Disability Exchange S4 E5

Dancing With No Shoes

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**Mike Hoenig:** Welcome to Disability Exchange, a podcast designed to center and elevate the voices of people with disabilities and those who support them. My name is Mike. Honig. I am a program coordinator with the Iowa UCEDD which is the Iowa University Center for Excellence in Developmental Disabilities.

**Judy Warth:** I'm Judy Worth. I'm a program manager at Iowa’s UCEDD, a lot of my work is in transition and employment and engaging people in community and our guests today really has embodied that in so many ways. Our guest today is Scott Lindgren, who is a longtime colleague of both Mike and mine. Mike, when did you first meet Scott?

**Mike Hoenig:** Gosh let's see. I started in 1993, so probably shortly after that. One of the ways that Scott and I really got to know each other was through an initiative working with students going into health care professions on disability accommodations and disability etiquette. We spent many a Thursday afternoon over at the medical education research facility proctoring those sessions.

**Judy Warth:** The way I got to know Scott was really because I got to meet his son, David.

**Scott Lindgren:** Yeah. I have two sons one living in Iowa city. That's David and another in California. That's Chris. And David is an interesting guy. He's in his thirties now. He has had challenges throughout his life, but his main issues in terms of disabilities are an intellectual disability and also speech apraxia. He doesn't really have much intelligible speech, but he gets his point across, in other ways. David, he's now living in a group home in Iowa city. He's got a little more independent life of his own now.

**Mike Hoenig:** And David's quite a golfer.

**Scott Lindgren:** Yeah, he is a good golfer. He and I, as a team, have won lots of medals through Special Olympics and Unified Sports.

**Mike Hoenig:** Earlier this summer Center for Disabilities and Development celebrated its 75th anniversary, and many people who formerly worked at CDD came back to join us, including Scott. And during our conversation that day, he told me that he has written a book.

Scott, if you would, we'd really like to have you introduce the book,

**Scott Lindgren:** The title of the book is Dancing With No Shoes. It’s a young adult coming of age novel that kind of blends together elements of romance and mystery and a quest for independence.

The main character is 18 years old and has significant disabilities that affect speech and mobility. He uses a wheelchair to get around and a speech device to help him talk. But he's also coping with many of the same challenges that confront any adolescent as they transition into becoming an independent adult.

I've always felt that disabilities are so common that they really need to play a more central role in the daily life of people in our society.

Mike's heard me say this before, but I often say that everyone will experience some type of limitation or disability if they live long enough. I'm certainly finding that out myself with various issues that I have that didn't limit my functioning previously. Disabilities should not be hidden away because we're too uncomfortable to look at them or talk about them.

They should be included in art and literature, in education, in government, really in many things. So I wanted to write this book to maybe help teens and the adults, who care about teens, to feel that disability is just a natural part of life.

People with disabilities really don't have the opportunity to become characters in books or movies or any kind of artistic effort like that. And when they do, they're often there for show or sidekicks to the main characters or distractions for the main characters.

But when they are a main character in the story, the focus is often on how inspirational it is for them to overcome their disability in some way. Too often, it seems to me anyway, that what they accomplish wouldn't stand out if they didn't have a disability.

The main character, David Hardy he has cerebral palsy and uses a wheelchair and uses a computer to help him talk. And there are issues in the book where he fights back against society and the medical establishment that he's had to deal with his whole life. But he's also trying to find his own personal path to independence as a young adult, just like every adolescent I've ever met, with or without a disability.

And I think that's what interests me most about David as the hero of the book. So it's not, I'm not trying to make it inspirational in the sense of, oh look, there's a disability he's trying to overcome, but more a matter of he's trying to be his own person. He's trying to be the person he's meant to be,

**Judy Warth**: Scott, I think that is what makes David inspirational in this book, is he's just like everyone else. There's nothing special. He's awkward with girls, but he's noticed them. As a reader, you get to feel the challenges, but then all of a sudden you get past them and you're in David's world. David's disability is all just part of his life.

**Mike Hoenig:** Knowing you, Scott, and from hearing your description, it sounds like you have drawn upon your personal experiences as well as your professional experiences.

**Scott Lindgren:** That's definitely true. It may be helpful for me to read a couple of pages from the book:

As they began to eat lunch, David made a few awkward efforts to grab his turkey sandwich with his hands and to lift it toward his mouth. Unfortunately, his poor muscle control resulted in large chunks of turkey and bread falling onto his lap tray with very little food reaching his mouth. Ari let him try on his own at first to see if he would need more help. Finally, she asked David if she could help, and he cautiously agreed.

Ari then asked whether he wanted her to lift the whole sandwich for him to take a bite, or whether he preferred that she pull off smaller pieces and feed those to him individually. David chose the small pieces. Ari alternated between taking a bite of her own sandwich and presenting David with a piece of his.

She also set up a cup with a straw so that he could take a drink whenever he nodded to her. David was amazed at the physical connection that was developing with Ari while she was helping him eat. And he was pretty sure she felt something too. The touch of her hand was light and delicate as she picked up each small piece of bread.

And her fingertips would sometimes brush against his lips as she gently released the food. This was not the experience he was used to, with cafeteria food being fed to him by a personal assistant. Instead, it was a sensual treat that overwhelmed the sense of dependency that he had been dreading when he agreed to Ari's picnic plan.

For Ari, feeding David a turkey sandwich was transformational. She had liked David since they first met during the speed dating session. But she felt that there was some sort of physical barrier between them that she was struggling to overcome. She'd been feeling embarrassed that she was so sensitive about her own limp when David's physical challenges were much more significant.

She'd also been worrying that David might be so fragile that it would be dangerous for her to touch him or interact with him in any physical way. But now those worries had melted away. They were gone. Completely. And in their place was a feeling that interacted with David, whether talking or touching, was completely natural.

And it was surprisingly exciting, too. As soon as Ari had shared the last small piece of sandwich with David, she leaned over and kissed him on the lips. While David finished chewing the sandwich, he scanned a few words onto his laptop. ‘Best dessert I've ever had,’ he said.

‘You mean the kiss?’ asked Ari.

‘Yeah, for sure’

‘Better than cake?’

‘Without a doubt.’

‘Even better than cake and ice cream?’

‘Yup, absolutely, no question.’

‘Wow, I didn't know I was that powerful.’

‘Get used to it, you are.’

‘But I hope you realize this doesn't work like Beauty and the Beast. Your kiss is powerful, but it won't turn me into a prince.’

 ‘Stop it, David. That's not funny.’

‘You're not a beast, and I'm not a beauty’

‘Of course you are. My eyes work fine, and they tell me you're beautiful. On the other hand, if you're looking at me, on a 1 to 10 scale, it must be about a minus 10.’

‘Come on, you're being too hard on yourself. Looks are far down on the list of things that matter. And anyway, I love your smile and the way you look at me. It's like you've just seen the most beautiful, precious, irreplaceable creature on earth. I really like that look in a guy.’

‘That's exactly how I feel. I could stare at you for hours and not get tired of looking.’

‘And all I have to do is look at how you make me feel. And then I know the world is a safe place.’ As Ares said this, she was thinking of all the times she felt alone and unappreciated, even when she was with family or friends. To keep from tearing up, she blurted out her latest impulse.

‘Hey, let's dance!’

 ‘Dance? I can't dance,’ said David.

‘Of course you can,’ responded Ari. ‘You've got that great power wheelchair to move you all over the place. And I can help with the dancing part.’

‘Okay,’ said David, reluctantly, as he surveyed the paving stones that cover the open patio, leading to the entrance to the labyrinth. ‘How do we start?’

Aerie removed her shoes and placed them carefully in the basket behind the seat on David's wheelchair. She also gently removed David's slip-on shoes and placed them in a basket next to hers. Ari was wearing a loose white sundress that created flowing waves in the warm summer breeze.

She moved gracefully around the wheelchair and then climbed smoothly onto David's lap and gave him another kiss.

‘Am I too heavy?’ she asked.

‘No, you're perfect,’ said David, who was enthralled by Ari’s closeness and not at all concerned about her weight. In fact, she seemed weightless.Aritook David's hand so they could move the wheelchair's joystick together.

First, they guided the chair into a smooth arc, circling the outer edge of the paved patio near the labyrinth. Then they turned more sharply to create a figure eight pattern, after which they spun around to trace more figure eights in the opposite direction. Moving to the center of the patio, they danced by directing the chair forward and back, laughing as the chair changed directions, and Ares slid back and forth across David's lap.

Finally, they set the chair in a tight spin, and increased the speed until the bright flowers around them became a blur, and they felt the joy of being almost weightless, floating, with their feet never touching the ground. Releasing pressure on the joystick brought them back to earth, and they sat together for several minutes, dizzy and breathless, holding each other tightly and exchanging gentle kisses.

When Ari finally realized they were going to be late for the van to take them to an important voter rights meeting downtown, she whispered in David's ear, ‘Hey, Prince, it's time to get your royal rear in gear.’

David smiled and quickly powered the wheelchair off at top speed, with Ari hanging on nervously as they zoomed back to C 28, their shoeless feet dangling in the breeze.

**Judy Warth:** People oftentimes look at people with disabilities and don't believe they're sexual beings. That's not part of their humanity, and that's absolutely so wrong. And I think that passage, as well as a number of others, really embodied that the normalcy that every person feels, and that romance blossoms, love ensues, and you get all the beauty, pain and the full gamut of emotional and physical experiences, whether you have a disability or not. I think about having those thoughts 1st, having those thoughts as an 18 year old, and then trying to put them into your talker.

**Mike Hoenig:** Another thing that caught my attention was just. Something as basic as a meal and how that how Ari figured out how to make that work in a very respectful way. There are many times, people again are afraid to eat with a person with a disability or laugh and some of those things just in that short passage really came through.

**Judy Warth:** These young adults who are coming to the camp have a wide array of disabilities, and there's some beauty in that because you get a flavor for the uniqueness of individuals.

**Scott Lindgren:** It does focus, on several characters David and Ariadne, but also their roommates Zelda, and Buzz. The four of them are a team that develops throughout the story.

**Mike Hoenig:** So, where's David headed?

**Scott Lindgren:** There is a sequel in the works and I hope to finish it sometime in 2025. Both David and Ariadne come to the University of Iowa for college.

**Judy Warth:** I'm sure they're going to be LEND trainees. Let's just be honest.

**Mike Hoenig:** Of course!

**Scott Lindgren:** That's great. I love it.

**Mike Hoenig:** Scott, as we start to wrap this up, One of the things that we find interesting is to ask a person 50 years from now, what do you think about as being at least one of your legacies.

Scott Lindgren: That's a tough question. I'm hoping that the books that I'm working on now will compliment what I've done before. I'm hoping that my career as a psychologist and as a professor at the University of Iowa has helped a lot of students become better doctors and nurses and psychologists and other health professionals. And I hope. That I've also been able to help families and children live happier, productive lives. Those are the things that I really am hoping will stick around.

When I was a Boy Scout, they used to tell us to leave the campsite in better shape than it was when you arrived and I'm hoping I'm doing that.

Judy Warth: I would I hope that young adults, With and without disabilities read this, I also hope some adults do who want to see the array of. Opportunities and personalities that go along with it that's the whole purpose of this podcast is to center and elevate the voices of people with disabilities. Imagine if people read this book and they start to see that we're so much more alike than we are different.

You will change the world, Scott. You already have.

Scott Lindgren: Thank you. Thanks for having me on the podcast. This was fun to do.

Mike Hoenig: Yes. Thank you so much for joining us.

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.