.

I would say there's about four to six distinct appointments where the nurse said we can handle it. I knew they were going to come up against something. One of the nurses finally came out and said, yeah, we need you. I'm like, OK, I'm here to help. It was tempting to say I told you so, but I kind of refrained from that and thought the better of it. I'm here professionally and I'm here to love my neighbor as God has loved me. OK. So, at that point I said, what would Jesus do? And I was respectful, but I did tell people and did voice my concerns in public comment and in different areas. It is not always exactly easy and being a good caregiver means you're not always going to be popular all the time. But hey, not just being a good caregiver, how about just being a great real human being, you know?

Interviewer (off screen):

Do you still experience this ongoing or has there been improvements?

Lawrence Brown:

To a point there's improvements, but there's still much work to be done, you know?

Especially that one time where I was in with this PMnR, physical medicine and rehab doctor and, you know, I was trying to see how I could work a little bit more better with him and Mark. He literally threw me out of the appointment. So, I acknowledged where I may have had a role in it. But you know what? I'd rather air on a little bit not aggressive but pushy side a little bit than say I have to say to myself, maybe you didn't do enough, you know? And so, would I do the same thing over again?

Well, I might try to use a little more tact, but I'd still if I thought it was necessary, I would because it's for his wellbeing. So I don't want to start trouble, but you can't win them all.

Interviewer (off screen):

What would you say to somebody that's in your position but doesn't know what to do?

Lawrence Brown:

I would tell them to speak up. I know my friend, my dear friend Cindy Bentley, she would speak up. And she says, God gave you a mouth. And she's right. And so, I would say to people, speak up don't be afraid to speak out. It's for your good and the good of people around you. And especially if you're a caregiver, people whose life is quite literally in your hands. And God has entrusted me to make sure Mark's life is in good care, good health, and I take that sacred.

And so, whether that means I need help and I ask for it, knock on wood, it hasn't been often but that includes at medical appointments. Speak up, speak out. People can't correct what they don't know about. And if they keep ignoring you, I would say escalate it if it's medically necessary and for their wellbeing, escalate it for sure. We're not dealing with popular opinion here or politics. We're dealing with loved one’s health and safety.

So, while you're not always going to be the most popular dude on the planet, you can do the right thing and you can always choose to do the right thing.

Interviewer (off screen):

What about what would you say to the caregivers that don't quite see that, you know, maybe they're in their mind, they're not doing something wrong. They're following protocol, but what would you say that might help somebody in the caregiving realm realize what's going on?

Lawrence Brown:

I would say for a moment, think clear and pull yourself back. Even meditate and think why we're here. Protocol only is a guideline. It's not something that replaces human intelligence and love and emotion. Nothing can replace that. If everything were by protocol, you could program R2-D2 to be a good caregiver. Instead, use your mind and do the right thing and ask questions where you don't understand. Even ask for protocol exceptions in mitigating circumstances. Don't be afraid to do the right thing just as long, I suppose, as you got your butt covered a little bit. But still, even then, if you're in an emergency, you don't have hours to decide. You have seconds, seconds matter and you have to do the right thing. And that, my friend, only comes with good experience and trust your judgment. So, I guess there is no right and wrong way to be a caregiver.

And no matter what you do, mistakes will happen. Judgments will happen that could have been a little done a little differently just so long as you knew you did the medically best thing and the morally the right thing and loving thing. That's always the right decision.

Interviewer (off screen):

Other folks we talked to are pretty rural, located rurally. What would you say it's like in the greater Milwaukee area? Successes, failures in finding and receiving health care.

Lawrence Brown:

Oh my gosh.

Interviewer (off screen):

Let's remove COVID for a second, in general.

Lawrence Brown:

Yeah. And things are a lot more fast paced in the urban areas as well. So, I mean, you still have to make up your mind like you can in a timely manner. You still have to report things. But yes, you got more resources. Use them, of course. But if you're in rural areas, you still have other folks that can help out and send emergency medical care. Have a list of places and emergency numbers you call and rehearse it in that urban areas, you got more resources, but make some decisions. Oh, what the heck? Our self-defense instructor in taekwondo, in hapkido class, yes, they adapted to people in chairs. They say in a self-defense situation you've already made these decisions in advance, so know what you need to do.

That's part of it. And the urban area is a little different in that you have more options. It can also be confusing. So, to people in the urban areas, it's more important to be prepared as a Boy Scouts model used to say and know just exactly what you want and have a backup and a tertiary backup plan if x, y, z is not available, know who you're next on the call list. A lot of times in urban areas, from what I understand, it's a little bit more simple to a point, but it also is a little bit more desolate.

For those folks it's a little bit more in-depth planning. But here in the urban areas, I don't know if there's any real such thing as in-depth planning where you make a Sony motion pictures production out of it anymore. You have to know and have a lot of backup lists in this area, including be prepared to move forward. You've got options in the urban area. That's what I think from a medical standpoint is way different than if you're in outlying areas.

Also, let's not forget that we have access to more public transportation here and ambulance options and such. People in the rural areas, they may still have Veyo. We've got Veyo here, but we've got other options. So again, put that on your list and have a list of backup. Don't think that you have to just use Veyo. There are other options.

Interviewer (off screen):

Do you have a success story that you received just awesome health care?

Lawrence Brown:

I do. Well, for Mark, he was in the hospital getting what the heck was it? A stone removal from his kidney. Now those things are somewhat invasive. But at West Allis Memorial, they gave us great service, even though the nurses in the unit Mark could pull the cord all the time and it would take forever for a nurse to come. But still, when I talk to them about a pressure relief mattress, they acted on it. Again, I did have to get a little annoying at times, but they did follow through. The one disappointing even thing to that, though, however, caveat was that his pressure sore got a little worse because they may have turned him, but they put the pressure mattress not on the wavery mode, but on the constant inflation mode.

Then again, he may as well just have almost had an Invacare mattress, which is more like Beetle Bailey style. It's a little softer but it's constant pressure. So, what is an alternating pressure mattress? That's something that keeps alternating and distributing the pressure periodically. Doesn't replace turning in bed, but they did an awesome job of trying to turn him.

They really catered to him for food and meals. They really catered to let listen to me and my concerns and Mark and his concerns. So, all in all, that's one of our success stories where now his urinary health is a lot better, his urine is a lot better on the average. Where it used to be, he was plagued for years and years with dark urine and UTI stuff. It's more clear, everything. And because of Dr. Jonathan Kiechle, because of West Allis, his life is much better. You know, I had a good idea that that's what it was, but when radiology told me what kind of four by two by four stone he had, I'm like, oh my God, no wonder he's been suffering UTI off and on a lot. But they really had a two-stage surgery, and they made a success of his urinary health. That's one of our better ones.

Another example is when we got referred to Doctor Niezgoda, Jeffrey Niezgoda at his wound care clinic. Everybody else had a lot less hope for his wounds. This person and me work together and of all the wounds he's had on his body, all but one of them healed up and that one is 90% done.

A lot of hope. And I'm saying to people don't lose hope. You don't have to give up, you don't have to submit, and never to never, ever give up hope.

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.