

Episode 5: Never Give Up with Melanie Davis

Mike Hoenig: Well, hey, it's Mike Hoenig with the Iowa University Center for Excellence in Developmental Disabilities or UCEDD. We are very excited to bring you another episode of Disability Exchange. We have crossed the state line for this episode and we'll introduce our guests very shortly, but first, I'd like to ask our cohost from the UCEDD to introduce herself.

Caitlin Owens: Hello, my name is Caitlin Owens. I work with Mike at the set and I'm very excited for today's guest.

Mike Hoenig: Excellent. Well, I am too. Our guest is Mel Davis or Melanie. She says she goes about either one, kind of like Mike and Michael, I guess. I got to know Melanie through a planning committee that I'm on, which I'm sure we'll touch on during this call, where I'm organizing a four-state conference. She's been a huge help, so I invited her to come on and tell her story today. Mel is a second-year trainee at the Munroe-Meyer Institute, which is in Nebraska UCEDD. I'm going to shut up and let her tell us more about that. Mel, go ahead and introduce yourself.

Melanie Davis: Hello. Again, he called me Mel, so everybody can know me as that. I am, as he said, a second-year UCEDD trainee at the Munroe-Meyer Institute. However, I am no stranger to that institute by any stretch of the imagination. I was a patient there as a child. I then started volunteering for their Recreational Therapy Department at age 12. I did that until about 16 when they hired me on as a camp counselor for... This was a camp for varying levels of developmental disability. And then, I did that until I turned about 17, and I went into their AmeriCorps program that was housed within the institute. It was one of the first of its kind in the country to focus on disability-related issues. I was the first member. I served for a year and a half, then I moved on to Minnesota in 2005. It was not a move I wanted, but I just did it. Lived in Minnesota for 12 years. While I lived there, I took Partners in Policymaking, which makes a lot of people happy. It's a leadership development program for people with disabilities and their families to create systems change.

By the time I turned 30, which by the way, I'm 35, I realized I have hated every moment of living in Minnesota, and I said I'm going to go home to Nebraska. So, I've been back in Nebraska the last six and it was the biggest goal I could ever make to get myself back into the institute. I applied for the UCEDD program and I got in for the first year and I was offered the opportunity to do it a second year, so here I am.

Caitlin Owens: Awesome. That's so great. Can you tell us just a little bit more about yourself kind of in general? Outside of your work with the UCEDD, who is Mel?

Melanie Davis: Mel is... I live, eat, and breathe the disability movement. That's literally everything I do. People probably want to kick me out of the room, but I can't help it. I volunteer for a dog rescue called Husker Weim and we work on rescuing Weimaraners. I own a Weimaraner. They're a German hunting

breed. He's actually my service dog, but he's on the verge of retirement. He got some health issues. So, that's kind of how I got connected there. I do some fundraising stuff. Though, I should say that was all pre-COVID, so that's on hiatus. I am on an access team for a group called Canine Commons, building accessible indoor dog parks across the country. I don't really know how I got involved with that except for a Facebook post. It's a thing. Dog parks aren't usually accessible.

I am a board member for the Nebraska Assistive Technology Partnership. I'm a board member for a local group called Mode Shift Omaha, who their main focus is multimodal transportation within the city of Omaha. There's a larger aspect of disability inclusion there and I found that the organization really needed someone to represent that. I said a lot and they said, "Could you please come serve around our board?" I'm sure Mike can relate to this. Once they find out that you have a voice, they kind of pull you into everything. So, here I am. I'm on all kinds of stuff. I'm on two different committees for a managed care organization within the state of Nebraska. So, here I am. That's just a little bit about me.

Mike Hoenig: So, what led you to be so interested in disability stuff?

Melanie Davis: I have multiple disabilities. My main disability is cerebral palsy. I use the wheelchair every day to do everything for me to be... I can walk, but it's not a functional skill. I also have hearing impairment. Most people don't know that. I have a mental health condition, which really didn't surface till I hit college because K-12 education kind of keeps you all structured that everything's good and go. So, I have that. Life just threw a lot at me and I wanted to make a change.

Mike Hoenig: You're definitely doing that.

Melanie Davis: Thank you. Those are my reasons for being at the table, but it's not what keeps me there.

Caitlin Owens: What keeps you at the table?

Melanie Davis: People listening to what I have to say. When you feel like you're being heard, you just keep coming back. When I don't feel like I'm heard, I'll give them a couple of chances to hear me, but then I step away and find another way if it gets too frustrating.

Caitlin Owens: Yeah. That sounds like both self-preservation, but also an effective advocacy strategy, stepping away and trying to figure out if you can find another in, or another group who will listen, or something like that. It's cool.

Mike Hoenig: I think most, anybody with a disability, somewhere along the way, has gotten onto a board or a committee or some type of decision-making entity where a person has felt like being a token. Based on what you just said, Mel, about, "If they don't listen, then I move on." Have you had that experience of feeling like a token person with disability on a board?

Melanie Davis: Oh, yeah. I won't name the names of the entities but I served on two centers for independent living in Minnesota, and both the center said, "Well, you really have a great voice. You should come serve around our boards." I really didn't know what I was doing. These were my first boards. So, any in those first board meetings, you're really lost. Learning the Robert's Rules of Order for one is hard. Usually, I just kind of sat in the room. No one ever asked for my input. I couldn't read through the documents. It wasn't accessible documents for one. I'm real big on that. Mike knows that, just based on how I send emails.

Mike Hoenig: Absolutely.

Melanie Davis: When I found out that they just really wanted me there to fulfill a slot, I served out my year and left. That's probably good and bad, but they weren't serving what independent living centers are supposed to be doing. So, I left.

Caitlin Owens: Can you talk more about kind of your process or experience kind of finding your voice and what you would tell somebody who was just getting ready to... Who is thinking about serving on a board but feeling a little intimidated, or somebody who's doing it for the first time, because I hear a lot about kind of the Robert's Rules of Order? Yeah. I mean, that's something that I think freaks out a lot of people, whether or not they have disabilities.

Melanie Davis: Two things for me. I guess one, I ask a lot of questions and if they don't like it, that's not my problem. I will ask questions that people don't think need to be asked but is worth asking. Second thing is when I get on a board, if they're talking in Robert's Rules of Order and I'm not fully understanding their process, they need to break that down and the board itself needs to see that their board members aren't being able to be active. I mean, what's the reason? I guess, I kind of flip it on them. I know that sounds really strange, but I flip it on them. If you want your board members to be active, they need to know the process.

Mike Hoenig: Absolutely.

Caitlin Owens: Yeah. That's great.

Melanie Davis: The other piece of how do people find their voice? I guess, for me, I didn't have a choice. My parents said, "If you don't speak for yourself, there is nobody else." I'm an only child. So, they kind of put me in a position of, "Well, you're going to be an adult soon. We're not going to be here. So, figure out what you need to say and how to say it, and if you have to say it multiple times, so be it."

Mike Hoenig: Wow. I was really curious about that, Melanie, because we had a lot of discussions at the UCEDD and just in various places about what... We can do all the advocacy trainings in the world, but a person has to have a desire to speak up, and to be open to learning and to have that passion. You clearly have that, which is one of the reasons that I wanted you to come on the show to talk about this. So, you give a lot of that credit to your parents then, as far as pushing you into saying, "Okay, you're going to have to speak up for yourself."

Melanie Davis: All I can say is you haven't met them. If you think I'm powerful, you haven't met them. My dad passed away about two and a half years ago, but he was a Marine. So, it speaks to his training, and what he learned in the military, you don't give up. My mom, she's a nurse. So, she had to advocate for patients. And then, she was thrown a disabled kid. So, they had to advocate for me and I was part of everything they did. They say the guideline is 14. Well, I was involved to seven. [crosstalk 00:11:13] I mean, you're just there because you're their kid. They didn't have a babysitter. So, of course they went to every meeting and I went to all the decisions. Maybe I didn't understand, but I was there.

Caitlin Owens: That's great. Can you talk more about that kind of experience of being so involved in your own sort of transition planning and just sort of planning in general?

Melanie Davis: I'm going to be as nice as I can about transition because it's a point of contention for me. I didn't really have a really good transition plan because those don't really exist. We all know people who struggle with services with that, but for one, my parents just said, "You're going to these meetings. We have nowhere else for you to go. So, if you just have to sit there and color in your coloring book, so be it, but you're going to be in the room." So, I don't know that my parents really made it out to be that I wasn't a disabled kid. They just raised me as their kid. What do other parents do with their kids? They take them with them. I don't know. It was never pointed out to me that I was any different.

Mike Hoenig: We just finished a Youth Leadership Academy, but I think a lot of the young people that we interviewed do not attend their IEPs, or their meetings, or whatever. So, I think it is a real tribute to your parents that from an early age, there was a statement made that you were going to be there. I had a friend. Some people on this podcast may have heard of him. His name was Tom Slater and he was the founder of a group called the State Public Policy Group. He learned to be a disability advocate, but he had been on the state Senate in Iowa and he had been a lifetime advocate for other issues. And he said,

"90% of life is showing up." And I kind of buy into that. If you were comfortable or you were going to those meetings from a young age, hopefully there were some teachers and administrators anyway that said, "Hey, wait a minute. We can't be just talking about her. This kind of goes back to that Nothing About Us Without Us philosophy."

Melanie Davis: Yeah. No. I'm no stranger to bad teachers. I had them. I mean, my third-grade teacher said, "Well, you're not going to have recess because you don't play like the other kids." Well, that's an experience. I learned from it. My parents learned from it because, I will be honest, there was an argument about why my kid doesn't get a recess. Believe me, there was something to be said.

Mike Hoenig: Now, that.

Melanie Davis: That's pure discrimination and I had to learn what that felt like. You can't hide your kid from that feeling because eventually it's going to come. That's just the reality of life, whether you're disabled or not.

Mike Hoenig: That's true. That's very true. Let's face it head-on.

Melanie Davis: It was never something I wanted to go through and I don't think my parents did either, but it's kind of part of raising kids, to teach them how to deal with life lessons.

Caitlin Owens: I know you mentioned before we met today that you have some kind of particular passion areas within disability advocacy. Can you talk just a little bit about that?

Melanie Davis: Sure. Probably my biggest hot topic that Mark Smith at our UCEDD will yell at me if I don't say something, would be durable medical equipment access. When I talk about that, I'm talking about wheelchairs, walkers, shower chairs. People don't realize how hard that is. They have no idea how hard it is to get a wheelchair. No idea how hard it is to get a shower chair that there's even a process. I spent about a year and a half without a wheelchair and that was during my first year with the UCEDD. Because of COVID, I was fortunate enough to be virtual. So, wheelchair didn't affect me as much. Nobody should ever go that long. Nobody should [inaudible 00:15:12]. Nobody should ever go 24 hours, nothing.

I encountered so many barriers getting a wheelchair. Everything from my health insurance saying, "Well, I don't understand what the problem is. What do you need a chair for?" I want you to understand, you don't have to know anything about disability whatsoever. If someone says to you, "I need a wheelchair. I have this diagnosis," that's all you need to know. Everything else, just keep your mouth shut. Give them

what they need and move on. When you're told that, as the person who needs the thing, how are you supposed to be respectful and all the things that you're taught, because what they just said was not respectful to you?

So, I did a huge research project. Well, I say huge because the data and the information about durable medical equipment doesn't really exist. We don't talk about it. And I put it on a poster, which was very hard for me to do a poster. My brain is not set up to do academic posters, but I submitted it to SOAR. So, Mike seen it. I will hope that we get to do a continuing ed video later, but I continued the research now.

Mike Hoenig: Well, first of all, it has to be terribly frustrating. I was having a problem with getting a replacement for a long white cane a few weeks ago. I had to do a lot of searching and finally found a place to do that, but I still was fortunate enough to have a couple other ones that weren't in great shape that I could at least use them. But something as essential as a wheelchair, if you don't have that, it gets pretty difficult to get around. So, once again, I really commend you for turning a really difficult situation into something that's going to benefit lots of other people, by conducting a research.

Melanie Davis: I think the way I always look at things that happened to me is that if it's happened to me, it happened to someone else. And they didn't have the skills, the desire to know how to make the changes or to say something, so it's up to me to do so.

Mike Hoenig: It's great. Well, one of the other issues that you mentioned that was a passion of yours... We've talked a little bit about education already, but in terms of people with disabilities accessing higher ed, is that something that's a big advocacy issue for you as well?

Melanie Davis: Yeah. I'm in my fourth attempt to get a bachelor's degree, which sounds purely exhausting and it is. I'm 35 and most of my peers have long completed a master's and maybe PhDs if they wanted to or at least in PhD school. Here I am still trying to get that bachelor's screen. So, I want you to understand what that does for me socially in connecting with others and getting jobs and all the things.

But the reason I'm here, I've had multiple issues with really understanding. They give you an atlas of accommodations you can receive in college and I use them, but it's not the same as an IEP process. It will never be the same as sitting down in a resource classroom. It will never be the same as that one-on-one assistance from someone. So, I always struggle. So, I flunked out three times. I have huge issues with anxiety. Everything from testing to systems navigation causes me anxiety, directional anxiety, so navigating a college campus. Again, that goes back to in K-12 education. If you can't find the classroom, you have a teacher to ask who's in the hallway, who have seen you every day, but when you're at a college, who are you going to ask? Some random stranger that you don't even know how to talk to because you aren't in the same social classes now? So, those caused a lot of barriers for me.

Caitlin Owens: So, what do you think are some of the ways that higher education can be more accessible to people with disabilities?

Melanie Davis: I have a lot I could say there, but I think some of the main things would be... We had individualized education plans for a reason because we needed individualized supports, education, all of that. When you go into higher ed, literally everybody gets basically the same set of accommodations. I can't tell you the number of students with disabilities in college who say, "Yeah. I get extended time on tests." It's the same thing for all of us. If you're in the realm of visually impaired, yeah, they get a screen reader. All the things are the same. That doesn't mean it was the same for them when they were in K-12 education. So, what did they do different? We need to recognize those differences, I guess, would be the big thing and being able to tailor the accommodations. I don't know that college is allowing you to do so. I'd also like to see a lot more flexibility with programs such as the first-generation college student programs. They're usually called TRIO or something along those lines.

I found that those have barriers that they only help you through your freshmen and sophomore year of college. And then, they're just like, "Well, you should've figured it out." No. Just because I figured it out, doesn't mean I don't need your support. Why do you just kick me out of the program? That's been an area that's bothered me. I've gotten kicked out of the programs many times.

Caitlin Owens: Can you tell us kind of more about the experience of being a UCEDD trainee?

Melanie Davis: It's a job for me. Something many people with disabilities don't have. That's why I applied because I could get paid an hourly rate at a better wage than I would find anywhere. I get to do things that I like. I get to connect with people that understand what I deal with. I mean, if I wasn't in a UCEDD, you guys wouldn't know me.

Mike Hoenig: It's true and we're glad we do.

Caitlin Owens: Yeah.

Melanie Davis: I've enjoyed my time on SOAR. I don't really even know how I got there. I just did. That's the thing about the UCEDD or programs like that is it gives people like me opportunities we wouldn't have had.

Caitlin Owens: Can you tell us a little bit more about SOAR and the conference you all are planning?

Melanie Davis: I'm probably going to putt-putt, so I'm going to really try and if I need help, Mike can help me. I don't know if every day, I fully understand what it is, but SOAR is a multi-state self-advocate conference. I believe it's in its second year. We have breakout sessions as well as, I think the term is lead speakers or keynote [crosstalk 00:22:18] speakers.

Mike Hoenig: Keynotes, yep.

Melanie Davis: I originally was asked to serve on the social media advertising committee, and I was like, "That is not me. No. No. Can't do that." I originally said, "No." And Dawn Francis, who's also on the planning committee, said, "No. No. We really need somebody like you. And I said, "I have zero interest in social media advertising at all." And I said, "Is there any other committees? I mean, if you really need somebody else, squeeze something in." She said, "Well, we have a planning committee," and I said, "Okay, that sounds more like me. I can do that." So, that's how I got there.

Caitlin Owens: Can you remind me what does SOAR stand for?

Melanie Davis: I don't think it stands for anything. It just-

Mike Hoenig: Yeah. Actually it does.

Melanie Davis: Does it?

Mike Hoenig: It stands for Seeking Opportunities for an Advocacy Revolution.

Caitlin Owens: I love that.

Melanie Davis: Would have completely not gotten that right because I couldn't remember.

Caitlin Owens: Again, for our listeners, the four states are Nebraska, Iowa, Kansas, and Missouri.

Mike Hoenig: You got it.

Caitlin Owens: And the conference meet is every other year. Is that right?

Mike Hoenig: Yes. Yep. And this conference will be September 17th through the 19th. It will be online and it will also, for registrants, going to be archived. So, that's kind of a cool thing. The other thing about SOAR is actually an initiative of a larger project or program called the Heartland Self-advocacy Resource Network. Melanie, I don't know if you knew that because we've been so focused on SOAR that we haven't talked a lot about the HSRN, but that was a grant that we got a few years ago, for the four states to strengthen self-advocacy. So, one of the things that's going to happen after SOAR is that... We are going to have breakout sessions at soar, but for those who didn't get selected, we're going to offer opportunities for them to do webinars. We're looking forward to continuing advocacy-related stuff after SOAR, so the HSRN becomes a living entity within our four states.

Caitlin Owens: Oh, that's great. We'll put a link to the archived conference in the show notes and mark your calendars listeners for fall 2023. Hopefully, you all will be able to have an in-person conference somewhere.

Mike Hoenig: Yes. My vote is either for Nebraska or Kansas because Missouri and Iowa have had it now. So, we need to move it elsewhere. Well, we actually met one of Melanie's coworkers, colleagues, whatever. Kellie Ellerbusch, who is with the Nebraska LEND, has sort of been the point person. She just stepped aside at one of the Zoom meetings, so we nominated Nebraska to do 2023, but I don't know if Nebraska has quite joined that fully yet.

Melanie Davis: I wouldn't know, but we will see, and if they do, I'm sure I'll be involved.

Mike Hoenig: I hope so. So, Melanie... One of her many talents is plain language. One of the things that we've really tried to do is make this conference as accessible as possible. I'm not sure, Melanie, if you were the person who originally brought it up, but anyway, it came to our attention that we really needed to get the language for all of the breakout sessions and the keynotes and the conference itself, into something that's readable and not academic. So, talk a little bit about the work that you and our copartner in crime on the committee, Zach, did to clean up the language for SOAR.

Melanie Davis: I don't know. For me, plain language is just people overthink things. We don't have to talk in academic terms. You don't do it when you go out to lunch with your friends. Why do we have to do it all the [crosstalk 00:26:29]? So, it started with just every time I get an email from someone and I'm like, "I don't know what they just said." I read so many emails every day and I'm like, "I don't know what they're talking about." And I can only ask questions on so many emails because I actually have to get work done. So, when I've been involved with SOAR, all of a sudden I realized like, "Wait a minute, I don't

know that self-advocates know that they can submit their own topics to this." It was because I didn't notice that. If I didn't notice that, who else didn't notice that?

So, I think that's kind of how I brought it up. So, we've been looking at the schedule of how it's laid out. Is it easy to understand? Bios of speakers, can people understand what they mean? I'll be honest, some of those stuffs is challenging. How do you break down what somebody went through college for into a readable term? I don't and I'm really not done a whole lot with, I guess quote, unquote, translating documents or anything, but I guess when I do it, I put in words that I would recognize because if I'm going to recognize them, somebody else will too. That's just how I do it.

Mike Hoenig: Well, I wanted to ask Mel one quick question, before we wrap up. I know Caitlin, we also have one additional question, but this is sort of a shameless plug too. So, now, that you mentioned, when we were, I guess emailing before the podcast, that you really had a passion for independent living and Ed Roberts and Judy Heumann. We're very fortunate in Iowa that Judy Heumann is going to be coming in late October for a visit, or at least that's the plan. Although with COVID on the rise, who knows what's going to happen? But is there anything in particular that attracted you to... I mean, for people who don't know, these are big names and people who really started the independent living movement in moving toward a social model, and as an empowerment model, rather than the medical model of disability. So, how did you find out about them and why do they speak to you?

Melanie Davis: Well, I found out about Ed Roberts and Judy Heumann because of my Partners in Policymaking, [crosstalk 00:28:56].

Mike Hoenig: Oh, sure. Yeah.

Melanie Davis: But I think you kind of spoke to directly why they interest me and why I'm passionate about who these people are. People don't know them. We don't get taught that in higher education. You know how many friends I have that have no idea there was a civil rights movement around my life? So, when I'm out in public and people say things that are just so not appropriate like, I don't know, "Well, that place is fully accessible once you get past the first couple of steps." Those are types of statements people make and you're like, "No." And I think of people like Ed Roberts and Judy Heumann, who would say so much more than me just saying, "Well, no. That's not right," They would make something of that, make an example of these places and processes that are not inclusive. We don't have leaders like that anymore. That's just something that sits with me is that we don't have [crosstalk 00:29:55].

Mike Hoenig: Mm-hmm (affirmative). Well-

Caitlin Owens: It sounds like you're a pretty fierce leader in that spirit. So, I think give yourself a little more credit there.

Mike Hoenig: Absolutely.

Melanie Davis: Thank you.

Caitlin Owens: Mel, a question that we like to wrap up with is asking people, what would you like your legacy to be?

Melanie Davis: I never gave up.

Mike Hoenig: Wow. That was quick and succinct and to the point.

Melanie Davis: Literally, I never give up. In fact, the way my parents raised me is if they wanted me to do something, they would say, "Well, you can't do that." And I would go do it. It drove me crazy, but they said I couldn't like, "You can't make your own bed." "Well, yes I can." "You can't fold your laundry." "Yeah, I can." Well, look, my parents just got me to do all my chores because they said I couldn't.

Mike Hoenig: Hmm. [crosstalk 00:30:50] Very-

Caitlin Owens: As a parent, I'm going to maybe put that trick in my back pocket for when my kids get older.

Mike Hoenig: Yeah. I was going to say, Caitlin's got a two-year-old. He's a smart little guy. That might work already.

Caitlin Owens: Oh, yeah. We'll see. I'll test it out tonight.

Mike Hoenig: There you go.

Caitlin Owens: Well, Mel, it was so nice talking with you. Thank you so much for taking the time to talk with Mike and I.

Melanie Davis: Well, thank you for having me. It's been fun.

Mike Hoenig: Yes. Thank you and we also want to thank our loyal podcast followers. Thank you for listening and tune in again next time when we'll have another engaging guests for Disability Exchange. Thanks all.

Speaker 4: 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 the music contribution.