

Transcript: Disability Exchange S4 E2

Improving Work in Iowa: Ben Grauer

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Mike Hoenig: Hey, everybody. My name is Mike Hoenig. I am a program coordinator at the University Center for Excellence in Developmental Disabilities in Iowa City.

We are part of the Center for Disabilities and Development, which is also part of UI Stead Family Children's Hospital. Disability Exchange is a podcast which focuses on centering and elevating the voices of people with disabilities, their advocates, and their allies.

We're grateful for the continued support for the Center for Excellence in Developmental Disabilities, or Iowa UCEDD, as we are often called. I'm really very excited today to talk with a new colleague and friend. Before we do that, I am going to turn this over to my illustrious co-host, Judy Warth.

Judy Warth: Hello out there. I'm excited today because it is unique and wonderful when we meet new people in our field, new people who bring a wealth of talent, experience, and passion. A colleague and friend, and I'm confident he's going to be another one of my mentors, Ben, welcome.

Ben Grauer: Thank you so much, Judy and Mike. Really happy to join you guys today. Judy, you hired me, so appreciate that. Hopefully I can pay it forward.

Judy Warth: Ben, how did you come to be involved in disability related issues? I hired you because you have a master's degree in public health and an interest in policy. It was not until we met later that I came to understand that you, too, live with a disability. I didn't hire you because of that. I hired you because of the skills you brought to the table. How did you come, become involved in disability advocacy?

Ben Grauer: Quick disclaimer. I do have a master's degree of health administration.

I acquired my disability 15 years ago. I was diving and swimming in an Iowa farm pond dove the wrong way and compressed my 5th and 6th vertebrae rendering me an incomplete spinal cord injury.

Now I'm quadriplegic and I use a wheelchair full time. All four of my limbs are impacted. I've been blissfully ignorant of issues that are related to a disability community outside of my own individual experience for the last 14 years.

And Judy, bringing me on here and putting me in this space has allowed me to understand that I have a voice and an obligation to speak to issues that impact not only myself, but, others across the state.

I'm using my own personal experience and the knowledge that I'm gaining through my work at the UCEDD. It's encouraged me to find new opportunities to speak to issues that are so important and really impact all of us with disabilities of all kinds. It's been really, rewarding.

Judy Warth: I was, I'm curious, Ben, had you not gotten this job? What are you, what were you thinking you were going to do? I didn't necessarily see myself in this space.

I was hoping to use my degree to move into the traditional healthcare space, whether that be in a smaller clinic or a big hospital at the University of Iowa Hospitals and clinics where I did my internship. I, throughout the course of that next year, was applying for positions within traditional health care providers in the area, but really not being offered anything that was really compelling to me.

Judy and others within the AUCD and the CDD team, approached in a way that was welcoming and made me excited to pursue work in this space, I did have that educational background that would make me an incredible asset and all those things together really set a fire under me. And I think that's been really exciting.

Judy Warth: Ben, I'm humbled by that. But I would tell you I think big for you.

Mike Hoenig: I find it really interesting that this has all come together in such a quick way really. You mentioned that you had the accident and then just hadn't really connected with the community. Tell us a little bit about your journey.

Ben Grauer: After I had first gotten hurt here in Iowa, I was flown out to Denver, Colorado and spent some time at Craig hospital there. I came home back to central Iowa here in Winterset.

It's a really traumatic experience for the whole family. A lot of things at home that were difficult for me. It was really isolating to be out in the country, so I tried to then come back to University of Iowa on campus.early winter of 2010. And that was just way too soon for me. I was not ready to be back on campus wasn't ready to be here, so I moved back home and then entering the next fall of 2011.

I was then able to go to Ames. at that point in time, was able to become independent enough where I didn't need any home care and things like that. So I was completely independent for all my activities of daily living. Which made a huge impact in how I saw myself in the world. And how I could maybe start to see different things that would be an option for me.

My friends and I decided to move out to Colorado in 2012. And I was out there for three years and wasn't really actually working on goals that were going to set me up for future success. So knowing that I moved back to Des Moines in the summer of 2015 and started living on my own for the first time.

I really started to understand that, okay, like I don't need to, or I can't rely simply on SSI and SSDI. Because of the nature of my accident, I received a settlement which had allowed me to live more comfortably than some. It was something that really allowed me to stay and participate in the community in a way that I liked,

I also got my first part time job I was working at the front desk of the downtown YMCA. It got me back out there. It let people see me in a way that I didn't think that they would ever see me take me seriously. Give me opportunities.

Then that springboard means to going back to school in Iowa and finally graduating with my undergrad degree, virtually in 2017. I was given a full-time opportunity at the Y as their kind of office assistant, but it was really flexible and they're really patient with me.

My abilities and my skills were valued and so I saw that people who saw that value in me would then be patient with me and give me the chance to really shine in a way that I didn't think would be possible. When I thought of full-time employment, I thought of eight to five, getting up at 4am to get ready in the

morning, knowing that in my situation, you just have to have that extra time to get ready and get out the door. That seemed miserable to me.

Through that kind of experience, I saw that it would be a great option for me, and there are opportunities there if I find the right people who I can then engage with. For, other young people who are going, 'Oh, I think I can work, but I'm not sure I can. And can I work full time?' It just takes time, but then you have to surround yourself with people who have high expectations of you and in doing so, let them nudge you and want you to achieve things. If you find yourself surrounded by individuals who don't think that you can work, I think that would be a real challenge.

I don't want to make less than 2,000 a month. That's not an option for me. And that's not an option for the person that I've found that I want to spend my life with as a romantic partner. It's not a good value proposition to say, 'Hey, we're in this together, but also we're going to have to be pretty poor.' That's not the most exciting way to phrase that. You don't want to start off that kind of. . .

Judy Warth: No, No.

Ben Grauer: relationship.

Mike Hoenig: You don't, we don't want to be poor. No.

Ben Grauer: I frequently participate in online support groups for spinal cord injury and the discussions I see about oh, 'how can I then get a job and get money out of the table to avoid the Social Security Administration finding out that I'm working' or, 'what's going to happen if I lose my benefits' and that sort of thing. Instead of trying to play a game that lets you stay in that situation, if you direct your energy in a way that enables work, it's going to be a much better outcome.

Judy Warth: If I were going to boil that down, I hear don't ever settle when you want more and surround yourself with people who have high expectations and won't let you settle. I can't imagine how many lives are wasted because we encourage them to settle or we don't lift people up to do their magic.

Mike Hoenig: And I, it seems like it's come full circle I know that one of the things that you're doing in your position now is actually working on employment related policies that relates to other people with disabilities. Is that correct?

Ben Grauer: Yeah, I'm working on a project called the Iowa Blueprint for Change. It's really working to advance opportunities for disabled Iowans to be able to engage in what is known as competitive integrated employment. And that is just the understanding that all individuals, regardless of the severity of their disability, if they want to work, we have an obligation to help them find that work and that work needs to be competitive in the sense that they're being paid the same or commensurate to the position to which they're working in.

And it needs to be in an environment in which they're working with non-disabled peers. And so knowing that, and knowing that we have this big system there are things that can be changed within that system at all levels to then make that easier and make it an expectation. There are those things that are standing as barriers and so how then within that system, do we address these barriers, identify them, and then work to remove them? What we'll see really commonly is discussions, like I mentioned before about being able to work and maintain your benefits. While SSDI and SSI, are designed to limit how much you can work and hopefully then you might not even need either of those things to put yourself in a situation in which you can have a good living. People with disabilities need access to Medicaid. If I have health care, that is through the employer at the University of Iowa here, if I were to need services like home care again, or personal care attendants and things like that just to get through my day to do my job.

I can't get that sort of care through my employer health care I would have to have access to Medicaid services and as they sit currently, there are some pretty low income and asset limits through Iowa's Medicaid buy in program, otherwise known as Medicaid for Employed People with Disabilities, that then serves as a block or disincentive to finding that real, robust, full-time employment. And it forces people to then say, 'Oh maybe I could work, but I'm going to lose access to Medicaid. And if I lose access to Medicaid, a litany of other bad outcomes is a much higher likelihood.'

So I'm going to stay in the situation in which I have less than \$40,000, I think, per year as my average income. And I can't save more than 10,000 as an individual and that's a problem. If we can't live and achieve and save like everyone else, there's an arbitrary block to that system there.

Knowing that we want to encourage employment through our work, how then do we refocus our energy and say, hey, this is an arbitrary block? And if we allow people disabilities to work to their fullest potential, they then will be able to play in the system just like everybody else does, meaning that they can earn and save as much as they can while still maintaining access to Medicaid.

And they're also paying a premium for that Medicaid access. And so that's one thing that would be specific and worth changing in the state. Additionally, we can really focus our intentions on, promoting employment first as the first and preferred outcome for individuals with disabilities.

We don't want just the obvious answer after high school, if you're someone with a severe disability to then go to a 'day hab' or go into shelter to work where you're working for pennies on the dollar on the hour, in a setting, which is not integrated in the community.

We don't want that to be the outcome and then we also want to use technology to enable that and ensure that people can live and work in their communities, which is the mandate of the decision and then we have to allow systems to change to reflect that.

Judy Warth: Ben, you state that so well. As you, say that, I know that you're doing some work locally on our ADA, Americans with Disabilities celebration this year, here in Iowa City. What's, popping? This is a big year for the ADA.

Ben Grauer: Yeah, absolutely. Every year is a big year for the ADA. I think any attention we can bring to it, is much needed.

As we know, the ADA was landmark legislation that was largely drafted and passed with energy behind it from Senator Tom Harkin, back in the late 80s. And it's, was a hugely important bill to mandate that individuals with disabilities were able to even work in their communities to the best of their ability with the help from the government. Here in Iowa City. We're, really going to focus on celebrating at the end of September as we lead into October, which is National Disability Employment Awareness Month.

I'm going to talk about employment too much probably, but employment is that thing that truly allows us to live with the autonomy that we really desire. That is made possible through the ADA and other sorts of programs that have happened and policies that have been enacted that make that a reality.

Representative Josh Turek, is going to talk to the crowd about how he was able to leverage his disability, and become Iowa's first, permanently disabled and wheelchair using, state legislator. We're then hoping to spotlight the ADA let others know that there's still work to be done, but we can really make it robust if we choose to.

Mike Hoenig: That's super exciting. Representative Turek, was a guest on Disability Exchange last year.

Judy Warth: It sounds like it's going to be a really great event.

Mike Hoenig: What will be some ways that people who hear this podcast will be able to find out more specifics about the celebration?

Ben Grauer: Yeah, absolutely. you can reach me at, first initial last name, B, Grauer, G R A U E R at uiowa dot edu, and I'd be happy to answer any questions

Judy Warth: If you want to volunteer, email that same bgrower at uiowa dot edu. I believe that your voice is powerful, I know you're young, but tell me, what do you hope your legacy will be?

Ben Grauer: Probably flexibility and the ability to be adaptive if I see an obstacle in my way and somebody says no, and I know that's going to harm what I was ultimately hoping to accomplish. I don't necessarily just take the no. I think that I have developed a way to engage with people and come to common understandings and reframe our thinking and approach the same issue from a different angle and hopefully achieve a better outcome?

Mike Hoenig: As we start to bring this to a close, I just really want to thank you. I think your messages is going to resonate with many people. I would also like to thank my co-host Judy and Joanna Sabha for production, certainly want to thank the listeners that have taken the time to get to know a great guy and a budding star in our community.

(Musical Interlude over voice)

Narrator: 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 Delvaux for the music contribution.