Episode 55- Unpacking Disability Pride: Voices from the MDA Community

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Mindy Henderson: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest family of content. I'm your host, Mindy Henderson. Together we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them.

We are here for you to educate and inform, to demystify, to inspire, and to entertain. We are here shining a light on all that makes you, you. Whether you are one of us, love someone who is, or are on another journey altogether, thanks for joining. Now, let's get started.

July is Disability Pride Month, and with me today, I have three talented and accomplished MDA Ambassadors joining me to discuss what Disability Pride means to them. I think you will find that what is ahead is an empowering conversation about the beauty, power, and strength we can all find in ourselves because of those things that make us unique. So first, I would like to welcome Amy, Payton, and Fred. Thank you all so much for joining me today.

Payton Rule: Thanks for having us.

Amy Shinneman: Thanks so much for having us.

Fred Graves: Thanks.

Mindy Henderson: So before we dive into Disability Pride, would you each introduce yourselves and maybe just tell us a little bit more about yourself? I'm going to start with you, Amy. Amy is an ambassador alumni. Was it 2023 and '24 you were our National Adult Ambassador. Do I have that right?

Amy Shinneman: '22-'23 I think.

Mindy Henderson: Okay.

Amy Shinneman: I should know this.

Mindy Henderson: I wasn't sure which way it slid, but yes, I'm so glad you're here today.

Amy Shinneman: Thanks for having me. Like she said, my name's Amy Shinneman, and I live with a type of muscular dystrophy called Bethlem myopathy. And for those that aren't familiar with my story, it took me 44 years to finally get my diagnosis, even though growing up we knew there was something, but it just took a really long time to figure out what that something was.

But I just see that as part of my story in shaping who I am today. And I am a columnist for my local newspaper writing about my disability and all the experiences I've had with that, as well as I have a blog called Humbly Courageous and do some freelance writing also regarding accessibility in my county. I'm so glad to be here.

Mindy Henderson: Love it. Thank you, Amy. Payton, how about you?

Payton Rule: Yeah. Hi, I'm Payton Rule. I have Charcot-Marie-Tooth disease or CMT, and I was diagnosed when I was five. And I am currently a PhD student in clinical psychology at Washington University in St. Louis, where my research focuses on disability and well-being, including a little bit on Disability Pride. Extremely excited to be here both personally and professionally. I'm just excited to learn from everybody.

Mindy Henderson: Amazing. Last but certainly not least, Fred.

Fred Graves: Hello, hello, my name is Fred Graves. I'm also living with Limb-girdle muscular dystrophy type 2A. My journey was really odd because I had several muscle biopsies, and this was before genetic testing, so I've been through the gamut of it all. I was originally diagnosed with Becker muscular dystrophy, and maybe about 10 years later I was re-diagnosed with limb-girdle.

And currently, I'm a commissioner for the City of Hartford Commission on Disability Issues. This is my second year as a MDA Ambassador. I'm here. I'm excited as well to learn from these ladies, these wonderful ladies, and just share my journey.

Mindy Henderson: I love it. I love it. Like I said, a very accomplished group of people. One thing that I think you all have in common, Amy, you write professionally, but Fred and Payton have also written for the Quest blog for us. And you're all incredibly talented writers. Let's dive in and talk about Disability Pride Month.

I would love to just do one more round robin. I may go in the opposite, counterclockwise this time, and I would love to hear from each of you what Disability Pride means to you. I feel like it means something a little bit different to everybody. So Fred, let's start with you.

Fred Graves: Wow. I would say Disability Pride for me, first of all, it's been a journey. With the progression of this condition, it's like you start in the place and you dip into it, and then you come into this acceptance. I think Disability Pride for me is loving yourself where you are and not comparing yourself to other people and knowing that you too are worthy. During my years at the state police, I was a dispatcher for almost 10 years.

I dealt with a lot of ableism, and I was the only person with a physical disability in the agency. And this is an agency of 4,000 people. So every day I was met with, how's he going to do this? And how's he going to do that? And I think that over those years I was like, "Oh, I'm going to show you." You know what I mean? So I think that Disability Pride is that, but it's also just loving yourself and being kind to yourself and with the changes that come with the conditions, whatever you're dealing with.

Mindy Henderson: That's a great answer. Payton, what about you? What does Disability Pride mean to you?

Payton Rule: Such a great question, and I completely agree with what Fred was saying about it just being a journey, I think, and it's not a linear thing. I don't think that I have always had Disability Pride. I think it goes up and down. But I think to me, I really view my disability as a source of something valuable, positive experiences, something that's really enriched my life in a lot of ways. And so that's not to say that there's not hard things about it.

There's absolutely ableism out there, like you were talking about, and there's a lot of difficult aspects, but I also think that it's something that's brought a lot of positive, enriching experiences and friendships and relationships to my life as well. And so I think that's what Disability Pride means to me. But it's cool to see how it's different for everybody, and I don't think there's any right or wrong answer.

Mindy Henderson: Absolutely. And I could not agree more that it's not a straight line. To get to Disability Pride, it ebbs and flows. I think any person who's living with a human experience have hard things in their lives. It's just part of the human condition. And yeah, you said it beautifully. There are good days and bad days. And you may not always feel it, but I think what's important is getting back to it, however you see fit to do that. Amy, what about you?

Amy Shinneman: Yeah. So for me, I mean; to be honest, Disability Pride is for me a new thing to celebrate. In the past I would say five, six years growing up, when I did, I certainly wasn't encouraged, I didn't feel like, to have pride in my disability. But as Fred and Payton both said, it is a journey and it does fluctuate. But for me, I'm so excited for this Disability Pride thing that I'm now involved in.

And I take really great pride in seeing other members from my community, like all of you and so many more, and just learning. I've learned so much in how to accept myself and what that looks like, and that does bring about a sense of pride when you can accept yourself just as you are. But I also think that with that comes knowing that as with anything, that it is going to fluctuate, and some days you're going to maybe not be proud of who you are.

But when we take time to celebrate as a whole, I think that's just a really powerful statement that helps all of us to fully accept who we are.

Mindy Henderson: I agree, and I'm going to throw this out there because I think... I don't know that everyone listening may be aware that I live with spinal muscular atrophy, and so I'm also a member of the neuromuscular disease community. What each of you are saying resonates with me so much because this is going to sound strange to say because I'm a wheelchair user, and so it's obvious when someone looks at me that I have a disability.

But the strange part is that growing up, and I think I've got a couple years on probably all of you, but growing up, like you said, Amy, it wasn't something that I was encouraged to be proud of that particular piece of me. I was taught to be proud of a lot of things about me, but that wasn't one of them. And so I spent a lot of my life trying to almost hide my disability, which is again a weird thing to say. You can't really hide a wheelchair. But anywhere I could downplay it, I did.

And I tried to fit in and move with the crowd. And it wasn't until I was an older adult that I started to really look at the community around me. And that's when I started to see the beauty in it. I saw it in others first, and then I was like, wait a second, I'm one of them. If it's beautiful in them, it should be beautiful in me too. And I started to really embrace it and enjoy what it had...

Even though a lot of it was difficult, really enjoy what it had brought into my life. So through the journey of living with a progressive neuromuscular disease, how has your perspectives on embracing your disability and finding pride in your strengths evolved? I shared how it had evolved for me. And I'm going to let anyone who wants to grab that first answer, but what's that journey been like for you?

Amy Shinneman: Mindy, I've heard you say that before about how you tried to downplay something. And same for me, I'm a part-time wheelchair user, but growing up I was not. But the way that I walk is very obvious that I have a disability, but I spent so much time and effort trying to downplay my struggles or just make myself fit in because as a kid, that's what you want. You want so badly to fit in. And I think that as with anyone growing up and aging, you learn and you become more mature.

But even more than that, I think that it's just a beautiful thing. When I heard you say that, I had never heard anyone talk about how they tried to hide themselves. And I spent probably 40 years doing that. And at 51 now, it's not been that long that I have accepted myself. But I think that the overall message there is just to be patient with who you are and don't try to be everybody else. Just be yourself. I think the acceptance comes with learning and finding your way.

Mindy Henderson: 100%.

Fred Graves: That's super powerful. I think for some of us who were encouraged to love yourself, when I do my ambassador stuff and I do the camp, the fundraising things, and I get to touch the younger ambassadors, I'm so proud of them because they embraced this condition and this life way more than some of us from that earlier generation. I'm in my 40s as well, so it's like I too. I'm six-three. I used to tell the guys, "Oh, I have a basketball injury." I went through all of those phases.

And it's like for some of us, I mean, I don't want to put any words in anyone's mouth, but it was like this brick wall I hit where I couldn't hide it anymore. And I had to embrace this community. And like you said, when I started embracing the MD community, it wasn't, oh, I only wanted to connect with people with limb-girdle. That's what I came in first. I want to meet people with limb-girdle.

But then Jose Flores, the SMA community, you guys are so inspiring. SMA people are awesome. I don't know why you guys have the personality that's through the roof. You guys are just great.

Mindy Henderson: I want a t-shirt that says that.

Fred Graves: But I've learned so much. And like you said, you see other people and you see qualities you wish that you had in yourself. And it just empowers me to say, "I can do that. If that person can do that, I can do it too." And to touch base with people who struggle like you, it was like blinders came off. And I went through a lot of adversity to get there. But like I said, I hit that brick wall and I said, "You know what? I can't hide it anymore." I've blossomed, I think, so much more post 40 than I did in those first 40 years. I don't know.

Mindy Henderson: Yeah, it's really well said. And Fred, I'm going to say, I see a lot of personality in you too. And so I think there's a lot of just such magnificent people in the neuromuscular disease community. And to echo what you said, there's something... I mean, anytime I hear about whether it's disability or some other aspect of life where someone feels like they have to hide any part of who they are, it just breaks my heart because of how I felt for so much of my life.

It's so stifling. And I think that you hit the nail on the head. When you do finally step into and embrace all of who you are, the hard and the easy and everything in between, it's so freeing, and that's when who you truly are can really shine. And so I love your answer. Payton, how about you?

Payton Rule: I think what everybody has said so far about feeling like they need to hide, I think that really resonates with me as well. My parents were always very supportive, always never taught me that I should hide anything, but I think the world in general is there's ableism. And I think disability is often viewed as a tragedy or an inspiration in media. There's not a middle ground. And so I think I viewed it that way growing up as well. You either overcome it or you are just tragic.

But I think I when I was a teenager started connecting more with the disability community. And I remember going just for an outing on actually Hollywood Boulevard with a bunch of teens with CMT and an adult with CMT and he had a lot of Disability Pride. And I remember him just up to people on Hollywood Boulevard, random people, and starting to tell them about CMT, and me just wanting to run and hide.

But nothing bad happened. And I think reflecting on that experience, it was just like you were saying, Fred, it was an attribute that I really wanted to have to be able to go out there and just own it. And so I think that was one thing that started shifting my mindset about it and really started that journey for me towards a little bit more Disability Pride.

Mindy Henderson: Yeah, I love that. Payton, I want to ask you a follow-up question because the term ableism has come up already a couple of times in this conversation. And honestly, until a couple of years ago, I had never heard that word. And I feel like it's something that as the conversation has evolved, it's something that more and more attention has been called to.

And it's something that the disability community has gotten more comfortable talking about and talking about their experiences with it. For anyone that's listening that may not be familiar with the term ableism or exactly what that is, do you mind giving us a little bit of background?

Payton Rule: Yeah, absolutely. Honestly, I don't think ableism was in my vocabulary until I got into research either. So completely agree. I think a lot of people are familiar with discrimination, which is related to ableism. But when people think of discrimination, I think they often think of these big events, things like getting fired from your job because of your disability, or being denied housing because of your disability.

And those things can be forms of discrimination, forms of ableism, but I think a lot of ableism can also come in the form of microaggressions. So things like people telling you that you're inspirational for going to the grocery store if you have a disability, or people assuming that your partner is your caregiver because you have a disability. Things that are really I think well-intentioned by non-disabled people, but can be very harmful for people with disabilities.

So I think that's how I think about ableism. It can be big things, but it can also be these little subtle things every day that can really impact disabled people's well-being, but also maybe are well-intentioned and not necessarily recognized as ableism by most people.

Mindy Henderson: That may be the best description I've ever heard of it. That was really well done. Let's switch gears just a little bit and dig into... Because I think there's so much power in people sharing their stories of the hard things that they've maybe had to walk in life. I think that there's so much about it that makes people feel less lonely and maybe less isolated.

Can any of you share any personal experiences where you may have had to really, really dig deep and intentionally choose to invoke pride or self-confidence regarding your disability in order to navigate a particular issue or circumstance in your life and come out of it trying to feel a bit more empowered?

Amy Shinneman: I can go. When I had my first son in the hospital, I had a really bad experience with... I had had a C-section. It was in the middle of the night and my husband had to call the nurse to come and him help me walk to the bathroom because it was really hard. Number one, I had just had surgery and my body had been through all that I have a disability and just walking after any of that is hard.

And so he called for help. And the next day I found myself in my hospital room alone while my husband had gone to grab dinner and a social worker from the hospital popped into the room. And the nurse had called the social worker because she thought that I was unable to care for my son. And what had happened is she hadn't truly researched to know even that I did have a disability.

And I think I found myself at that time just being so proud of myself for stepping up and saying, "No, this is my son and I'm quite capable of taking care of him. That might look differently than you would think it would, but this is how we're going to do it." And I just felt like in that moment, maybe that was the first time I had really stepped up and stood up for myself in a confident way. I guess that probably has to do with I was protecting my child, but I think that's what for me something that stands out that was really hard, but also I felt so good on the other end of that.

Mindy Henderson: That's really great. Fred, how about you? Does anything come to mind?

Fred Graves: I mean, there's so many different ones, but I would say the one I'm most proud of was my time with dispatching for the state police. Like I said, those first few years, everywhere I went, every troop that I went to, every person I worked with, it was always, can he do this? And you hear that. You can hear people saying these things. And it was the first time that I said, "You know what? No, I'm going to keep showing up. I'm going to keep showing up."

And then eventually you get into these situations where a trooper that you're working hand in hand with, he's like, "High five, man. Thank you so much." And you know that you really showed up and it showed them that, wow, it didn't matter that he has anything. He showed up. And he's actually a good dispatcher and he helped save my life. So I think that that was something that I was so proud of. I mean, eventually I had to...

Being an essential worker and having a condition like this is probably not the best thing, but I was able to leave on my own terms, but I was able to show up and show that you shouldn't just look at someone who's in a chair or whatever case that you might see them in and recognize that they are more powerful than you even think. And I think that that's directly combating ableism, because ableism is seeing someone and then, "Oh, well, she couldn't walk in the hallway. How's she going to deal with her son?"

It's like, you don't know. That's the thing about having a disability is that people tell us we're inspirational, but it's like, dude, if you had this issue, you would figure out a way to work through it. That's all it is, is just dealing with adversity as it comes and people respecting that. I think that was a great point where I showed up for myself and I was so proud of myself.

Mindy Henderson: Yeah. Well, and I have to go there because your example is so perfect and so relevant for I think a lot of what people with disabilities come up against in employment, in our world today. And there's so much education and awareness I think that is still needed among employers and then by extension the people that work for those employers because so many assumptions are made about what a person with a disability can and can't do.

And that seeps into job descriptions and interview processes and requests for accommodations and the whole enchilada. I love that this came up today because I think it's a really important area to mention and just to encourage any employers that might be listening to really think about getting some outside consultation about what their operating processes and procedures are when it comes to hiring and employment and maintaining staff because it's so fraught with bad assumptions and unconscious bias.

I think that people may not realize that they're making certain assumptions a lot of the time too. And Amy, I've got to say, I'm right there with you too. When I applied to adopt, actually I was denied based solely on my disability the first time. And not much in life has made me more angry than that. And you want to see a mama fight for her child. I don't think I've ever fought so hard for anything in my life. I don't speak about it a lot publicly, but I'll share that today.

Amy Shinneman: Well, thanks for sharing that. And yeah, nothing like mama bear, right?

Fred Graves: Absolutely.

Mindy Henderson: No, that's right. Don't poke her. So Payton, what about you? Any specific instances come to mind?

Payton Rule: I think you just mentioned accommodations, and I think there's been some points in my journey where I've been denied accommodations, like workplace or academic accommodations. And I think in the past, if I was younger, I think there might've been a point where I would've just accepted that and accepted that the accommodations that I was asking for were too burdensome for people or maybe were unfair or something like that.

But I think the fact that I have Disability Pride now and can recognize that my disability is something that brings a unique perspective to everything that I'm doing. And so being able to have equitable access is not unfair. It's something that makes the world a little bit better for all disabled people, all people in general. And so I think that's given me the courage or the ability to push back against those denials and to be able to actually fight for the accommodations that I need to be able to do my work and be on a level playing field with other people.

Mindy Henderson: Absolutely. There's a term that I heard, Payton, that I want to share with all of you today because I think it is one of the smartest things I have ever heard when it comes to disability employment and accommodations. There's a company called Inclusively that I went to a training session once and they talked about accommodations and actually encouraged people to flip the script and talk about them in terms of success enablers instead.

And you talked about leveling the playing field. I mean, we all know language makes such a difference, and a success enabler versus an accommodation has a completely different connotation, I think. And really that can apply to anybody, disability or not. It's just about what a person needs to be successful to do their job.

Payton Rule: Absolutely.

Mindy Henderson: So maybe that's something that can go in one of your research papers that you will inevitably publish and become famous for.

Payton Rule: I love that though. I love that that change in terminology is so powerful, and I think a lot of the accommodations that we use as disabled people are actually benefiting non-disabled people too. Microphones in classrooms help non-disabled people who are sitting in the back hear better. Curb cuts help people with strollers get around a little bit better. So I think they actually end up helping everybody, but I love that change in language.

Mindy Henderson: Absolutely, absolutely. So Payton, I'm going to stay with you for a second because I mentioned earlier that you recently wrote a really, really good guest blog for us. Actually in some of the email back and forth with you about the article itself, it actually opened a discussion amongst us on the Quest team that I really appreciated. And I was so glad. I, of course, want to be educated if there's something that we should be doing differently.

And sometimes as a person with a disability, you think you've got it all figured out. But you open this discussion about identity first versus person first language in the disability community and how we speak about people, how we write about people. And you shared, I think, that you prefer maybe identity first language.

Because I have sort of become accustomed to person first over the last few years as the conversation about disability and inclusion has started to emerge more and more, but can you tell us why you prefer that and whether it's representative of a widespread shift in the disability community and how people are speaking about themselves or maybe what preferences may be?

Payton Rule: Yeah, absolutely. For anybody who maybe has not heard about identity or person first language, which I know I had not when I was younger, so person first language would be saying, "I'm a person with a disability." You're always saying you're a person before you talk about the disability, to where identity first language would be more like, "I'm a disabled person," putting the disability as a descriptor.

I want to be completely transparent, but I don't think there's one that's right and one that's wrong. Everybody has different preferences. And I usually will use identity first language for myself when you hear me talking about myself. But that being said, I will not be offended if you use person first language or anything like that. The reason why I prefer Identity first language is I really view my disability as a part of my social identity, so similar to my identity as a woman.

I view it that way because it's really shaped my experiences and my perspective and the way I navigate the world in a similar way that I feel like my other social identities do. And so if I said, "I'm a person who's a woman," that would sound a little weird. You just assume that I'm a person first. But by saying person with a disability, I feel like that implies that you have to say that you're a person first. It's not implied by saying you're a disabled person.

For me, I think person first language separates me from my disability in a way that doesn't feel super authentic. But that being said, I don't think that one's right and one's wrong. The American Psychological Association, who gives guidelines for writing for my field, they actually say you can go back and forth in your writing. So that's generally what I'll do when I write scientifically. I don't think there's one right and one wrong answer, but that's just why I prefer it when I'll talk about myself.

Mindy Henderson: That's really helpful. And for anyone who finds themselves listening to this who does not have a disability and maybe doesn't have a person with a disability in their life, because to your point, everyone may have different preferences for themselves. And so how do you know when you are a person speaking with a person with a disability what the right way to describe them or talk about them may be?

Payton Rule: Yeah, it's tricky. I think it probably depends on the situation that you're in, but I think the safest bet is probably just to ask them if you have that kind of a relationship. If you don't have that kind of a relationship, I think the consensus might be that person first language is maybe a little bit safer, but I don't think that there's a right or wrong answer. I think there's a lot of discussion out there about that.

I know there's been some research studies that have shown that the majority of people prefer identity first language or don't care, but there's still a sizable amount of people, I think it's around a third of people that said that they prefer a person first language. So it really I think just depends and varies across people.

Mindy Henderson: Oh, interesting. I love having the three of you here today. You guys have such smart perspectives on things. Amy, I want to go to you next and talk about your writing. You talked about your blog, Humbly Courageous, which is wonderful, and your local newspaper, which we can certainly name if you think that they would be okay with that, that chronicles your journey and your advocacy efforts.

Talk a little bit, if you don't mind, about the role that your writing has played in your disability journey, so to speak. Has it helped evolve how you look at your disability, how you feel about your disability, anything like that?

Amy Shinneman: Yeah, absolutely. I think it's been the number one thing that has changed me as a person. And I write for the Hamilton County Reporter is the newspaper that I write for. And writing my blog and the newspaper, they're not always the same. They're similar. But when I started writing and the more vulnerably that I was able to share my story... I mean, I'd heard sharing your story is so powerful so many times, and I always thought, well, okay, sure.

But when you start doing it, and even when I was doing speaking things and talking about my story, it wasn't the same as writing about it. It was kind of like I could... And I write a lot about childhood and all of it combined. So I'm going back in time and I'm able to see myself through a different lens. And that's so interesting to show that just transformation that has taken place in me throughout the years.

I was actually talking with my son, who's home from college right now, about that. He happened to see the list of questions and he said, "What do you think you're going to say to that?" And I said, "Well, I don't know if I'm sure yet." And he said, "Can I tell you what I've seen?" And he hit the nail on the head. He said what I've seen in you is that I'm a negative thinker naturally.

I have to really fight against that just because I take on what I think other people are perceiving me to be. And when I started writing and getting feedback from my community, I was proven very wrong. And it helped me to turn my mindset from the negative view I had towards myself and my disability. It turned that around for me hearing that I've taught people things or what they've learned from me, or the things they say are empowering to me because it allows me to look at myself in a different way and not take on so much of those negative feelings.

It's transformed me into a much positive thinker, which has been really interesting to me, I think fighting that negative mindset that I could get really down on myself. But I think we're all probably hard on ourselves at times for different reasons on different days, but I've just been astonished at how it's changed me for the better as a person. And I've really enjoyed it.

Mindy Henderson: That's interesting. That is not the answer that I was expect... I mean, I never quite know what to expect in terms of the answers people are going to give, but I don't think I was expecting that answer. It's really poignant. And you're right. I think speaking and writing are very different things. And writing, to be original all the time and to always have new thoughts and new experiences and things to write about, you have to dig pretty deep.

And it's interesting to hear you say that it's changed you in that way. I've known you for a few years now, and I have to say I never thought of you as a negative person, but I suppose that's something that maybe only someone living in our heads would know. So I love that for you. I love that that's been your experience.

Amy Shinneman: That's a good point that you make. I mean, I think that a lot of people might say what you said, "I never viewed you as a negative person." And I think because a lot of that negativity was internal and it was in my head and the way I talk to myself has really changed in my mind. And I'm glad to know that I'm viewed as a positive person. I like that. That's what I would like to be. And I think the change has really taken place inside of me in the way that I talk to myself for sure.

Mindy Henderson: Absolutely. Absolutely. Well, Fred, I want to talk to you a little bit about being a father, because you recently wrote a really great Father's Day blog for Quest where you shared parenting experiences and advice. What advice can you give regarding teaching children about Disability Pride and finding strengths in our differences? Do you have one child?

Fred Graves: I do. I just have my son.

Mindy Henderson: Okay. Does he know what Disability Pride is?

Fred Graves: I don't think he knows those words together, but I think we talk about it all the time. Especially because he's eight years old, so he's becoming aware that my dad's different than other people's dads. And sometimes he'll go, "I really feel bad that you can't do this or that." And I'm like, "Well, son, it's okay because I can do this." And he'll go, "Good point." I try to replace it with the things that I can do. I replace it with unique opportunities. Like yesterday we went on a little walk.

He wanted to bring his razor out to the skate park. So we went to the skate park and I'm like, "Are you going to ride it all the way there because I'm not carrying it back," even though I know I'm going to have to do it anyway. So as he's riding back on the back of my chair and I have this razor on the front of my footrest, he's like, Those people are looking at us." And I said, "This is because they're interested and other little kids want to stand on the back of my chair."

And I try to frame it in a way of, it's different, but it's just as vivid and fun and it can be just as much as a learning process as anything. It's just our experience, and it's part of life. It's part of someone's life. Not everyone can see that, but you have a different perspective. And I think that's something that how I instill that pride in him. I don't want him to feel like, oh, my dad's in a wheelchair and he can't do these things.

No, we do different things. When we go to amusement parks, we get to the front of the line. You know what I mean? So it's just about finding what's good. And something that Amy said reminded me of a point that I've learned in the last I want to say two years. Because when I left the state police, I said, "What am I going to do with my career? Do I want to do advocacy? Do I want to go back to school for social work?" All these different things.

And it hit me one day that advocacy is just showing up wherever you are and being uniquely you. And whether it's in Payton's program that she's in for her PhD, whether it's at the newspaper with Amy, whether it's what you do in your day-to-day life, Mindy, advocacy is us showing up being a person with a disability or a disabled person and showing up and showing what we can do. And that's how I show my pride and how I advocate for myself and people like us. It is just showing up.

Mindy Henderson: I love that. And it sounds like your little boy is already a sweet, empathetic person and you're absolutely really instilling that in him I think in everything that you just said. I think that one of the most beautiful things, and you talked about this, that parents with a disability have to teach their children is just the beauty of differences. I always say the kiss of death when you're a kid is being different than your friends or anybody else.

And I think that our kids in that sense, or in a lot of senses, but in that sense are lucky because they have living, breathing examples every single day of the differences that we have from one another and how that can be a good thing. It can be a positive thing. It doesn't have to be a good or a bad thing. It just is, and it's the way of the world. I love that that's something that your son is taking from you.

Fred Graves: Yeah.

Mindy Henderson: Yeah. Well, we're almost out of time. I have one last question that I want to give each of you the opportunity to answer, and then hopefully we can... I think we just need to all hang out on Tuesday afternoons and have virtual coffee. Yes. But for anyone who's listening, maybe our younger listeners who may be struggling to find the beauty and recognize the unique strengths that come with living with a disability, what advice would each of you give to them on maybe how to be begin to shift that mindset to one of a more powerful pride kind of mindset in who they are?

Fred Graves: I'll go first. I would say community. If you can't get out to a conference, if you can't, if you don't have a hospital that has clinic days, I love... That was my starting point, clinic days for... I don't know if the MDA does it now, but just fellowship with other people in the MDA community or whatever community you're part of, whatever it is, the things that you struggle to identify with, community, because there's somebody who's a little further down the road than you or around that bend where you can't see something for yourself.

I see it all the time. For me, career was a huge thing. How am I going to provide for my son with this condition? And you see other people and you say, "You know what? Let me stop worrying because I can see it now." And sometimes your family, they want to encourage you, but they just don't have it. They don't experience it, so they don't know what to say. But community, the people who go through it every day just like you, they can help instill that in you. So that would be my biggest advice, and that's helped deliver me in a lot of ways. So I would definitely suggest that.

Mindy Henderson: That's such good advice. And I will say there are people in this community, the three of you are amazing examples of this, but there are people in this community that are so spectacular and problem solvers and creative people and pragmatic people. You name it. MBA has got a lot of ways to connect you with people in this community that I think can be really great examples for you, mentors for you, friends to you, all of that.

I couldn't agree more, Fred. I think it's so important to seek out people that are living a similar experience to this one because it is very unique and the sky's the limit. And I think there are a lot of people out there that really want to help. Payton, what about you?

Payton Rule: I completely agree with that. I think community was the number one thing that came to my mind too. With the disability community, like you were saying, and then also non-disabled people as well who can just be there to help advocate, to help support you when you're going through ableism, those kind of things. And I think just finding spaces where you feel accepted, disability and all.

I think I used to want to find spaces where I felt accepted despite my disability, but I think now I look more for spaces where I feel accepted with my disability, where they see my disability and me. And I think personally that's been really helpful. They're out there. Those spaces are all over the place. So I think finding them can be really helpful.

Mindy Henderson: Such a good point. Amy, we'll let you have the last word.

Amy Shinneman: I would agree with both of them. I think that community is a great source of wealth, of knowledge. I wrote a blog piece called Disability Defined, and it was just talking, and I know that can be a controversial thing, but it was mainly talking about how I can't separate from my disability. That is a part of me. In my mind, it does define me, but that's not a negative thing, but that can be a powerful and positive thing. And looking to our communities and just...

I think a lot of times when we're talking to younger people with disabilities or they're thinking, well, I have to learn from somebody that's gone before me and they have all this wisdom, but I've learned a lot about self-acceptance from people much younger than me. I've just been blown away. And the younger group of people have helped me so much and just used that. I wish that I had a community like that growing up. I think it would've changed my life. So really, I think we all agree, just tap into the community that's available for you and find the beauty in there.

Mindy Henderson: You guys are the actual best. I have loved this conversation so much and I wish we had two more hours. But thank you from the bottom of my heart for being here and for talking about such an important topic. I wish everyone who's listening a wonderful Disability Pride Month, and I hope that you'll come back and listen again soon. Thank you.

Amy Shinneman: Thank you for having us.

Fred Graves: Thank you.

Payton Rule: Thank you.

Mindy Henderson: Thank you for listening. For more information about the guests you heard from today, go check them out at mda.org/podcast. And to learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved, and to subscribe to Quest magazine or to Quest newsletter, please go to mda.org/Quest.

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