

Disability Exchange S4 E3

Speaking Out to Create Change: Carlyn and Sam Crowe

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Mike Hoenig: Hey, everybody it's Mike Honig from the Iowa UCEDD, or University Center for Excellence in Developmental Disabilities, welcoming you to another edition of Disability Exchange.

Disability Exchange is a podcast which is dedicated to centering and elevating the voices of people with disabilities and their families through casual conversation and open communication.

Before we get to today's guest I would like to introduce the co-host of Disability Exchange, Judy Warth.

Judy Warth: I think that Mike is Mr. Professional and I'm wild and crazy. Prepare for the ride. I'm Judy Warth. I'm a program manager with the Iowa UCEDD and delighted to serve as a co-host of this fun program.

I learned so much each episode and today we're delighted to welcome Carlyn Crowe and her son Sam. I met Carlyn when she came on as the public policy manager for the Iowa Developmental Disabilities Council. Carlyn, would you mind sharing a little bit about your background and how you got into that role?

Carlyn Crowe: Thank you Judy.

I've been with the Iowa Developmental Disabilities Council for just a year and a half. I came into this, position after working for seven years with the Spina Bifida Association of Iowa. That job brought me into the disability community formally or professionally, before that, my experience has been in public policy, but in different areas.

I worked in journalism and public relations, so I've come full circle from my first job where I did public policy.

This is a pivotal time for us to be talking because our son, Sam, is going to turn 30 years old next week. A lot of people will say 'Oh, it seems like yesterday that my child was born.' For us, it seems like a lifetime ago. Like we were living a different life. He was born very ill with a lot of medical conditions that probably come together in some sort of syndrome but nobody has identified it

yet. He's been quite a trooper in managing to, first of all, survive that initial seven eight months. Since that time has still had a lot of physical ailments, in addition has intellectual disabilities. But when he was young, because he was not diagnosed with anything in particular, what we were told from his medical professionals and team were that he was developmentally delayed. So, beside the fact that he had a heart condition, a lung condition, some other things, it's just he has developmental delay.

So to us, that meant, 'Oh he's delayed and he's got these medical things that are probably going to get cured. And so he's going to catch up.' And so I never thought of him having a disability. Today, I think parents and individuals, even with intellectual disability identify themselves with that terminology. Whereas, 30 years ago, if somebody had told me when he was sick in the hospital that he was going to spend his life with an intellectual disability, I probably would have been devastated because we didn't talk about it that way back then.

Judy Warth: Carlyn, I think your view on it may be very healthy that you saw your child as having different needs and needing different help, but you didn't see it as a disability per se. One of our opportunities here is to see disability as was stated in the Rehab Act, as a natural part of living and this is part of the human experience and we all need help in different ways.

Carlyn Crowe: My professional work and my personal experience come together in what I'm doing now for the Iowa Developmental Disabilities Council.

Mike Hoenig: Things are intersecting between your work life and your family life, could you talk about that a little bit?

Carlyn Crowe: When I started work with the Spina Bifida Association and started working with people with Spina Bifida, who have physical disabilities some have intellectual disabilities, not all and started hearing about the problems that they have managing their conditions, managing whether they're on Medicaid and what that looks like for their services and supports. I started seeing the big picture, so to speak, but when I saw the big picture, I was like, 'wow, I hope that because of my personal experience and what I can bring in professional experience that I would be able to help the disability community now in a different way.' And support not only through policy provisions, but just systems change and having a parent's perspective on how systems aren't working and could be improved. Um, Sam has been very lucky.

We really wanted him to think about going into the REACH program at the University of Iowa, the program is for kids with learning disabilities, intellectual disabilities that helps them learn job skills learn independent living, all while they are participating in a college campus, much like traditional students do.

While they're there, they get support from the reach program, but also from being on a waiver. He can get supported community living. He had help with his laundry.

He had help with getting around Iowa City getting groceries, if he needed to get groceries, figuring out if he could go out to eat, how to spend money. All those kind of supports were there for them.

Sam is getting ready to move back to Iowa City and actually live in an apartment with a roommate. He's looking for a job right now to hopefully capitalized on being able to live as independently as he can. And with still having those supports, he'll have the support of job development, job training, and the supported community living because of the ID waiver.

Judy Warth: We'll include a link for the University of Iowa REACH program in the notes. I was going to ask you before we get to meet Sam, what is the superpower with something that's truly awesome and amazing about him?

Carlyn Crowe: You might think me a little bit nutty for saying this, but he has an aura, like people come up and start talking to him and all of a sudden it's they've known him for years. He can talk to anybody. People are attracted to him. We've been in other cities across the country and have been walking down the street and somebody will say, 'Isn't your name Sam?' That happened in New York city, in Minneapolis. He's, he must be memorable.

Judy Warth: It feels to me like it'd be a good time to meet Sam. Hey, Sam, I'm Judy.

Sam Crowe: Hi.

Mike Hoenig: And I'm Mike. How are you?

Sam Crowe: I'm good.

Judy Warth: So Sam, congratulations. Two things. I hear you've got a birthday coming up. Happy birthday.

Sam Crowe: Thank you.

Mike Hoenig: 30, huh?

Sam Crowe: Yeah,

Mike Hoenig: That's great. Happy birthday.

Sam Crowe: Thank you.

Judy Warth: And what are your birthday plans? What would you like to do for the birthday?

Sam Crowe: Don't know yet.

Judy Warth: Fair enough. The other congratulations is you just graduated from the UI REACH program.

Sam Crowe: I did.

Judy Warth: For people who maybe don't know about it what is the UI REACH program? What did you do there?

Sam Crowe: It's a program for disability students to get them into internships and then, they look for jobs after REACH.

Judy Warth: I hear you're looking for a job right now.

Sam Crowe: I am.

Judy Warth: What kind of job?

Sam Crowe: Something with hospitality.

Judy Warth: When you say that, what do you mean? Help me out.

Sam Crowe: Oh, customer service.

Judy Warth: Customer service? Like on the phone? What are you thinking?

Sam Crowe: Grocery store or a front desk. I did my internship at a dining hall and at, at the front desk at another dining hall.

Judy Warth: Oh, okay. Okay. Cool.

Mike Hoenig: Sounds like you like being around people a lot.

Sam Crowe: I do.

Mike Hoenig: Your mom said that you were planning to move back to Iowa City and I'm just curious to know what you do there?

Sam Crowe: The people, my friends, going to football games, basketball games, and sporting event.

Mike Hoenig: It's like you're going to have a busy life back in Iowa City.

Judy Warth: Moving here for the sports

Mike Hoenig: and friends.

Sam Crowe: Yes.

Carlyn Crowe: And a job.

Mike Hoenig: And a job.

Carlyn Crowe: You gotta afford all those football, basketball tickets.

Judy Warth: When you move here you're moving from home, you're moving from the UI REACH program. What kind of help do you think you're gonna need to be able to have an apartment and take care of all your business without mom around?

So when you move into your apartment, Will you need help with keeping it clean? Are you good at that?

Sam Crowe: I'm pretty good in keeping my room clean.

Judy Warth: And when you get to Iowa City, how are you going to get around? Do you drive?

Sam Crowe: No, I would take like a bus.

Judy Warth: Yeah. And you already know the buses in Iowa City.

Sam Crowe: Yes.

Mike Hoenig: Iowa City is a great place for public transportation. There are quite a few choices.

Judy Warth: And you said you have some friends here too.

Sam Crowe: Yes.

Judy Warth: What sort of things besides going to games do you and your friends like to do together?

Sam Crowe: We like to, I like to go out to eat, walk around campus.

Judy Warth: Will your plan be to live close to campus?

Sam Crowe: No, think it's far away from campus. In Coralville.

Judy Warth: Oh, but you're close to the mall. Do you like going to the mall?

Sam Crowe: I do.

Judy Warth: Have you begun to apply for jobs or do you have one lined up?

Sam Crowe: REACH is supposed to, help me with jobs.

Judy Warth: They'll help you look for a job. When you first get that job, do you need some extra help to learn it, or can you run with that on your own?

Sam Crowe: I would probably need some help with it.

Carlyn Crowe: You remember the job that you had in the Iowa Senate?

Sam Crowe: Yes.

Carlyn Crowe: In the bill room? He had a job in the Iowa Senate copying bills and handing them out to legislators, , and anybody who needed a copy of the

bill. Do you remember that you had a job coach with you and what kind of things did they help you do? They help you learn how to run the machine, like the copy machine and how to file things.

Sam Crowe: Oh, yes.

Carlyn Crowe: That was really awesome experience for him.

Judy Warth: Yes. Sounds like a good job.\

Carlyn Crowe: And then the other way that kind of public policy has come full circle is he was on the REACH Student Council last year, and their student council came to Des Moines to talk to legislators about REACH and the supports that students with disabilities need. And also, you went all the way to Washington, D. C., right? To talk to your members of Congress. Do you remember who you talked to and what you talked about?

Sam Crowe: Rob Sands, Grassley, and Joanie. And Zach Nunn.

Judy Warth: Wow, you talked to the bigwigs.

Carlyn Crowe: And what did you tell them, Sam?

Carlyn Crowe: You talked a lot to our member of Congress is Zach Nunn, and he asked you a lot about

Sam Crowe: Oh, yeah.

Carlyn Crowe: Getting a job, and the kind of help that you needed getting a job.

Carlyn Crowe: Congressman Nunn said, 'I want you to send me a letter and tell me what your job is.'

Sam Crowe: Yeah

Judy Warth: You know what, Sam, my superpower is knowing ideas for places for people to work. I have an idea for you. There is a security company that works at all the sporting events. They have people who greet people when they come into the basketball games, the football games the swim, swimming meets And that might be a bullseye for you.

But my question to you is what is your superpower? I told you what mine is. What's yours? What's something that's awesome and amazing about Sam Crowe?

Sam Crowe: Hanging out with friends. working with people

Judy Warth: You're a friendly guy.

Mike Hoenig: And a people person.

Sam Crowe: Yes.

Mike Hoenig: And we haven't asked your mom yet. Carlyn, what is your superpower?

Carlyn Crowe: I try and be a connector of people. Like Judy just gave that idea to Sam about a particular job. I hopefully in my role at the DD council have helped to connect people who don't think they have a voice to people who can listen and whether that be through the legislature or by connecting them to state agencies, where you might not think that you're able to get through to talk to who you need to get services. If we don't hear each other's personal experiences, then we don't understand what other people are going through. And especially those lawmakers and policy makers and people that are making decisions for us need to know what those decisions will impact and who they will impact and who they will impact and how. And when you hear people's personal stories that can sometimes change the course of policy or make it better, hopefully for those people who will impact.

Mike Hoenig: You do a wonderful job.

Judy Warth: Carlyn, as you look into this next year, what do you see happening? What do you think are priorities in terms of policy that that would benefit people with disabilities at the state and federal level?

Carlyn: There's so many things that we could be working on in the disability policy arena. And then one thing I think that's happened in the last couple of years is that policymakers are starting to understand a little bit more about the disability community and some barriers that individuals have for things like employment. That there are some barriers in place that don't allow people like my son, Sam, to reach his full potential because he's still going to need job supports in the future and depending upon the job that he gets and how much

money he makes if you go over your base limit, which is very low you lose those supports.

Medicaid is there because there's no other option for people like Sam. He's got to have health insurance and that's the only thing available to him right now. And that's unfortunate, but that's the way our systems are set up. It'd be wonderful for him to be employed full time and have private insurance, but then private insurance, isn't going to cover some of the supports that he needs like supported community living, which helps him get to his job and have a job coach there if he needs one. We can tell those stories to policymakers, so they really understand what's going on and then hopefully we can break down some of those barriers together, allow people to live and thrive in Iowa. The buzzword now with our state leadership is that we want everybody to flourish. And right now there are some systems in place and some policies that need to be changed in order for people with disabilities to be able to flourish and not just be in a survival mode.

I'm hoping that we can work on those things in the upcoming legislative session and that people who are in the position to make those changes will continue to listen more to people's stories.

Judy Warth: Carlyn, thank you so much for bringing that up, because one of the projects going on in Iowa right now is the Iowa Blueprint for Change, which again will include a link in the information of this broadcast.

Any Iowans with disabilities or businesses who are looking for workers to reach out to us at this project to share your stories of successes, stories of failures, because the whole function of this federally funded project is to help Iowans with disabilities move from poverty to flourishing.

Sam, every person who has a disability who works changes the system. One person at a time. One brick at a time. Sam, just by the internships that you had to and that work at the legislature, you've already educated a lot of people.

Sam, we need your voice. People don't believe me. But they do believe you, if what your mom said before you came in is true, your superpowers is people like you and they remember you and people want to talk to Sam and that's important.

Mike Hoenig: I would just like to thank both of you for joining us today.

Sam, you are a really great ambassador and I want to thank you for sharing all of your experiences. I also want to thank Joanna Sabha for producing and editing and keeping us on track.

Judy Warth: And I'd like to thank my esteemed co-host, Mike Hoenig. Sam, I want to close by saying you are the future of what happens in the world of disability.

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.