

Disability Exchange S3E2 Keith Ruff Memorial Episode

[Introduction Music]

Judy Warth: We're excited today because we are going to look back at the life of 1 of our important contributing disability leaders in Iowa.

Disability Exchange is a podcast that is produced and presented by the University Center of Excellence in Developmental Disabilities. Iowa's UCEDD and the Center for Disabilities and Development. You can find this on Spotify, or wherever you listen to your favorite podcast. Disability Exchange is designed to center and elevate the voices of people with disabilities through meaningful conversations and connections.

Today we'll connect you with some disability leaders in Iowa to celebrate Keith Ruff. Today's episode is dedicated to Keith, his work and his legacy. My guests today are none other than Bob Bacon, former director of Iowa's UCEDD, Dr. Diane McBrien, our medical director of the Center for Disability Development, Mike Koenig, my infamous co-host, and Joanna Sabha, all of whom had different relationships with Keith. I'm going to go around and let you guys introduce yourselves, Bob, why don't we start with you?

Bob Bacon: I was, the director of the UCEDD for close to 20 years. I worked at the Center for Disabilities and Development for closer to 40 years, I did not have a lot of experience with the disability world, when I joined CDD, Keith turned out to be one of my major teachers and there's no way that I could have anticipated all the lessons that he taught me and also the benefit of him being incredibly important friend someone who became really part of our family in so many ways. When I drive by Gilbert street, his apartment, I really feel the emptiness.

Judy Warth: Yeah, Keith passed away September 29th at the age of 78. He played a critical role here in our community. Diane, would you like to introduce yourself?

Dianne McBrien: Thanks, Judy. I am married to Bob. Keith. was the best man at our wedding. And Bob is right. he was a member of our family. That's taking some getting used to.

Judy Warth: Yeah, for all of you who are participating today and our listeners, we are so sorry for the loss. Mike.

Mike Hoenig: Thanks, Judy. This is a new role for me being a guest, so my name is Mike I worked full time for the UCEDD for nearly 30 years and retired as a program coordinator in August of last year.

I first met Keith actually in grad school. At Iowa, in '84, we were both in the rehab counselor education program. I knew that he was a good friend. We reconnected when I worked for the Illinois Iowa Center for Independent Living. We ended up partnering on a personal assistance services advocacy coalition. When I came to work for the UCEDD in 1993, we partnered on a variety of projects and I want to highlight a public access TV program called *Hello, It's Us Perspectives on Inclusion*.

Our good friend and mentor the late Terry Cunningham hosted *Hello, It's Us* with Keith for quite a number of years. That was another cool story. At an ADA celebration some panelists hadn't shown up. It was just an organic thing where he and Terry got together and started just chatting about disability issues and how far we'd come and how far we had to go. That's how their connection formed into doing *Hello, It's Us*. And then after Terry passed, Bob honored me with the opportunity to work with Keith for several years on *Hello, Its Us*. That was the predecessor to *Disability Exchange*. So as I talk about Keith I think about how his legacy lives on in many ways. But one way is through this podcast.

Judy Warth: Thank you, Mike and Joanna Sabha.

Joanna Sabha: So I actually know Keith more from the community. In the 90s, my mom had a terrible car accident and ended up physically, emotionally, intellectually disabled. And I remember meeting Keith at church and just being like 'this guy's killing it.' Like he's happy. He's doing all the things in the community that he wants to do. When my mom was leaving rehab they were saying she needs to go to a nursing home and our family was saying 'No! We were going to at least try and take her home. I remember days that were really difficult for us trying to transition to figuring out how we were going to do things with my mom. Seeing Keith, was that reinforcement that there was success to be had in the community, that there was a space for my mom and there was a space for our family.

Judy Warth: Yes we highlight that Keith was a disability advocate, but he was really a community advocate. We want everyone to hear through this podcast is that disability may be the thread that ties us together, but it is not the rope that binds people to this world.

Joanna Sabha: I think once we met Keith, we saw him everywhere. If there was a community event, he was there. If there was an opportunity to advocate for really any cause that was important, he was there that showing up was really important for us to see because it set the example that we could create the life that we wanted for our family. And that disability didn't need to be an obstacle to us achieving happiness and the things that we wanted to do in life.

Judy Warth: Yeah, I was reading that he had done some consultation and assistance in planning for The Kernel's stadium. Oh, yeah. Englert so he was involved in the arts and sports and everything that was Iowa City. Let's talk about Keith's work for a second. When you think about that, what pops into your mind?

Bob Bacon: Back in the 1980s, Medicaid dollars were pretty much controlled by providers. The idea of giving people with disabilities control over those resources in ways that made sense to them was a new idea and Keith wound up sharing that with me in a way that I could really embrace it and understand it.

Keith and I wound up traveling to the DD council and sharing that idea with the council and the council was very receptive.

Mike Hoenig: There was a grant to work with Centers for Independent Living to create a model for personal assistance.

Judy Warth: For those of you who don't know what the DD council is, Iowa has a Developmental Disabilities Council that provides advocacy at the state and local level to help move things forward for people with disabilities. It's designed to be the voice of people with disabilities at the state level.

Keith was a coordinator as well. Let's bring people together and create a common voice.

Joanna Sabha: He was a multiplier, you know?

Bob Bacon: That's a good, that's a good phrase.

Mike Hoenig: Yes.

Joanna Sabha: Instead of being a diminisher, he was like, 'let's take this thing and how can we make it five times better?'

Bob Bacon: Yes, individuals and families didn't have control over Medicaid resources. Keith helped policymakers get more comfortable with the idea of having more consumer and family control.

Mike Hoenig: Keith was also chairing the DD council. And then he got appointed to, it was called Mental Health, Mental Retardation, Developmental Disabilities and Brain Injury Task Force. Keith was maybe the only person with a disability that was on task force. I think his input was really integral in that process too.

Bob Bacon: That's exactly right. Keith wound up making a couple presentations to the council and when an opening on the DD council appeared, they recruited him to join the council and that was because of his interest and work in personal assistance services.

Mike Hoenig: He wrote a book. it's called a *Wheeling Through The Years*. I was able to work with Keith to get it recorded through the Department for the Blind Library.

Judy Warth: *Wheeling Through the Years* is available from Amazon.

Dianne McBrien: It's a fascinating book. His story is incredible. it's a story about, in some ways, disability in midcentury and his family not understanding. In the book, he went to a school for children with physical disabilities. He remarked that at the school, it was not important to do things a certain way. It was important that you got them done. I'm assuming that he was talking about like some skill, like using scissors or washing dishes. He said, at home if I didn't do things just a particular way my father would. . . would get very angry and sometimes beat him. And it's the theme of sort of disability is running under all that, the desire to be perfect and being like everybody else. And it's. . .it's in some ways it's a tough read, but it's a very honest read.

Judy Warth: Diane, you walked us into that. We've talked about Keith, the professional, tell me a little bit more about Keith, the man.

Dianne McBrien: I think in some ways he was hard to get to know. some ways he was very stubborn, but I think he had to be. he had to be to create the life that he wanted. He valued his friends dearly. And he was kindhearted and loyal.

Mike Hoenig: One of the things that, that I found interesting about Keith is that he had a way of attracting people to him. When we planned our *Hello, It's Us* shows, we would typically meet at the Bread Garden. That was one of his

favorite places to hang out in Iowa City. And of course, When I would come in to meet with him, there would be somebody talking to him.

Bob Bacon: Yeah.

Mike Hoenig: And. . .and it was just casual conversation, but people wanted to get to know him.

Bob Bacon: Yeah, and the people who worked at the Bread Garden always knew what his favorite drinks were. Somehow that word spread.

Joanna Sabha: Everybody knows Keith.

when I'm telling somebody about Keith, I say, do you ever remember seeing a guy in a wheelchair going about three times faster than you think anyone should go in a wheelchair? And they'll be like, Oh, that guy. And I was like, that was Keith like he knew where he wanted to go. He had control over his wheelchair and he did not waste time.

Judy Warth: I want to pull you guys together here. You guys have shared wonderful memories of Keith as a professional, Keith as a family member, Keith as a friend, Keith as a community leader. This is a question we asked our first season of everyone who came is 'what do you hope your legacy will be?' I want to ask you, this is the first time we've been able to ask it in retrospect. So I want you to think about this? What do you think Keith's legacy is, certainly as it's filtered through your eyes and your heart?

Joanna, I'm going to start with you.

Joanna Sabha: I think what I learned from him is put yourself out there. He wasn't sitting in a corner. By himself, he was meeting people. He was starting communication and then he would figure out ways to get things done based on what he wanted to see happen.

Judy Warth: Dianne.

Dianne McBrien: I would say that the autonomy of someone's independence cannot be overstated. Even at the end, Keith's own wishes, just very important to him. He. . .He lived the way he wanted to. He was probably the first person I knew with that degree of disability who had that degree of independence and it struck me.

Bob Bacon: I'd say his legacy is his tremendous effect on the city of Iowa City. So many people knew him. And I think that had to change a lot of people's understanding of disability.

Judy Warth: Yeah.

Bob Bacon: And the fact that he loved Iowa City, and he made that clear in his book, and so there's a reciprocal relationship there.

Judy Warth: Awesome. Mike.

Mike Hoenig: This is cool because we all have different legacies. I would say that when I think of the legacy that Keith left, it's the establishment of personal assistance services in Iowa for people with disabilities. I know we still have a long ways to go, but I look back and think that when he expressed this need, those of us in independent living at the time knew what personal assistance was, but so many people didn't. I've often wondered where we would be with personal assistance services in Iowa if it hadn't been for Keith.

Judy Warth: As I listened to you guys and I try to and try to bring it all together. the lessons learned are be real be authentic. Strive for those things you want and you too can change the world. I mean he did he changed things for all people with disabilities in the life he led and that's about as good as it gets. On behalf of all of us here at, as you said, the Center for Disabilities and Development and all Iowans with disabilities, we express our deepest sympathy for those of you who love Keith and those of you who didn't get to know him because now you need to know him.

I thank you guys. I know that each of you were individually touched by Keith so thank you for coming and opening your hearts to our listeners today. This is Disability Exchange. We are hopefully having meaningful conversations and making new connections.

It is hosted by the University Center for Excellence in Developmental Disabilities. Iowa's UCEDD, at the Center for Disabilities and Development. You can find this on Spotify, or wherever you listen to your favorite podcast.

Narrator speaking with music playing: 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.