

Episode 11 – Parents of Children with Special Needs and a Fight for Diagnosis with Catherine Hahn.

Caitlin Owens: Welcome to "Disability Exchange," a podcast brought to you from the University Center for Excellence in Developmental Disabilities. My name is Caitlin Owens, and I'm here today with my cohost, Judy Warth. Judy, you wanna say hi?

Judy Warth: Good afternoon.

Caitlin Owens: Judy, I'll let you introduce our guest, so take it away.

Judy Warth: You know, I got to meet Cath Hahn on a couple of different projects, and Cath tells such a powerful story of her son, Jeff. And when I was telling somebody about this podcast, I said I'm so excited for Cath to be able to share this story, because your story's powerful and painful, yet simultaneously, you show the power of families who listen to the voices of their children and are willing to help all of us grow and learn. And so we really appreciate you coming and sharing the legacy that you and Jeffrey bring to us and to the system. So welcome.

Cath Hahn: Thank you very much for having me.

Caitlin Owens: Yeah, thanks for being here. Cath, do you wanna just start out by telling us a little bit about yourself?

Cath Hahn: Sure, my name is Cath, actually, Catherine Hahn, if you look at me professionally. I am a parent of a young man, as Judy said, Jeffrey, who we lost in September of 2020 after a difficult medical year. A very difficult medical year, not only from the standpoint that his health was not good, but trying to get coordination among medical people, and just the whole idea of COVID, and being seen as his parent but not as his medical advocate, and not being allowed to be there when I needed to be. So it was a really difficult year. He came into our lives in 1987. We were first-time parents, and we think he had a reaction to his Pertussis shot at that point in time, which started us on a journey, we started for very many, many, many years, obviously. He was 32 when he passed away. In the meantime, Jeff became not only my child and a reason for me to advocate for people with disabilities, but also a reason for me to change work professions. So when he was five, I put myself back in PT school at the University of Iowa. And I was actually in either, I think, your first or second I-LEND training class when I was there. And I went on to become a pediatric physical therapist, and have worked with the Mississippi Bend AEA 9 for the last 25 years, actually, since then. So I consider myself not only a parent of a young man with a disability, you know, our family is obviously a family of a young man with a disability, but also as a professional advocate not only for Jeff, but for the families that I serve and the school districts that I

serve, as well as a community advocate in the sense that I chose to get involved in different advocacy things. I now currently sit on the CPAC Committee over at the university, as well as the TRAC Health Grant Committee I sat on as well. But locally, I've been involved in our county's CPC, when we still had CPCs, long before Medicaid Managed Care came in. And just every opportunity, sat on the Eastern Iowa Regional Board for awhile, which was more mental health and mental illness than developmental disabilities, but certainly a very interesting process. And so have, all along, tried to just be an advocate on all levels that I can.

Judy Warth: You threw a lotta stuff at us.

Cath Hahn: There you go; that's me.

Judy Warth: You mentioned you were a trainee with the LEND Program, which is a program here at the Center for Disabilities and Development. It's Iowa's Leadership and Education in Neural Developmental and Related Disabilities. It's a graduate-level program that is designed to develop leaders, and clearly, it was successful in the work that you do. And then you mentioned CPAC. What is that?

Cath Hahn: Well, isn't that a consumer, it's a consumer-

Caitlin Owens: Community Partnership Advisory Committee.

Cath Hahn: Yeah, I get involved in acronyms and then forget what the words actually mean.

Caitlin Owens: Yes, I know, yes. And that is an advisory group that helps advise where Judy and I work at the University Center for Excellence and Developmental Disabilities. And we really appreciate all of your contributions to that group. And then I think you also mentioned being involved with the TRAC Grant.

Cath Hahn: Um-hum.

Caitlin Owens: And Judy, help me with that acronym.

Judy Warth: Well, that's-

Cath Hahn: Transition Resources Accessing Health Care, isn't it?

Caitlin Owens: Yep, there we go, and that's-

Cath Hahn: That's the one I remember; it was the last one.

Caitlin Owens: Right.

Judy Warth: Well, and the exciting news, Cath, if you haven't heard, is we did get funded for the ON-TRAC, which is Phase Two.

Cath Hahn: Yay, very nice.

Judy Warth: The TRAC grant was a grant that was designed to do some exploration of what were the needs for young adults with intellectual and developmental disabilities, as they move to adult care. What are some of the health care needs for providers to learn about; how do we develop self-advocacy? And we were just last week notified that we were awarded Phase Two, where we're gonna begin to implement some of that planning.

Cath Hahn: Thumbs up on that one. That's great; definitely needed. It's a very different world from when your child, who has a disability, is a child, to when the child with a disability becomes an adult, particularly when they're multiply involved and severely involved. The whole world changes.

Caitlin Owens: Yeah, can you talk more about that experience?

Cath Hahn: Well, I think, honestly, you guys, what happens is, is that there is some coordination or attempt to be coordination when you're as a child coming up to the university and the CDD. And it seems like those doctors talk to us, when Jeff transitioned, I mean, and actually he didn't transition off being some of his pediatric providers until well into his almost-late-20s, but when the decision was made, it's been a disaster on the road ever since. Departments don't talk to each other. They do not, I don't know how to say this politely, they didn't buy into my expertise as his parent and truly his medical advocate, who had been his medical advocate for the last 32 years. And we just had a difficult time getting people to respond to us. And I couldn't, I don't know. It wasn't even just the last year; it was everything. It was trying to get answers from GI. It was trying to get answers from, even the transition

process of trying to go from his pediatric GI to the adult GI system was a total disaster, as far as scheduling appointments, as far as having them understand that we've done something successfully for 20 years, and the new docs don't like what we have done for the last 20 years, and we have to try something new. But what we had had was being successful, and I didn't really feel we needed to change, and no one left around to be able to address those issues. So that and just neurology, and I mean, in orthopedics, nobody, in and of by themselves, they were probably all okay. But the problem is when things got really complicated with Jeff and having a medical background myself, I started trying to put pieces together, and I was coming down a road that I thought was appropriate, but I was kind of being blown off by each of the individual disciplines, and which is after the last hospital, or the hospital stay in April and May, which had been a kind of a really total disaster. I wish I'd reached out and wrote an eight-page letter back to them saying, "This is why everything is wrong." Judy, you reached out to me with Pixie's name, and through her assistance, we were able to really not be on the path that I wanted to be on, but certainly gave me a chance to help better understand, and for the first time, have someone tell me I'm not off my rocker, basically, you know. So I really felt that, I think two problems exist when you get into health care with adults who have really severe disabilities, is first of all, they can't advocate for themselves. And secondly, the system sees them as adults and doesn't see them as someone in need of an advocate to be there, but yet they can't make decisions. I mean, we learned so many things during that last year that Jeff was alive that I had no awareness of, that I probably should have had awareness of, just things like when we had a guardianship on him since he was 18. But when he was in the hospital in April and May, and we felt he was doing really poor, we wanted to switch his status from code to basically being DNR, only to be told we couldn't.

Caitlin Owens: Wow.

Cath Hahn: Yeah, we were told we couldn't, because apparently, Iowa changed the rules, and now in order, that has to be written specifically in your guardianship papers for DNR and end-of-life care. So then I asked to speak to Palliative Care, because I knew we were not on a good path, and was told that we didn't have a DNR, so we couldn't. So it was really just very difficult at times to, and I probably didn't help myself. And some of the one floor we kept getting kicked off of was probably because I was a little concerned why they, and probably more concerned than they wanted me to be. So their answer was just to not allow me back the rest of the time.

Judy Warth: You know, Cath, can you introduce us to Jeff? Can you tell us about-

Cath Hahn: Who he is?

Judy Warth: This young man, yeah. Tell us about him.

Cath Hahn: Jeff was a great kid, and he leaves his own legacy as we go forward. Jeff was born to us in 1987. Right after he'd had his six months', or just short of his six-month DPT shot, we brought home a screaming baby that we couldn't get consoled for three days, and then he started having seizures. Now, he was ultimately diagnosed with infantile spasms, from a medical standpoint, which is a seizure disorder that evolved into Lennox-Gastaut. But the correlation was kind of, we were not sure what actually happened, you know? And for awhile, we kept trying, medically, we were all over the place. We started at the University of Iowa, and we ended up down at St. Louis Children's Hospitals for many years, and I will tell you the difference. Iowa City, at that point in time, when Jeff was just 18 months old, told us that he wasn't gonna do anything; just take him home and be happy, and he probably wouldn't live to see five. You know, we took him down to St. Louis to Children's Hospital to start ACTH, which wasn't being used at the University, at that time, of Iowa. And the doc there said, "I don't know what he'll do," he said, "but we'll do the best that we can." And so for the next, until Jeff was a junior in middle school, we went down to St. Louis Children's Hospital on a regular basis. We were involved in many different drug trials. So, unfortunately, Jeff's seizures never got controlled, and he just, we've been through pretty much every drug known to mankind and then some others. And we went through phases where we took him off and put him on. But Jeff as a person, he was fun. And we learned a whole lot more when he had a sister. When he was about eight years old, his sister came along, and, oh boy, we found out a lot about Jeff that we didn't know, or that we were taking for granted, because Jeff doesn't have any verbal speech. He has lots of nonverbal speech, but he has lots of intentional behaviors, which we did not realize until his little sister came along. And then one of the funniest stories, I think is still funny, is that when I came home one time from Frank and I being out, the lady we had watching both kids, said, "Your kids had a fight." And I'm thinking, Jeff has no motor abilities other than the independently role, and Cara was less than two years old. And I said, "Well, how did they have a fight?" She said, "Well, Cara wanted the pillow Jeff was laying on, so she went to pull it out from underneath him, and he rolled to the side and swiped at her. And then she went around the back, trying to do the same thing, and he anchored his head. And then she went to the other side, and he tried to do the same thing again. So he really, at that time, we really began to know what he could. And education for Jeff was really interesting, too, because school systems really don't know, even to this day, what to do with our multiply-involved kids. All these guys have really scattered skills. Receptively, we still feel, and I will always feel, that Jeff understood much, much, much of what was said to him with no way to be able to really effectively tell us what it is he wanted to say. So we went through many challenges with Jeff along education, too. And so Jeff did and did not like school; it depends on who he was with. And I mean, he had his preferences, just like you and I have our preferences. He had people he liked and he had people he definitely did not like. And we were able to tell that relatively easily as time went by. But, you know, as we journey through and we're going through that whole school process, I actually, I don't know if you know this, Judy, but I actually took him with me on my clinical out to Omaha Children's Hospital to Meyer's Rehab out there. Because they were doing, at that time, Omaha was one of the big leaders in assistive technology for kids who had multiple disabilities. So we took him out there with us, and then came home and said, "Guess what, guys?" You know, and I think it's interesting, unless you were around him and knew him, you would just write him off as not knowing anything. But people who knew him really have great stories to talk about how he receptively understands. I mean, when we were out in Omaha, one of the big moments was the teacher who had him, she had him in class for awhile, and then she asked me to come in. And how he behaved around me was totally different than how he behaved around her. And so she had the psychologist come in, 'cause I think they scored him at zero to six

months or something. And I knew that, receptively, he was higher than that. And so they had the psychologist meet with us, with him, with me, and got a totally different picture of him, just because he's there. So I think that's kinda what started us on our Jeff journey was we had a lotta people around us, a huge village that was built as we went through life, and people who are still lifelong friends, and people who loved him. And we actually just got him interred. It was very nice, guys. We had the people from Harmony Hall, all his roommates came, and then his caregivers, and some of the caregivers that we'd had since when he was a baby. And so it was really kind of a really nice final goodbye with all the people in our life who had kind of walked through our life. So it was really very, very nice. But he was like you and I. He definitely had likes and dislikes. We know he didn't like country music. One of my favorite stories is that he was in high school, and his teacher called me in to have a behavior meeting with him and talk about having to write a functional behavior plan. And he said, "He just screams and screams and screams "in my class," which is not typical of Jeff. He was not much of a, I mean, he could be if he didn't like something, but if you told him to knock it off, he would knock it off if he knew he was in the wrong. And so I walked in to go to the meeting, and I said to him, you have to understand, I work in the schools, too, so I know all these teachers. So I just said, "Teal," I said, "do you always play this music?" And he says, "Yeah, my guys like it." I said, "Mine doesn't." It was country music. He had country music playing over the speakers. I said, "I'm not saying "that you have to never play country music," I said, "but you need to give him a choice," you know? And so the next day, he put something else on and Jeff was totally fine. Because it wasn't a, yes, it was a behavior because he was trying to tell him that he didn't like it, but it wasn't a behavior in something that we needed to write a behavior plan for. So along the way, we just, I always say Jeff was kind of a trendsetter. We kinda made a joke with his high school at the end of his graduation, I said, "His legacy to the Muscatine Schools District "is that now there is a wheelchair-accessible bathroom "with a track and a high/low table "in all the buildings he was in, not just ADA-accessible." So that was his legacy through school. Other than he also, he was kind of on the cutting edge, guys, of assistive technology learning. And the teachers he had, had the ability, or the teachers that we impacted, continue to use that with other kids, you know? So he has that legacy as well, coming through school. But then he got to the end of school, and life was getting a little harder 'cause we were having trouble finding home care for him, you know, supportive community living and some of those things. And we were concerned, very truthfully, Frank and I were concerned of he was always very social, and we were concerned about where was his socialization coming from when he became an adult? Because we knew the adult system was so isolating. And so we started looking, and I remember this trip forever because we went up to, you know the ICFR's are, up at Hills & Dales and up to Guttenberg. And we took a trip up north and took our daughter. At that time, Jeff would have been 16, which made her eight. And we went up to take a look at them. But my concern had always been, we'd always worked at trying to have him in an environment where there were verbal people with him, and there's no verbal going on in those types of places. And Cara just cried and cried on the way home, "Mom, no, no, no, you can't do that. "I will take care of him and you're not going to do that." So about that time, Mike Johannsen, who's our CPC for the County, I sat on his committee quite a bit, and he gave me information about a project up in Webster City that was done by Maureen Seamonds and her families, whose kids were about six to eight years older than Jeff at that time. And they had gotten the legislature to change the HCBS rules so they could have more than four people. So they could have five people in a home to make it actually work. If you go to six, then you're in a residential care facility, so the magic number was five. So we had the opportunity then to go up and meet with them. Mike went up with me, and Kathy Anishanome, who was head of Community Services at the time, and another

parent. And we all went up, and looked at it and talked to them, and said, "How did you get this done?" And on the way home, I said, "Mike, this is what I want, "but obviously, I don't want it in Webster City," so. And I have to tell you on that journey, guys, it was very interesting, because at no time during that journey was I ever told "no" by my local community. What I was told is, "We don't know how long this will take." So because of what I do professionally, I have access to that population on a regular basis. So in 2004, I put together a survey to determine if there was a need to have a house for people who are multiply disabled, medically complex, to live in the community. And I think I sent out 12 and got 10 back. So clearly, there was a need. So in January of '05, we met with Muscatine Welfare, the organization here in town who develops housing for people with disabilities and low income, and they're not-for-profit. And we met with John Beckey, who's representing them, and Mike and myself met, and gave 'em the results of survey. And they agreed to help us write a grant for a HUD house. And so we wrote the grant, and I was amazed by the process, that no, we could never have done that without a grant writer, because it is so complicated. And the number of pieces of paper that you have to have, and the numbers of community support you have to have to make that happen is unreal. So, in 2005, we wrote the grant. We were awarded the grant in January of 2006, only to find out it was not going to pay for any of the things that made it truly accessible, like a track system that we put in and some of the other accessibility features. They are not considered by HUD to be essential. But if you're working with people who have multiple disabilities, some of those things are.

Judy Warth: What is a track system?

Cath Hahn: The ceiling lift track system that allows us to move throughout the whole house. So it's like a railroad track; think of a railroad track. So we set it up so it goes down the hallway, it goes into each bedroom, it goes to the bed, it goes to the shower, it goes to the toilet in each bathroom. And then it comes out to the center living room, and it's called an H track or a transverse track, where you have two parallel tracks running and a cross track. And it allows you to move and take someone anywhere within that whole square you just set up. So the kids could rearrange their living room, basically, if they wanted to, and do whatever they wanted. It took us about a year to raise the rest of the money, about a little over a year. We broke ground in October in '07. The house opened in June of '08, with the first five that were the residents there. And I will be forever blessed that we managed to get that done. It was our dream for Jeff. Our dream for Jeff coming out of school was that he had a community to be in; he had a place, something to do during the day; and he had a family, or an extended family to live with, and people of his own age to be around. And so Frank and I feel really blessed because of the community we live in, and all the stars aligned, and we were able to get it completed, and he had 12 years there, guys. It's hard to believe, I got to thinking when he passed away, that, oh, my gosh, we were on year 12. And it's still a great project. It's his legacy. I suppose it's somewhat my legacy as well, you know, with this community that we got it done. And I'm really excited, the young lady that moved into his room I worked with all through school. She's a wonderful lady and a little bit younger now than everybody else, but it's always interesting to add new dynamics. And so Jeff had a huge impact on the world, even though a lot of people didn't think he did. I look at the things that we were able to get accomplished for him, no more than any parent would want for their child, which is to feel like there's a place that's home to do something productive during the day, and to be part of a community. And we did manage to get

that. I mean, we did set some things up when he first moved in to kind of develop that family relationship. So the HCBS Waiver House is different than an ICF-MRID. Funding streams are different, how the setup is different. So where they lived in Harmony, which was the house that we had built, they paid their own rent, and they were responsible for all their own personal expenses. So really, the only cost to the State was the cost from the HCBS waiver to cover their 24/7 care. But we set that up after learning that, in Webster City, the provider had built the house. And so the minute there was a disagreement between the parents and how things were going, they had no recourse other than to move out. And that is what we didn't want. So when we set up it here, we set it up differently. So the understanding was that Muscatine Welfare Association owns the house. LS, Lutheran Services of Iowa, is our service provider, and we just had a working relationship. And then it was a challenge. I mean, I think, as much as anything else, Jeff taught me so much throughout my lifetime, how to be a flexible, adaptable; how to kind of go in the back door sometimes; how to keep asking the same question in different ways; and to really just, I mean, to have those skills and apply them, not only to me personally but also to what I do professionally, and the ability that I have to empower the families that I work with to try to do kinda some of the same things for them. So it's really very interesting.

Caitlin Owens: Got it; I mean, that's a truly incredible story of just, I mean, not only did I love hearing about Jeff but the just like tenacity is the word that comes to mind, you know, and hearing, I mean, hearing you talk, you are so clearly an expert in your son's life experience and what he needs in his care. So that takes me kind of all the way back to what you said at the beginning about how your experience with adult health care was really that you weren't seen as an expert. And it's so hard for me to imagine you not being taken seriously as an expert. Because I mean, I just had my mind kind of blown by your expertise, I mean, truly. And I think only enhanced by the fact that you're both a parent and a professional in the disability services world. So I just, I hope that the medical world catches up with seeing the value and the importance of taking parents, and people, as the experts of themselves and the people that they care for.

Cath Hahn: Yeah, I mean, I think there's a lot of ways they could improve things to buy in. I think one of the hardest transitions is gonna be for my families that I have now that are moving from child. If you look at Stead Children's Hospital, and they have the big room for the parents, and they have places for them to be, and then you end up in adult care, like we end up on the neurology videographies floor more than once. And I wasn't, well, the last couple years, staying was much more difficult that last go-round in that last year. But prior to that even, there was no room for me to stay in. I was in a double room. There was hardly room and space for us to turn around. They wanted his \$6,000 wheelchair out in the hallway, and I said, "No, it's not. "You're gonna find a place for it in the room, "because we're not putting it in the hallway," after I had one of my families have theirs taken to the trash. I said, "Yeah, that's not happenin'." And then only to find out that there wasn't even any place on that floor that I could go to take a shower or go to the restroom, that I had to go up five floors, and go from A to F to be able to find a place where I could even take a shower. So that's a huge dichotomy, guys, from what happens when you're in a hospital with a child and when you're in the hospital with an adult. And it's just hard. It's an educational process all the way along. I don't know what the adult world thinks, that our people with multiple disabilities don't think, don't care. A lot of things were taken on assumptions, I

guess, is the best way to say it. Particularly in that last stay where I got kicked out, there were things done that I would never have allowed to happen had they bothered to ask. But being who I am, we, of course, followed that up with a eight-page letter to Office of Patient Experience, which followed up with a Zoom with some of the bigwigs onboard. And the bottom line was, even though it was COVID 2020, I wasn't his parent at that point. I was the only one who truly knew what was medically going on with him. But there were things, too, I think things that could be, something like they put in the wrong size G-tube. And they didn't bother to sit him up. They just laid him down and put it in, and put in the wrong size. And then we had to have it, two weeks later, once we got home, I realized that it was the wrong size and we replaced it, obviously, again. But why make him go through two weeks of uncomfortableness because you didn't bother to look, you know. And in all fairness, I'm sure his record was humongous, but why can't we have a lead page that talks about some of the very basic things that you need to know about someone who's multiple complex, you know. What's their verbal communication style, what things do they have for adaptive equipment, kind of what the parents' expectations are. Just like his G-tube. Why was his G-tube not listed there on the front, the size that he had and the type he had, on a lead sheet where every doctor or every resident could say, okay, here's one, two, three, four, five, six. These are the things, the most critical things we need to know about Jeffrey Hahn when he's in the hospital.

Judy Warth: Those have been really important suggestions and stories, as we've been working through this TRAC rent to figure out how we can better the system, so hopefully no one ever experiences the dual challenge of a child who's ill during COVID, of all things, who has no voice to be able to be heard. And then to subsequently have your voice be not heard, I just can't imagine how painful that was.

Cath Hahn: I was more frustrated, I think, than painful, Judy. I was just, I was frustrated and then I was angry. This is totally asinine, you know? And the problem was I probably challenged some people's, what they consider their professional credentials, but so be it, you know? When I took him into emergency, 'cause he was having difficulty breathing and things, and having seizures, they were gonna send him home that next day 'cause they couldn't find anything out. And I said, "Oh, no, you're not." And I sat there, and they weren't gonna let me stay, but I did end up staying. And I will say some of the doctors, like the neurology team advocated that I stay with him that day, because I sat there and recorded, for four hours, every seizure he had. And I said, you guys are ready to send him home because he lives in a group home. That was what I was told. He lives in a group home, and he'll have the care that needs there. Jeff lived in an HCBS Waiver House. It did have a nurse that oversaw a lot of the kids' medical things, but their staff were direct staff that we trained that had no medical background, necessarily, and it was never set up to be like that. So sending him home because he lived in. quote/unquote, "a group home" with some medical background, we would have lost him sooner than later, if that had happened, too, so.

Judy Warth: In the midst of all of this, did you see points of excellence? Things that you went, oh, my gosh, if we could only have this be the standard practice? Were there points of excellence?

Cath Hahn: Yeah, I mean- I do think, every time we were in the emergency room, I actually felt the care we got in the emergency room was far more superior than the care we ever got when we got up on the floor. They seemed to listen to me. They seemed to respect what I said to them. I mean, even down to that final weekend, when we had already made him a DNR, and honestly, guys, he had a seizure I'd never seen before, and I've seen his seizure for 32 years. and we could not, I mean, they were trying their darndest, you know, medication, a different medication every 10 minutes. Nothing was, you know, and they said, "We're gonna have to intubate him to keep him." And I just said, "Wait, wait, wait, wait." I said, "You know he's a DNR," and they said, "Yeah." And they said, "But there's no way "we're gonna get the seizures stopped unless we do this." And I said, "Well, I can't make that decision by myself." So I called his dad at work and I said, "Frank, what do you wanna do?" I said, "They're still saying it's pneumonia. "They're still saying "that we're not gonna get the seizures stopped "unless we intubate him. "What do we wanna do?" 'Cause we had made him a DNR after that April/May stay. And I just wasn't ready to let his quality of life continue to kind of slip away from us. He was clearly not happy and clearly in pain, and I was reaching my limit of what I felt was reasonable to keep him with me. Even though I miss him dearly, I just couldn't do that, physically watch him any more. So we did decide, and they were very respectful. I told them two things. We will consider intubation on a short-term basis, to see if he truly is going to get better. And secondly, we wanna talk to Palliative Care today to talk about and go over everything that's been happening over the last, since December of '19, really. And I said, "We want those two things to happen," and they did. And the beauty of the whole thing was it gave us the opportunity to get our daughter home to see her brother, 'cause she lives in Ohio, before he truly passed away. But contrast that to, the agreement was that we would have a family meeting with the ICU docs, the neurology, palliative care, and us on Monday to talk about what path were we gonna take. And I just wanted from each of the disciplines, what they thought his future looked like, based on what was happening right now. And when I called in the morning to find out, the ICU docs to do that, they actually put the professor on the phone who pleaded with me to give them three or four more days on the vent. And I said, "I'm not saying I won't consider it," I said, "but I want our family meeting this afternoon, "to talk about it." And then it just became clear in the family meeting that this was to be Jeff's path. I mean, home two weeks, in three weeks, never knowing, nothing was stable, everything was unstable. He clearly wasn't happy. So we made the decision to go to palliative care at that point. And, honestly, Judy, that was the best four days we've ever had at the University of Iowa Hospital. I wish they would take some of the elements of palliative care that those people use to practice with and then ingrain them in some of the other divisions. Because they were concerned not only about Jeff; they were concerned about us. But even though it was COVID, because it was palliative care, we were able to all be there. So we kept Cara home for a week. We had four days with us before he came home to Harmony, on hospice. And we weren't actually gonna bring him home, 'cause I was concerned truly about what was gonna happen at Harmony with his roommates. And the lead nurse staff came up to us one day and said, "You do realize this is part of the process," "and LSI is aware this is part of the process." And so we've already had counselors in to talk with the roommates, and counselors in to talk with the staff, and we all want him home. So I don't know how much more heartwarming that can be, because the alternative would have been, because he was, by University rules, stable enough to go home, he would have ended up either in a nursing home or in a hospice care facility, neither of which would have had any idea on how to take care of him. And so he came home on Thursday, and then we lost him that Friday night, 24 hours later. But everybody had a chance to say goodbye. I mean, I'll

forever be grateful to Pixie for her support during all of that time. And she was actually down there the Friday that he passed away, and not only helped us, obviously, and helped with Jeff, and then helped with all the roommates, just to be there to process. I can't say enough how grateful we are that that all transpired the way that it did. And she came down because we'd been talking about Harmony and the impact that Harmony had on all of our lives, and she had wanted to see it. And so it was just by nature's, you know, coincidence, whatever, but it was really very, very helpful, so. And individually, nurses, some of the nurses are phenomenal. Some of 'em were not phenomenal. Some of 'em were really awful. But I think they're frustrated, too, because they don't have control over the narrative. It's just like, you know you have someone like Jeff who's multi complex, who's five-nine, who weighs 140 pounds, and you put him in a bed in a two room, little tiny room on a A-wing of a neurology wing without any way to lift him. 'Cause you can't get a Hoyer Lift in there on the floor, and they only have one bed that's tracked, or one room that has track over the bed. And so, I mean, if that's already taken, you're just out of luck. But they did get the message after a couple of times I'd been there, 'cause it seemed like every time that we were there after that, we got the bed that had the lift over it. But I made it clear to them that he wasn't just gonna stay in bed. And I think that's what would have happened, very honestly. He would have been in bed 24/7, and they chose to use his G-tube to feed him, which we never did. But there are, yes, I do think there are. And I think that the role that Pixie played for us as kind of a coordination, looking at the whole person and looking at us as a family, and looking at all roads, my goal wasn't just to keep him alive to keep him alive. My goal was to let him have a quality of life. And at some point, that's no longer there. And the palliative care doc was phenomenal. Everybody we met on the palliative care floor was really very good. And I think it's the approach. It's because we care what the family has to say, and yes, you do have a say in the decision. But then the lead doctor I was talking about, I didn't understand how he said one track on one bed on a whole floor for someone who's multiply involved, or even somebody who's elderly and can't stand any more.

Caitlin Owens: Especially on a wing like neurology. I mean, I guess-

Cath Hahn: Well, that's the thing. I think that neurology video unit's on the oldest part of the hospital, and I don't think any renovation's been done since the '50s, to be very honest with you. It's awful. It's awful, awful, awful. So I did send him information about the track system that we put in at Harmony. I sent him pictures of Harmony. I told him, 'cause I was very frank. I said, "Quite frankly, at the point we're at now, "he can get better care at home than he's getting here." And so we took him home. And we tried to stay out of the hospital as much as we possibly could. But in the end, obviously, they came to the point where, the problem is we can only manage things locally with our local people, you know what I mean? Even though we had good working relationships, there's just levels of expertise you don't have. And as you add more layers of complexity, you're almost at a tertiary center at the University of Iowa. And really, by the time Jeff was in middle school adult, it was too hard to try to travel. Of course, by then, we had Cara as well. And it was just too hard to go five, six hours to get medical care. And even though we did quite a bit by phone and email, it's still, there were times you had to be there. So we really, we ended up back at the University of Iowa as sort of a default, because we didn't know what else to do.

Caitlin Owens: Absolutely, yeah. Is there anything we haven't asked you about that you wanted to share, that you wanted to-

Cath Hahn: I'm really happy that they got the ON-TRAC grant, because I did see, working on the group that helped develop the proposal to go, a lot of nice thinking processes going through, a lot of vlogs that we could get into, I think, people can get into, that we're gonna have to be careful of. But I think there's the opportunity there, too. Because the biggest thing is the community connection to the university connection. And a lot of times that just doesn't exist. The university docs say one thing, and you come home and the community docs either don't follow through. I mean, I even see that professionally. I have recommendations coming from the university that have no relevance to how the child participates in their education, but yet they feel like the family comes home empowered to say that they have to have those services because Iowa University says so. And then you have to go through that whole dance about what is educationally relevant and what is not. But I always look at it as a good opportunity for education. Somebody's gonna get educated along the way, one way or the other. But, truly, guys, Jeff was a blessing to us, and we walked a path that I didn't expect to walk, but had many, many people who were our religion and our supports all the way through, and met many, many people we would've never have met that had a huge impact on our life and his life. And the joy of being able to see him live with roommates was, we made that dream come true. And that's what I will always be able to have, to know that we made that happen for him. And now it will continue to happen for others.

Caitlin Owens: And you know, a question that we always like to finish on that you've already touched on is, talking actually about legacy. And so I'm curious to hear if there's anything you wanna add about what you hope Jeff's legacy will be, but also what you would want your own legacy to be.

Cath Hahn: You know, it's kinda like are you a small fish in a small pond? Are you a medium size fish in a small pond? Are you a big fish in a small pond, and what can you get done and accomplished? You know, Frank and I, the last thing we did for Jeff and his legacy was when he was moved into Harmony and we were needing things that were beyond the scope of what HUD or the funding was going to cover. We created the Friends of Harmony at the local community foundation for people to be able to donate money to pay for things that weren't gonna be able to be paid for by either their standard level of care through government. Like, if the kids wanted to go on a trip, they would still have to pay for their site visits and their hotel, but it was gonna take extra staff to do that, and there was not money in the budget to necessarily bring extra staff. And so then they could have written to the foundation to say, can we have so many dollars, we wanna do this. If there was something that was gonna benefit everybody in the house, the money was set aside there. So Jeff's legacy, in the end, it was pretty much our family, my family and our friends that put money in there. So in the end, after Jeff passed away, I did go back and ask the foundation to switch that name. So his legacy is that foundation right now. He has, this is the Jeffrey Hahn Friends with Harmony Foundation. And right now, we just use some of his memorial money that's in that foundation to pay for a new, the lifts are now 13 years old as well, that they use every day. So out of his memorial money, we paid for one of them. We were able to pay for one of them. I was able to negotiate with the company, because all three needed to be replaced. I was able to go to the

community foundation and write for a community grant. And then I negotiated with the company, and we were able to get all three lifts replaced for \$9,000. So that's probably my legacy, is figuring out how to make things work. Given what we're given, how do we do that, and then how, you know, firstly, my dad, I'm one of six kids, and my dad gave us the ability to be able to talk. And we always had to ask questions three or four times to get an answer, particularly if there was some answer we wanted. So I think that's probably my legacy going forward, is to be able to look at a situation, figure out some of the back doors. I always say to people, you know, I'm not much of a let's-go-out-and-rally, let's go out and do those kinds of things. I'm more about let's look at the systems and how do I get in the side door, the back door, so we can impact change, that's then gonna benefit everybody else down the road. And that's just style. I mean, everybody's style is different and that's where I'm comfortable. Sometimes I enjoy making people uncomfortable, particularly some, I mean, we had some, when the waivers changed over to the Medicaid system, wow. Yeah, lots of rights were taken away from everybody. And I remember telling UnitedHealthcare that they couldn't do that, we had to have a case meeting to talk about it. And they wanted to challenge, and I said, "I'll go to the federal rules." I said, "This is what the rules say." I said, "We will meet and we will talk about this." Yeah, so and, of course, it was all related to funding. It's always related to funding.

Judy Warth: Well, and you know, Cath, for those people who wanna learn more about Harmony House, it is located in Muscatine, Iowa. And do you know, is there a place they can reach out to, to gain more information?

Cath Hahn: I don't know that there's anybody, Judy. I mean, you can use my name as a contact if they're really interested in learning about how we got the project going. Muscatine Welfare Association is the owner. Muscatine created what they call Vision 20/20, which was to take a lot of these smaller not-for-profits and have kind of involved them underneath this Vision 20/20. So you can call them and they'll probably call me.

Judy Warth: You know, Cath, I do have one more question, because really, the legacy question is usually our last question. But you mentioned about Cara, your daughter, and I'm curious about her. We don't hear much about her, and she's as much a part of Jeffrey and you as everything else.

Cath Hahn: Cara had a very different upbringing, I think, than probably most kids who have siblings, because Jeff was not a typical sibling. But, in many ways, he was a typical sibling. I remember in third grade, when Cara was 10 months old, Jeff was, they were doing kind of a show-and-tell thing. And we had a golden retriever at the time. We'd had a golden retriever before we had our kids. And Jeff loved that golden retriever. And so his teacher was great, and we lived just down the street. So we walked the dog and Cara down for show-and-tell, and we were trying to make the point that people, even if they can't communicate verbally, do communicate. And so we were making the point to these third graders that Jeff, like everybody else, has likes and dislikes. And so, for example, we took the dog named Brandon over to Jeff, and Jeff got very excited, tried to reach out for him, clearly, clearly enjoying the

dog. And then I said, well, I said, Cara, who's his sibling now, is kinda new to the world and has sorta rocked Jeff's world. And I said, "So watch this, guys." And I sat Cara on Jeff's tray. And he immediately started yelling and swinging, because it did. He was an only child for eight years. We tried, Judy, really hard. Cara is a phenomenal young lady, very introverted, unlike me, unfortunately, but she's very, it's not unfortunate, it's just that she has a very different style than I do, but always cared about Jeff, always very tender. I remember her coming home from school one day just in tears because they'd been on a school field trip and somebody on the bus had called one of the Special Ed kids "retarded." And she was just beside herself. And I just said, "You can't control what other people say and think." But it was Frank and my goal for her that, and when she was in her 20s, that she wasn't going to make decisions for Jeff if something happened to us, you know, that it was not her responsibility. It was our responsibility to have something set up in place. Interestingly enough, I mean, she tried and she is now out in Ohio. She works for Nationwide Insurance, is moving up through the system fairly quickly, and a very talented young lady. But she was funny, too. I mean, she was as stubborn as Jeff was, and it was kind of funny sometimes to watch the two of 'em, because they, in some ways, had a very typical sibling relationship along that way. And we tried to give her her opportunity. I remember being in the car and she said, "Mom, you don't love me as much as you love Jeff." And I said, "Wait a second." I said, "That's not fair, Cara," you know? And she must have been 11; ten, 11. I said, "That's not fair." I said, "Jeff requires a lot of my time "because of the physical things that I need to do with him "and everything else." I said, "Everything we do takes double the amount of time "that it does for you." I said, "But Jeff doesn't get to go do the things "that you and I get to go to do." She was involved in dance, she was involved in all things. And she understood it, you know what I mean, Judy, as time went by. And when he passed away, she took it really hard. I remember that Friday, the final Friday when we, she'd been with us all week, and she needed to go back to work, and I said, "It's fine, Cara. "We don't know how long he'll be with us. "Just go ahead and go home, "get done what you need to get done." And then she felt really bad 'cause he then passed away that night. But up to the airport, she said to me, "Mom, I never expected Jeff to die "before you and dad, ever. "I never, ever did." And I said, "Cara, up until the last year, "I would've told you the same thing." He was healthy, guys. He was healthy other than his seizures and his neurological system fading out on him. But it's interesting because, as she got older, she was more interested in what it actually did to take care of him. 'Cause I remember the year before that, she asked me, I have a notebook of kind of everything I did for Jeff, all the systems I had to keep in place, basically. And I took it out with her, and we went in her back bedroom, and we sat for an hour and a half, and went over everything. And she was kind of, you know how you get the deer-in-the-headlights look? She's like, "Oh, my gosh," and I'm like, "Yeah," I said, "It's a lot, isn't it?" And she said, "Yeah." So she said then, "Mom, I don't want anybody else "to be his guardian if something happens to you and dad." So you see that whole switch. All along, as parents, we had said, "You're a young lady. "You need to live your life. "You love your brother. "We want you involved with your brother, "but at the same time, you have to determine who you are." But by the time she was 24, 25, she had determined who she was, Judy, and said that "I wanna be an active part of this." So we are blessed in many, many ways. And like I said, we made life work when we had to. Just like every other parent that I work with that has a child with special needs. And I think the take-home message on that for me is, there is not a general path. I mean, there's a general path that we all sorta walk, but there are many, many branches of that same path that each individual walks, and each individual family has to make that decision for themselves on where they're comfortable. And that was a hard take-home message for me as a young professional. Even though I had Jeff, that was a very hard lesson for me. But thank you, guys, for your time. I appreciate it.

Judy Warth: Well, thank you for sharing, walking us down this most intimate path, and for sharing so openly. I mean, I can say that we all feel your pain and your joy, and the pride. And I look forward to our continued efforts with ON-TRAC.

Cath Hahn: Yeah, yeah.

Caitlin Owens: Yeah, thank you so much. This was an incredibly moving conversation, I mean, really.

Cath Hahn: Systems are sometimes really hard to change when you look at the whole system. But I think that's probably why I took the route of trying to find the side door or the back door.

Caitlin Owens: Yes, oh, my gosh. I mean that, and as somebody who intimately, like personally familiar, but professionally, like, gosh, yeah, the systems are so complex, and what you were able to accomplish, I mean, I think it's like, it's really amazing.

Cath Hahn: Life was on our side, things on our side, and ran into the right people at the right time. And I feel like, you know, every time a door slammed on us, we had a window open somewhere that somebody helped us get through, so.

Caitlin Owens: Well, thank you so much for taking the time to talk to us today, so we appreciate it.

Cath Hahn: Yeah, you're very welcome.

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 Disabilities and Development at the University of Iowa. A special thanks to Kyle Delveau for the music contribution.