

Episode 2.4 - Discovering Disability Later in Life & Advocacy with Hugh Kelly

Mike Hoenig: Hey everybody, it's Mike Hoenig from the Iowa University Center for Excellence in Developmental Disabilities, or UCEDD at the University of Iowa Center for Disabilities and Development, which some of you might recognize as CDD. Welcome to another episode of Disability Exchange. Disability Exchange is a podcast which is designed to center and elevate the voices of people with disabilities through casual conversation. We also recently have added the voices of families to this discussion, which really we believe is giving an even broader picture of life in the disability community. We're very pleased to be partnering with the Midwest Public Health Training Center at the University of Iowa College of Public Health to produce Disability Exchange. We have a great guest today who I will be introducing shortly, but before we do that, I would like to introduce our Disability Exchange co-host, or one of them, Caitlin Owens. Caitlin.

Caitlin Owens: Thanks, Mike. Nice to be here. My name is Caitlin Owens and I am the Associate Director of the UCEDD, and I'm very excited to talk to our guests today.

Mike Hoenig: Well, thanks, Caitlin. It's really a thrill for me to introduce our guest today. His name is Hugh Kelly, and I've known him for I think just a little over a year, and I've really come to respect him as a person and as an advocate. So, Hugh, we'd like to welcome you to Disability Exchange.

Hugh Kelly: Thank you, Mike.

Mike Hoenig: This has been really fun getting ready for the podcast today, because I haven't known you really, really long as I said, or really, really well. So, I've learned some very fun things that hopefully he'll share throughout the podcast today. So, first Hugh, tell us a little bit about yourself, where you're from, and how you got involved with the disability movement, the disability community.

Hugh Kelly: Okay. I'm Hugh Kelly, I'm 49 years old. I live in a little old town in, you would probably call it Southeastern Iowa, 70 Iowa, only town of 2,100 people, but born and raised here. And kind of asked you about my fact, I never considered myself to be disabled. I was a pretty outgoing person, pretty capable person up until my 20s. Then I started having issues with my walking, and then slowly but surely it got worse and worse as it went on. And now I have to... I'm only 49 years old and I have to walk with a cane if I don't want to stumble around everywhere. And how I got... I actually got involved in the disability movement is an interesting story.

My family were in the process of buying Rick Shannon's former public policy manager buying his parents' house and we started talking with each other and he mentioned about the thing he was involved with and one thing led to another, and I actually applied it to be on the DD Council. And I've been on it now for, let's see, seven years. Learned a lot and really, really know about how to really speak up for myself and other people and other disabled people, instead of just myself.

Caitlin Owens: Wonderful. Thank you so much, Hugh. So, can you say a little bit more about your disability? I don't think I caught.

Hugh Kelly: Oh. Well, it's like I said, just it's not something that happened overnight. It's something I just started having issues and I just started having issues with my walking. And then first I didn't think it was anything, but my family said, "No, you need to get this looked at." And I saw a bunch of numerous doctors. No one can give me a definite response, but then this one neurologist gave me a response of

well, maybe I was born with cerebral palsy, and he just took to adulthood to come out in. And I had a hard time believing that, but then I started doing some research on it. Yeah, there is something about being born with something but not coming out until later on in life.

Caitlin Owens: Okay, interesting. Thank you.

Mike Hoenig: That's very interesting. That is the first time that I've heard that, that cerebral palsy isn't always immediately diagnosed. Just curious, how did it feel to get a diagnosis like that as an adult? Was it frightening or did you just take it in stride or?

Hugh Kelly: Well, at first it was kind of frightening. I'm like, "Oh, boy, is my life going to change for a lot worse than it is now?" But yeah, I do have my issues, but I still live a pretty normal life overall, so not really that bad.

Mike Hoenig: One of the things that's impressed me about you, Hugh, since I've gotten to know you, is just your attitude and you're just kind of like, "Okay, I'm going to do this." And one thing I know, because I'm fortunate enough also to serve on the DD Council with Hugh. This is my first term, is that he is Vice Chair. And if I understand correctly, that means that next year you'll be chair of the council, is that right?

Hugh Kelly: Might be. Not for sure, because the current chair Brady Werger, he has a couple years left, too. And usually it's when the chair's leaving the Vice Chair takes over. But I guess we'll see what happens.

Mike Hoenig: So, how do you like being Vice Chair?

Hugh Kelly: Oh, to be honest with you, when Brooke asked me, I was thinking, "Oh, what? Is this is going to be a lot of responsibility?" No, it's not really a lot of responsibility. Just being there for meetings and putting in my input when they need it, I guess.

Mike Hoenig: That's great. That's important. We need that kind of input. And I think that one of the things that's happened, Hugh since you've gotten involved in the council, is that the council has really shifted so that people with disabilities are having more and more say in how things are run and decisions that get made. And I know that I've had a chance to sit in on a couple of the executive committee meetings, and I know that you don't hesitate to speak up and voice your opinion, which I think is fantastic.

Hugh Kelly: Yeah.

Mike Hoenig: Got to do it.

Hugh Kelly: Thank you.

Caitlin Owens: Hugh, I was wondering for people who might be listening who aren't familiar with what the DD Council does, could you talk a little bit about what it is and some of the work that you've done in the time that you've been on the council?

Hugh Kelly: Oh, it's a council that's formed by the state of Iowa with the Volunteer Council, where there's a form you had to fill out called Iowa Talent Bank, and you fill it out and say you're interested in

it and says, "What's your connection with the council you're applying for? Why do you think you'd be a good fit?" And then you send it in and then whatever. Then probably to whatever, two, three months later, you hear back if you've been selected or not.

Caitlin Owens: Yeah, that's very cool, because it's a governor appointed council. So, that talent bank is how people express interest, if I'm correct.

Hugh Kelly: Yes.

Caitlin Owens: In serving, so that's very cool.

Hugh Kelly: But if it wasn't for Rick Shannon, I would've not known anything about it.

Caitlin Owens: Yeah, absolutely. Can you talk about any of the projects that you've been involved in with the DD Council over the years or anything you can think of that they've done that the council's weighed in on?

Hugh Kelly: Well, like I said, well, they have an annual conference called Make Your Mark every year. Well, this past year it was in West Des Moines at the Sheraton, no not the Sheraton, excuse me. I'm getting that... No, I'm getting that geography [inaudible 7:41], it was at Prairie Meadows, sorry, it was at Prairie Meadows. And this year's theme was, "What's your superpower?" Which was cool. And then we also do some various voter trainings through different regions in the state. And we also get involved legislatively. We keep up, always put, well, not me personally, but the council puts out our legislative agenda for what we like to see in the legislative agenda. And also the way to contact your legislators too. It's called, there's something you put out called infoNET where all that information is at.

Caitlin Owens: Yeah, that is such an awesome resource. I use it all the time during the legislative session.

Mike Hoenig: I'm glad you mentioned those voter trainings, because I know that one of the things that you volunteered to do was to host one in Sigourney, right? And I understand you had a little bit of problems getting people to sign up, but it wasn't just Sigourney. I think it was all over the state. And it's really unfortunate. I think this is just a shout-out to people that might be tuning in, that when those opportunities come up, especially in the rural areas, jump on them. Because when nobody signs up, it's hard because then you don't know what the next step is in trying to get the word out to people with disabilities and even family members.

Caitlin Owens: What was the goal of the voter trainings? And who was the intended audience?

Hugh Kelly: Oh, the intended audience was more young people. I think young people that had disabilities that were in were maybe intimidated about the voting process and just how to get involved in the voting process. And also them too, and then we were also going to talk about the DV council as well too.

Caitlin Owens: Oh, very cool.

Mike Hoenig: So, I understand, Hugh, that the next steps in promoting that self-advocacy training and voter training for young people is to reach out to school districts around the state. Have you heard anything more about that yet?

Hugh Kelly: No, I just, I'm like you right now. That was what Brooke was telling me at the last DD council meeting about reaching out to high school, but I haven't heard anything more about it since.

Mike Hoenig: I think that Judy Warth who, some of you know that our podcast listener, she's also a co-host, is on the DD council as well. And I think she's coordinating that with some of the schools. So, it's pretty exciting to think that we might actually get some training in those key areas for young people with disabilities.

Caitlin Owens: Yeah, that's wonderful. Very cool. So, Hugh, I understand that you and Mike first met through your work organizing the SOAR conference, which let me really dig into the depths of my mind and recall. That stands for seek, oh my gosh, I forget what it stands for. I know there's the word revolution in there, self-advocates. Oh, Seeking Opportunities for an Advocacy Revolution. I just should have done that. So, can you tell me a little bit more about that conference and the experience of working on that conference and attending that conference?

Hugh Kelly: Oh, well, it was a good conference, but it happened during the height of Covid, so it was all virtual, but it was still a pretty good conference overall. I heard a lot about some disability advocates that were famous that I knew nothing about.

Caitlin Owens: Nice.

Hugh Kelly: A couple of people called Squirmy and Grubs, and can you help me out, Mike? Who was the other guy? I forgot Michael, I forgot.

Mike Hoenig: Michael Beers.

Hugh Kelly: Michael Beers, yeah. He's a comedian with developmental disabilities. And then what was cool was father of the ADA, Americans with Disabilities, the former senator Tom Harkin gave the keynote address on the first night, which I thought was pretty cool.

Caitlin Owens: That is extremely cool and such a great Iowa connection. I wondered, I know it was disappointing that Covid derailed so many things and took something that might have been in person and made it virtual. But I also wonder if there were a few just kind of unintended benefits of maybe more people were able to attend because it was virtual and they didn't have to travel and that kind of thing.

Hugh Kelly: And Mike just pointed that I forgot and we also had Mia Peterson's sister speak about, I don't know if you know Mia Peterson, well she's passed on now, but she was a well known disability advocate with Down Syndrome that lived in Cedar Rapids, and I'm not for sure who actually did it. But then the WHO instituted the award, but put an award for her name. Well, I think it was Iowa.

Caitlin Owens: Yeah, I think it was the DD Council.

Hugh Kelly: DD Council here in Iowa.

Caitlin Owens: Yep. And Mia, I think, was from Des Moines.

Hugh Kelly: They give to an outspoken person that with developmental disabilities, that that's a very good advocate for them and people like them.

Caitlin Owens: Yeah. That is-

Hugh Kelly: The disability community.

Caitlin Owens: That is so wonderful. Yeah, I think that that was a very nice tribute. So Hugh, I'm wondering, can you tell me about your interests and hobbies and how you spend your days?

Hugh Kelly: Oh, okay. Well, I guess in terms of interest, I'm a big sports fan. I'm a big basketball and football fan. I'm a football fan, of course, the football seasons right now is not going very well for me.

Caitlin Owens: I'm not a sports fan, but even I know that, so...

Hugh Kelly: Yeah, just blocking [inaudible 00:13:35] off with the program right now. But anyway, but I also then, I'm a huge Iowa men's basketball fan.

Caitlin Owens: Nice.

Hugh Kelly: And I also, I guess in terms of the interest, I guess I also like to get out and when I'm going, not right now, the weather's not nice, but get out and enjoy nature every now and then. I like to garden and I like to just go out and I guess not walk, but just go out and enjoy nature.

Caitlin Owens: Nice. Do you ever encounter any kind of accessibility issues when it comes to trying to enjoy nature or anything new?

Hugh Kelly: No, not really. Not really.

Caitlin Owens: Good. Great. Mike is prompting me. Can you tell your story about having to walk across town?

Hugh Kelly: Oh, okay. That was about three or four months ago. I was careless for a few days. I was in a little bit of an accident. I mean, I wasn't hurt, but I didn't have a car and I had to go to a doctor's appointment, and I'm thinking I had to go from the North end of town to South end of town thinking, "Oh, I could probably walk there in a half hour, no problem." Oh, boy was I wrong. I started out there. It took me an hour to get from one side of town to the other. It was kind of an adventure, but then I thought, "Boy, I'm walking back." But then luckily the hospital gave me a ride back home, so that was good.

Caitlin Owens: That is good, yeah. Transportation can be so challenging, especially in a rural area where it's not easy to just hop on a bus or that kind of thing. Hugh, I'm wondering, so when you got involved in the DD Council about six or seven years ago that was... Did you say that was your first, your introduction to advocacy and that kind of thing?

Hugh Kelly: Yeah, it was. Yes. It was.

Caitlin Owens: Yeah. Would you have any advice for people who are also not involved in advocacy but maybe want to get involved, but maybe feel intimidated?

Hugh Kelly: Well, I guess that's the plug for the infoNET right now that the Iowa Disabilities in Action puts out. You can go to that site and that gives you all sorts of resources to get involved with the voting process or the legislative process, or learn how to be a better advocate.

Caitlin Owens: Absolutely, you did mention that. And we'll put a link to that in show notes for this episode. I understand from your conversation that you had with Mike earlier today, that driving is really important to you. Can you talk about driving and the independence that it provides you as a person with a disability?

Hugh Kelly: Oh, yeah. I like driving. I know people in my situation that don't drive, and especially in the area like this, I don't know how they get around without being able to drive if they need to get out of town. I'm sure the logistics there if you're going to have to get out of town, so just to give an example. My doctor is all the way in Des Moines, so if it wasn't being able to drive myself, I don't know how I'd get there for all my appointments.

Caitlin Owens: Yeah, absolutely. I'm sure, as Mike can attest, that it isn't easy. Our poor Mike is experiencing some technical difficulties, so he was cutting in and out, but...

Mike Hoenig: We'll give it a shot and hopefully-

Caitlin Owens: Yep. There you are.

Hugh Kelly: There you are.

Mike Hoenig: ... When it cuts out. It's just in and out, but it's hard to keep me quiet for too long.

Hugh Kelly: Oh, I'll concur with that.

Mike Hoenig: Hugh, have you ever thought about getting on any other boards or commissions that are disability-related?

Hugh Kelly: Yeah, I have thought about that. In fact, I brought that up back in May. I said something to Brooke about when my time is up on the DD Council about getting involved in some other boards. "Well, we can help you out with that." She said.

Mike Hoenig: Oh, good. There's a lot out there.

Caitlin Owens: Absolutely. And something that we talk about a lot within the UCEDD is the value of people with disabilities. Also having voices on boards that aren't specific to disability too, if that was ever an interest, so that the disability perspective is included on park commissions and boards of transportation and things that certainly affect people with disabilities.

Mike Hoenig: I think you should go up and do some advocacy about the Iowa offense.

Hugh Kelly: Okay. If I could, I would.

Mike Hoenig: Or as a friend of mine from Pennsylvania, they've started calling it Iwa. Iowa without the O because we have no offense.

Hugh Kelly: Oh, okay. Or you could be the late Hayden Fry called Awa.

Mike Hoenig: Awa.

Hugh Kelly: Yeah, that's what I remember. Whenever he ever said Iowa, he would say the Awa Hawkeyes.

Mike Hoenig: The Awa Hawkeyes.

Hugh Kelly: I think that was because he was... His Southern drawl got involved, because he's original from Texas, or was.

Mike Hoenig: Have you ever gotten to go to a football or basketball game up in Iowa City?

Hugh Kelly: Oh, I used to go to football games all the time, but I haven't been to one for several years, to be honest with you. I remember all the walking that was involved. I don't think I could do it now.

Mike Hoenig: Yeah, it's a long walk up the hill.

Hugh Kelly: Mm-hmm. And also getting up the up and down the stadium steps too would be a challenge for me now.

Mike Hoenig: They do have accessible seating if you ever decided to go that route.

Hugh Kelly: Oh. Oh, yeah. Yeah, I forgot about that. Yeah.

Mike Hoenig: Yeah.

Caitlin Owens: And parking too, I think.

Mike Hoenig: So...

Caitlin Owens: Yeah. Well, I mean, they definitely have accessible parking. Hugh, is there anything we haven't asked you about today that you want to talk about? Any stories you want to tell or topics you want to hit on?

Hugh Kelly: Well, I was a pretty active person like I said, up until my early 30s and I've started, then it slowly went downhill from there. But I'd just really like to say to people that might be in my situation, nothing's going to change if you don't do anything about it, I guess.

Caitlin Owens: Absolutely.

Hugh Kelly: I guess the old, the old Nike slogan: Just do it!

Mike Hoenig: You're a great example of that. Hugh, one more question I wanted to ask you about was your work, because you told me today about your work. Could you tell us a little bit about that?

Hugh Kelly: Oh, yeah. I work at, well, our headquarters are in Des Moines. I work for Goodwill of Central Iowa, and I work at one of the retail stores in Tama, Iowa where I run a cash register. Then I also help put out product too, in terms of clothing goes out. But I really like my job because I guess my boss, which just always hasn't happened to happen. My boss doesn't expect the whole world from me. She understands my limitations and she understands that I'm not going to be able to do as much as some of my other, more should I say able body coworkers. But I really kind of like it, but I also really like just the daily interaction I get to have with customers, like there's customers that'll come in everyday I always joke around with. I tell them, "If this didn't happen, this back and forth didn't happen. You thought something was wrong with me, or vice versa." So, it's just the daily social interaction that I kind of like about it too.

Caitlin Owens: That's so nice.

Mike Hoenig: That's so awesome. It is. And Goodwill's a great organization, so...

Hugh Kelly: Yeah, we recently at the DD Council's most recent Capital Chat, they had a guy on there by the name of Joel that worked at a cat cafe there in Des Moines, and I looked at him and I'm thinking, "Why does he look so familiar to me?" Then I went back and looked at my Goodwill calendar. He got job training through Goodwill, central Iowa.

Caitlin Owens: Nice. Small world, isn't it?

Hugh Kelly: Mm-hmm.

Caitlin Owens: I want to visit a cat cafe as a side note.

Hugh Kelly: Actually, the only other time I've ever heard about Cat Cafe was a show They Called Me Cat on Fox.

Mike Hoenig: That's good. Well, we promised you one final question, and it's now time for you to let us know what is your superpower?

Hugh Kelly: Oh, God. My superpower, I guess in a good way, I guess would be assertiveness and not wanting to take no for an answer, if that's at all possible.

Caitlin Owens: Absolutely. The makings of an advocate, not taking no for an answer and being assertive by... Absolutely. You also seem like a really positive guy, which seems like yeah.

Hugh Kelly: Yeah. That's another thing about my work. People often ask me is it that, the other lady asked me, "Why are you so happy all the time? Why are you always so good going?" And I guess I look at it this way, the old Serenity Prayer, "God, give me the strength to accept my weaknesses." What is it? Accept my weaknesses...

Caitlin Owens: It's "accept the things I can't change..."

Hugh Kelly: Yeah, "Things I can't change the things and the wisdom to know the difference."

Caitlin Owens: There you go.

Mike Hoenig: Yeah.

Hugh Kelly: Thank you. Yeah.

Mike Hoenig: Yeah, I can't believe I was struggling with that too, so...

Caitlin Owens: Yeah. I could have butchered it a little bit there, but... Well, Hugh, it was such a pleasure talking with you today. We really appreciate you being willing to come on and chat with us, and just thank you for all of the advocacy work that you do through the DD Council. It's an organization that we at the UCEDD work really closely with, and they do so much to just make it more possible for people with disabilities to live and thrive in the community and be involved in voting and policy decisions and that kind of thing. So, we really appreciate the work that you helped them do, so thank you.

Hugh Kelly: Thank you. And like I said, they go to infoNET, they can learn all about it.

Caitlin Owens: Absolutely.

Mike Hoenig: Well, Hugh, I just want to second what Caitlin said, and to thank you very much for your participation today and for sharing all your good work.

Caitlin Owens: Well, thank you all so much for listening. Thank you, Mike, for co-hosting despite your technical difficulties, and as always, we want to say thank you to the Midwestern Public Health Training Center for producing our podcast as well.

Hugh Kelly: And thank you for once again for having me today.

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. Special thanks to Kyle Delveau for the music contribution.