

GCPD Becky DeBuhr Interview Transcript

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

Becky, Caregiver and Owner/operator of an adult family home.

Total run time: 22:28.

Becky DeBuhr:

My name's Becky DeBuhr and I'm in the Platteville, Wisconsin area, which is the southernmost corner of the state. Grant County is the largest state in Wisconsin or the largest county in Wisconsin, and so we're always enjoying the gently rolling hills where our adult family home is situated.

We have four unrelated adults who live in the home with us and all of their various limitations, so to speak, are due to intellectual delay, physical limitations and things of that nature. Our home has been operated for 13 years and today when I speak about our resident, he was our very first original resident who came to live with us and he still resides at our home.

I spent quite a bit of time and my career working with dementia patients. And as the family was transitioning towards retirement, my parents were transitioning towards retirement. I decided to leave my professional career and memory diagnostic clinic and working with families and caregivers to enter the adult family home work. I'm finding it very rewarding and enjoying every day. Every personality of each resident is very different. We have a lot of fun and we take a lot of trips. And during COVID, we had quite a few medical situations that arised that were perplexing at times. Definitely challenging and unfortunately set at least one of our residents back quite a bit. When he did recover, he did not recover to his full baseline.

And so we still are dealing with that today.

Interviewer (off screen):

I can imagine a lot of stories beyond this story today, but I gotta to ask what brings us here today? Obviously, there is either an incident that was good or an incident that was bad. Can you tell us about that?

Becky DeBuhr:

Sure, the resident that I'll speak about is a male, and he's in his late fifties and he has a very complex medical history. And in our home, we offer health, maintenance and health monitoring, medication management, healthy living style, both for the brain and the body. And these are all of the things that he was requiring from our staff. He did take a fall in January of 2020, which started the cascade of issues for him. Unfortunately, those co-morbidities that are underlying were under control at the time, but due to lack of being able to be seen in the medical setting

during COVID, his physical abilities began to fade and we also moved towards specialty doctors, depression and things of that nature.

Interviewer (off screen):

So, what he didn't have that access to health care because of possibly the rural setting here or were there barriers due to the pandemic that were creating the issues?

Becky DeBuhr:

The barriers were due to the COVID pandemic and just our local hospital not knowing really where to turn or what to do. Our appointment was canceled three times. We were directed to go to the E.R. when I was told this over the phone the medical provider did state that she did not feel comfortable seeing the patient. With all of the changes rapidly happening during COVID and knowing that things were changing almost on a moment-to-moment basis, I didn't know what that appointment might look like.

So as his caregiver, friend, and advocate, I called the E.R. before I took - as we went to the E.R., we sat in the parking lot and I called them and said, he's here and he needs to be seen, medically he's not doing well. And I was told that as a caregiver, I could not enter the facility with him. Due to his intellectual delays, he would not have been able to communicate to the degree that he was physically failing.

I explain this to the E.R. personnel, and they still were adamant that I could not enter the facility. So, at that moment, we hung up and we sat in the parking lot and I asked him, what did you want to do? What should we do? And we decided to do nothing because we didn't know what to do.

So we drove home. And we drove home to think about what are our next steps? Do we have options? How do we secure access to medical expertise during the pandemic?

And we decided to try a different hospital that was nearby, and I called first and explain the situation, and they said to come directly in and as the caregiver you can come with. And so, we got in the car again, which was difficult for the resident, but he knew he needed help. And we entered the hospital. He was seen immediately. And he was admitted to as an inpatient.

So, the first scenario, it took from January, when he had his original fall and did not progress, he did not improve at all and began to fail more in March and in April, and we were not able to be seen until May.

Interviewer (off screen):

And did they give you a reason? Just the pandemic sorry? Or did they try to explain it?

Becky DeBuhr:

The second hospital that did take us in and saw our resident and talked with him talked with me. They were very upbeat. They reassured us that they could help and do something about the multiple things at this point over the course of four months of what had happened physically with his what had happened with him over those four months, they could help us. So, we were lucky

to meet his new, or now primary care physician who came to me in the waiting room and said that he understood all of the diagnoses that the person had, our resident had, and that he could help. And his reassurances, his smile was all we needed to hear at that moment.

So, in May and June and July, we were six to ten office visits and lab appointments per month. We had home health visits from the nurse. We had specialty appointments where they talked to us about hospice for the patient, for the person or the patient in July. We kept plugging along and caring for the patient as aggressively as we could, and I was thankful for that aggressive treatment for him because come September, we had finally plateaued back to, you know, more stable and we were talking about stabilizing those illnesses that he had, and things were looking much better for him.

Interviewer (off screen):

Can you talk about how that felt kind of feeling like you were up against a wall and what do you do? How do you get health care and importantly, how the patient felt? I mean, how did that affect his mindset?

Becky DeBuhr:

The most I would express my emotions as fearful; I didn't know what to expect. I was learning about the pandemic along with everyone else and the things that we needed to do. I had a resident who was at a very high risk of doing very poorly if he contracted COVID. So our precautions were in place, we're doing everything that we could. I was disappointed in medical providers that turned their cheek, so to speak, and that didn't reach out to help.

Ultimately, where we ended up is where we needed to be, and we continue to stay with that medical facility, and we have a very close relationship with his new primary physician.

And I think the pandemic really for people who have limitations, be it intellectual or physical, cognitive, the access to medical care is difficult, but I think that it heightened it even more during the pandemic.

The first hospital we went to was the hospital he had a primary physician with for ten years, so his history was there and I felt that they should have known him well. And so that was quite disappointing for us. The fact that the patient progressed to depression and medication changes didn't seem to help that, really speaks to how difficult it was for him. As caregivers, we were doing everything that we could do and our new medical providers were right by our side, but we needed his help and we needed his positivity and energy to come back so that he could recover.

Interviewer (off screen):

So, it sounds like it took just so much longer to get to a positive outcome here. What should have been done right away? What could have avoided all of this?

Becky DeBuhr:

Well, what should have been done right away was to be seen in that E.R. in the first hospital. He did not have symptoms of COVID at that time. His symptoms were simply related to the multitude of diagnoses that he had. So, they were things that we had managed in the past and we could have continue to manage despite the COVID pandemic.

So even though COVID was high on everyone's radar, that's not what we were calling about. And that's not the expertise that we were looking for in that moment. We would have been happy to be screened for it, tested for it. We had no, you know, we did not reject that or would not have rejected that because we knew the medical care that he needed.

Not being seen and canceled appointments just started a whole cascade of appointments and additional medical issues that we could have avoided. So even though he did plateau in September, and we were waiting to see would he continued to stay there in October and he did in November, he did.

However, on Thanksgiving Day, him and I were in the kitchen preparing our pumpkin pie for Thanksgiving, and he was telling me he wanted cool whip and not ice cream only to have him collapse to the floor. And so we started a whole new series of appointments and what to do now. We took him in immediately to the E.R. and he had fractured a hip just standing there.

So, this tells you how fragile this patient was and the care that our home provided to him was of high, exceptional quality, but even a collapse we didn't see coming. So during that E.R. appointment, he again was hospitalized with a fractured hip.

He tested positive for COVID, even though he was asymptomatic, and he remained asymptomatic his entire time that he was hospitalized. We're lucky that he was strong enough from September to November, that he was able to withstand the surgery, withstand COVID and came out with a new hip.

And unfortunately, then his recovery was delayed because there was no one in Wisconsin who would accept him. He was COVID positive, but he needs to recover. So, when the social worker called us from that hospital, we said, of course he can come home, you know, bring our bring our resident back home and we continued to care for him.

Interviewer (off screen):

So, what would you say to maybe about the hospital that did take the patient and was helpful? And also, what would you maybe say about places that aren't doing that? How can they be making this better for everyone?

Becky DeBuhr:

Right.

His current primary care team did an outstanding job, and I commend them for being by our side. It continues to be emotional. He is back home. We did in-home physical therapy because they

were able to set that up for us. They did not deny any appointments based on his disability or his intellectual delay or COVID. They simply showed up every day and he did physical therapy in the home. He did physical therapy as an outpatient, which gained so much independence for him to be able to, even though he uses a walker now, walk into that hospital and see people he knows who are cheering for him and who helped him get better.

So, for them, we're very thankful. His final appointment was in March, so we went from January 2020 to March of 2021, before he no longer had to go for multiple office visits every month. He no longer had to have multiple lab visits every month.

He was released to go back to his work center and resume the life that he wanted, things that he needed to do. And as his primary care physicians said to him, I admire your enthusiasm. I will sign your work release and you are free to go back to be with your friends and to go back to your job.

And so, even today, he did not fully recover to prior to the fall. But he is independent again and he is smiling and laughing. And we continue to monitor his health at our adult family home. We were happy during those very difficult times to have his family rally with window visits and card showers and all of the things that boosted his spirit during the COVID pandemic.

So, with all of the things that we continue to care for him when he was more ill to when he is now better. He is family to us and he remains at our home. He's doing very well, and it is that partnership. It's the team who brought that together. It was everyone taking their piece and running with it and making him being, whether you were a cheerleader or, you know, you were giving some test result, everything was now improving.

And so, his mood improved. Just overall, he's doing very well.

Interviewer (off screen):

This probably isn't your only instance that maybe didn't go so good. Is there anything else with health care that you've noticed that there are barriers that you weren't able to access beyond just being seen?

Becky DeBuhr:

I would say during the COVID pandemic, it was more interactions that were of the electronic nature. Using email, using the phone, calling in, trying to discern without seeing the patient because we didn't want to put them at further risk for contracting the virus, but it was determining what is the next step? What are the options? And I commend those hospitals and clinics who went the extra mile. They're doing the telemedicine has been a savior for our people who live in our home because they're not as easily able to get out at times when they're not doing as well.

And so, where it has opened other ways that we can communicate, we can see people through the lens of a camera or a cell phone or a laptop. And even though it was very foreign, it was something we all needed to do. And for some of our residents, we still do those things because it

ended up in the end to work better for them. And they still smile and they still laugh and they communicate through whatever means necessary because that provider has made the extra effort to know their patient. And so that makes all the difference.

Interviewer (off screen):

Now that you're on the other side of this, what would you tell yourself you know, a year ago? Going into this, what have you learned now that you wish you knew then?

Becky DeBuhr:

Being an advocate for people with intellectual delay or a physical limitation, it's really finding that provider that you click with, the person clicks with that they get them, they understand them. And that provider is the provider who gets down on their eye level and talks to them. I'm simply there to give extra detail if it's needed or a reminder of something that they wanted to tell them, because we do prepare for those visits. And we're so actively involved in their life and how they're doing on a day-to-day basis that it's so important that we are there advocating for the most high-quality care that they can receive, like we would want everyone to receive. So, it is giving the medical treatment on the same scale as it is for everyone else, those who don't have a disability.

We've learned how to communicate more effectively. I think that's a positive outcome of COVID. We've seen the stress that it's had on everyone, and I think that we're giving more grace at times when things aren't maybe it's quickly happening as they once were or the bottlenecks that have occurred because COVID is taking a main stage.

So, I think those are all positive things, things that we can all do to help the situation that we're all in.

Interviewer (off screen):

And what we heard from another person that we talked to that it's important for other caregivers or people with disabilities to know their rights, know what health care you are entitled to because we are all entitled to it. What other advice might you have for other caregivers or a person with a disability that is out there struggling?

Becky DeBuhr:

I would encourage other caregivers to connect with each other. It's sometimes a very lonely job. It's you and the resident are you and the patient, depending on how they're how well they're doing at that moment. And it is day in and day out with staffing shortages that affect all sectors of health care, including adult family homes. It's important to have that network of other caregivers that you can ask questions, ask how a provider may be with someone with a physical disability or an intellectual disability. Sometimes those recommendations can set us on a whole new course or open a pathway that we didn't know was there.

So having those conversations reaching out and connecting with others who are doing similar work to you has been very valuable for me.

Interviewer (off screen):

OK.

Is there anything else that you'd like to share that we maybe didn't touch on involving your experience or advice you might want to give?

Becky DeBuhr:

I think that the COVID pandemic has really set a light on looking at persons with a disability or an intellectual delay. We know they have trouble accessing health care in general, whether it is the facility itself, it is getting the recommendations or the referrals, it's having an advocate. Not everyone does. So perhaps it has opened the door for us to look at that even further if we have made mistakes, it is going back as a team or facility to say how can we help this? How can we change it, make it better and including the people with the limitations at the table so that they can give their input, they can explain where they're coming from and what barriers they are having. It doesn't get more honest than that than to just ask that person.

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.