Disability Exchange S4 E7

Patient Centered Care for All

Recorded 12/9/2024

**Judy Warth:** Welcome to Disability Exchange housed here at Iowa's University Center for Excellence in Developmental Disabilities and hosted by myself, Judy Warth, and Mike Hoenig.

Special thanks, to our producer, Joanna Sabha. Disability Exchange is designed to center and elevate the voices of people with disabilities through meaningful conversation and connection. Today we're really excited because we're coming at this from a different angle. Disability touches all parts of life.

Today we're going to find out more, but first let me kick it off to my esteemed colleague, Mr. Hoenig.

**Mike Hoenig:** I am a program coordinator. I retired a couple of years ago from full-time employment but I'm still very pleased to be involved and this is one of my very favorites. I believe that getting the voices out there people with disabilities, family members, and our allies, is a critical task that we are fortunate enough to be able to do.

We have Kelley Kirby, with the radiation sciences training program here at the University of Iowa. We have Emma Nibaur, who is a student in the radiation sciences program, and Lilly Parker, who is a student also in the program.

 Kelley, tell us a little bit about yourself your role on campus. And how it came to be that we. are talking about radiation sciences on a disability podcast?

**Kelley Kirby:** Thank you, Mike and Judy, for including us today. I am an academic advisor in the Carver College of Medicine for the Radiation Sciences and Nuclear Medicine Bachelor Degree Programs. I get to teach their patient care class I work with every first semester student in the radiation therapy, diagnostic medical sonography students, x-ray technology and nuclear medicine technology.

You can't practice an x-ray on someone. You can't practice giving radiation therapy treatment on someone. Our students are in the hospital working with patients virtually day one because you can't practice giving radiation therapy treatment on someone. They are in working with patients immediately. Mike has been gracious enough and him and his team, I should say have been gracious enough to come join us. Oh, my goodness. Mike. . .

**Mike Hoenig:** At least 10 years.

**Kelley Kirby:** Over. I like to have experts come talk to our students. Luckily, at the university, we have experts in a lot of different topics. We have a child life specialist come in and talk to them specifically about how to work best with a preemie to an eighteen year old. Mike and his team come and talk during our diversity section. Because I think it's really important for students to be exposed to people of varying abilities and I can talk about that but it's more impactful when it's coming from someone like Mike and seeing and meeting somebody like him and his colleagues. I get feedback every semester from students that they really appreciated that lecture. I want to expose my students to the people that are going to be the most impactful.

 **Judy Warth:** Kelley, as I'm listening to you, I'm hoping that other university faculty are listening and thinking gosh, could we do a class on this? Emma and Lilly, I'm curious as to the impact this sort of information makes on you as practitioners. Emma?

**Emma Nibaur:** My name is Emma Nibaur. I'm a junior in the radiation sciences program, so this is my first year being in radiation therapy. I help with cancer treatments. Mike, I met you during our patient care class.

I went to the University of Dubuque and was on the nursing track but as time went on, it just wasn't working out the way I wanted. I was able to find Iowa's Radiation Sciences Program, specifically Radiation Therapy. I've also worked here at the university as a patient care technician for the past 2. 5 years on the burn and trauma unit. I see so many different people between being a patient care tech and also working in the clinic.

It's super important knowing how to work with people with disabilities and how to bring awareness. It touches my heart, my grandpa had a renal stroke in one of his eyes around 2015. Then about 2 years ago, he unfortunately had a stroke and his other eye so he is now completely blind.

**Mike Hoenig:** When we do the trainings I'd like to ask a student to volunteer to come up and practice sighted guide. They will lead me around the classroom, Emma was a very willing and ready volunteer sometimes students are a little shy or nervous about that, but Emma jumped right in.

**Judy Warth:** Emma, as I'm listening to you, that individuals with disabilities want to be heard, to be listened to, to be treated fairly. In a lot of respects, talking about disability patient care is a little bit of an oxymoron. It's how all want to be cared for. Lilly, please tell us about you.

**Lilly Parker:** My name is Lilly Parker. I'm a senior in the ultrasound program. After graduation I'm going to be working at the OBGYN clinic. I've been in the program for about 3 years now, and I've learned a lot, not just about ultrasound and physics but patient care, that empathy has really carried over into my personal life as well.

It's not just patient care that this program teaches you. It's about how to make people feel wanted and heard and seen, especially in those important medical decisions. At the University of Iowa, we see rare cases. We see patients who speak different languages and who have sight disabilities or hearing disabilities. It's very important to expose people to that and have them realize that we're all the same.

**Judy Warth:** That's so interesting, Lilly. In one of our programs, we often have families come in and talk about their experiences having a child with a disability. If a baby is born and has a disability, how professionals respond to the normalcy and the beauty of this child changes the course of a lifetime for those families.

It’s a simple thing is that person going, ‘Oh my gosh, this baby is beautiful’ and celebrating the life that maybe doesn't look exactly like everyone else's is so impactful for those families.

**Mike Hoenig:** It's refreshing to hear Emma and Lilly, talking about seeing people as people because it hasn't always been that way for people with disabilities and kiddos with disabilities.

We could tell way too many stories about people that have either been institutionalized or medical personnel telling parents not to bond with the child. It's a new day and it's really great to hear both of you getting it so clearly.

**Judy Warth:** Kelley, I suspect that has to do with your work. How did you get started with this class?

**Kelley Kirby:** It was given to me when I started in Radiation Sciences Education I was thrilled. I love that class because It's a safe place if a student has a question they're not going to hurt your feelings if they say something wrong.

That's why they're there, to learn and talk about it. I want to expose them to as many people as possible. If they have a blind patient, for example, a lot of my students have never met someone blind. They've never talked to anybody and then they meet you and you're hilarious and kind and you share your life story with them. They feel like, okay just because someone's blind doesn't mean that they're not going to have a career, a life, a home, and love baseball, and the arts, and all the things that you love.

That's why I keep calling. That exposure to people that are not the same as them takes that mystery out of it and at the end of the day, we're all human beings.

**Mike Hoenig:** Thanks for the kind words. Emma, when you mentioned your modality is radiation. I'm a cancer survivor, and just got a report on Friday that one of my spots has started to grow a little bit, and we're trying to figure out what the next step is going to be. One of them that's being considered as radiation. I thought wouldn't that be ironic that you would work with me? And then I thought about it a little more. I always ask, if I end up in whether it's a CT or a PET or radiation, which I have had previously, ‘Did you go to Iowa?’ I think it's always fun to make that connection. And then they'll say, ‘Oh, yeah we remember you from the class, as a guest presenter.’ That really makes my day.

I do hope that our disability training has made a difference. Also, as Kelley said, you're good people and you want to help others. It's been my theory that the reason that I've gotten such great treatment and very patient centered treatment as a blind patient is some of both.Yes, hopefully we're creating some awareness, but that there's a desire to help. And just by getting into the program and learning what you were learning, you have a desire to figure out how best to support patients.

**Emma Nibaur**: First, Mike, I'm sorry about the news of possible growth, and I hope that everything turns out to be okay. If you have to have radiation therapy, you will see us there. Hearing the disability talk resonated with me. We were really happy that Kelley was able to give us that opportunity to meet you guys and to hear about different ways that we can do our job in a hospital or clinic or whatever.

**Lilly Parker:** I agree with you, Emma, I remember from the disability patient care chat, you walk out of the auditorium with a new look at life, a different perspective, I think. Because. you try to put yourself in, for example, Mike’s shoes. I definitely agree that it helped me create some intrinsic motivation to really help out those patients who may need a little extra care. For some patients coming to the hospital, that might be the only interaction they have that day. So, it's important that you make it a good one.

**Mike Hoenig:** Very true.

**Judy Warth:** I can envision this podcast, being something that Kelley has as a prerequisite for the class. And so if you were going to give advice to future students, what things would you say are important to remember, with every patient, but especially with a patient who may have a disability?

 **Emma Nibaur**: The number one most important is communication. Communication is going to be in all different forms, sometimes when people are nonverbal, someone just gets placed a trach and they can't speak, we have whiteboards for them that they can write. We go above and beyond to make sure that all our patients are taken care of.

**Judy Warth:** Emma, can I jump in there?

**Emma Nibaur:** For sure.

**Judy Warth:** You just said something that is so important to me. No matter who your patient is, whether their eyes are open and looking at you or not encourage people to talk directly to the patient from my perspective, it's one of the most respectful things we can do as professionals.

**Emma Nibaur:** Patients that are vented they don't, they can't speak some they're unresponsive, but I still make sure I introduce myself. I tell them what I'm going to do.

If I was the one laying in the hospital bed, how would I want to be treated? How would I want to be taken care of? No matter how bad of a day I could be having, I go in there and do my best because that's how I would want to be treated.

**Lily Parker:** I agree with that, Emma. One of the key points of my patient care technique is I try to put myself in that patient's shoes. After a long day of appointments, or they had to drive from 4 hours away for a scary type of procedure, or maybe newborn baby has some genetic condition, to put yourself in their shoes and really understand how you can make them feel better and have a human conversation or connection with them.

If someone's blind, you don't need to raise your voice and speak loudly at them. You don't need to talk down to someone because they have a mental disability.

They may be able to understand you.

You pointed out, Emma, whether they're on a ventilator or not, it is important to introduce yourself. You never know what patients are able to hear or understand in those conditions as well.

**Judy Warth:** When I think about people who communicate differently, if we communicate and they don't understand a single word we said, what have we lost? But if we don't, and they do understand, what have we done? And that's to me remarkable. Kelley, I can see this smile on your face. This is the fruit of your work.

**Kelley Kirby:** Yes. And not just me. There's a huge education team the clinical technologists and therapists that model patient care every day. I hope there's little seeds that are planted in patient care. They're learning all this technical stuff. There's a process to all of these things that they're doing. Whether it be sonography, therapy, x-ray, or nuclear medicine technology, learning the techniques and how to do things properly so we get diagnosis or treatment. But you're also trying to take care of that patient as well. They're learning how to balance all of that and do it well. It takes time and practice to do both well.

**Judy Warth:** You have been quite inspiring. For all of the medical professionals, families, and individuals who are experiencing like you have, Emma, the introduction of disability in their life, reach out to us and see what the Center for Disabilities and Development as well as the University Center for Excellence in Developmental Disabilities can do to provide you support and resources. On behalf of all of us here at Disability Exchange, I really want to thank you for spending time with us today and imparting your wisdom,

Please join us on Spotify and share with your friends freely. Thank you.

**Narrator with background music:** 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.