

Episode 9 - Beyond the Diagnosis with Cat Hafsi

Caitlin Owens: Hello and welcome to Disability Exchange, a podcast produced and presented by the University Center for Excellence in Developmental Disabilities, Iowa's UCEDD at the Center for Disabilities and Development. My name is Caitlin Owens and my co-host today is.

Mike Hoenig: Mike Hoenig. I have the pleasure of working with Caitlin at the University of Iowa, at the Center for Disabilities and Development, our UCEDD or Center for Excellence in Developmental Disabilities. We're really excited today to have, have Cathy or Cat Hafsi, so we'll start out, Cat, by asking you which you prefer. Are you Cat or are you Cathy today?

Cat Hafsi: I'm always Cat.

Mike Hoenig: You're always Cat. All right. I have known Cat for a long time, primarily through her assistance with some health provider trainings that we do through the UCEDD. Maybe we'll actually have a chance to get into that topic a little bit. Over the years, Cathy and I, we have some friends in common, we've done some advocacy in common. So, I knew that she would be an awesome guest for Disability Exchange and I think we'll all learn a lot from her. Cat, welcome. Why don't you go ahead and introduce yourself and tell us a little bit about who you are?

Cat Hafsi: Hi, my name is Cat Hafsi and I live in Cedar Rapids, Iowa, after living quite a few years in Los Angeles, California. I have two lovely daughters and I have one grandson. My diagnosis may be changing, but I've grown up with a diagnosis of having cerebral palsy. It probably will change to hereditary spastic paraplegia.

Mike Hoenig: It's fascinating to me, because I've always known, obviously, that I was blind. But, up until about, I don't know, maybe 15 years ago, I thought it was due to an optic nerve condition and then learned that it was a retinal condition. Not that it really changed my functioning at all, but just to know the cause of it and the hundreds of people that I'd probably told it was an optic nerve issue, I was wrong. So, if you're comfortable doing so, Cat, tell us a little bit about how this possible change in diagnosis has impacted you so far and how you think it may change just the way you cope and everything going forward.

Cat Hafsi: I think the biggest change has been, I've always been told that CP is static, that nothing will change, except the secondary conditions like arthritis and things like that. HSP, as it's known, is a progressive disability. How far it will progress, I am not sure. So, at some point I was told that I could probably look forward to losing the ability to ambulate. That's a big blow to me, because I'm pretty fiercely independent.

Caitlin Owens: Oh, yeah. That is really big news. Must be difficult.

Cat Hafsi: It also holds ramifications for my children, if they want to have more children. It's something to think about and to be tested for and to just watch for.

Mike Hoenig: So, I guess on the one hand, it's good that you're aware of it, but it's just knowing that the prognosis has been a challenge for you, then?

Cat Hafsi: That is correct. When I tell people that my diagnosis has changed, it's like after I'm dating myself, after 55 years of being told that I have CP, cerebral palsy. Then now, all of a sudden, I don't, it's interesting. So, I'm still in process of learning about HSP and how it works and how it doesn't work. Things that I should look for and keep in the back of my mind.

Caitlin Owens: I'd imagine, in addition to just sort of taking in the news about what the new diagnosis might mean, also, it sounds like just an identity shift. I mean, after having identified one way for so long, it's this whole new way of understanding your experiences.

Cat Hafsi: Correct. I'm still getting used to saying I have HSP instead of cerebral palsy. It's interesting, that my travel through this is still ongoing, but I think the more information I learn, the more I have, I will have the ability to make choices and just tilt my life a little bit.

Mike Hoenig: Well, and knowing you, I know that you are fiercely independent and a strong advocate. Will do everything that you can, as you already are, to learn about and then adjust to your situation.

Cat Hafsi: Yes, I've already been in touch with some people that have HSP and the HSP Foundation. They're helping me navigate the changes.

Caitlin Owens: Well, Cat, you mentioned that you have two daughters and a grandson. I'm wondering, could you talk a little bit about your experience of being a parent with a disability?

Cat Hafsi: Not only am I a parent with a disability, I also have a daughter with a disability. With my diagnosis change, I'm pretty sure that her diagnosis will also change. Because she was diagnosed with cerebral palsy when she was about a year, maybe 18-months-old and she doesn't handle change well. So, it's going to be a bit of a struggle.

As far as being a parent, my children's deliveries were fine. I definitely did not have any problem in that respect. When I was pregnant with my second daughter, I was just getting my first daughter into her early education program and her IPPs and physical therapy and occupational therapy. I didn't sleep very much, but we got through it and she's doing well. She's a university graduate.

My youngest daughter hasn't had any problems so far, but with HSP, it's pretty rare for the symptoms to show up as a child. It can develop later in life, so hopefully it doesn't, but she's well aware that she needs to be on the lookout for different things that would indicate that she might have some difficulties.

Mike Hoenig: If she's going to have it, she's got an awesome parent to support her. I wanted to go back a little bit, too. Full disclosure to our audience, Cat and I have shared some pretty interesting experience through the health provider training initiative. But, one of the things, Cat, that I know about you, is that there were some healthcare professionals along the way that even doubted or questioned. Or, maybe even that's too light of a phrase. Whether you should be a parent. Would you be comfortable talking about that, sharing with our audience?

Cat Hafsi: Sure. When I was early in my pregnancy with my oldest daughter, I went to the ER, because I thought she was food poisoning, but she wasn't, obviously. So, they did a CBC and the lab technician came into the exam room and he said, "By the way, did you know you're pregnant?" I almost fell off the table.

The first thing I thought was, "My mother's going to kill me. Thank god I'm 2000 miles away." But, the ER doctor came in and she was so clearly agitated. She just wondered aloud how I could be a parent with, the word that she used was handicapped. Then, she strongly suggested that I be admitted to the hospital that night and they would perform the abortion in the morning.

I was stunned that I was pregnant. Then, it's like I'm not the only person involved here, so I need to talk to the child's father. It's like, "I'm out of here." I left and 33 years later, my daughter is thriving and so am I. We're doing well.

Caitlin Owens: Wow. I mean, I almost don't have words to process that. I mean, that's such a bias-laden.

Cat Hafsi: I was thinking, "Is this 1987 or is this 1955?" I'm like, "Wow."

Caitlin Owens: Yeah. Well, I'm sorry to hear that. It sounds like everything turned out really wonderfully. But, that's certainly not the first time I've heard a story like that. I hope things have changed since 1987, but I do know that it's still a commonly-held belief that people with disabilities or certain disabilities are [inaudible 00:11:13]

Cat Hafsi: Correct. There is still that bias. I had a neurologist in Los Angeles who, right from the minute she saw me in her exam room, she asked me how I got to the appointment. She just rattled off, "Did your parents bring you? Did you ride the bus, take a cab or use [inaudible 00:00:11:38] transit?" I said, "No, my car is in the parking lot." "Oh, you drove?" She was shocked that I was married, that I had kids, that I was educated. She was even surprised that I cleaned my own house. It was just like, "Can I be done now?"

Mike Hoenig: We just finished up a seminar Caitlin and I were fortunate to attend, where the whole topic was implicit bias. You have given two amazing examples, that sadly, it's still among us. That people, they don't even necessarily realize how insulting those remarks are and dehumanizing.

Caitlin Owens: It affects the quality of care that, I mean, it certainly, if a doctor of mine said something like that to me, I would have a hard time trusting the recommendations they made. Or, it really disrupts the trust that you want to have with a healthcare provider.

Cat Hafsi: I did not see her again. I asked my primary physician and to help me find another neurologist within the Cedars Sinai system, but I was like, "I am not going back to her. I'm done." It's like, "Oh, my gosh." That was in 2010, so that was not that long ago. I'm like, "Oh, my gosh." It's amazing what people think that we don't do or can't do.

Caitlin Owens: Right. That model of starting with the deficit instead of looking at a person and starting with what they do and what their strengths are.

Cat Hafsi: Very much so.

Mike Hoenig: One of the things, Cat, that I have always admired about you, from the time that I've known some of these stories, is how you've taken these experiences and used them to educate other people. As I mentioned at the top of our podcast, I first got to know Cat through the health provider training program, which we do with the College of Medicine.

It's an opportunity for individuals with disabilities and family members to talk directly with second and third-year medical students on some of their experiences with the healthcare system. In the hopes of really educating them, from a first-person perspective. Would you care to comment on just how that experience has been for you, working with the students? Any particular things that have stood out in some of those interactions or even in our debriefing sessions afterward?

Cat Hafsi: I love doing them and I'm grateful that I can participate and help the medical students look beyond the diagnosis. Because, with my CP diagnosis, there's such a wide variety of CP that, if you've seen one person with CP, you've only seen one person with that, because we're all different. I'd like to take that opportunity to show the students how bias can be fairly detrimental. That you should go in and listen to the patient and really work with the patient.

I also try to instill the idea that, when they're working with families that have a newly-diagnosed child, that it's important to check on the family and see how they're doing. To see if they need any supports or any services that could be helpful to them. Because a lot of new parents are expecting wonderful, healthy children and that may not be the case. Some parents have a difficult time in accepting that and it can be, really, a tragic situation.

Mike Hoenig: I think it's cool when you remind them to do that. For those of you out there listening, at the end of our sessions, we come back together and we do a debriefing with the students, after they've had a chance to visit with the volunteer patients. That's one thing that, Cat, you're very consistent about sharing. I always find it particularly powerful, because you play so many different roles and you are a person with a disability. It could very be very easy.

Some of us who aren't fortunate to be parents and haven't experienced that. First one I've heard, when I heard parents talking about that and saying, "Oh, my gosh, we have needs too and this is a change for us." That sort of thing, I didn't know how to take that. But, when it come from somebody who has a disability and is also a family member, that brings a whole new perspective on it. So, I'm always moved when you share that advice.

Cat Hafsi: When I heard the diagnosis, I'm like, "Yeah, I've got this." But, it was a little more difficult for other family members. I had to tread lightly, but it's helpful if the healthcare provider is aware. Just ask the parents, "How are you doing? How are you coping? Do you need extra supports or counseling or anything like that?"

Caitlin Owens: Yeah, that's, I think, an important reminder, especially for folks who are so immersed in the more medical side of things, to remember to take a step back. Look at the whole family system and the whole person. While they might not be the one to make those recommendations, they can still connect them with a social worker or somebody who can-

Cat Hafsi: Correct.

Caitlin Owens: Provide more support.

Cat Hafsi: The parents may not even know how to access those other supports. So, with the medical team, I'm sure if they have three or four people working on it, they can find appropriate support.

Mike Hoenig: Speaking of supports, Cat, one of the things that I wanted to make sure that we covered today was that you you've been very open about having your disability since birth. When Caitlin introduced us at the beginning and kicked us off, she talked about being Iowa's University Center for Excellence in Developmental Disabilities.

Our program is called the UCCED and we're housed in the Center for Disabilities and Development, which hosts of variety of other programs besides the UCCED. But, once upon a time, it was a residential program. It was, back in the day, called University Hospital School. I know, again, from having worked with you in the past, that you lived here for a time and were educated here for time.

I'm a person that loves history and how things circle around. I just think it's fun that we're talking to you today from the very building and area where, at one time, you were a student. I'm wondering if you'd be up for sharing a bit about your experience at what was then Hospital School.

Cat Hafsi: I was there, not for long periods time. I think the longest I was there was for two months. When I was three, I was there for quite a few months, because I was learning how to walk. So, I stayed at the Hospital School. Before I went to kindergarten, I stayed there off and on, but there were definitely kids that lived there 24/7. I was fortunate enough to be able to go home.

It was an interesting time. We all had disabilities, of course. But, it was a camaraderie kind of thing. When you find someone else that went to Hospital School, it's like, "Oh, yeah. Do you remember this or that?" Or, "I swear, they're the ones who caused my sweet tooth." But, our snacks were woefully under-nutritious.

Caitlin Owens: Were they at least delicious?

Cat Hafsi: They were okay.

Caitlin Owens: Okay.

Cat Hafsi: In fact, I have a picture of me in the room where the entrance is right now. It was a nursing station at one time.

Mike Hoenig: Really?

Cat Hafsi: Yes. Across the hall, there's a big room. It was a big room, at one time. That's where I stayed at one point. There was a long table and we were eating our snacks of donut holes. No bananas in sight. Their go-to was donut holes and graham crackers with frosting in the middle.

Mike Hoenig: Wow.

Cat Hafsi: Yeah. I'm sure that would not happen today, but-

Mike Hoenig: Of course.

Caitlin Owens: Probably not.

Cat Hafsi: When I stayed there for two summers, I think for six weeks, we would go to a program at Lake Macbride. We would ride our buses and go out to Lake Macbride. The first summer we studied Indians. Amazingly enough, I still have my wampum belt that I made when I was in second grade, third grade.

Mike Hoenig: Wow.

Cat Hafsi: The second summer I stayed there, we studied the pioneers. They took us into the abandoned cabins, which probably wasn't too safe. But, yeah, it was a fun summer. Every Saturday, we would go to Sycamore Mall and our parents would deposit so much money in an account for the weekend trips to Ben Franklin. I still remember that. Every week, I would buy my Barbie doll a new outfit. It was funny.

So, there were definitely good times. I was not a particularly adventurous eater, so that got me in trouble, a little bit, because I wouldn't eat my vegetables and I just wouldn't eat this and that. There were definitely good times. There was a program for the people that stayed there, to be an Independent Traveler, to be able to travel from room to room or whatever. I talked too much, I could never make my time, ever. Was never an Independent Traveler. It's like, "Aww."

Caitlin Owens: Talked too much? They would time how long it would take you to get from point A to point B and you just stopped and talked too long?

Cat Hafsi: Occasionally I talk to people who have been patients there. "Oh, yeah, I was an Independent Traveler." It's like, "Shut up. I could never make that."

Caitlin Owens: I probably would have had the same problem.

Mike Hoenig: I find it a little bit ironic, though. I wonder how many others of your peers ended up in California. Speaking of traveling and living there.

Cat Hafsi: Oh, I don't know. I honestly would love to do some kind of a reunion. If I could somehow do that, that would be so cool.

Caitlin Owens: Yeah, that would be interesting. I'm sure CED would be interested and be involved in that if there was interest. I think one thing I find really interesting, and that was so interesting for me to hear about, because I just really don't actually know a lot about the history of the Hospital School.

But, one thing I've always thought is really interesting about our building is how it's really, and the programs within it, of course, but have really followed the path of the disability rights movement. From a residential place, to morphing over time to then be, probably, doing part inpatient and part outpatient. To fully outpatient, and even actively working to keep people in the community. That kind of thing.

Cat Hafsi: I was surprised. When I took my informal tour, especially on, well, what would've been in the basement, where the hearing booth is, and that's where PT was. I walked down the halls and I'm like, "Oh, my gosh. They still have the pink tile." It's like, "That hasn't changed." But, I walked down the halls, especially on the third floor. It's like, "Okay, I know what this room was, this room was." It was pretty neat to do that.

Caitlin Owens: Well, if you're ever down here, I would love to walk through the building with you. I'm always just so curious. I'm like, "I mean, where do people sleep here?"

Cat Hafsi: Right across from the nurses station.

Caitlin Owens: Oh right. Where you were saying that big room, was it bunk style, or, I guess, more patient curtain kind of thing?

Cat Hafsi: No curtains, just beds.

Caitlin Owens: Okay.

Cat Hafsi: Beds. The room right next to it was, I think, three rooms where we slept. Dorms, they would be called.

Caitlin Owens: Sure, sure.

Cat Hafsi: Yeah, it's fun.

Mike Hoenig: Yeah. I attended residential school for 11 years as well. This is bringing back all kinds of. I was a full-time student. My parents lived three hours away, so there wasn't a lot of choice in the matter. Just to clarify, you would attend classes, but then you would also be getting therapy and so forth, while you were here, is that right?

Cat Hafsi: Correct. I actually learned how to type in third grade, during the summer at Hospital School. That was one of the things.

Caitlin Owens: Well, I'm wondering, as we're nearing the end of our time, if there's anything we haven't asked about that you want to talk about, or?

Cat Hafsi: No, I think that everything that was on my agenda, we spoke about. If you guys have any questions, I'll be happy to answer them.

Mike Hoenig: I get to put you on the spot this time. Sometimes, Caitlin does a great job of asking this question, but I get to today.

Caitlin Owens: You'll do a great job too.

Mike Hoenig: This could get at the one on topic that we didn't talk about a whole lot, but Cat, if you could leave one legacy behind. I know you've got a lot of living yet to do, but if we could just say, let's

just pretend that you're retiring. We said, "Cat, what legacy would you like to leave behind?" What would that be?

Cat Hafsi: Hmm. I would hope that people would say that I was a good advocate. That I taught others how to be their own best self-advocates as well. If she saw a issue, she let people know. I do that quite regularly. I hope I have many more years to be active. I've also had a great mentor, so I had to give her a practice [inaudible 00:30:30]

Mike Hoenig: Yes you did. Yep. Well, Cat, I just want to thank you for joining us today. For taking time out of your day. It's really been a pleasure talking to you. Even though I feel like I know you pretty well, I learned some new things about you today. Thank you so much for sharing your thoughts and your memories and your ideas.

Caitlin Owens: Yes, thank you so much. It was very nice getting to hear your story and meet you.

Cat Hafsi: Well, when I'm in the area, I'll come and show you where I blew out the electricity.

Caitlin Owens: Yeah, let us know. Keep us posted on the reunion too.

Mike Hoenig: Maybe it'll be the subject of a future podcast.

Caitlin Owens: There we go.

Cat Hafsi: Thank you very much for inviting me to participate in this podcast.

Caitlin Owens: Yes, thank you.

Cat Hafsi: Been awesome.

Caitlin Owens: Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for

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