

Episode 7 - Living with Acquired Disability and Advocating for Change with Michael Penniman

Mike Hoenig: Hey everybody. It's Mike Hoenig from the University Center for Excellence in Developmental Disabilities, UCEDD, excited to welcome you to another episode of The Disability Exchange Podcast. I'm very excited to be here. We'll be introducing our special guest shortly, but first, Caitlin, take it away and introduce yourself.

Caitlin Owens: Hello, my name is Caitlin Owens. I'm one of the co-hosts of Disability Exchange and ready to get in to this conversation with Michael Pennimann.

Mike Hoenig: Well, I've had the privilege of knowing Michael for the last, I don't know, several years now. We actually tried this on an episode of Hello, It's Us a few years ago with Michael, and unfortunately he didn't get recorded, but we're going to have a much better result today. So, Michael, I want to welcome you to Disability Exchange and invite you to introduce yourself.

Michael Penniman: Hello. My name is Michael Pennimann. I am a 29 year old individual. I just graduated from the University of Iowa this past fall of 2020, and I identify as an individual with an acquired disability, and that disability is a spinal cord injury that left me a quadriplegic individual from the neck down.

Mike Hoenig: To the extent that you're comfortable, tell us a little bit about when you acquired your disability, how it happened and kind of what some of your first reactions were.

Michael Penniman: I acquired my disability January 28th, 2012. I was just simply messing around. I was a sophomore in college at Kirkwood Community College in Cedar Rapids, and just simply was hanging out on a night in with some roommates and friends. We started horseplay wrestling, one of the guys and I, and he put me in a wrestling hold and started to squeeze. Tried to tap out like you do just to say you kind of give up, and he squeezed a little harder and that's what caused my spinal cord injury. I kind of just knew immediately with the loss of feeling, loss of control and everything that there was an injury. Tried to guide my friends to help me in the moment of panic, and I guess from that moment forward just kind of knew that things would be different and change.

To the University of Iowa Hospital where I began my recovery and kind of learning how to live and manage a new life as a paralyzed individual. One of the unique things though about that injury is with a spinal cord injury, you're either in a complete injury, which means you severed the spinal cord and have no ability to kind of regain anything below your level of injury, but I was an incomplete injury. So you never really know what you can get back, and through therapy and stuff I've been able to get some things back.

Caitlin Owens: Thank you so much for sharing that, Michael. Can you talk a little bit about how your, I guess identity as a person with a disability and maybe also just your self advocacy journey has evolved since your injury?

Michael Penniman: As far as my identity, like I mentioned, I just knew right off the bat that I was injured, kind of saw myself as a, immediately off the bat, kind of like a disabled individual. I realized that everything in my life now I was going to need help with in a sense, and really had to put all of my faith and life in others' hands from the start. That was a lot, but I quickly learned that I could rely on the providers, my family, my friends, everyone around me that was coming to help out and stuff. Really in those early years it was just relying on everyone else, but once I was able to kind of gain the strength through therapy and rehab and those initial years, kind of learned to get up in my chair, and just my identity changed from just being a disabled individual now relying on others kind of live my life, figure things out to kind of taking back control of my own life and getting back in the drivers' seat of...

I was a sophomore in college when I was injured so I still had education dreams. I, through therapy, realized that I could still do some of the same things that I wanted to in life, whether it be sports, working out, whatever that there were possibilities. So kind of began to focus on not just recovering and needing others' help, but kind of stepping into, how do I get back to these activities that I love and higher education, and started scheduling my own rides to get to those classes, started getting to therapy on my own, and kind of driving my own life. Graduated from DMAC, hunting, adaptive rock climbing, adaptive fishing, and that's when I was finally able to really fly the coop and get to the University of Iowa. Because my parents, even though they were supportive in those early years, they were pushing me too, which I am very thankful for, to give back. And so my parents and siblings pushed me to not become complacent.

And so in 2016, 4 years after my injury, I transferred to the University of Iowa where I would start my journey in Dirty Burge, the dorm, and begin at Iowa as a full-time student. And I was going to be living on my own and was going to do this through traditional home care. In those early months after transferring to the University of Iowa, I kind of quickly realized that traditional home care, it was working. It was able to get me through the day, but it wasn't allowing me to continue to grow and stay in that driver's seat. It kind of quickly began to fail me. It was too much to not only just live on a daily basis with this care, but to be really prosper and be a student that was on time, and additionally being able to get involved in things that I still loved here in Iowa City like I was in Des Moines. It was just too tough. Home care didn't really allow for that because there was some unreliability in the care that I was getting.

It continued to decline where there were a few days where people didn't show up in the morning and I wasn't able to get out of bed. So I had to really rely... I was lucky, my brother was here at Iowa when I transferred in those early years and had some good friends as well. And eventually just kind of said, this home care situation isn't working so I need to find a solution and realized that with those students stepping in to help and my brother stepping in to help, that's where I was getting the best care. So I transitioned to a waiver option that Iowa has where you can take your Medicaid funding and put it into a Consumer Choice Option, or a CCO waiver. And what that allowed me to do was instead of using home care, I would now be hiring, training, onboarding, and scheduling all of my own care and staff. And that's where I targeted college students to begin providing my support.

The benefits were immediate. There was just a sense of understanding with my fellow students and just a sense of care that they knew what it took to have to be on time to a class. And so that was great. And like I said, the benefits were immediate, my health improved, my attendance improved in classes, my involvement in the community and social life was able to improve with using fellow college students.

Caitlin Owens: That's really interesting. I think a lot of times when I think of consumer choices option, I think of it being an option kind of exactly like you said, so people can sort of skip the agency and have a little more control in that way. But the idea also of the huge benefit of being able to hire people who are in a similar stage of life and have just like a shared kind of understanding of the environment that you're currently living in is such a hugely important benefit, and just something that I hadn't thought of. That's really cool.

Michael Penniman: Yeah. It was great. They became my caregivers but also just friends too. Anyone that kind of came on board, there was a sense of friendliness and being part of the community and just each individual brought their own kind of unique character or interests that really pushed me to kind of explore and get involved or got to see different opportunities from each kind of caregiver that helped out. So that was kind of a unique thing and got to really learn a lot from each individual college student that I hired, or kind of learn new unique interests and kind kept life interesting too.

Mike Hoenig: So Michael, one of the things that I happen to know about you is that you didn't stop with just identifying caregivers for yourself, but you expanded that, recognizing other college students that might have been in somewhat similar situations to you, probably were facing some of the same barriers that you were. So talk to us a little bit about how you went about addressing that.

Michael Penniman: So like I mentioned, it was transitioning myself from home care to hiring my own care. The benefits were really just immediate and they stuck around and I grew my care team as big as I needed to support myself and just realized how beneficial this was, how great it was, how much it increased and made my college experience better and academic experience better, both through my ability to get better grades but also just get involved in the college experience and community that others could benefit from this as well. And just so happened I ran into a good buddy now, just outside airliner one day, getting food, his name's Derek Esbek and he was in a wheelchair. Didn't even know who he was, but just started talking to him one day with a good friend, Peter Eastler and realized he was me, but he was kind of struggling, needed better care and was looking for that sense of involvement and belonging with his fellow students.

I know Peter and I thought, what great opportunity to kind of guide him through the same kind of system that I had just transferred to and learned how to use with hiring fellow students that we decided to just start a nonprofit here in hopes of benefiting others the same way that I had been benefited from hiring students. All got together one day and applied for a nonprofit seminar at the college of law. That was a 12 hour process where the three of us founded this nonprofit called Students Care, all in one 12

hour day with that goal of teaching and training others how to hire, train, onboard and schedule their own care so that they could have a reliable system to not only receive care, but get involved in their college community. And so Derek who I mentioned earlier was our first client through Students Care and he saw the same immediate benefits.

We helped him through that process, kind of taught him to be his own self advocate with that waiver system, help train his own caregivers and everything and find caregivers for himself, and then also set up times for him to go to games and get involved, and just go out to eat with friends in the local community. It didn't stop with just Derek, we started putting job ads to get others involved. And soon we had almost 10 individuals with disabilities a semester that we were training how to use the CCO system so that they could get better care and college involvement or to use our assistance program to get tutoring, note takers and any other resources they needed.

Caitlin Owens: That is so cool. And it's such a beautiful example of self advocacy sort of just very naturally evolving into systems advocacy. And I will also say, I remember reading about that in the newspaper many years ago.

Mike Hoenig: I really like the model too, because you involved people with and without disabilities and it began with friendships and expanded. I know that Derek, I believe pretty early on in the process that you guys started that organization, his dad went out of town and so he really needed that service. And I'm sure there are probably other testimonials too, but I think that just the fact that you were there providing that service and helped him get through a pretty difficult spot meant a lot to him.

Caitlin Owens: And another thing I love about it is, it sounds like what you're really doing is you're providing this education and consultation to people on how to utilize CCO. And so you're really kind of giving them the tools also, because those things can be so complicated and bureaucratic. So you're taking this really complicated information and you're helping it be more accessible to people, but then that's also giving them the tools to kind of like sustain that, well after they're in college. So that's really cool.

Michael Penniman: Yeah, absolutely. Like I mentioned, it was a learning process. It took years to understand the system and all the paperwork and bureaucracy like you mentioned. Once we founded the nonprofit, that was kind of the goal, was to help individuals fast track that process and really teach them everything just to get through that process quicker, to get the care that they need and the support they need to be not only healthy individuals from the care but then be able to get involved and just do the things that they love. And it kind of made them their own self advocate, make their own platform and lay the foundation for their future with this care that they now understood how to utilize.

Caitlin Owens: So let me also ask, I know this last year you were a LEND trainee in our Leadership and Education in Neurodevelopmental Disabilities program. Can you talk a little bit about that experience?

Michael Penniman: Yeah. The LEND experience was an unbelievable experience, and I'm so glad that Ed Esbek reached out to me to apply. I didn't really know what I was applying for, but I was happy that I did and got through the interview process. I applied to be a self advocate role and that didn't work out, but I guess they liked me. So they brought me on still as a community trainee for the LEND program, kind of created a new position and I was able to get involved that way. It was right after orientation, just being able to see all the interdisciplinary roles and kind of understand what I was going to be doing with learning with and together with all these different healthcare specialties that had the goal of just really creating a better healthcare system and process of healthcare for individuals with disabilities, was just an amazing opportunity.

Mike Hoenig: Was there one particular part of LEND, Michael, that you felt like really kind of had a major... It sounds like it had an impact in many ways, but was there one area in particular that really stood out for you?

Michael Penniman: Yeah. There's a few things that stood out that I can talk about. But one of the goals that I had going into the program was I have a lot of knowledge with my acquired disability and physical disabilities. And that's primarily what we assisted with, also through the nonprofit Students Care that I mentioned. One of the big things that I wanted to learn in areas that I felt I could improve and advocate veteran was intellectual disabilities, specifically those on the autism spectrum disorder, so that we could include them and properly helping them through the nonprofit as well in their educational and care needs.

One of the biggest learning moments that helped me with that was being paired with my PAM family, parents as mentors. Mine was from Puerto Rico actually, which was really unique because there was an additional language barrier there, where they spoke only Spanish. So it gave me the insight to not only learn about [inaudible 00:21:26] intellectual disability and someone who deals with seizures and how that impacts their life, but then how to work through a language barrier and how that impacts someone's life. And it was just every meeting we had with the family or communication was just such a learning experience and just eye opening to things that I never would've thought of with how to access care, to just how to even get to a doctor's appointment in a different country, or like I mentioned, with a language barrier. There was just so much learning involved in that process and left me with a lot of lessons that I still carry today.

Caitlin Owens: That's awesome.

Mike Hoenig: And we talked a lot about when, on Disability Exchange, and one of the hopes is that those of you that are out there listening, people with disabilities, family members, support people, that this is a really cool opportunity. It's not for everybody, it's a lot of work, as Michael found out real quickly, but there's just a lot of learning. And I mean just things that you shared Michael, about being able to have better understanding of what somebody with an intellectual disability deals with and the cross-cultural issues, learning about another culture. Those are really big takeaways.

Caitlin Owens: Well, Michael, as we're kind of wrapping up here, I'm wondering first, is there anything that we haven't really asked about or touched on that you wanted to talk about or mention?

Michael Penniman: One of the other great opportunities I know that I've been able to be involved in is the patient trainings that we do. And that's been a great experience. The opportunity is I get to go in and speak with first year graduate students, a makeshift healthcare setting where I'm in what's kind of like a doctor's room and they come into me and they have a half an hour to pretty much ask any questions or gain any insight that they want from me as a disabled individual, or even just put hands on someone who has a disability just to gain that sense of comfort.

It's just amazing, breaking down the barriers and that I'm just another person, there's nothing special about me besides just that I have a disability, I'm no different than anyone else. So it's really, really cool to see these individuals that come in and get this training, just have us leave the room with a sense of comfort and a sense of excitement with. That they know that I'm just another person that they know how to treat now and have that comfort to approach anyone who comes into their practice in the future that they interact with.

Mike Hoenig: Michael, we're really grateful to have your perspective in those trainings. We tend not to have as many people with an acquired disability and the fact is, they're probably going to run into somebody or many patients over the course of their careers that have all kinds of disabilities. And so we're grateful for your participation and whenever you can... And join us for that. And that's, again, one of the benefits of just getting involved in programs, whether it's like LEND or putting yourself out there as Michael has. That is a great way to get yourself recognized and get involved with some of these activities.

Caitlin Owens: Michael, as we wrap up here, we have a question that we have started asking everyone, and that is, what would you want your legacy to be?

Michael Penniman: Oh man, it's kind of a tough one. I'm just an open approachable individual and I'm here to be a resource for anyone that does have a disability and that hopefully I can be seen as kind of like a trailblazer doing things differently. The system as it is, there's a lot of problems and things that don't work within it. I have had to advocate and fight battles and approach things differently in the

system to benefit not only my life, but others' lives. So if I can be kind of a trailblazer in that aspect and continue being, not only a self advocate but an advocate for others and working and learning in this disabled community through programs like LEND and things like that, to continue gaining my own experience and knowledge to help myself, but not only others. That I think I can be someone that really creates a lot of system change and benefits, not only myself, but anyone with a disability in our state or our nation.

Mike Hoenig: I would say that you're definitely living out that legacy, which is really a privilege, when you're wanting to leave that footprint. And you're doing it, as we speak. So we really would like to thank you for joining us today Michael, it's kind of great experience to learn. I thought I knew you pretty well, but I've learned a lot of new things about you today and trust that that our audience will have learned a lot from you too. And so I also want to just thank our audience for tuning in and invite you to join us the next time for another very interesting guest on Disability Exchange.

Michael Penniman: Yeah. Thank you for this opportunity.

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.