

Episode 4: Journey to Independence with Kelsey McVey

Mike: Hey everybody, it's Mike Hoenig from the University of Iowa's Center for Disabilities and Development at the USAID, University Center for Excellence in Developmental Disabilities, welcoming you to another episode of Disability Exchange. And I'm joined once again by my esteemed friend and colleague and many other things, Judy Warth, hi Judy.

Judy: Welcome you guys to Disability Exchange today. We're very excited because we have got probably ... second only to Mike and about 1000 other people, one of my favorite people in the whole world here. Someone who I'm especially fond of, Miss Kelsey McVey.

Mike: So welcome, Kelsey.

Kelsey: Thank you very much, Mike and Judy. It's a pleasure to be here. I'm very excited.

Judy: Kelsey is this your first podcast ever?

Kelsey: Yes ma'am. This is my very first podcast ever. I've never been on one. So I am very excited. I've never done one before ever. So, this is pretty awesome. This is cool.

Judy: For those you listening out there, just be prepared, you're meeting room one of American Iowa's was finest young leaders out here. So, make note, save this podcast because you're going to want to save it for the future when she's rich and famous.

Mike: You'll see. I heard Kelsey when? Yes. So Kelsey, tell us a little bit about yourself?

Kelsey: Well, Mike, Judy, I'm 29 years old. I live in Iowa City, Iowa. I've been living in the Iowa City Area for nine years now. Originally I am from Wellman, Iowa. That's about 10 minutes south of Kalona. And so I moved up to the Iowa City Area when I was 20 years old, and I've been living in the Iowa City Area for nine years.

Mike: So, this podcast is all about disability and people with disabilities expressing their voices. One of the things that you've taught me Kelsey, and I think us is about terminology. Because we used to say, "Well, this is an opportunity to give people with disabilities their voice." And now it's all about people with disabilities have the voice, it's just us needing to make it possible. So we're like the facilitators here.

We're just here to provide an opportunity for you to use that voice. So tell us a little bit about your experience with a disability?

Kelsey: Well, Mike, Judy, I was born with cerebral palsy. I've had cerebral palsy since I was born. I was born three months premature. I've had a lot of challenges in life to be honest, and having cerebral palsy is just one of many. But, it's a physical disability. And I've had many things that I've had to do relating to cerebral palsy. One of those was, I had surgery at 12 years old, leg lengthening surgery to just make my legs less bowed in, they're bowed in I should say, and that's where the legs are ... they're bowed in so you don't walk as straight well with the correction of the surgery that I had, it allowed me to walk straighter.

So my gait is much more, less severe than it would have been if I wouldn't have had the surgery done at 12 years old. I haven't had to have a surgery for 17 years, which I'm very thankful, I hate hospitals. But I've not had to have anything done for 17 years now. Cerebral palsy is just a ... it's a disability but it might be a disability, but it does not deter me from doing something or things that I want to do in life. So I've accomplished a lot, and I'm very thankful for everything I've accomplished, especially this past year.

Judy: Well Kelsey, you bring up something there, that you've accomplished a lot. Do you want to share with people some of your accomplishments and go back and hit some of the ones in the past too. I know this past year has been a big year. But, what was the first thing that you felt like, "Wow, I'm taking off in this life and it's going to be mine." What are some of those things that happened?

Kelsey: Yeah, some of the things that happened for me is at 20 years old, one of the things was that I moved out of my mom and dad's house. And I had to start in steps, but I lived in a group home in Iowa City for about a year and a half. Then after that, I moved to living with one roommate at the complex I'm currently at, then I moved to live by myself at the same complex, I did that for four years. And now I'm living with my partner, and I've been with him for about four years and we now live together, and we've been living together almost two years. As far as personally, I've accomplished a lot there.

Judy: Yeah, you're talking about some pretty positive changes in your living situations. For those people who might not really know what the differences are, you talked about living in a group home then living in an apartment with a roommate then by yourself and now with a partner, what are some of the differences? What are the good and bads about those?

Kelsey: Well, first off, living in a group home and I did this from age 20 to 22, or almost 22. So with living in a group home, I had to deal with so many different personalities, personality clashes. It was ... Oh gosh, that was difficult. I was 20 years old but, I was in a 24 hour situation. So they were treating me more like a five year old child than a 20 year old adult at the time. So yeah, that was hard to handle. And then living, and then going from that to living with one roommate. And that was a little bit easier. But I

had to do all the chores, all this stuff that came along with that. My roommate at the time ... oh, gosh, she had a hard time keeping clean.

So I had to help with the chores more so. So that really irritated me very much. And then living by myself obviously got easier. Did that for four years and now living with my partner, it's been a wild ride, I should say.

Judy: So just for clarity's sake, is Jon is he a neat freak like you?

Kelsey: He likes to keep things very clean like me. I'll say he's not a neat freak, but he enjoys keeping our home clean and tidy, and we're both very clean and tidy individuals.

Judy: That's good news for him.

Mike: Yeah. Hey Kelsey, one of the things that I think is really interesting is that there are a lot of people with disabilities that were probably in situations similar to yours, that continue to live at home well into their 20s, 30s, 40s and sometimes, families haven't necessarily even planned for the day when their son or daughter has to move out. So I'd like to hear a little bit more about you moved out at a really early time to about when a lot of students or a lot of people without disabilities are still hanging out at home. So was that a thing that you and your parents talked a lot about and mutually decided or was that something that you pushed for? How did that come about?

Kelsey: Really Mike Judy, it was a combined effort. I really wanted to be out of mom and dad's house before 20 years old, but I needed to finish high school first. At 20 years old I was at that time where I was ready to move out, not living as independently as I am now, because I needed to start somewhere. I needed to be out of mom and dad's house first before thinking of the next steps. So, in order to make that happen, mom and dad and I we looked into some options, so then we found my provider that I've been with for nine years now, reach for your potential. I've been with him for nine years. And they're a great company. The people are awesome.

So it just took motivation. The first time when I moved in the first time to the house that I lived at, it was a very nerve wracking time, it was emotional for me, I had never lived out of their house. I had been there since I was a baby really. So it had been quite ... it was a journey for me at 20. I had to move out when people were moving out at 18, I started at 20. So I had some obstacles to get through but, I managed eventually. But I had [inaudible 00:11:01] the score to mom and dad from the get go. And yeah, it's been great ever since as far as just going from one place to the other.

Judy: What made you decide Iowa City versus staying in Wellman or going to Washington? I believe there were reasons you came up here?

Kelsey: I do not drive. I wish, but I don't drive to be honest, I really don't. So I have to I take Johnson County Seats. And Johnson County Seats is a transportation provider. I've ridden with them for about nine years. So about as long as I've lived in Iowa City, I love them, they always come to my door, whenever I ... to be able to be picked up, and I wait for them and they're great providers, and the people are nice, the drivers. I love having them four days a week with me to be able to drive me up there. Sometimes they're a little bit later in the window, sometimes they're late.

But I've managed to keep my emotions in check [crosstalk 00:15:54] because it's not always easy. I'm sure all you guys, I'm sure understand. It's not always easy, transportation even for people that can drive themselves. Sitting in traffic is not always fun. But, I manage. [inaudible 00:16:13] I talked there, you're off to keep them busy.

Mike: Keep them awake.

Judy: So hard for me to imagine, but I'm thinking Johnson County Seats is going to take a clip and use this as a new marketing thing. You spoke extremely highly of them. How can you said a lot of good things about them, how come you don't ... What about the bus? Iowa City Transit?

Kelsey: I don't feel comfortable taking the bus just because Johnson County Seats, their bus is smaller in size and the people that ride with me, when they do ride are the same folks. Riding Johnson County Seats, they are a smaller bus service, I feel comfortable with them and I trust them to come and get me and I enjoy it and I continue, I enjoy using them. So I want to continue with it.

Judy: So sometimes for people with disabilities having transportation that is smaller and feels safer and more convenient is really important?

Kelsey: Yes, that's what I was trying to get to.

Judy: Yeah, I think you said it well. I was just making sure I got it right.

Kelsey: But yes, you did get it right. That's exactly. Just having a smaller people sometimes ... I'm very good in big crowds as well. But when it comes to transportation, I prefer to just have a smaller amount of people. It creates less stress.

Judy: When it takes you right from your home to where you're going instead of transferring buses and such.

Kelsey: Correct. Yes. And so it just makes it a lot easier that way. Yeah, for sure. So that's why I love it so much.

Judy: So you've talked to us a little bit about living, and you've talked to us a little bit about work.

Kelsey: I have.

Judy: What about learning? What have been some of the milestones for you in terms of your learning and education?

Kelsey: Wow. Well, 10 years ago, I completed high school, got my high school degree, I didn't think 10 years ago I'd do ... 10 years later excuse me, that I would be doing ... or that I would complete a college level program, and I did. I did that and I didn't think I would be able to do it. But I had the support of Mike and Judy and Ed and just all these wonderful, wonderful people that ... the other trainees, I was a ... so I'm a former ILEND Self Advocacy Trainee. I'm a self advocate now. Just because you have a disability, you don't give up on learning after high school because you're going to find those other opportunities.

And yeah, May was a busy month for me.

Mike: So just to clarify, I know that we talk about ILEND a lot in these podcasts. Do you remember what ILEND stands for?

Kelsey: So ILEND stands for Iowa Leadership in Neurological Developmental Related Disabilities Program.

Mike: Yeah, I think education might be in there somewhere.

Kelsey: Education, yes. Sorry, yeah.

Mike: No, you're good. I think we got it all in.

Kelsey: Trust me. I've remembered it many times the full time before. But yes, that's what it stands for. Yeah. And it is a amazing program and they're funded. And they do an amazing job with all these wonderful trainees. I had the opportunity, the gracious opportunity to do this program, and I did it. I didn't think I'd be able to do it because it was 300 hours of painstakingly work, but I will say it was also very rewarding and heartwarming, just all the emotions in the book. Yeah. And having to handle that virtually, that was a challenge as well. But, I did it and I completed it and I got my certificate.

So I'm very proud to sit here and say that it was one of the best things I could have ever done.

Mike: What were some of the things that you liked about ILEND the most Kelsey?

Kelsey: Yeah, wow. I liked a lot of it. I will say that it was one of the things I loved about ILEND is the camaraderie of the trainees and the people that we worked with. The other thing is that just everything that we learned. From what people's disabilities we're, and I learned and saw that even the students, University of Iowa students, a lot of them are dealing with things such as anxiety, which I didn't think that ... I thought it was just people with disabilities deal with anxiety, but people without disabilities can deal with anxiety too and, knowing that I wasn't alone doing this program, that was very helpful knowing there was a lot of support.

But, I had a lot of favorite things. But I will say the camaraderie and and the joy of being with everyone and being social was probably my favorite thing out of everything. But I learned a ton as well. So it was great.

Judy: Kelsey you keep talking about these other trainees. What sort of trainees take part in ILEND?

Kelsey: Anyone can do it. If they put their mind to it. But as far as-

Judy: Can you remember some other disciplines?

Kelsey: Yes, I do. I remember a lot of them. So we had an audiology trainee or trainees, there were a few of them. So, audiology is hearing and things like that. And then also, we had a community trainee, that was the first time they've ever had a community trainee. Which I was quite surprised, because it's such a great role in general. And then we had two self advocacy trainees, me being one of them. And so that was, they've done that what? For four ... this will be-

Mike: [crosstalk 00:23:44] number five, yeah?

Kelsey: Number five this year, which is pretty exciting, because I get to mentor one of them.

Mike: Who would that be?

Kelsey: My partner, John.

Mike: Oh, so he's going to be one trainee this year?

Kelsey: He will be, yeah. I get to just support him, so I'm very excited. Yeah, there were just a ton of different trainees, and that occupational therapy speech, everybody was in the pool, just to name a few. But I know there was a lot of them. And I know there's a lot of disciplines. Oh and we had a few family trainees as well, two of them. So a lot of different variety. So just all the people came together and I think it was really great just to be part of it.

Mike: One of the things that made this last year's ILEND really challenging in many ways was the pandemic. So, most of the interaction except for maybe the orientation at the beginning, was done virtually and online. Was that difficult for you? Obviously, you adjusted to it because you completed the program, but was it hard at first to be doing these classes online?

Kelsey: Well, I will say I think the hardest thing to do them online, not necessarily getting for the Zooms, when we did our seminars, but to adjust it was at first because up until doing ILEND I had never used Zoom before. So it was a new experience, but I've become a pro at Zoom. Now, I know what I'm doing with it now, but in the beginning, I will say it was a challenge. So I had to adapt ... I enjoyed the orientation, because we I got to meet who I was going to be in the cohort with me. But doing ILEND was a challenge in the beginning, especially with Zoom, but I managed that well.

Mike: It's definitely a different way to communicate.

Kelsey: Yes.

Mike: Just tell us a little bit. I know that there was one time when you had to come into the office, near the end of the academic year, I don't exactly remember what it was for ... Oh, I think you observed a telehealth meeting.

Kelsey: I did, yeah.

Mike: And so then you got to meet some people. Obviously, you knew Judy, but I think you met some of the other staff and maybe even a couple trainees, what was that like, after all that time and COVID. And then to being able to meet some people in-person that you'd been interacting with all year?

Kelsey: Wow. To not have to see them on the screen, was a very, almost like an out-of-body experience, if that makes any sense. Just being able to see them in-person. I've seen Judy over the years, so I know what she looks like. But, as far as the other trainees, some of them that were in the office that day, yeah, it was really great to actually put faces to names. And just to be able to say hi and catch up a little, it was really nice. Because over a screen that's different than in-person. So it made me miss being social. I'm a social butterfly by nature nowadays.

Mike: It's good.

Kelsey: Yeah.

Judy: Kelsey, you talked about ILEND being a leadership program. What leadership skills did you acquire, do you think?

Kelsey: Wow, I have to say that ... I acquired a lot of leadership skills. But it's just like, there's a lot that I learned, but for leadership though I would say how to first and foremost, what was my discipline? Self advocacy. So I learned how to advocate and I've advocated even before ILEND just with my friends, helping them but doing ILEND and with it being a leadership program, I learned how to do it even further. And they went a little more in depth and so that was neat. So, I got to see that, oh it's a little more in depth than just helping your friends out, so to speak.

But I got to ... yeah, leadership skills, advocating. Number one, like advocating further. And then just obviously, asking for help, which I'm very good at doing, but just having to ... I had to every once in a while. And then learning to work in groups again. That was a challenge over Zoom, that was pretty neat. Just everything was really cool. But, yeah leadership skills I acquired quite a bit of things. But yeah, advocacy in furthering that, and realizing that, oh, it's not just helping your peers out that it's other things also.

Mike: Well, I know that you had a couple of several first [inaudible 00:30:09] ILEND. But one of the first that I remember real distinctly is that you had your first two opportunities to speak with legislators, first

state legislator and then a our federal ... your local state or not your local but your representative in Congress?

Kelsey: Yeah.

Mike: So what was that like and ... I remember you saying once, "It was a little easier the second time." So what was that? Were you nervous? How did you feel about going into that process?

Kelsey: Well, the first time around mic duty, the first time around ... gosh, oh, I will say the first time it was emotional. Because I didn't think that I would make an impact like I did the first time. Yeah, the first time was just [inaudible 00:31:03] I didn't really know what to expect the first time around. But Representative Bergen, who I spoke to ... oh gosh, he was so warm and kind, and that made it a little easier even though I was nervous and in tears, just because I knew I was making an impact.

But the second time around with Representative Miller-Meeks, she was also very warm. But that got easier with that one, because I knew what to expect so I didn't get as emotional, since I knew what to expect and she made it easy going like talking to a friend.

Mike: And I understand that she requested to meet with you and with the family trainee, maybe sometime this summer, right?

Kelsey: Yes. And I haven't heard anything about that yet Kelly. One of the girls that I had talked to about that said she would be letting us know when that would be happening.

Mike: That would be great.

Kelsey: And I'm hoping that it's still going to happen, because I really do want to meet her. So that would be really great, especially after speaking to her, that would be just an amazing opportunity, and I hope it happens.

Judy: That's pretty cool Kelsey, thanks for sharing all that. So you've covered living, learning, working. And you told us that you've got somebody who you're living with. You said you've got a partner, can you talk to us ... Lots of people out there go, "Oh, wow, people with CP don't get married and don't have partners."

Kelsey: Right.

Judy: Can you talk to us a little bit about all of that, and how that's come about? And why and if you think it's important for everyone to know?

Kelsey: Well I think that this topic is very important for folks with disabilities, especially to know, because not everyone is able to do that. And I feel lucky that I am able to and got the opportunity to do it after. And it's pretty awesome. One of the things I will start out by saying is that two years ago, we had a commitment ceremony. For all you people with disabilities out there that don't know what a commitment ceremony is, essentially, it is a wedding, but you are not ... A commitment ceremony, you don't legally bind. So, you don't have to sign anything at the end, if that makes any sense for you guys.

And my partner and we did the whole wedding dress tux thing, so that it would look very traditional, because I wanted it to be as normal, and as possible, because this was my one time in a wedding dress. I had my moment in my prom dress 10 years ago, and I wanted that. But I wanted my wedding day, essentially. But we had to do a commitment ceremony and-

Judy: Why was that Kelsey? Why would you be committed to each other versus married? Why did you make that decision?

Kelsey: We made that decision, because both myself and my partner are on disability SSI and disability. And in order to make that happen, we needed to know that if we got legally married, our benefits would get cut by a third, like that. And so in order to keep things how they are and we're going to be, we needed to just not legally bind but we have bands, so wedding bands that we wear. Yes, we have wedding bands, because we want to feel as ... So we are, but I look at it as we're married to in the heart. We might not be married legally, but we're married here in our hearts.

And that's what I tell people. What's commitment? Commitment is how much you love a person. It's not a piece of paper. So for us love is what matters and the commitment to each other. But we love each other, and we did the commitment ceremony to show how much we love each other, we wanted to do it because of that.

Mike: It's one of those systems issues that sometimes gets called a marriage penalty, that maybe because you have personal experience. And I know you've shared that with several different audiences even since ILEND, that maybe someday you'll have a chance to really make an impact to change. Wouldn't that be exciting?

Kelsey: Yes. I hope so someday. Wouldn't that be really cool? To see that happen. But you know what? We're happy with how things are, we were able to ... and Judy's in agreement here, we were able to do

what we wanted to do, it might not have been the normal way, but we were able to make it happen and I'm living with him. And that's another thing I wanted to do. It's exceeded a lot of goals. Those were two things in my personal life I wanted to make happen. And I did, even if it wasn't in the normal way, as far as the ceremony, but we made it as normal as possible for us and our family.

Judy: Kelsey, I know there's somebody out here listening, they just called in, okay they didn't but, are you guys going to have children?

Kelsey: We are not. I am on birth control. I've been on birth control for 10 years now. So I use it for me. And then my partner is on birth controls, or and he uses it as well, so he wanted to make sure I was protected, so to speak. So, children is not in our future, a lot of things are but that's not one of them. We're a happy couple. Just children's not in the mix.

Judy: Absolutely. And it's great that you have that choice and you're able to make that decision.

Mike: It sounds like you've both given a lot of thought too.

Kelsey: Yes. And it's-

Mike: You know what you want.

Kelsey: Yes, we do. And we are very happy. We've got social lives, and we've got each other and our families and we've got a lot to be very proud of. So it's a joy really.

Mike: So Kelsey, you mentioned a lot of times today that your social. So, other than hanging with John, what are some of the other things especially now that we're starting to come out of the pandemic here, what are some of the things that you'd like to do for fun?

Kelsey: Wow, well, I like to do a lot of things. Some of those things include hanging out with friends. We have pizza parties at John and I's home, we get together with ... I like to call them our crew, the same people we hang out with on a daily basis. About every two weeks or so we get together for just eating and enjoying each other's company. But then I'm in Special Olympics, but right now with the pandemic and especially this year, I'm not comfortable yet getting back out into it, I'm not ready to do it yet again.

But prior to the pandemic, I was doing a lot of things with Special Olympics activities such as buckyball and I did track for five years.

The ages 17 to 22 I did Special Olympics, I should make that very clear, Special Olympics track. So I did that for five years. I enjoy my activities and my friends. And John and I have a lot of the same friends. So we hang out with a lot of the same folks. Oh yeah. I really like to watch movies, and I love cooking. I love healthy meals these days, especially because I've been eating more in, instead of ordering takeouts, if that makes sense, so yep. So I'm a very good cook. I've learned that over the years.

Mike: During ILEND, I had the privilege of being one of your core faculty advisors along with Ed and of course Judy. And one of the things that we ended up doing is talking a lot about goals, and I know that you are one of the things that happened in ILEND that you haven't mentioned is that you really I think, caught the advocacy bug. And now that ILEND is over, I know that you've applied to be on the DD Council for one thing.

Kelsey: Yes.

Mike: Have you heard anything back from that yet?

Kelsey: I haven't yet.

Mike: Okay, well, hopefully-

Kelsey: I'm still waiting. Yeah, so I'm still waiting on that.

Judy: Kelsey, do you remember some training that you took part in? That was developing your leadership skills? You want to share about that?

Kelsey: Sure. I was just waiting for the right time to-

Judy: Well, it's now-

Mike: This is it.

Judy: ... it's now, right after the cheesecake.

Mike: Yeah.

Kelsey: Not on camera. No. Okay.

Mike: No cameras here.

Kelsey: Okay. So I will say some of the ... I did do another ... and before like I said, May was a very busy month, not only did I finish ILEND, but towards the end of the month, I did another training, and it was four days long or so, and it was a sexuality educator training. Train the Trainer training. It was four days long, I did it, and it almost felt like taking ... I'll be honest, the training felt like I was taking parent Ed again, kind of. Some of the terms I heard were, oh, I heard that term in high school. It was an amazing course, thanks to Judy and all her hard work for [inaudible 00:43:18] and doing it because I learned a ton. Some of the stuff we talked about, made me blush a little bit, but what doesn't?

It was an amazing opportunity and I'm glad I did it.

Judy: Ready to teach?

Kelsey: Am I ready to teach?

Judy: Ready to help teach about-

Kelsey: Am I ready to help? I am but who's not nervous? I'm nervous, but I feel like I could do it. I did the training to learn how. So I think it'll go smoothly.

Judy: Kelsey we've been asking everyone who's been doing this about, we know you're still a babe, young.

Judy: But, oh, that's right. Almost all. When everything passes, what do you hope your legacy is? What do you hope people remember about Kelsey McVey? What's your mark?

Kelsey: Oh, I see what I want to leave on the world?

Judy: Mm-hmm (affirmative).

Kelsey: That is a very emotional thing for me to talk about. You don't want to die. But everyone's going to. That I was a good person, that I achieved my dreams, and I'm a self advocate, that I learned to advocate.

Mike: So 80 years from now, [crosstalk 00:45:06] be able to say that yeah.

Kelsey: Yeah, definitely. I hope so. Before I pass for sure, I've got a long time. So, I don't want to think about it. But for sure. Certainly. What I want to leave on the world is that I also had a lot of spunk of course, and that I managed my disability well. And also I kept my emotions and my anxieties in check. Because that's always been difficult for me, but that I managed them very well, but also people that know me also know that I have a very kind heart and that I've been through a lot, that I have a kind heart and that I hope I made an impact on the world. And I know I'm going to. But yeah, that a lot of people will know that about me.

Judy: We hope that the people listening to this are some people in the community, some people who want to be their own self advocates. Maybe there are some people who are providers. What advice would you give them? They go, "Oh, my gosh did you listen to that today? That's Kelsey McVey." What advice do you want the world to know about disability and what are your lessons?

Kelsey: Well I got a few here that are really important for everybody with disabilities You guys can do whatever you put your mind to. For me, advice for me would be just stick with it, don't give up because I didn't. It gets tough out there sometimes, and you don't always get what you want in life. But if you go after it, it may be able to happen but you got to persevere, and I did. And a lot of things have happened for me. But you just got to try. Put yourself out there. It's not too hard if you just give yourself courage, talk to yourself, talk to people that care about you, family, friends, providers, co-workers, anybody that you want to talk to.

Open up to them. I had to do that several times and it wasn't easy, but I managed and having all the experiences I have had, has definitely helped me. So, just persevere. That's some of the advice that I would give.

Mike: I think that's excellent. And you certainly are a model of that Kelsey, whether it's been in your own personal life with moving and moving forward and with your life with John now and now moving on into the next phase where you're starting to be able to mentor and, you've definitely are a model for perseverance. So, it's been really awesome talking to you today, and we hope all of you have enjoyed it as much as we have. Somehow I think you have, and we invite you to join us next time for another exciting and inspiring episode of Disability Exchange.

Judy: 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 in Development at the University of Iowa. Special thanks to Kyle Delveau for the music contribution.