

Episode 2.11 - Promoting Change in the Iowa Medicaid System with Dr. Matthew Conaway

Mike Hoenig: Hey everybody, it's Mike Hoenig from the Iowa University Center for Excellence in Developmental Disabilities, UCEDD coming to you with another episode of Disability Exchange. Disability Exchange is a podcast dedicated to centering and elevating the lives of people with disabilities and their families, and we do this through casual conversation.

We are grateful for the support of the Midwestern Public Health Training Center in the production of these podcasts and appreciate their strong commitment to education about the disability community and those of us who live in it. I serve as a program coordinator with the Iowa, UCEDD, and I also serve as one of the co-hosts.

We're very pleased that we've got a great guest ready to share unique wisdom with us in just a few minutes. But before we do that, I'd like to turn it over to our co-host Laurie for her introduction. Laurie.

Laury Scheidler: Thank you Mike. My name is Laurie Scheidler and I am a social work practicum student with the UCEDD.

And I am also a mother of a teenage son who has autism and A D H D.

Mike Hoenig: All right. Thank you Lori. It's truly an honor to introduce today's guest on Disability Exchange. Dr. Matt Conaway and I have been colleagues for many years. He has assisted us with many medical student trainings at UCEDD.

And recently I've gotten to know him in a different way as he's become very active as an advocate related to Medicaid issues and serves on the Iowa DD Council.

Dr. Conaway: Hi I'm Doctor Matthew Conaway, I use a type of assistive technology that creates text to communicate. For this interview there will be an AI voice reading the text I've created.

I currently live in a nursing home in Indianola. With multiple degrees, I am a Ph.D. Biomedical Engineer (from U. Iowa) with a completed Postdoc in Physiology (online through Ohio U.) and a Doctor of Bioethics (online through Loyola-Chicago). My education continued in the Executive Juris Doctor in Health Law program for non-attorneys at Concord Law School of Purdue University Global. I expect to contribute to societal and academic discussions on technology, law, healthcare, and bioethics. On top of all that, I have a severe congenital disability. My roots are in Iowa though and I consider Iowa City to be my hometown. And, I am a third-generation Doctor to boot.

My scholarly interests are not only in research ethics, public health ethics, narrative bioethics, neuroethics, and criticism of technology issues as well as transhumanism, but also in disability ethics and related issues in the healthcare arena. Furthermore, I have served as a Volunteer Patient through The University of Iowa Center for Disabilities and Development and helped train health profession students in issues related to disability and healthcare for many years.

As I come from a medical family, I grew up in the healthcare business. My father is a retired orthopedic surgeon.[00:03:00] My mother and grandmother were both nurses. Other relatives were in ancillary professions. Hanging out with cadavers or at a hospital is absolutely normal to me.

And, I am a total Hawkeye! I had a full conversion when Iowa dominated Georgia Tech (where I went to undergrad) in the Orange Bowl some years back.

Functionally, I have mixed quadriplegic spastic athetoid cerebral palsy, of which the exact perinatal cause is still unknown. I am unable to walk at all or use my hands that well, and thus, I use a wheelchair. I was diagnosed at three. My speech is moderately garbled. Now in my fifties, I am medically stable, aside from chronic pain due to trigger points in my neck and shoulders from over 50 years of typing with a mouthstick.

Additionally, I have PTSD, anxiety/depression, pseudobulbar affect (PBA), and autistic characteristics.

As a child, my health care was done by my father's colleagues. It was very interesting. We all learned a lot.

Mike Hoenig: Matt, describe your technology and how you use it to communicate.

Dr. Conaway: I use a commercially available mouth stick to type. My Mac is set to my accessibility specifications. Less technology is better, I believe.

Mike Hoenig: I agree with that. Matt, as somebody, who has been blind since birth, I attended a residential school. So I'm very interested in hearing about your school experience. So did you attend public school and what was that experience like for you?

Dr. Conaway: I came from way back in time when special education was first implemented in the 1970s. I did it in Georgia where I grew up. I was the first disabled student to be mainstream to regular and advanced classes. The prejudice was electrifying. Each year I had to prove to the teachers that I belonged, though I still had to be in special education, to receive physical supports in school, which did not know what to do with me. I really never fit in anywhere, as I also had to be bused off my home district to physically participate or to a physically accessible schools.

After public school and a year at a small college in North Carolina, I ended up at Georgia Tech. Though tech tried to fail me, I ended up with two bachelor's degrees on the dean's list and with pre-med preparation.

Laury Scheidler: Oh, Matt, I truly have an appreciation for your tenacity and proving them wrong. What an accomplishment. Can you tell us about your move to Iowa and what's been good about living here and what hasn't necessarily been so good?

Dr. Conaway: As I say, my roots are here. My parents came from Des Moines, so Iowa truly is home. Having lived in many places, including Chicago for six years, Iowa is really the only place that makes sense to me. My only complaint about Iowa is the decimated healthcare system. Before privatization of Medicaid, the system was much better.

Mike Hoenig: I think you'd get a lot of consensus on that, Matt. And speaking of which, you told us that you lived in a nursing home. How did that happen? And then also what are your feelings about living in a nursing home.

Dr. Conaway: Due to the caregiver shortage privatized Iowa Medicaid. I lived at U I H C from October 2019 to August, 2020. In some 30 years of being on my own, I had never been in such a situation. From there, I was sent to a nursing home in Indianola, aside from a brief, but disastrous and inappropriate placement in a host family, I have been institutionalized ever since.

On the other hand, I do not want to go back to managing caregivers by myself. Due to multiple, abandonment, and much neglect and abuse by previous caregivers and age or disease, I can no longer do that emotionally. I expect to go to a supported community living apartment at some point in my future.

Mike Hoenig: So Matt, with your lived experience, can you tell us about your advocacy work with the Iowa DD Council in Medicaid?

Dr. Conaway: I've served out in the Iowa DD Council and the H C B S redesigned steering committee. My primary focus in advocacy is reforming the home and community-based system in Iowa. With an extensive training and lived experience I feel that I must be part of this Herculean, but worthwhile and necessary effort,

Mike Hoenig: and it is a Herculean effort. Wow. This, again, may be somewhat related, Matt, but we'd like to hear a little bit about some of your personal and professional goals moving forward.

Dr. Conaway: Personally, I expect to get out of the facility and go back to community living in Iowa City, buy a home get married and have a family.

Professionally, I expect to continue my advocacy efforts for H C B S reform, obtain gainful employment, doing such work, and continue educating health professionals on disability issues.

Laury Scheidler: Okay. Matt, I really have an appreciation for everything you are doing to. Advocate and assist others, with disabilities, it truly is needed. One of the things that we always ask individuals at our session is, what is your superpower?

Dr. Conaway: My superpower is stubborn toughness, Or tough stubbornness.

Laury Scheidler: I love it, Matt. Thank goodness.

Mike Hoenig: Oh, and you have proven that. I love it too. So for those of you, they're listening we decided. For everyone's benefit to have some preset questions so that Dr. Conaway could be prepared. We have some extra time here on disability exchange, so we're going to ask Matt a few extra questions. My first question is, you talked about the importance of educating people about Medicaid. And how privatization has really made things, go south, so to speak. What do you think it's actually going to take to at least begin to fix some of the Medicaid issues related to the provider shortage and the low wages?

Dr. Conaway: Increase funding. Plus, caregiving needs to be treated as a profession that offers opportunity for career advancement.

Mike Hoenig: Very well said. And I completely agree both counts.

Laury Scheidler: Matt, I'm gonna take you in a little bit different direction. I have a question that's burning in my heart and that is, What advice would you offer to others to obtain that stubborn toughness and tough stubbornness? Is that something that you learned or do you think that's something that was innately in you? What advice can you offer others?

Dr. Conaway: You gotta be born a Conaway.

Laury Scheidler: I love it.

Mike Hoenig: The docs have it.

Laury Scheidler: so can people rub shoulders with you and will that Conway rub off a little bit?

Mike Hoenig: It might. So I have a philosophical question for you. For those that may not be aware, there is a disagreement or a difference in, in thought within the disability community. When I was growing up and well into my adult years, we talked about using people first language, and that meant that you would say a person with a disability, a person in a wheelchair, so forth. Now many advocates prefer to use identity first rather than to say I'm a person in a wheelchair, I am a disabled person. I am, I have cerebral palsy, those kinds of things. It's thought many times people put it into a generational concept and they'll say the younger people like the identity first language. While those of us maybe that are little older, typically use the people first language. But I know that you've stated very publicly that you prefer identity, first language. What brought you to that thinking process?

Dr. Conaway: I've always hated people first language. It's dehumanizing. Plus, I'm just ornery and contrary anyway. I'm not a trend follower and I never have been and never will be. Yup.

Laury Scheidler: I was just thinking about how different people, think differently. There's always these trends that keep changing. Is that something you just ask or expect someone to state their position on that? I'm not sure if I'm asking that question correctly.

Mike Hoenig: So, you mean if you wanted to know how Matt, for instance, what type of language he preferred?

Laury Scheidler: Yes. Like just in like normal, everyday interactions

Mike Hoenig: What do you think, Matt? Would you like people to ask you those kinds of questions or do you just want to let those things be known as you get to know the person?

Dr. Conaway: The people with acquired disabilities seem to deal with that differently

Mike Hoenig: . . .than people that were born with a disability? Is that what you're saying?

Dr. Conaway: Yes. It depends on the situation.

Laury Scheidler: That would make some sense. Yeah.

Mike Hoenig: And sometimes people aren't gonna know the answer. I taught a class this morning and it was with the Iowa Department for the Blind. They have a training center there, and for many years the standard terminology for whatever reason, within that center was blind guys.

So, it didn't matter if it was a man or a woman. It was blind guys. And trying to be conscientious of pronouns and everything. This morning before we started, I said, now, in the past we used the term blind guys, what do you use now? And everybody had a different answer. I think there's sometimes where a person isn't gonna know, you can certainly walk up to somebody right away, but certainly within the conversation, asking them how what terminology they like to use

Somebody asked me how long I'd been using my cane. I said, 50 whatever years. and I'm 59. then she said, so you were born and I know what she wanted to send. She didn't know what term to use.

And I said, yeah, I was born.

Dr. Conaway: Cool Mike. We're born, we die. That's normal.

Mike Hoenig: That's right.

Laury Scheidler: I see why the two of you are friends. You have to have some humor.

Mike Hoenig: Yes, absolutely. Matt, I wonder if there are any other general words of wisdom that you would like to share with podcast community?

Dr. Conaway: That's a loaded question. I think I'll just say, that everyone should be themselves. You can't get any more normal than that.

Mike Hoenig: I love it. But I do think, I think that's a wonderful message in all seriousness about being ourselves. And that's Matt, one of the things that I've always appreciated about you, even in our medical student training, you don't sugarcoat anything and future docs, need to hear your comments. I've read some of your writings and I just know that you see the world in a way and you share that, and I think that's, that genuineness is something that we should all be a part of. Absolutely.

Dr. Conaway: It scares people

Mike Hoenig: It also enlightens them. I would agree with that.

Laury Scheidler: And sometimes the things we need to hear are hard to hear. It's true. I think you could write an amazing book and interject your sense of humor in there. you speak very straightforward. I think would be very interesting.

Mike Hoenig: And I know that you've already written a manifesto, so you could use that as your forward.

Dr. Conaway: Wrote a 420 page PhD thesis!

Laury Scheidler: Oh wow.

Mike Hoenig: Glad it was you instead of me.

Dr. Conaway: Yup

Mike Hoenig: Is that the one that you told me that you would tell me more about it, I wouldn't understand it.

Dr. Conaway: See, I'm not normal.

Mike Hoenig: Matt, we just wanna thank you very much for being our guest today on Disability Exchange. It's been very entertaining. As our listeners will figure it out, we learned as we went and that's okay cuz that's part of creative disability journalism. So I just would like to thank you again.

As I said Matt, I'd also like to thank our friends at the Midwest Public Health Training Center for all of their support. I'd like to call out, Joanna from our team for coming up with some very creative solutions and also for producing and editing this podcast. And finally, I'd like to thank all of you listeners for, joining us.

Dr. Conaway: Thanks for letting me help.