Disability Exchange S4E9

Tick, Click, Jerk, and Hop: Jackie Nau

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Judy Warth: Welcome to Disability Exchange. This podcast is hosted by the University Center for Excellence and Developmental Disabilities and is designed to center and elevate the voices of people with disabilities through meaningful conversations and connections.

Our hope is that by bringing people to the table who are living, working, and learning with disabilities, we can help people hear the beauty and the challenges of disability. We're really excited to have one of my dearest friends, and colleagues, join us on the show today, Jackie Nau, but first I'd be remiss not to introduce my co-host, Mike.

Mike Hoenig: Hey, thanks Judy. We can't have anybody being remiss. I am so excited to be a part of this podcast in general and specifically today because we have Jackie!

Jackie, welcome to Disability Exchange. If you'd go ahead and introduce yourself.

Jackie Nau: Thank you all for having me.

My name is Jackie Nau. I grew up in southeastern Iowa and went to Mediapolis High School, which is near Burlington, small town. I went to cosmetology school and I cut hair for 14 years, which is a lovely career.

I have two children. My oldest son, John lives in Lisbon. He's a police officer. My other son, Samuel came home on hospice 27 years ago.

We were told to take him home and love him. he would not be able to survive the weekend. And I'm happy to say he outlived that weekend by almost 12 years. So, it was through him that I was introduced to the whole disability world and all the lovely people that belong there, including all of you. Samuel was the heartbeat of her home. And brought us so much love and joy. Kelly Von Lehmden was the Parents As Mentors coordinator at the time. And I met her speaking on panel and she asked if I would be interested in Parents As Mentors and I said ‘absolutely.’ So that was my first introduction to the LEND program.

Judy Warth: For our listeners' sake Jackie has been referring to the Iowa Leadership and Education and Neurodevelopmental and related Disabilities, or the I-LEND program an interdisciplinary program that brings students, parents as mentors, people with lived experience together to infuse disability in their discipline as well as to infuse disability in policymaking and in systems change. The goal is to make disability a regular part of life.

Jackie Nau: The trainees come out to the house, and they get a first row seat of what it really takes for these families to operate at home. Samuel had a whole lot of medical equipment; a suction machine and he was G-Tube fed and eventually he had a J-tube as well, and he had wheelchair and a hospital bed. We also had another son, Jonah, who was a typical growing child and he was in things at school and sports and stuff. So we're trying to balance out the two and we did really well at home. The trainees, they get a behind the scenes look at what our lives are like. The true experts are the family and the parents. So, it was so gratifying to be able to pour into these students.

On the reverse side being a program director for Parents As Mentors I had the great pleasure of reading the journals that they would write after these home visits. The scales were dropped off their eyes as far as the beauty that these families represent and how they just wanna be like every other family.

Mike Hoenig: That's great Jackie. What was that process like for you to open up and share about your own disability experience?

Jackie Nau: Thanks for asking Mike, because it is, it was a journey. I think we're all on journey of acceptance of ourselves and each other. I started having ticks when I was a child and didn't know what they were, didn't even have the word tick in our vocabulary.

Unfortunately, I wasn't diagnosed with Tourette syndrome, until I was 22 years old, as well as OCD and ADD and anxiety. When Kelly recruited me she thought the the program was a good fit for me. She was spot on.

I know that I've been loved and embraced and felt an equal, like in a salon setting I did waitressing work years ago at, the gym where I've taught classes forever, but I never felt like I could truly be myself and let my guard down, like I could at the CDD every day. I'd go to work and I didn't feel like I had to suppress, tick, or explain anything or say I'm sorry the rest of my life just there's enough stigma still around Tourette Syndrome that we just feel ashamed of it anyway.

I'm telling the trainees that they need to show dignity and respect all people. And it started off with Samuel.

We just loved him. And I firmly believed he was made the way he was for a reason. But I didn't believe it about myself. I felt like I was defective. Something was wrong with me and it was all my fault.

So I'll never forget when Kelly said, ‘I wondered if, when you're talking about Samuel and dignity and respect, could you also weave into that story your own backstory about disability?’

And this was so new to me. I was just taken aback, and it isn't for the reason people probably would think ‘oh, I don't have a disability.’ That wasn't it. I knew that I did, I knew that Tourette's is covered under the Americans with Disabilities Act and as well as the Education Act, but my shame level had me in a place of, I'm not worthy of the label of a disability, I do have a disability, but putting it out there in that way just was so foreign to me.

It caused a lot of anxiety. I. Never apologize for advocating for Samuel, He didn't ask to have this condition and neither did I.

I really blossomed into my own advocacy. I stopped apologizing. I started educating I looked forward to speaking to the trainees, not just about Sam and my role as a mother of a child with severe, profound disabilities, but to my own disability and dispelling the myths.

Judy Warth: Jackie and one of the ways that you've done that is you have just published a book Click Tick, Jerk and Hop: the Story of Tourette’s Syndrome

Jackie Nau: I wrote a poem just by myself, for myself, to myself five and a half years ago. And it poured out of me in one day.

I'd originally tried out for a program called, This Is My Brave, which is a stage production for persons with neurological differences. So, I thought that was gonna be my big opportunity to share my story. I was chosen and I was so happy and then COVID hit which was such a letdown. I spent many decades of my life never talking about Tourette’s 'cause I just didn't have anyone it felt like in my life who understood, or I think they thought as, as long as they were cool with it, then I should be too.

It just wasn't an easy conversation for me to have or them to listen to. I have some pretty violent head and neck ticks at times and it led to severe damage at my spinal cord. I had a disc removed in my neck. I was in a neck brace for six weeks and it was very difficult I was

Pretty down and out. And this poem surfaced again, I started looking online if there might be a way that I could make a children's book out of it. Next thing I know I get an email and it said we were looking for female authors with diverse stories. That checked all the boxes for me. I sent in, my manuscript and the rest is history.

I never would've thought that I could do anything like get a book published. My simple poem turned into something.

Judy Warth: I found Click Tick, Jerk and Hop to be a really enjoyable, fun read. The rhymes are fun. The pictures are beautiful. Do you mind sharing a little bit with our audience about that?

Jackie Nau: I would say my favorite part about the entire process, was working with illustrator, Gasper Sabater. I knew how I wanted the main characters face to look, how every tick I wanted to look, how I wanted their reactions to look and reactions to her tics that they were seeing and hearing. And he just nailed every one. It was such a beautiful process

Judy Warth: we have a first here on Disability Exchange because you have mentioned the name Kelly Von Lehmden. We've had somebody just drop in. So welcome Kelly,

Kelly Von Lemden: Mike and Jackie. It's good to see you.

Jackie Nau: You too Sweet. What a nice surprise!

Kelley Von Lehmden: I remember sitting together about five years ago when you. Read the first draft of this book, and at the time you thought I don't know that I'll ever be able to do this, but you wanted to, and I've loved watching you over the years make your dreams come true.

Kelly Von Lehmden: And by doing that, you're helping others too.

Jackie Nau: The first person I ever wrote read it to be besides my husband was Kelly.

I just knew I wanted do something with it. It has been the coolest experience. The outpouring of love and support since writing the book, I have a gig in two weeks to take my books to a retirement home.

And I am speaking at Kirkwood College for their psychology class. I was interviewed this last Friday by, AARP magazine. the journalist called me and we talked for an hour. And it was so cathartic for both of us to be an adult with Tourette’s, I thought I was old, finding out 22 and he was 42. I hope that this finally starts to squash the narrative that Tourette's is only childhood disorder. I run across people all the time.

Even medical people that, that we come in contact with are like, I thought that was only childhood disorder. And you're like, there's such a misconception that everybody grows out of it. They're finding most don't, and there's also evidence now, that women tend to get worse as they get older. And I thought I was the only one that had gotten worse as I got older.

I'm challenging myself and went to National Tourette’s Association and said, ‘Is there any way we could have some adult programming?’ We were welcome to come as adults, but there was no programming for us. They heard from enough of us they we need something, so now it's a very equal track. You can go to an adult track, a kids track.

Then I said, ‘is there any way we could have women's programming?’

I give them the list of reasons, one being menopause is challenging. They devote entire weekends of Tourette's programming for kids approaching puberty and rightfully so. The big changes and Tourette’s being exacerbated with hormones. But then no one ever really addresses puberty 2.0 when women go through menopause. At first they said, ‘we hear what you're saying but our biggest partner is the CDC and they only fund up to age 26,’ but they circled back and very fortunate to be able to start this Women's series. Last fall we had 91 female participants. It was amazing.

It's been so gratifying. I've got friends upon friends, circle upon circles of friends but not one female friend that's an adult that has Tourette’s in all of Iowa. And I used to think they just didn't exist that. But statistically, they do I live in Cedar Rapids, the second largest city in the state. So there has to be more than me. What makes me sad is. I feel they don't feel as comfortable being out in public as I do and I understand why. And it's because of stigma.

Judy Warth: Jackie, if you were gonna give advice to Somebody who doesn't understand or know about Tourette’s, what are things that you would say that they should do to reduce the stigma?

Jackie Nau: When I give talks even though they're all adults I have to assume that they need Tourette’s 101. There's so many nuances.

There's something they call, the Tourette’s Iceberg and the visual for that: is an ocean and what's sticking out above the water of Tourette’s, the pointy parts are vocal ticks and motor ticks. And that's the things that people can see and hear and experience and to the lay person, I think they think that’s Tourette’s. So once they think whoa, that doesn't bother me, or I don't notice,

So what's the big deal about Tourette's? It's a very big deal. And if they would look long enough, they might see, think and realize that must be really embarrassing. And it is. And that must be really exhausting. And it is. What's under the water, a typical iceberg, that's where two thirds of its weight is the part that you can't see, but that's where the real damage is done.

Co-occurring conditions are often more debilitating, and they have been in most of my life. that's the mind games, the A DHD, the OCD rage, depression, bullying, sleep issues, impulsivity, anxiety, disinhibition, executive dysfunction, those go hand in hand with Tourette’s a lot of time.

So you're not dealing with just the primary diagnosis of Tourette’s, but all it's dirty little friends. Whoever's driving the bus, if it's anxiety, of course your ticks are gonna get worse. Of course, your obsessions are gonna get worse. If it's OCD and you know you're trying to do all of your rituals in a perfect manner and you're on a time limit, of course your anxiety is gonna get worse.

And of course your ticks are gonna get worse. If you're out at a restaurant and people pointing to you, whispering that's gonna increase your anxiety, the biggest thing that I would want people to know is what Tourette's is so much more. It's not controllable. We don't have a light switch where you turned it on.

When I'm educating people and I'm giving a talk about Samuel, things I'm passionate about, my ticks can go way down. When I'm teaching exercise classes, I almost never tick because I'm so focused on the exercise at hand and the routines I've set up.

Tourette.org is the best research that, that you could find. It's the most accurate and up-to-date information medically and socially. Last year in June, we started a Tourette Clinic at Mercy Hospital in Cedar Rapids.

Scott Nau is a, mostly retired pediatrician with 40 years of experience, in Cedar Rapids and he is able to see kids in his office with definite Tourette's or suspected Tourette's and also comorbidities such as OCD, ADD, depression, rage and those things. He can do the diagnostic, exams and everything there. He usually spends at least two hours with them and their families. At the end of their appointment, then I come in and introduce myself. It's just really gratifying to be able to just be there for them and let them know that they're not alone.

Anyone can reach us through Mercy Pediatrics in Cedar Rapids and then tell them what they're looking for, the Tourette's Clinic.

Judy Warth: Before you read to us where can our listeners get that book?

Jackie Nau: They can find it at Amazon.com, Barnesandnoble.com, Swamp. Fox Books in Marion, Iowa is a wonderful independently owned bookstore. The publishing business Biblio Kidd Publishing is based out of Ankeny, Iowa, so that's pretty exciting too.

Judy Warth: So Jackie, you give us a little read?

Jackie Nau: Okay. I click and I tick and I jerk and I twerk. I don't understand why my life is such work. I jump and I hop. Why can't I just stop? I try to be good and sit on my hands. Soon they're waving like I'm leading the band. I scrunch up my nose like a cute little bunny. But when I can't stop, I don't think it's funny.

My head and my shoulders have a mind of their own. Will I still be like this? When I'm fully grown? I spit and I sputter and blow on my chest. It's hard to relax when your body won't rest. I tap and I clap and do things I can't mention. How could anyone think I do this for attention? There are people like me who just hide in their homes.

It makes me feel sad that they feel so alone. But just when I thought that I'd never belong, I went to a camp that made me feel strong. There were other kids there who had ticks like me. We laughed and we played and felt totally free. I finally realized I'm more than my movements. Doesn't everyone deserve room for improvement?

This funny condition is what makes me, ME. I know it's the way I was meant to be. Most people just try to blend in with a crowd. It's okay to be different, that should make you proud. So be who you are and do what you do and make everyone else wish that they were like you.

Judy Warth: Such a wonderful story. Accept others and accept ourselves for who we are.

Jackie Nau: Uniqueness is what makes a beautiful life.

Mike Hoenig: Yes.

Jackie Nau: It doesn't matter what the disability is, we're all deserve, dignity, respect, a place at the table and a seat in the community. I never asked to be the poster girl for Tourette's, but I'm okay that I am if not me, who else? The message is too important to just stuff it away and not do it because it makes me uncomfortable.

Mike Hoenig: Yes, On behalf of our crew here Joanna Sabha our producer and my co-host Judy. thank you so much for sharing with us. It's been a wonderful conversation. Of course, we want to thank our listeners and invite you to stay tuned for the next Disability Exchange, which you can catch on Spotify and any number of other platforms.

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 Delveau for the music contribution.