

Episode 6 - Grassroots Disability Advocacy and Organizing with Jenn Wolff

Mike Hoenig: Well, hey, everybody. Welcome to another episode of Disability Exchange, our podcast coming from the Iowa University Center for Excellence in Developmental Disabilities or much more user-friendly, UCEDD. We're really excited to have our guest today, and we'll get to her in just a second. My name is Mike Hoenig. I am a program coordinator at UCEDD, and I would now like to turn it over to our Disability Exchange co-host to introduce herself.

Caitlin Owens: Hello. My name is Caitlin Owens, and I am a co-worker of Mike's at the UCEDD. I am so excited to be here.

Mike Hoenig: Excellent. Thanks, Caitlin, and we are really excited. I've been looking forward to this for a long time. Having the chance to really sit down and talk with our guest today. She is Jenn Wolff, who identifies as a disabled occupational therapist, and an organizer of Upgrade Medicaid and Iowa Disability League. So, Jen, welcome to the show, and you can help us break down what some of those roles are.

Jenn Wolff: I would love to, and I've also been very looking forward to this conversation. I go by she/her pronouns, and a brief image description. I am a white female, chin length, purple-tinted dark hair, dark brown glasses in a messy bedroom/office wearing a gray t-shirt that says, "Public health policy, not politics."

Mike Hoenig: Ooh.

Caitlin Owens: Awesome.

Mike Hoenig: Talking our language here. I know that our listeners will be very interested to know about Upgrade Medicaid and Iowa Disability League. Clearly, our focus is on disability. So while you're doing that though, we'd like to... So giving us some description of those organizations, but also including why this is such a passion of yours would be really important.

Jenn Wolff: So I became disabled in 2003, although I wouldn't have identified as disabled then. When you get an acquired disability, it's... Well, I think anytime you grow into that identifier, and like at a certain point, I became politicized by that identifier. So I had an ependymoma, which is a spinal cord tumor. I was kicked out of grad school because of mental health issues. I had really bad depression and just wasn't able to get out of bed to attend classes.

Just when I was ready to go back to school is when I was diagnosed with this spinal cord tumor that was probably partly causing some of the mental health because of the pressure and I wasn't having pain. So it was all literally in my head, all that, but it was from T7 to L2. So a really long tumor. Had surgery, and

went through rehab, and part of what helped me get through that is having the experience of being a patient while knowing I was going to go back to grad school for occupational therapy, and so it was... Actually, it was very, very helpful both as a patient then and as eventual therapist. So five years, six years into my OT career, I had to get my first wheelchair through Medicare, and they said, even though I talked to wheelchair companies and they'd let me try all those ultralight chair that was really good for my shoulders and easier to use, insurance said, "No, you just need what will get you around your home."

As an occupational therapist, I went, "There's something wrong with that," and so I happened upon a scholarship to go to DC for a three-day conference, four-day conference, where I got to learn about all the policies behind wheelchair policy, which is called Complex Rehab Technology, and then have a day on the hill, where you get to go visit all your congressional visits. That empowered me in a way that even being a professional healthcare professional that I didn't feel empowered. I still felt, in a lot of spaces, people just saw me as a wheelchair user. In the advocacy space, I'm like, "I have power just through my lived experience in creating change." So I got addicted. Healthy addiction.

Mike Hoenig: That's a very healthy addiction.

Caitlin Owens: Yeah.

Jenn Wolff: And got more involved. Gale, who was an OT and a social worker, had created a group called Users First, which is wheelchair users telling their stories on the difficulties of getting equipment, that eventually got absorbed by United Spinal Association. I eventually became the advocacy manager for their grassroots efforts for several years and got really, really sick doing both jobs. Now that I look at it, I think I was trying to prove something, which I think a lot of us feel like we have to, to get any attention, and I paid for it. I went septic what? Three or four times in a row and was out of business for about a year, year and a half.

Around that time is when I was... Medicaid was privatized. For the first time in, I don't know, eight years I've been advocating, I started hearing from fellow wheelchair users, fellow advocates going, "What can we do, Jen? We've got to do something." It's all those forces combined that... I think Tucker Cassidy and I were the first two to kick around the idea of starting a group, and Upgrade Medicaid was born. Well, I shouldn't say that. It started with an advocacy day through United Spinal Iowa Chapter, and a lot more people than just spinal cord injury showed up and caregivers, and we had... Even though there were only 13 of us wheelchair users that were there, folks said that's probably the biggest amount of wheelchair users that had probably ever been at the Capitol.

Mike Hoenig: Probably right.

Jenn Wolff: That day, taking pictures on the Senate Steps, one of the senators actually looked over us, not at us and said, "They're in my way. They just need to get out. They just need to move." I'm like,

"That is what we're up against is we're not even seen as entities where we can be communicated with." I'm like, "That's what we're up against."

Caitlin Owens: Wow.

Mike Hoenig: Wow.

Jenn Wolff: Yeah. At the time, you can't think fast enough too. You're like so shocked that that would actually happen that you just... Now, I would say, "You know, it's my space too." But yeah, that's how we started, and we've just been growing ever since, and it's... The Medicaid. First, it was easy to be angry at the MCOs, the Managed Care Organizations, and focus on them, but it's gone beyond anger to organization and realizing that it's not just the MCOs. It's the fact that our state and its entities didn't really have policies and procedures, and home and community-based services programs set up to protect folks with disabilities before the MCOs came in.

The MCOs are doing what they're supposed to. They're supposed to be making money and making profit where they can. But I think we're at a very unique time where we've built relationships with legislators. We've built relationships with state organizations. We built relationships now with DHS, and with the mess with Glenwood and other investigations, they know something needs to change, and they're... At least it looks like they want to hear us and include us in decision-making, and we'll hold them accountable. We're at the point where we've been using digital organization to do the outreach, to make this very, very wonky policy stuff more understandable to both folks with disabilities and general public.

Caitlin Owens: I loved what you said about... So it's been about six years since the MCOs came into Iowa and talking about this evolution of like... The beginning stages of the advocacy was really like a lot of anger and grief. Then, it sounds like there was a lot of maybe discovery and learning like, "Okay. Wait. Maybe this problem is bigger than just these companies," and then evolved into a relationship building, more action-oriented phase, which is really amazing, I mean, and I just... I don't know, I just wanted to point that out. I think that's really cool, and it's great to hear that you feel like those relationships and that action is making an impact. Even though I'm sure sometimes it still feels really slow, but that's cool to hear.

Jenn Wolff: There's hope, where I think for a couple of years didn't feel that at all, and I say that from a point of privilege. I don't deal with needing to need care every day. That's a privilege really when you look at it. I can take care of most of my daily care things. That is a privilege. So many folks out there are still dealing on a daily basis, wondering if they are going to have a caregiver show up, or if they're going to call in sick or not show up at all. That's neglect and abandonment, and people are feeling it. I've been talking with folks across the country. Connie Arnold in California. She said, "Jenn, people are suicidal.

Because if the systems aren't showing that they have value in the fact of having adequate care, so many people feel like a burden anyway with a disability that that just feeds into that loop, and that's horrible. It's just horrible and unacceptable."

Mike Hoenig: Do you think privatization has led to some of the increased abandonment and lack of providers showing up? I mean, I know that's been an issue for a very, very long time, but how has privatization impacted that?

Jenn Wolff: I think it exacerbated it just because low reimbursement rates and they have not changed. In fact, I think I can say this legitimately because Emily Ehlers has said it in several spaces. She's a disability rights lawyer is that... Folks in court have said that the rates have not changed in five years for caregivers at all across the board. The ones that get most... the least reimbursement are those with physical, complex physical care needs, and so those are the folks that... Everyone is impacted that needs care, but those with physical, complex physical needs are the ones that are really, really... Yeah, they're being pushed back into nursing homes or just being neglected at a level that they shouldn't be, which is hard. It's hard to see people suffering, and it can be... Advocacy can be re-traumatizing.

Caitlin Owens: Absolutely.

Mike Hoenig: Absolutely.

Caitlin Owens: I want to ask you. You talked in your intro about this burnout you experienced, which is a topic I'm really interested in, and so I'm wondering about how you practice self-care and prevent burnout in general, but also, specifically related to this really emotionally intensive advocacy work that you do that is also so personal.

Jenn Wolff: It's learning in progress, and I... It's funny. I catch myself not practicing it, and I'm like, "It makes a big difference," but it's gratitude and compassion. I took a class from Dr. Amit Sood at Mayo Clinic on resilience, and it was a stress management program. One simple trick, waking up in the morning before you do anything else, before you even open your eyes, is giving gratitude to five different people or five different memories and going into detail of what those people look like, the specifics of the memory, and giving gratitude for those moments or those people. It really only takes a couple of minutes.

But when I practice that regularly, and granted I don't, and I should, dealing with things that could potentially be traumatic or could spiral you into downward thinking, you can fend that off a lot easier because we as human beings, our pain center, even when we're hearing other stories, our brains, our pain centers trigger just like it's our own pain that you have to build up that bubble wrap, that kind of

self-support of going, "I'm going to give compassion and gratitude that that person is simply sharing their story with me." How huge that is that they trust someone with their story because it's very vulnerable. It's extremely vulnerable, and it's hard, but it's the super secret super power at the same time I think because it's those folks that can tell their story with impact and share those personal details, which are so hard that make the impact when we speak in policy places.

Mike Hoenig: I was fortunate enough a few months ago to sit in on one of your earlier early meetings. Maybe shortly after the first of the year. I knew there were some DHS folks on the Zoom. I think some legislators came in, but I do remember, and one of the things that I was amazed at was how freely people did share their stories. I think you have gift for listening and making it okay to talk about those personal difficult issues. I was really impacted by that town hall.

Jenn Wolff: I will not take credit for that. I will take credit for just giving the space for people to feel comfortable because it's a group of people that are willing to talk to each other, and then they get comfortable sharing those stories. Then, we've had the marvelous Zach Mecham, and Hannah Sawyer also did a storytelling workshop to help people give the tools to tell those stories with impact that... We're trying to provide the tools to people to be more empowered in telling their stories effectively and owning their own story. So it doesn't feel like, "Oh, I'm just sharing all my vulnerabilities, and this is sucking my soul out," to, "I am telling this to create change."

Mike Hoenig: That's great, and yes, Zach is marvelous. He's helping us with our SOAR Advocacy Conference, the digital components of it. That man has a lot of talent, and he's a future guest of Disability Exchange.

Jenn Wolff: Wonderful. He really helped Upgrade Medicaid get the attention initially with all his help with the video campaigns, and podcast, and things.

Mike Hoenig: So tell us, Jenn, is... because I introduced you as an organizer with Upgrade Medicaid and the Iowa Disability League. Are those two movements? Are they one? Straighten us out on that.

Jenn Wolff: That is a great question, and it is still evolving. So Upgrade Medicaid was... It needed to happen, but it was also an experiment to see if we could get the disability community to talk to each other. We have been so siloed, and a lot of it has to do with funding. It has to do just with systems as they are that we don't have one entity that truly is led by people with disabilities in going beyond self-advocacy or individual efficacy. Because I want to give credit where credit is due, ID Action does a fabulous job. Fabulous. We try to promote their work as much as possible.

The thing that makes Upgrade unique is that it's community-organizing, that we're trying to uplift together the multiple different identities within the disability community. My hope is that in some form, it will either be Iowa Disability League or Disability League-Iowa that will become a 501(c)(4), where we are a lobbying agent for folks with disabilities and we can endorse candidates that support disability justice, disability rights issues. That's my hope. Again, a lot of it comes down to funding.

Mike Hoenig: Yeah.

Jenn Wolff: So we've been totally grassroots. I've been funding this from my part-time job with occasional fundraisers, which I'm so grateful for the folks that have believed in what we're doing, but yeah, this is totally grassroots. It's something new and different. I took a digital organizing bootcamp from Beth Becker, who's in the Progressive Movement, and I've been utilizing her tools and her wisdom ever since in the efforts we've been doing, and it's still growing. We went through a huge restructuring this summer. Okay? So we needed to get back to our basics, what our mission really is, and because we don't have the funding is where we're stuck with.

Well, I won't say stuck because we're so small that the Upgrade Medicaid is enough work for us, but we want to turn into something bigger and really start delving into disability justice, which is social justice issues because people with disabilities exist in every other group. We are LGBTQ. We are Black, Brown, indigenous, Asian, every religion, and it shouldn't be such a stigma anymore because disability is part of the lifespan. That's my OT kicking in. It's part of the lifespan, and even the OTs don't get it, but trying to work in that space and trying to get them to be part of the independent living and disability as a social model.

Mike Hoenig: I just have to say how exciting this is because I'm old enough that I remember a movement back in the early 1990s, and it was called... It started out as being called the Systems Change Project, and then later became the Systems Change Network, and it organized the opposite way. Actually, it was a DD Council grant that was designed to strengthen advocacy in Iowa and bring people from across the state together to advocate on particular kinds of issues. But of course, since it was funded by the DD Council, we had to be very, very careful in terms of crossing that lobbying line.

So we had funding to bring people to Des Moines. We had funding to do regional retreats, and trainings, and all sorts of good stuff. But unfortunately, when the funding went away, so did the organization. So it's ironic to me that almost 30 years later now, we have an organization that is starting from the ground up. So your biggest challenge, it's sounding like, other than people's time, is the money. But yet, without one specific funding source at least at this point, you've got a group that's holding together not because of some grant, but because it's grassroots. I am just so excited to see where this goes.

Jenn Wolff: Thank you for that. That means so much because it feels mind-numbing sometimes when it just doesn't feel like we're getting anywhere. Even though I have hope, I know it's going to take a lot of work and keeping the groups accountable to what they're saying. It's hard work. I've told folks it's like

being a Simpson person and just poking, poking, poking, poking, poking the sibling shoulder just to annoy them, but keep reminding them that we're here. "We're here, and we're listening, and we're going to keep annoying you."

Caitlin Owens: So what advice might you give to a listener of ours who maybe is like new to the advocacy world, or isn't quite sure where to start, or anything?

Jenn Wolff: Find an organization you feel comfortable with and where you can feel like they see you for who you are. There are so many good groups. United Spinal, DD Council, Infonet, the Brain Injury Alliance of Iowa, the Spina Bifida Group. All doing amazing advocacy work specific to disability, which is also needed. Just to get comfortable in who you are. ID action and Infonet is the best place to go. They have the best resources on getting started and plain language. It's really great, and it's underutilized. We're going to try to make a difference in that because I'm like, "That's..." Some of the work they do, the action alerts, I'm like, "That's work I don't have to do."

Caitlin Owens: Yeah, yeah.

Jenn Wolff: They're doing it, and we need to promote it. Then, when you're ready, the Community Advocacy because it is different. You have to be pretty confident in who you are and where you are. The biggest difference for me, which is a struggle because in the world of disability, to get attention, a lot of times, you have to be the glossiness of, "Look at what I'm doing. I'm a superstar. I'm doing all these things," or...

Caitlin Owens: Against all odds and...

Jenn Wolff: Yeah.

Caitlin Owens: Right.

Jenn Wolff: I saw the best comic the other day. Well, it wasn't the best. It was really horrible, but it was about how you go to the grocery store and, "Oh, it's such an inspiration to see you out." If it's after an illness and you literally haven't been out for a year, that's one thing. But if it's a complete stranger telling you that you're an inspiration simply for being out of the house, that's not so much of a compliment. Your biases are coming out.

Caitlin Owens: Right, an indictment on how little they know about.

Mike Hoenig: Yes.

Jenn Wolff: Granted people are trying to be nice, so I don't... People tell me all the time I'm speeding, and a lot of people with disabilities who use wheelchairs, that's offensive, but I'm like, "It's because they don't know that I have a really ultralight wheelchair that's so much different than a hospital transport chair." So I educate them. I'm like, "It's because I have a really good chair." I digress.

Caitlin Owens: No, I find... I appreciate you saying that. I find those stories to be... and they're so perpetuated by media, these stories of, "This student who got invited to prom," which is... It's really exciting for them, but also, it just...

Jenn Wolff: It should be normal.

Caitlin Owens: Right, right.

Mike Hoenig: It should be normal, and I think that's where... I know that there's been some discussion even within the Iowa Disability League as you're evolving. That's a piece of what you hope to provide a vehicle for is to do education, and I think that's... We're in 2021 now. I mean, I know there's always going to be a need for education, but it's still... Just about the time you think maybe you've turned a corner, we're still in a need for some of the most basic kinds of education. We see it all the time in those kinds of interactions, and media, and all sorts of ways.

Jenn Wolff: The last two years, I've done a lot of... I saw the worst discrimination of disability, and Black and Brown community at Netroots Nation, which was supposed to be the most progressive headspace in the country. I'm like, "If that can happen there, there's so much work to do." So I've been doing a lot of looking at civil rights movements, at the LGBTQ movements. Each one of those made great strides just like the passage of the ADA. But then, it seems like we go backwards so much before we make another step forward. This year, almost because the world opened up virtually and so many more people with disabilities across the country are talking to each other in that virtual space, it feels like we're getting to one of those movements again. In fact, I've said it.

Mike Hoenig: Yes.

Jenn Wolff: It feels like we're getting close to another Capital Crawl movement or moment because that's how the ADA got passed. People got out of their chairs, and had multiple disabilities, and crawled up the Capitol steps, which gave the press a great visual, and it was enough press. The general society looked at that and went, "Ooh, yeah." It feels like we're getting close to that movement, and the best part about it is there's more people with disabilities who are talking about their disabilities in leadership places. That has not existed before. Like Reyma McCoy McDeid, the executive director of NCIL. That's huge, huge, and she's from Iowa, which is even better.

Caitlin Owens: Absolutely.

Mike Hoenig: No, it really is amazing. Just within our youth, we hosted with the DD Council, and Department of Human Rights, and Access to Independence a youth leadership academy. Last year, we had a grand total of six sign up, and this year, we had 19.

Jenn Wolff: Wow.

Mike Hoenig: These are young people ages 14 to 21 I think, and we had all ability levels. We had one guy that's in orchestra in college and everything. It was so cool to see some of the ideas. We had a 17-year-old. I guess I'm digressing now. I'm supposed to be, but it's just so... I mean, there's so much potential. We had a young woman who's 17 that identifies with a disability and also socioeconomically disadvantaged, and talking about how she volunteers for the food pantry because she says, "We've been there, and sometimes we're still there." Yet, she's taking her time out of her day to go in a community advocate and volunteer, and she's very, very serious and focused, and now wants to get involved in other disability advocacy. It's just so exciting to see this happening, Jenn, like you said, with people with disabilities and especially young people really. We just interviewed a young woman that's 35, and she's just got the passion all over the place. So it's cool to see it, the transformation happening.

Jenn Wolff: A lot of it is happening in the Midwest. It's not coastal things. There's amazing things happening in Kansas, and Iowa, and Missouri. So I'm really, really excited to see what the next two to five years holds. I mean, nothing is going to happen fast unfortunately. If we could get this increased funding for HCBS, Home and Community-Based Services, from the federal government, that could be a huge piece, a start. I've thought of things as a hierarchy. If we can get the basic level and... Right? What started things is people weren't getting adequate care in their homes. So let's start with that piece. Let's make sure there's more affordable assessable housing in Iowa is the next piece. Then, let's look at transportation.

Then, we can start looking at employment because if those people could have those basics, they could be more productive, and it doesn't have to be work, in the work. That's the biggest thing is productivity is being able to clean your house. It is cooking food. It is raising a family. It is volunteering. It doesn't

have to be just work, but so many people can't do that right now because they're unhoused, because they're living with their parents, because they don't have affordable assessable housing like myself. I would love to be on my own. Not going to happen where I live right now, but until people aren't suffering at a basic human level, I'm like, "I can't start fighting my fight." That's next.

Caitlin Owens: So as we wrap up here, we like to ask people to just tell us, what would you like your legacy to be? Just a light little question to end on.

Mike Hoenig: Yeah.

Jenn Wolff: I want people to feel their own power, the power of their voice, the power of their lived experience, and not... In the society we live in, it's so easy to feel burdened or to feel like you're a burden, to feel you don't fit, but we do. We fit in our humanity. The system just isn't made for us. The more we feel our power of owning the space that we're in, the more we'll get to be in those spaces, the more normalized it will be, and I just... I want more people to feel that way because there really is so much empowerment in doing advocacy work, whether it's self-advocacy, whether it's individual advocacy, whether it's community advocacy, and all of it is necessary. I want people to find their power.

Mike Hoenig: Yeah. That is so awesome and so needed.

Caitlin Owens: That is.

Mike Hoenig: We would like to ask a final, final question, and that is, how... If people want to get connected to Upgrade Medicaid, what's the best way for them to do that?

Jenn Wolff: Our website is down, so Facebook, and it's Upgrade Medicaid. Either that or contacting myself. We do have a membership form. We're working through Action Network, and so you can get on our email list. We have a Facebook for Iowa Disability League too, and what... The reason we have two separate, which can be very confusing, is Upgrade Medicaid is sticking to Medicaid and caregiving issues, but there's a lot of other issues that we want to talk about and make people aware of, which is why we have Iowa Disability League.

We've been doing things through Iowa Disability, like we got permission to show the recordings of the Crip Camp Virtual Camp from last summer, and we've been doing that through Iowa Disability League. We're going to have upcoming town hall, virtual town hall on emergency and disaster strategies I think September 2nd because there's exciting legislation that was written by people with disabilities for people with disabilities at the federal level that we want to promote.

With the year anniversary of the [DRHO 00:34:10], we want people to tell their stories of how they were impacted because people don't know how inadequate the system is because people with disabilities aren't included in the planning strategy space. But yeah, Bespoke is our number one way to get a hold of us. We are working on getting a website up and running, and we do have a PayPal account now for Iowa Disability League.

Mike Hoenig: All right. Facebook search for Iowa Disability League or Upgrade Medicaid.

Jenn Wolff: Yes.

Caitlin Owens: Awesome. Well, thank you so much, Jenn. This was just a fantastic conversation. I so appreciate and enjoy learning more about you and the really, really incredible work that you're doing in the state. So thank you.

Jenn Wolff: So much appreciate this, and I just acknowledge that people have done so much of the work before me. I'm just doing my cog in the wheel of getting a change happen. There's so many people that have done work before me, and I'm honored to work alongside as well, so.

Mike Hoenig: We're honored that you're in Iowa and that you're doing this great work, and we want to echo Caitlin's thank you. We also would like to thank all of our listeners to Disability Exchange and hope you'll join us again next time for another engaging guest. Thanks, everybody.

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.