

## Episode 2.6 – Tourette's, Lived Family Experience and a Big Heart with Jackie Nau

Caitlin Owens: Hello and welcome to today's episode of Disability Exchange. We are a podcast that centers and elevates the voice of people with disabilities and family members and other people who care for people with disabilities. We are based out of the University Center for Excellence in Developmental Disabilities. My name is Caitlin Owens and I'm here today with my wonderful co-host, Mike. You want to introduce yourself, Mike?

Mike Hoenig: Well, thanks, Caitlin. My name is Mike Hoenig. I am a program coordinator at the University Center for Excellence and Developmental Disabilities, you said, and I'm very happy to be joining you and to have a very special guest join us today. We also want to thank friends and colleagues at the Midwest Public Health Training Center for all of your work in producing this program because without that, we wouldn't have a podcast. So, thanks. Big shout out to them.

Caitlin Owens: Yes, absolutely. And we do have a very special guest today. We are so excited to welcome Jackie Nau. She is a, actually a recently retired employee of Center for Disabilities and Development. Jackie served as the parents as mentors coordinator through LEND, which we talk a lot about on the podcast, but again, stands for Leadership and Education in Neurodevelopmental and Related Disabilities. Jackie is just absolutely wonderful advocate. I won't say much more about her because I'll let her tell us about herself, but welcome, Jackie. We're so happy to have you here today.

Jackie Nau: Thank you. It's great to be here. I've known you and Mike for such a long time, and this is a different format to visit with you guys, but I'm excited about this.

Caitlin Owens: Yes, absolutely. Well, Jackie, to start out, do you want to just tell us a little bit about yourself and how you find yourself in the world of disabilities, I guess?

Jackie Nau: Well, that's a good question. I'll start from the beginning. First of all, I grew up in a small town in southeastern Iowa on a farm, and I loved it, loved being a farm kid and was a tomboy and have an older sister and younger brother. And around the age of six, I started clearing my throat a lot and just doing that pretty incessantly. But I hadn't really noticed, I don't think myself as much as when my mom was making dinner and I was at the kitchen table, and she asked me why I kept doing that. And I was young and said, doing what? I wasn't aware. And she said, why do you keep cleaning your throat? And I said, I don't know. And she said, do you feel like there's something caught in your throat? And I said, no. She said, well, does it hurt? And I said, no. And do you need a drink of water? No. And I really didn't know why I kept doing it then, but something even within me at that really young age made me feel like I just knew that I had to do it. I didn't know why I was doing it, but something just made me do it. And that was just the first recollection that I have of being aware of it and someone making note of it and then just wasn't a big deal for me. And when it didn't go away, they took me to a local doctor who was very, very well-known and very well thought of and in the area. And when he didn't see anything on the exam, then he thought, well, I must be allergic to ragweed, which would be, was happened to be the time of year and the perfect solution for somebody that lives on a farm and on a gravel road. And it seemed like, oh, okay, ragweed, that makes sense.

And unfortunately, it wasn't ragweed that was doing that. And I would go on to have many, many more tics over the next several years, and like they usually do with Tourette syndrome escalated around the time of puberty. And then my parents took me to another doctor at a hospital who was supposed to know more about things and no diagnosis had ever been mentioned. No reason for it. Sometimes people followed the requisite chain of doing what I did and clearing your throat or sniffing a lot and how

tics present themselves. And then a physician might send you to an allergist, which happened to me, or an ENT, which makes sense for kids or people who start blinking their eyes a lot, which I did too eventually down the line, then you get sent to an eye doctor and everything makes sense. It's not that anyone was looking at the wrong thing or barking up the wrong tree, but it didn't get to the heart of the problem.

So, when mine had escalated and I was around 14 years old, then that same family doctor said, I think it's time we move on to somebody that maybe would know more and a psychiatrist. And my parents took me to him off and on for six months. And we were also hopeful that we would find out what was causing all of this, because by that time I had a lot of rituals and compulsions, but nothing had a name to it. I just thought it was weird. I was sure I was weird. I was sure I was born wrong and a misfit and there was a lot of shame attached to it. And it was suggested I was doing it for attention, and I would've given anything not to have to do those things. And the things that people saw me doing were only a fraction of my day. I did so much when people weren't looking, that was exhausting and taking my time, and I truly thought I was crazy and that if I open up about what was really happening in my mind and the intrusive thoughts that I would be institutionalized. But as a child, you can't articulate those thoughts and you don't know that you're the only one thinking those things or that not everyone has to do the rituals that you're doing. So unfortunately, after six months there, that psychiatrist had said that he didn't know what my problem was and he thought I had the world by the tail, and he told my parents that he just didn't know what it was. So, he didn't have anything to offer. And unfortunately, it would be eight more long years of suffering privately and publicly and socially before I would ever hear the word tic or Tourette or OCD. And so, I was finally diagnosed at 22 years old with all of those. And I blamed myself my whole life for just not being able to get it right or be a good kid or just stop it, like I said, if I had a dollar for every time I heard, just stop it or cut it out or knock it off, I could fund research myself for it. So, I wish that would've happened. But had I found out earlier, even though there's not a diagnosis, or they don't know what causes Tourette is what I want to say. So, it's not like I would've had a magic pill to take anything or do anything differently, but just to have had a diagnosis to validate that I really I couldn't help it. And I kept saying I couldn't help it. And that would've been more beneficial to find out earlier in life than 22. But by that time, just to have a name for it, I had went on to graduate college and got married and still didn't have a name for it. And then my poor mom passed away before I was ever diagnosed at 22. So, when that doctor said within five minutes, well, you're a classic case of OCD, and Tourettes and anxiety and ADHD. And he said, they should never have missed that before because you're a textbook case. And, of course, I kept blaming myself and said, oh, I'm sure I was doing really good in his office. And he said, well, I'm sure you did really good in here, didn't you? He said, you've walked in, you've done, and he rattles off six different Dixie Zombie, not in a shameful manner, but just to show that. And I said, yeah, I did. So, I felt like I could do double back flips leaving his office that day just to have a name for it. And it's not a diagnosis anybody want to run right out and get for themselves or for their kids, but after waiting that long, it was liberating and empowering just to have a name for it.

Caitlin Owens: Absolutely.

Mike Hoenig: That's an amazing story that it got missed for that long. But because of that, you've suffered, and I know because I know you, you've shared that even as an adult, even after you got the diagnosis that it hasn't been easy, but just being able to put a name to it had to feel liberating as you said. So, you could move on and try to learn about it and-

Jackie Nau: Exactly. Yeah, it really did. And in those days, the internet hadn't come out yet, so I didn't have a way of research to do researching then, and there really wasn't a lot out there per se. And I was

married and working full-time and as a hairstylist, which was my childhood dream, and I was able to do that thankful and had a good following. And I even had a spare time job at a clothing store in a mall. So, I was still living my life and doing my thing, but I wouldn't have known where to begin as far as researching it. And when I was a kid, part of the mystery behind it was I was the only one in my family, in my school, in my church, in my community, the entire town. I was the only one that had this at the time. So, it wasn't like anyone could come alongside me and tell me what's going on. And I still am pretty much the only one in any of my circles of friends and relatives that has this. And I've met people at national conferences, which is wonderful. But I still wish I had somebody in my own personal orbit that I knew well enough that I could call or have coffee with or something to just say, wow, this has really come on strong in the last few months. And has this happened to you? Because it's a strange one. It's a strange, just when you think you've pinned something down, they use the term in Tourette's, wax and wanes, and it does. And oftentimes children that get diagnosed still in, there's a chance they'll grow out of it. In fact, the most recent statistics that I've seen are 78% of children who are diagnosed with Tourette's will grow out of it to the point where they may have a little bit of tics left, but it really does not affect their days like it does when they're younger. So that definitely gives them hope. And then it used to be much more of a misconception that adults didn't have Tourette's. And I started saying years ago, Tourette's, it's not just for kids anymore, it's a breakfast cereal, just enjoy, and you get a toy too, but it's not just for kids. And the National Tourette's Association has found that out too by the more of us as adults saying, we need our own support here too, because there's plenty of us that are still living with it to, at least to the degree as when we were kids. And then some of us like myself, who have gotten much worse as an adult, which isn't the normal trajectory. So I don't want to scare anyone in the audience that might be listening who has a child with it. It's rare to get worse as you get older, I think. But I think sometimes life circumstances can make a difference. And I just have things that have caused a lot of stress in my life that I wouldn't trade for anything. So that's the rest of my story.

Mike Hoenig: And you're a national speaker, is that right now, with the National Tourettes Association?

Jackie Nau: Yes. I was blessed to be able to have that. It's so interesting because of my job with LEND and after getting diagnosed and finding some freedom there, I'd started on a medication for my OCD, which worked wonders for me. It was like I'd been living with blinders on my entire life and suddenly the blinders were off. I could just see everything more clearly. And it didn't take away all of the obsessions and compulsions and rituals, but it definitely dampened them down to where they weren't ruling my life like they did as a child. So we went on to have two children. Our second child, Samuel was born, he was a week overdue, and we did not know anything might be wrong with [inaudible 00:12:45] health. And he was born with severe and profound disabilities. So, it was through him and his life that I found out about the CDD and then LEND and parents as mentors. And I spoke on a panel then about being a parent of a special needs child for years for PAM with Kelly Bond Lindon who I met at a mother's thing years ago and we became friends and then she recruited me to do that. And I took some training through Grant Wood for speakers training, and then it morphed into speaking to, oh, give CEOs for teachers and special education teachers and current educators and so forth. And then I started doing some local speaking about Tourette's for Kirkwood College and psychology classes and beginning to psych, an abnormal psych. And then when I started my position as the PAM coordinator and learned everything that I did along my awesome colleagues there, including you guys and Kelly and Julie and Lori and Judy and Ed and everyone up in the office. And I have to say that you people are my tribe. I know I've told you that before, but I've been a lot of places, and as my husband says, I've got circles upon circles upon circles of friends, and I do, and I love them all dearly, but I've never had a working environment or even just a friendship circle where I feel more at ease than with you guys and working there. And it just was the perfect platform for me to gain the confidence that I needed to branch out and start speaking about my

own disability and even allowing myself to say that I had one because I hadn't up to that point. And I've struggled with shame my whole life, and I have this just really abhorrent about feeling like I'm too full on myself or in any way braggadocious or whatever. So even in saying that I have a disability, to me smacks as, well, who do you think you are? As if you're not good enough to be labeled by that or whatever, or as if I'm trying to garner sympathy and I'm not. But I learned so much through my job there and I knew that Samuel was disabled, and I would go to the ends of the earth to advocate for him and what he needed and that he was treated with the dignity and respect that he deserved. But in the meantime, I was allowing people to make fun of me and pick on me and not call them out on it. And like you said, Mike, I've been made fun of more as an adult by other adults than I ever was as a child, and I don't really understand it, but I'm not okay with it anymore. Not that I ever felt good, but I just didn't feel like I was even worthy. I just called them out on it per se. So, through my training then back to your question then, the National Conferences for Tourette's are only every two years. And then during the pandemic, we had to cancel that and go virtual. And I always say it's the only time we get to be around my own kind, and it's only two and a half days every two years. So, when there's a four-year span in there, I'm like, I need to be around my people. I need to tune up because there's nothing like being around those of us who just get it and it's the only time in our lives where we don't have to worry about who sees what your body's doing. You don't have to be on guard, did they see that? Where you don't look around a room and people aren't pointing at you and whispering behind your hand like you suddenly can't see them or they're invisible or behind the menu.

I remember sitting in the front row of a packed conference room and listening to the speaker on a lecture, and they were doing a presentation on CBT, which is cognitive behavioral therapy or intervention for tics. And it was riveting. And this little boy who was nine reminded me so much of myself at that age and just loved life, super giddy, loved sports, loved to talk, and he was just riddled with tics. I was crying and [inaudible 00:16:49] on and I'm watching this, and I just felt so badly for him, but I could identify with him. And never once did I worry about the packed room behind me and what they were seeing my body do that I couldn't control. And that's the only time I remember in my whole 55 years of life that I could do that without a thought of what people were thinking about me. And I know it shouldn't matter what people think. That's easy to say, but-

Caitlin Owens: Very easy. It's a lot harder to truly believe, I think.

Mike Hoenig: Yeah.

Caitlin Owens: Jackie, you mentioned Samuel a little bit. Can you tell us just a little bit more about Samuel?

Jackie Nau: Sure. He is actually, who has given me my voice, I would like to say. So, when we had Samuel, I had followed my childhood dream, like I said, and we already had one son, Jonah, who was so easy to just bring up. He still is, he's 28 now, and just never gave us a lick of trouble and wonderful and full of life. And we just had no reason to think that the next baby there was going to be anything wrong per se. And I don't like to use the word wrong, but for lack of a better term right now. So, when Sam was born with severe and profound disabilities, we found out the day before on an ultrasound that he was breech, and that's why he hadn't come out yet, and he was a week overdue. So, your initial thought is, oh wow, okay, I might have to have a C-section. And it's one of those moments and time where, oh, maybe a little disappointed if you're not going to have him the other way or whatever delivery might look different than what you thought. And then as time went on, that was the least of my worries. So, on that same ultrasound then when they were able to see that he was breeched and he was pretty good size, they said that he had fluid on his brain and we were completely shocked and had no reason to

believe up to that point that anything was going on. And I felt totally fine. I had no morning sickness, he moved around anymore in my stomach than my first child did. So, they sent us to a university then, and we ended up having to wait till the next day to have this high tech ultrasound. And we were told some not very nice things or way about, it looked like he had a lot of fluid on his head. And then they chastised me for not having an ultrasound at 14 weeks because I would've had choices then. And I assured them it wouldn't have mattered to me then. And either, and I understand I was still in shock, but certainly had a week overdue and I was massively pregnant and stuff and ready to burst open. It wasn't going to do me any good right then to be scolded for that. And when you're dealing with someone who already has just mountains of shame on my shoulders just for who I am and how I was born, and it felt like a disappointment that just added more shame to my life. So, because I already felt like what did I do wrong to cause this? So then when he was born then the next day, we were told that his head would be basketball size is what they predicted from the ultrasound, which turned out not to be true anyway unfortunately. But he was perfect, he looked perfect [inaudible 00:20:04] C-section and he got better [inaudible 00:20:07] than our first child and went through the denial phase of okay, it was all a mistake, it all blur and then they whisked him away and the MRIs and CAT scans and everything proved that he was indeed missing large parts of his brain. And there was evidence he had full brain at one point in utero, but I'll never know this side of heaven, what happened. When Samuel was born then I often include in my story that I think part of the bargaining, grace can come in a lot of ways of loss, loss of a dream, like in that case, I'm certainly loss of a person, loss of a job, loss of a pet, loss of a marriage, a lot of losses, and you have stages of grief. So, I remember bargaining with God and oh, if Sam could just walk, that would be great. And then I decided that wasn't the most important thing at all, and I'd be glad to push a wheelchair and stuff, and that's a good work out and stuff. And then if he could just talk and that wasn't meant to be, and I thought, well, I talk enough for the whole family, and he can still communicate. And then if he could just see that would be the best, and he could see some things, he had acquired a vision impairment, we're not sure what all he could see. There was definite times he could see bright lights in darker rooms for whatever for a while I long for him to just look into my eyes, which he would, but I couldn't always see a complete lock on maybe in a look or whatever tracking you. But at the same time, he knew who his mama was for sure, and there was no mistake in him. And the bond we had was otherworldly, and he knew his dad's voice and his brother's voice and his friends and things changed. So, I started to rally, and I guess I just like to say here that at first I felt like I've always been a woman of faith. And before that I just didn't have the strength behind it. And I remember thinking, wow, God must have chosen the wrong mom to have this precious, fragile child, someone so fragile because I'm just going to be inadequate care for him. How can someone like me with all my challenges and I can't even sit still, let alone stay focused and do different things, care for someone who needs such a high level of care. So, when I assured them, the doctors and everyone every day when we would hear more bad news and I understood the prognosis sounded bad, looked bad, we were educated people, and we could see the tests and everything that it didn't look good. But at the same time, he was surviving without any support other than he couldn't keep his body temperature up, but no monitors, no tubes, no nothing like that. And I said, it doesn't matter. We don't care what he can or can't do. We just want him. And the neurologist would say, every day, I kid you not, every day, well, he'll never walk or talk or see or hear, he'll be a vegetative state, death before age one, he's incompatible with life. And then after day 10, and well, he's still living, and you said that last week. So, I don't know, the incompatible life is not imminent anyway. And I just started to get this fire in my belly of if you're not going to stand up for him, then I'm going to, and I will find people that will. I even had to fight to have a C-section the day he was born because we were guided, I guess I'll say, to allow them to do the birth, maneuver him in my stomach so we could have a vaginal birth. But they said his head was so large, he would get stuck in the birth canal and most likely die. And then they said, but that's probably my best option as he patted my knee. And I was just shocked and horrified and couldn't believe it. And I never

stuck up to anybody before in my life, and especially a doctor, someone in that position. And I said, well, no, I want a C-section, and I want it today. And he said, well, that's a surgery and you'll have a scar. And I said, I don't care if you cut me wide open. And I didn't. And what I didn't realize at the time then was I started advocating for Samuel when he was still in my womb, and I never stopped. And I joke around, they created a monster because nothing like a mama bear and that primal love you have for your children. And it was Sam and fighting for him, getting him home, they sent him home on hospice. And I said, what if he survives hospice? What will we do then? We need plan B. Well, he won't. Okay, well what if six months down the road and he's still living, what should we do and stuff? Are we going to need to know anything? Well, he won't survive it. He'll never walk or see. Went through the list of nevers. And he got out hospice and I'm happy to say, and they said, take him home and love him, he won't survive the weekend. And it was almost a 12-year glorious weekend. And he taught me and asked so much about life and love, and I advocated for him to go to school, and I learned my rights, his rights about free and public appropriate education, FAPE, and loved the school he was in, but they weren't sure what to do with him. And no one on staff was able to feed him except the school nurse who had other kids and other schools and miles between him. And he was at risk for seizures. So, I went out of my comfort zone to advocate for him to go to an appropriate school and open and enroll. And then it was the sky's the limit, instead of what can we do with him to what can't we do with him? And as the kids in his classroom said, everybody fights over Samuel at recess. Everybody wants to play with Samuel at recess. And it opened up a whole new world of beauty for me that I had always been drawn to anyway. I think I'd always, well, I knew I always felt different, and I'd always been drawn to the underdogs and people who felt less than, or didn't fit in, or were left out, or had disabilities, or anything. And I think a lot of it's because of my own. And I have compassion anyway, and I have such compassion and empathy for them. And it just would just pierce my heart when I would see people being bullied or made fun of for things that clearly, they couldn't help. And even if could, if it was a fashion choice or something that they did and people were picking, it's just not okay. And so, I felt at home in this world of disabilities, and I felt like Sam didn't have a voice, so I had to be his voice. And I remember just thinking, I can't even control my own voice because I am making all of these sounds and I had vocal tics, but it didn't matter. I didn't have time to worry about that, I feel sorry for myself about that at all because one of my children needed me and he didn't care what I was doing.

Mike Hoenig: So, advocating for yourself then or for Sam flipped the switch then and got you to the point where you not only advocated for him, but started really getting involved with Tourette syndrome advocacy.

Jackie Nau: Exactly, Mike. You and I were talking every day do you know what flipped the switch? And I was thinking about that more, and I'm like, that was it. It wasn't immediate after we had Sam, but it was over time I started speaking about him and being the mother of a parent with special needs. I had this mantra that everyone deserves dignity and respect, and they do. And I must say five times a week, it shouldn't be this hard. It just shouldn't be. Can we just treat people the way we want to be treated? It just shouldn't be that hard. And if you can't even treat them that way, treat them the way you'd want your kids to be treated or your grandkids or whoever is the most precious to you. It shouldn't be this hard. So, Samuel was not wholly shown dignity and respect, unfortunately. And he was routinely denied pain control at certain hospitals because, I don't know, because he couldn't say ow. I'm not sure, I'm being a little bit facetious there, but I think the true reason was because he was severe and profound, had disabilities, and they assume and sometimes would reference, well, he's missing the parts of the brain that feel pain. Well, he is also riding in pain, foaming at the mouth, screaming, and wailing, and I know the best and he's in pain. When he is not, he's happy and smiling and cooing. And it was very insulting that they would even dream of denying pain control. And I would say, why don't you err on the

side of caution that a person is feeling pain when they're experiencing what would cause anyone else pain such as pancreatitis when you have that, certain procedures that anyone else would've gotten lidocaine or certain kinds of pain control. And he wasn't afforded that respect, unfortunately. And after a while, it's like, I'm not either and neither are a lot of the sweet kids that I talk to and work with that have Tourettes and comorbidities. And we didn't ask STEP what we have either. And I still haven't called, and I enjoyed talking to their parents and giving them hope and maybe some ideas for how they can get accommodations in school and STEP. So, Mike, what you said is such a good question because somewhere along the way of me running around telling Samuel's story to everything from church groups and women's groups to colleges, to medical CEOs and stuff about how God doesn't make mistakes, and he made Sam perfect, which I truly and fully believe he did, and just exactly the way he was supposed to be. And because he changed lives and hearts and minds and had friends and impacted so many people, well, I firmly believed in the statement, God doesn't make mistakes. He made Sam perfect. I somehow felt like I was still a misfit, and somehow, I was the exception. I was a mistake. God made me this way. I somehow did it to myself or just whatever, I just hadn't gotten myself together yet. Then I thought, that just doesn't add up and it doesn't make sense. And again, it was through my job there at the CDD working with [inaudible 00:30:56] about people with disabilities and giving Sam's story even more credence that I thought, I'm not going to live like this anymore. I need instead of shame on me, shame off of me. The shame doesn't belong on me, it belongs on those who make fun of me, or who don't get it, or poo-poo, it belongs on the disease, the affliction itself. I've always thought, I feel like there's an invisible puppet master that has lived above my head my entire life, and he's jerking strings that are attached to my face and face and my neck and my voice and my hands and my body and my feet at all times, and I just want to cut the strings and I'm tired and I'm exhausted. And the underlying comorbidities are oftentimes even more debilitating with the intrusive thoughts and the compulsions and the rituals and having to do everything just right and the mind games and stuff. But the cool thing is I came to realize that those of us that have these disorders tend to be hyper-focused, have hyper-focused and vigilance, and we know, all around, it's like I can see around a room without, I've been trying my head sometimes, I feel like you're a mom with eyes in the back of my head, but I can feel if people are watching me and stuff, because I think you just naturally do that when everybody wants to fit in and when you know you don't you're more aware sometimes. So, there's other ways of being hypervigilant as well, whether it's getting your compulsions just right. But in Sam's life, when every medication had to be done exactly right, when every time I suctioned him, when I had to be on guard 24/7 for 12 years, that hyper vigilance is what helped keep him alive. My complete utterance, just tenacity and dedication to him, and that he was worthy of this kind of care and this level of care and the best of the best, and any sacrifices it took for me, for him, or for Jonah or any of my loved ones, was completely worth it.

Mike Hoenig: So, God chose the perfect mom after all.

Jackie Nau: Thank you, thank you. I finally started to feel that way. It took me a long time, but I do feel like that I did change my attitude of he must have chose the wrong one. I remember hearing early on in Sam's life, someone saying, God doesn't call the qualified, he qualifies the called. And okay, I could accept that. Then I'm like, I definitely felt like I was called to be Sam's mom. And little did I know, not only did Sam need me, but I needed him in... I don't think I ever would've gotten to where I am now and accepting myself had it not been for Samuel. And to just open up this world of disabilities where people just, we just love. We just want to be accepted. It shouldn't be that hard. I always like to say that my list of nevers I made about Samuel were much more important than the first list of nevers that they gave him at early in birth at the doctors and medical staff were so quick to write him off as, they literally said that kids like this can ruin a marriage. They can ruin your life. And he's a child, he can't ruin anything.

He's a joy, and we want him, celebrate. But they saw him as so imperfect that that's all they could focus on was he'll never walk, he'll never talk, he'll never see, he'll never hear, he'll never, never, never, never. And even if he never did those things, it didn't matter because we still loved him Anyway, but much later on when I got a little bit more bold and I said, here's my list of nevers about Samuel, he'll never think about thought or say a bad word or do a bad deed. He'll never judge anyone or hold a grudge. He just loves and wants to be loved. He'll never commit a crime. He was incapable of sin. He's closer to Jesus than we'll ever be on this earth. I truly felt like I was in holy ground around him, and he calmed me down. And in my mind, that is so much more important. If people just write off people with disabilities, they're missing out. All of the kids that were in his school learn how to be better citizens for the rest of their life by our kids being there. Did they care if our kids were drooling? No. They fought over them at recess. And I can't express enough how much people with disabilities have to offer if they're just given a chance. And my disability affliction, whatever you want to call it, is so weird and so quirky, and we get that. But I think the biggest misconception about mine and those like me, is that the worst part about having Tourette's is the embarrassment that it must cause. And I can see how outsiders would think that because everyone is very cognizant of how they look to others, we don't have to look much past social media for that or whatever. But no matter where you are, no one wants to stick out in a negative way. So, when you know you do, and you're acting in a way that seems strange or mysterious or comical to others, it's not a joke first of all at all to those of us that have it. And I give the iceberg theory, there's a diagram on the Tourette's website, and if you can picture this iceberg, and it's like a diamond where the lower half of the diamond goes much deeper and it's a little bit wider, but what you see above the water is just literally the tip of the iceberg. And that's what other people see about Tourettes. And above that is vocal tics and motor tics, and that's all people see from the outside. Oh, well then if that's all Tourette's is and stuff, well, wow, that'd be embarrassing, or they'll say, oh, I don't even notice anymore. I'm used to it. And I'm like, if you told me you had a scream and migraine for seven days and it's affecting your work and you can't get out of bed and you've thrown up twice today already, how would you feel if I said, oh, don't bother me. I don't even notice. Let's go to lunch. But that's how we get talked to. I don't know any other affliction in the history of afflictions where talking about someone's infliction, they would get met with, oh, that's okay.

Caitlin Owens: People think it's being done unto them because it's visible or different from what they expect or something. Yeah, that is really interesting. I haven't thought of that.

Jackie Nau: As long as they're cool with it, then I shouldn't have to worry about that pesky choice. I'm like, no, I'm trying to tell you, it's exhausting. And underneath the water, the iceberg is where the real damage is and stuff, that's where the intrusive thoughts and the dysgraphia and the rage and the ADD and the anxiety and OCD and rituals and all of the yuck is that makes our life really, really hard to muster. So anyway, but that's my new path is to be able to maybe articulate what other people can't down that venue and try and help educate people and demystify Tourettes because Hollywood and it has sensationalized it so much that it's no wonder, we're the butt of a joke. People think it's okay to make snide remarks and such.

Caitlin Owens: Absolutely. Well, Jackie, I feel like we could make this a three-part episode. Honestly, I have so many things that I want to keep talking about, keep asking about. But before we close, we do like to ask people a question. But before we get to that, I just want to say thank you so much for sharing your story. This is not even, I don't know how many times I've heard you share your story now, but I just appreciate how generous you are with it. It's just captivating every time because you are just so amazing. And the word tenacity truly makes me think of you. And I think this is only one small part of the story. But for you to share your experiences with people saying such, disempowering doesn't even



seem like a strong enough word. I hope that people hear that and that it changes. And that every single person who hears this conversation, or your LEND presentation thinks, oh my gosh, not only will I never talk to a patient like that, but I'm going to share that with my cohort, or I'm going to tell... Just I'm sorry that any of those things were part of your experience, and I appreciate you sharing them so freely. So, before we close, our second season question that we like to ask people is, what is your superpower? And then I feel like you just have to maybe just pick one.

Mike Hoenig: Pick one, because you told us-

Caitlin Owens: ... I can think of many.

Mike Hoenig: Absolutely.

Jackie Nau: I can never think of one. And I'm sure that comes from-

Caitlin Owens: This is a Judy question.

Jackie Nau: Our colleague cohort, Judy-

Mike Hoenig: Absolutely.

Jackie Nau: ... putting us on the spot during seminars and stuff like that. What's your superpower? And I can never come up with this, and I said different things or whatever over time, but I just thought, well, I was getting ready and preparing for this podcast, just I think probably would be empathy. I can't not like people. I've always had a soft spot for people, and all people. I referenced earlier, underdogs, those the less than, people with disabilities and all of that, the young deal, pretty much everyone in between. I used to always tell our trainees during LEND every year, I love people. I really love people. And I say, not in a weird way, but pretty-

Caitlin Owens: No.

Jackie Nau: So, I used to tease them and stuff because I like to hug and stuff. But it matters to me that people feel that they're seen and heard and that they're valued. And just going back to Samuel, whether it's Samuel, whether it's me, whether it's anyone with a disability that is hidden or unhidden or acquired or fighting all kinds of battles that life throws our way. Everybody is battling something. The takeaway and my superpower of empathy is I feel that everyone, every single soul has value and worth, and everyone of the sweet souls that we've been talking about deserve dignity and respect. And I just feel like when they, or we are looking down upon by whether it's provider or society or whoever it is, I think they have a way of trying to judge us like we're not worthy of their time or their pain control, or it's okay to offend us or mock us or make fun of us because we're weird or whatever. And I think in those moments, that puts no shame on us whatsoever. The shame goes on them. They are the ones who are foolish and simple-minded, and I want that to be a takeaway that it doesn't make them look stronger or more intelligent. I don't believe. So yeah. I just like to be a voice for the voiceless, but empathy is my jam.

Mike Hoenig: Yeah. Well, and it shows. We all know you and know that how much you do care about other people and how it reflected in your work with LEND and in the presentations that you make and just in our daily interactions. So we have hit the end of our time together today. So Jackie, I'd just again

like to echo what Caitlin said. Thank you so much for sharing your story and being so open about it, and we really look forward to sharing this with our audience and really hope that at some point we'll be able to have you back on perhaps in another context. So thank you so much for being a part of our podcast.

Caitlin Owens: 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.