

## Episode 1: A Lifetime of Advocacy with Mike Hoenig - August 4, 2021

- Welcome to Disability Exchange. My name is Caitlin Owens.

- And I'm Judy Warth.

- Today, our guest is actually our third co-host, Mike Hoenig, and we're gonna talk with him a little bit about his own journey as a person with a disability. And we're very excited to have him here.

- Thanks for having me. I'm very excited to be here.

- So Mike, why don't you start out by just kind of telling us and our audience just a little bit about yourself?

- Well, my name is Mike Hoenig, and I grew up in Fort Madison, Iowa, in Southeast Iowa, and have been blind since birth. I attended a residential school, the Iowa Braille and Sight Saving School in Vinton, Iowa until I graduated from high school. So it was from K-12 and then went on to college at Central College in Pella, where if you're not Dutch you're not much. And then to the University of Iowa, where I got my master's in rehab counseling. I worked for a little over three years for the Department for the Blind in Des Moines, worked then about that same amount of time for the Illinois/Iowa Center for Independent Living in the Quad Cities and where I still live incidentally. And then moved to work at what was then called the University Hospital School in Iowa city. I was hired to manage a three-year Self-Advocacy Training Initiative Project in September of 1993, and well, three years has sort of turned into almost 28 years. I'm still, as I said, live in the Quad Cities, I have a number of hobbies. I'm a big Cardinal baseball fan. I love to travel. I like a lot of different kinds of music. Got into gardening a few years ago. I got into dancing a few years ago and I think that between the gardening and the job, those are my dances these days.

- You know Mike, during the time at the Center for Disabilities and Development you and I started right around the same time.

- Yes, we did.

- Several months behind you. And we've had the opportunity to work on a couple of projects together, which have been adventures, uniquely and wonderfully their own. I would love it if you would share some couple of your favorite stories from our experiences, not only in working on self-advocacy here in Iowa, but in other states, some in Illinois.

- Yeah, I think our first cool connection was, I was for a short period of time involved in the Alliance Club Chapter in the Quad Cities. And we had the girl duck races, where they put all these rubber ducks into the water and set them off, and they each numbered, and I sold Judy a dollar ticket on a duck. And I'll be darn if that duck didn't come in first place. And I think-

- I won a \$1,000.

- What? \$1,000? That was a plot twist I didn't see coming.

- And it was... You know, Mike and I, one of our first adventures is we went to an ARC Conference in Decora and Mike taught me how you support somebody who doesn't see, who's blind. And so he held onto my arm and people assumed we were dating like right away, . It's like, I don't even hardly know him.

- And I think they said, "Well, there's a place for you two together." And Judy's like, "well, you know, I was kind of planning this with somebody else." Well, we got through the night. Well, yeah, we've had a lot of fun times. One of the most enjoyable, well, actually there were two that were associated with our work in Illinois that were just kind of funny. One was, we went to a restaurant, it was a diner. And the whole point of it was to just, you knew you were gonna get a hard time when you went in there. So I went in and I just decided, Hey, I was gonna give the server a hard time right back. And so she comes in and says, "Hey, you know, I'm throwing the menus down here telling me what you want." And I said, "Well, you know, a few people would get into the modern days and realize that there's some of us that are blind and can't read your stupid menus, then maybe I'd order." And it just deflated everything. She got real serious and said, "Oh, I'm so sorry." And so for the rest of the night she kind of tread on eggshells. So I think I kind of ruined the experience for a whole group of us that were planning to have a sparring match. And then we were in a car heading back from a restaurant and I decided that I wanted to go to a concert. I wanna say it was in Lincoln Park and nobody else wanted to go. So I thought, well, I'm gonna go and then I'll just hop a cab back. And so Judy, true to her support role as supporting people with disabilities to make their own choices, dropped me off. And I'll let Judy kind of fill in the rest of the story from there, because it's pretty funny.

- Oh my, I was transporting a group of mothers, probably seven of us in the car, me, the driver, Mike, the only male in the car, and the rest of these middle-aged women, all of whom were parents of children with disabilities. And Mike says, "I wanna go to the concert." I said, "fine." I drop him off. We pull away. Oh my gosh, I though they were gonna crucify me. "You just dropped him off there. How is he gonna get home?" You know, he travels all around the country, around the world and he does just fine. He's gonna be fine getting back. They ostracized me the whole night. I took them to Navy pier and everything. I was

still in trouble. They were so happy when he walked in the next morning. It was such a sigh of relief. "He made it." And what a great opportunity to teach them about the capacity of people with disabilities can make their own choices and have their own lives.

- Oh man. Yeah, it was very funny. In fact, I'll bet there was some sleep loss that night. Judy and I have had the pleasure and privilege of working with a program called the Iowa Leadership Education in Neurodevelopmental and Related Disabilities, or ILEND, or oftentimes LEND Program and for going into it, I believe it's our fifth year now. We have gotten people with disabilities. We only call them self-advocacy trainees. And hopefully some of you that are listening out there will become a self-advocacy trainee in LEND one day. But we have had the privilege of working with that program, and our first trainee that went through was a gentleman named Ed Asbeck, who's actually going to be a guest on Disability Exchange coming up in the near future. And so it was really exciting for me, not only to learn from Judy, but to see Ed grow during that year and to see myself grow, because I kind of had no idea what I was doing when I got in LEND. And that's just the way, you know, with any new program. I mean, Kelly, who is the training coordinator was great and Judy and everyone, but I just had to get in and dive in, just like kind of we're doing right now. But at any rate we nominated, I nominated Ed and I believe Judy wrote a support letter and helped Ed, we both worked with him to complete an application, and he was fortunate enough to receive the Healy Awards Leadership Award, which is available to LEND trainees and LEND graduates. And he was the first self-advocate, the first person who was not in theory of clinical services. In other words, was not in the area of being a service provider to win the Healy Award. And it was before COVID. So we had an opportunity to meet with the Healy family, have a luncheon, get to know Ed's family more, get to see people that we hadn't seen at CDD for a long time. But the most important part I think was Ed deserving that award, getting that award and then heading off to Uganda, his native country to do some teaching there, and to just go back and see what things were like and begin to launch his connections there. And so Judy, I guess I'd say that was another really important highlight for us working together.

- Like I was wondering if you could talk about, you know, how over the course of your career, you have thought, or even not thought of yourself as a self-advocate, you know, and I'm thinking in the realm kind of professionally and like sort of whether that's something that is, you know, you feel like is always a hat you're wearing, or whether you feel like you kind of go back and forth or just sort of what that's been like for you.

- Yeah, that's a really great question, Caitlin. And I think it's one that I have struggled with since I really got into this field. When I came really, when I started working for the Independent Living Center in 1989. So whatever that's 30 some years, 32 years or whatever now. But you know, there are always times as people with disabilities that really embrace the idea of advocating and speaking up for ourselves that we're gonna need to do that. You know, whether it's to get to be included in, I guess one of the first, you know, personal examples I can think about was, I was being asked to sign a waiver to go on a cruise. I love to go on cruises, and nobody else was being asked to sign the waiver, and I was. And so I really felt that was unfair. It was discriminatory and there were laws to protect me. So there are personal

situations where I really feel that's important, many times within even medical appointments, or even at the university where I work there have been times when I've really needed to speak up and ask for materials and accessible formats for instance, or you know, being able to... There were times in college and I needed to ask for certain types of support for taking tests. So there are always times in your life when you see yourself as the self-advocate. But I think one of the things that's really been great for me working at the university, Caitlin, is that, and working in so many different programs is that there comes a point in time when you realize how important it is to move that focus away from just yourself and support others to become leaders and self-advocates. And so for instance, we had a number of years ago, we taught a program called Living Well with a Disability. And we were focusing on helping people to live healthier lives, set goals for themselves and that sort of thing. And so initially I taught the course for awhile. So I was one level removed, I guess from being a self-advocate, but then I became, I coordinated the train, the trainer piece. So our goal is to help people with disabilities move into that space of being able to train their peers. And so in that case, I did not see myself as a self-advocate, but more as a mentor, as a leader, I don't know about a leader, but certainly as a mentor, as somebody that could be a resource for people that I was supporting. I certainly see that working in LEND now, being more in a mentorship type of role. But the interesting thing is I still learn from self-advocates all the time. You know, just because I might be in more of a mentorship role, and I'll share an example. So I've been, as I've mentioned Ed already, and we had a situation. A year or so ago where Ed was involved with a board and was struggling to get, not because of his own lack of trying, but there was sort of, there was a barrier, there was a concern that he had in getting his needs met. So my first thought was, oh, we've got to get this taken care of right away. So I kinda went into the, you know, I was supporting other people, but yet I was feeling, because I've been there. I felt that same fire in my belly so to speak as I might have, if the same thing had happened to me. The thing that's different now though, is I think that, you know, over time you learn to work with other people and cultivate and develop relationships. And in that particular case, the individual that needed to provide support is somebody who I knew quite well. And we got on the phone together, we did emails, we did whatever we needed to to kind of reach an agreement about how that can be done. So you know, in those examples, I saw myself as a self-advocate. I saw myself supporting Ed and also saw myself as sort of being a connector in using some of the experiences that I've had over the years to maybe tone things down a little bit from how I might've advocated a few years ago or several years ago.

- Well, I'm wondering Mike, what is most profoundly affected your self-advocacy efforts? If you were gonna find a point a juncture in time where you went, wow, and this is what set you on fire, or maybe set you on fire recently? I'm not sure because I imagine our life is full of lots of little fires.

- Yeah, lots of little fires.

- Do you have those defining moments?

- Yeah well, I have one for sure that comes to mind. It was a long time ago. It was actually when I still worked for the Independent Living Center. It was right after the Americans with Disabilities Act, ADA was signed. And one of the communities, it required, the ADA required paratransit. Meaning that if people couldn't get to a city bus for any number of reasons, the community had to provide the same type of service through an accessible vehicle. One of our communities decided that they were gonna try to do that with cabs, and we just knew that was not gonna happen. That was just not realistic for so many reasons. So a group of us got together and we started attending, shall I say this transit authorities board meetings. And it started out with about 10 people and it got bigger and bigger. And we started calling all these agencies and they'd show up and they'd bring the people that they serve. And a lot of those folks didn't necessarily say anything, but one day we all show up and we overheard the transit manager, he said, "Oh, you know, it's really rainy day. I thought maybe they weren't gonna show up today." So we knew we had their attention, and ultimately they changed their policy. And it wasn't because of me, it was because of a whole group of people. And it really made me realize that, you know, that there is power in just showing up. In fact, one of my mentors, Tom Slater, that was the Director of a State Public Policy Group back in the '90s and beyond. One of his models was 90% of life is showing up. And I've taken that very seriously, that if you really wanna get something done, you have to be able to show up and get things done, work together to get things done. One of the things Judy, that is getting me really kind of on fire right now is just the move in Iowa to really, we've kind of had a long role in self-advocacy and I think, you know, LEND was one of the first pieces where I really thought, okay, we're coming back. And so I believe that supporting LEND trainees each year has really been a defining moment for me, because those LEND trainees, the self-advocacy trainees keep in touch with us in many, many different ways. But showing us that they really wanna stay in touch and be connected to self-advocacy. And now we're doing two other programs, we're doing a youth leadership academy for the second year in August. And we're also going to be hosting virtually a regional conference called SOAR, which stands for Seeking Opportunities for an Advocacy Revolution in September. And I'm really excited about the interest that we're seeing. And then finally, it's not even so much defining for me, but I am so excited to see this Iowa Disability League upgrade Medicaid program, getting off the ground, because it is grassroots, it's Iowans with disabilities and those who support them. So I think we're living in a very exciting time right now for advocacy among people with disabilities. So I sort of rambled a little bit, cause some of those are not, you know, the Disability League isn't something that I really had anything to do with, but just knowing as I approach retirement, knowing that there are other people that are very much in line and ready to carry the torch.

- That's awesome. You know, as you were talking I was thinking too, about how you started in this field before the Americans with Disabilities Act was signed.

- Yes, I did.

- Now here we are 30 some years later, I'm wondering like what you've observed in that time. The reason I'm asking is I think a lot of people who started their careers or their own self-advocacy journeys much later, maybe don't even realize how much of an impact the ADA has had. And I would count

myself actually among that group of people, having not seen it unfold in my lifetime, having only read it and studied it, that kind of thing, you know. I'm always interested in hearing people kind of share their perspective on that.

- You know Caitlin, that is so true. And the time is so strange because I remember working and I was actually working at the Independent Living Center when the ADA passed. And I remember our director of programs at the time walking in our Monday morning and saying, "Well, the ADA passed this weekend." And that was awesome. It was 31 years ago almost. And in many ways it doesn't seem like that long ago, but you know, it's a whole generation ago. So you know, you can point to the things that you can easily notice. I think we've made great strides in making the physical environment more accessible. I think, the Relay program was for people that are deaf and hard of hearing and have speech impairments as a huge stepping stone. I mean, I think now with texting and so forth. Some of that has been replaced, but even now we have video relay and video interpreting. And I think, you know, so... And then in terms of those of us that are blind, having a braille on menus on elevators, you know, we've come a long way just in terms of the environment and programming. And I think maybe something that's less tangible. And I think the ADA had a hand in as did many other pieces of legislation and just social movements, is that how disability is so much more discussed and so open and I think that it's no longer, I don't know if I ever felt shameful about it, but it was, you know, you kind of had to tiptoe around. Oh yeah, if you're talking to somebody for the first time on the phone, or you know, maybe you're gonna go for an interview or whatever gets, oh gosh, you know I'm blind and am I gonna be able to get this done or that done? And I think that just the context, the social, the times that we're living in are so different now to where, you know... And one of the most interesting new things that I've noticed is that there are, especially among younger people with a variety of disabilities that are now for years, we have heard people first language, and I'm a person who's blind, or a person that's deaf or whatever. And a lot of people are now leading with their identity that you know, I'm a disabled person, or you know, I don't know, I'm a blind person or whatever. And the reason of that is that people are proud of that identity, and identify it as a specific identity. So I would say that that's, you know, indirectly even things like that are because of the ADA, because you know, it really was the kind of a foundation for getting us to where we are today.

- You know Mike, you just mentioned something about, you know, retiring, which is inconceivable to us here. But you know, if this is an opportunity to think about, what would you want your legacy to be? What's your hope that, and when we say Mike Hoenig, the Mike Hoenig Center on self-advocacy, or the Mike Hoenig Center on... I mean, what would you like your legacy to be?

- You know, and that's why I'm so excited about some of these opportunities in LEND and the Youth Leadership Academy. I guess part of it is just knowing that people have opportunities to be involved and be active, people with disabilities in programs like USAID. And I think so many of these things are things we all want, right? So this is a tough one. One of the things that I've experienced and many, many of my peers have experienced is sort of a tokenism. If you're a person with a disability, you get on a board or you get on some kind of a committee and well, we can check the box off. And I keep going back to LEND

and I just can't help it. But you know, one of the things when we started LEND I started this self-advocacy discipline in LEND. When I say discipline, that means that like a new, like a topic area in LEND. It was that people that go through it are gonna get to do the whole program. They're not just doing like a special program for people with disabilities, they're doing everything that everybody else does. And I think that's really important piece to me. And so I guess in some sense, I'm getting to live out what I see my legacy as being, which is a powerful, powerful thing.

- Very powerful.

- And you know, Mike, as I think about the work that all of us are doing, but I think you and a few other people are leading is that, kind of like curb cuts and doors that opened for us, the leadership training that we're offering to individuals with disabilities, the self-advocacy skills are something that all of us need. And I have a delusion that in these efforts we're changing the world for everyone.

- Well, you know, I think that's true. I don't know if this is kind of an off the wall example, but I think the part of that is getting to the point where we're educating maybe people without disabilities and even people that aren't necessarily in the disability movement about empowering people with disabilities. I was visiting friends and stayed in their home recently and they have kind of an unusually shaped house. And once in a while, I get a little turned around in there, and I figured out, and several times the host or hostess would say things like, "Well, we could easily just tell you which way to go, but we know you like to figure things out on your own." And you know, that's a small example, but they probably talk about that with their friends. And I think that those are the kinds of things where, you know, we get to a point of being able to move beyond people seeing, you know, the general public seeing people with disabilities as a group of people that lack abilities or can't do things or whatever, and just wanna be an independent like everybody else, with support just like everybody else needs support. I wanna go back to the legacy thing for a minute, because I did think of something else as I was kind of thinking through some of the work that I'm doing now even. And that is that I would like to see... So we have been training students in different health professions, different health programs for the last 15 years on how to work with patients with disabilities. And I would really like to see that kind of thing, that kind of training being offered all over the place. I don't wanna limit it to statewide, but there are so many people that aren't, so many professionals that aren't aware of how to treat people with disabilities and patients with disabilities, and what to ask and what not to ask. And we have started that and got that kick started pretty well. And so at some point in the future when a person with a disability goes into a doctor's office, that they don't have to advocate for an interpreter, they don't have to advocate for an accessible exam table, or they don't have to advocate for materials and alternate formats because somebody within a practice or within a hospital has internalized that and made it part of standard operating procedure.

- Totally. That's so important. You know, and you mentioned that earlier, and I think about how you... I mean, I know you've mentioned you do it personally, and I know for sure that you do it professionally as

well, that you just are constantly kind of put in a position where you have to remind somebody that you know, materials should be accessible or whatever the barrier might be that hasn't been addressed proactively. And you know, the way I've known you to do that is, you're never just looking to solve something for yourself, you always go up to the, you know, kind of wanting it to be put in policy or you know, solved for other people, which is so important. But I also think about how that is kind of this, especially in the workplace, you know, it's really this invisible second job or additional work that you do and you don't get compensated for. And even actually sometimes it makes your job harder. I don't know if I have a question there, but just something I-

- You know, I have a real strong reason for that. And that is that none of us is indispensable. You know, we're all gonna... You know, if you're a college students you're gonna graduate, and if you're working in a place you're gonna move on, you're gonna retire, you're gonna do whatever. And far too frequently, I've had situations where somebody will say, "Well, Mike needs this done." You know, whether it's an accessible document or whatever. I'm not gonna be the only one that needs it done. And if you try to solve a problem, one person at a time, part of it's a little bit selfish. I don't wanna be, you know, it's not all about... I don't want people to think it's all about me, it's all about accessibility. And it's all about really making the university here in particular has spent a lot of time on talking about being a welcoming environment and to the plane of doing those, what we call climate surveys. It's all about how welcome people feel. And unfortunately, many people with disabilities that respond to the survey feel that there's a room for improvement, that they oftentimes score, we, because I'm one of them that's filled out the survey. We often identify issues related to climate and welcoming that need to be addressed. So I think maybe that's part of the legacy too, but I don't know about that. I've felt this way for a long time that it's, and I think that's part of being an advocate and moving off the just plain old self-advocacy stuff and seeing the world from a broader picture. And I think part of it is also because I've been involved in disability coalitions, where I've had people with physical disabilities say, "Hey, I'll go with you to a meeting to talk about braille signage." You know, and it's kind of funny cause they would... We did it in a hotel one time and the manager even said, "Well, why do you care?" You know, to my friend that was in a wheelchair was like, "What's the issue for you?" And she said, "well, I'm just supporting my friend." And that was pretty cool.

- Well, I'll help carry that torch because you know, I do, I think that it is important when that type of advocacy comes from people who don't necessarily need, you know, whatever it is that they're advocating for. And hopefully accommodations and accessibility will become the way of doing business, not the way of backtracking and redoing

- And there's a lot of that happening here within CDD. And one of the things that's pretty cool is that there was a flyer that just recently went out. It was developed by a colleague and by a coworker. And she reached out and said, "How accessible is this?" And we walked through it and everything. So I think, you know, more and more, and it's not just because of me. I think people like yourselves and we have some other coworkers that are really gotten on board and including our administrator, you know. So it's happening, it's a good time to be involved in this.

- Well, and you know, I'm gonna coattail on what Caitlin said, and the respect that I love it when I see people partner, because the reality is we're all just one second away from disability. If you're considered neuro-typical, you know, whatever that might be. you know, I'm aging I could have a disability occur for illness or accident and as can a two-year-old, a five-year-old, we are all one moment away from disability. And every piece of foundation you've laid greases the skids for the rest of us.

- Mike, is there anything we haven't asked you about that you want to talk about?

- You know, I think we've got a lot of good stuff. I really enjoyed this opportunity to sit down and talk a little bit about advocacy. You know, one thing I'd like to share too, Iowa and actually the United States and the international disability community just recently lost an amazing advocate. I shouldn't say lost her. She'll never be lost. But a really good friend to a lot of us, Mia Peterson, was an advocate really her whole life, and she just passed away. There'll be an article about her out there for viewing through our [disabilitytraining.org](http://disabilitytraining.org) website. And I first met Mia when she was... She passed away at age 47, and I think she was either 19 or 20 when I met her. And she came to a statewide self-advocacy retreat just to see it, to check it out. She signed up and she quickly moved on and did some wonderful, amazing stuff here in Iowa in terms of training in so many different fields, and then went on to Ohio and presented before Congress. And at the 10th anniversary of the ADA just did all kinds of cool things. Was involved with writing a newsletter, poems, just really blazed a trail on so many, many ways. And you know, as I've been writing the article about Mia, I realized how thin and how quickly those lines can change about mentorship, because there was a time in my life when we were struggling and I would get self-advocacy going and I really needed my fix. And so I went out to the national conference for self advocates, becoming empowered, and Mia was there and she was living in Ohio and she was on the National Board. And she literally welcomed me with open arms, got this big old hug. And we had a flag ceremony for all 50 states and Mia, and I was the only one from Iowa and she said, "Oh, you're not gonna be the only one." So she came and helped me carry the Iowa flag again. And she was just an amazing woman. And so many people, I think there will have been a story in the register and she received some recognition from Senator Harkin or her family did recently. So anyway, I wanted to give some tribute to Mia because she taught me so much about advocacy and just speaking up and just being a good human being.

- Her organization was called Aiming High. And I loved that. And I think what we're shooting for here is to aim high and keep people's energies up. Not only aim high for where people are, but aim high for where people can be.

- You know one of her other quotes, and it might even be on her website is, I can't quote verbatim, but something to the effect that, be a star, because we're all stars. And I just really liked that because, you

know, we are on our own, we all have our gifts. And Mia was one of the best people I knew at helping everybody find their own gift and celebrate it.

- That's a super power.

- Yep.

- "Aim high for the stars, because we are the stars."

- And as the third point of the triangle or whatever here, I just hope one of the things that doing this brought this podcast will give a lot of people with disabilities an opportunity to share their story. And I hope that those of you that are tuning in to this one will help us get the word out, because if we're going to provide space for people with disabilities to really share their own experiences and their challenges and things, their advice, we want there to be an audience. So we're really excited about having lots and lots of folks tune in and share their ideas with us.

- Yeah, you know, Mike, I wanna coattail on that one too, because if you're listening and you know, somebody with a disability who has a story to tell, we wanna hear it. Those of us who've done this for a while, we know the stories are what feed our souls, feed our minds, and they change the world. And we really hope that you will share not only what you hear, but people you know who might benefit or benefit us by sharing their stories as well.

- I was thinking the exact same thing and thinking we can put contact information on our website. So please get in touch if you or someone you know would like to be on the podcast. If you have ideas for topics, feedback, anything like that, we would love to hear from you.

- We're fearless.

- We are.