



Episode 57- Voices of Inclusion: Celebrating NDEAM with Disability:IN

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(Music playing)

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.

In honor of National Disability Employment Awareness Month, we're joined today by a true leader in the field of disability inclusion, Russell Shaffer, Executive Vice President of Strategy and Programs at Disability:IN. Russell's career spans journalism, communications, and corporate leadership, including his work at Walmart where he advanced global diversity, equity, and inclusion strategies. He now leads key programs at Disability:IN, including the Disability Equality Index, accessibility, supplier diversity, and next-gen leadership. Russell also brings a deeply personal perspective to this work shaped by his own experience with vision loss and by the lasting friendship he shared with a childhood friend who lived with muscular dystrophy. Russell, thank you so much for joining me. I'm so glad to have you here.

Russell Shaffer: Mindy, thanks so much for having me on the Quest Podcast. Thanks for the very gracious introduction and the opportunity to chat with you a little bit today in honor of National Disability Employment and Awareness Month, looking forward to it.

Mindy Henderson: Thank you. It's a busy month with lots of activity and awareness. You and I spoke on a panel together this morning, which was-

Russell Shaffer: We did?

Mindy Henderson: ... kind of an uncanny coincidence, but there's a lot to talk about. So first of all, I would love to start with that personal connection that I mentioned. You shared that one of your best childhood friends, Josh, lived with muscular dystrophy. How did your friendship with him shape your understanding of inclusion apart from your own disability that you also shared with me, and ultimately influence your life's work in this space?

Russell Shaffer: Yeah, thanks so much for that question, Mindy. When the opportunity to be a part of this MDA podcast came through to us at Disability:IN, it came my way, and nobody on my team really knew my connection to muscular dystrophy. It just was one of those serendipitous coincidences that I just knew it was meant to be, and it was really an opportunity to draw on the experience that I witnessed with my friend Josh as we were growing up and getting ready to go off to college and enter the workforce, opportunities, or lack thereof for him were very, very different. And so this is just an opportunity for me to really pay homage to somebody who was a really critical part of my life. But Josh and I, we grew up in a small town in Ohio. He was a year younger than I.

And so I would see him in school in the halls. And I remember when we were in elementary school, Josh would walk. And as we got a little bit older and into middle school, he started using a wheelchair. I remember our middle school in town was very, very old and not terribly accessible, but I remember the school district purchasing a special piece of equipment that would help Josh and his wheelchair get up to the second floor of the school where 7th and 8th grade classes were. We didn't have an elevator in the building, but they made it work. It was a pretty wild contraption as I remember it. It was-

Mindy Henderson: Wow.

Russell Shaffer: ... something out of a science fiction movie it seemed like, but it worked, and every day Josh would make his way up there. And the thing that always struck me about Josh is that he just wanted to be in the thick of it with everyone. And I really got to know him when I was in high school. We were in a computer class together, and I think that that was a prevailing theme. I really got to know just what a wicked sense of humor Josh had, which is indicative, I think of a sharp mind. He was brilliant, and he was particularly adept at computers, and in the early 2000s, online and all that went with that. And when we graduated high

school, he went and studied computers at one of the local community colleges. And I remember that transition for him from high school, with having an IEP and all of the things, to going to college where accommodating disability at the collegiate level is quite different than at the high school level. And that adjustments and some of the challenges that he faced with access to campus buildings, and with faculty, and just some of the patronizing approach that some of his faculty and fellow students would take to him. But he was there to learn, and he wanted to push himself and perform just like everyone else.

I think the thing that for me is the most disheartening is Josh passed away in 2012 at the age of 33. And a lot of the advances that we've made in digital accessibility and work-from-home, AI and all of the things that I think would've really closed the employment gap for Josh and allowed him to be able to lean into his deep technology love and his IT education and knowledge he just wasn't able to fully leverage in his lifetime. And so I think that's one of the things that makes me so passionate about accessibility, makes me passionate about the advances that we've made as a society, particularly post-COVID in remote work, virtual work, and how that helps those of us with disabilities that are transportation constrained especially be able to enter and contribute in the workforce. I know that our workforce today is vastly more inclusive and accessible for individuals like Josh than it was in his lifetime. And my goal is that by the end of mine, it will be even more accessible.

Mindy Henderson: That's so beautifully said. And I've got to say that by continuing to share his story, you're doing a real service to his legacy and continuing to have important conversations and create progress. To your point, we've certainly made progress in the world of employment for people with disabilities. I think there's certainly still a lot of work to do, but I think it's conversations like these that are really making the difference.

Russell Shaffer: Absolutely.

Mindy Henderson: Yeah. So October is of course National Disability Employment Awareness Month. From your perspective, what does NDEAM mean in 2025, and how can we ensure that it leads to real action in the workplace, not just the awareness that I just mentioned?

Russell Shaffer: Yeah, Mindy, you went where I was going to go. I think this is the 80th anniversary of what we celebrate as NDEAM. And I am not 80, though my kids tell me I'm old all the time. I'm not that old, but I have been a part of the labor force as a person with a disability for almost 1/3 of that timeframe. And so I've seen a lot of progress firsthand from when I entered the workforce in the early 2000s to now just in terms accessibility, companies prioritizing disability inclusion in terms of culture, policies, processes, companies' intentional recruitment efforts for people with disabilities, recognizing the differentiated skills that a diverse workforce that includes people with disabilities can bring.

We often say as people with disabilities that we are natural problem solvers. I don't know if natural is the case, but we are definitely very practiced problem solvers from living each day in a world that's not necessarily built for us. And I think that that is a transferable skill into the modern-day workforce. I mean, every industry is facing disruption from competition, from technology, from a variety of different angles. And I think the one thing, if you ask most companies what are they trying to do, they're trying to innovate. They're trying to innovate so that they don't become extinct. And I think we as people with disabilities, that adaptation to a non-accessible, non-inclusive world, one that is becoming increasingly so by the day but is still not there, makes us very valuable to a workforce that prioritizes innovation, if they also prioritize inclusion. If we are able to bring our experiences to bear, then we really can help drive the business forward, not only in terms of being able to broaden market reach for other customers with disabilities, but also the talent pool for other potential employees with disabilities. But just also in totality, when you give people the space to be able to bring their whole self to work, when they view a problem and idea differently, they might have the unlock, but they're not going to necessarily share it if that psychological safety is not there.

That webinar that you and I were on earlier today, one of our fellow speakers talked about FOMU, fear of messing up, which I hadn't really heard before, but so encapsulates, I think a lot of people with disabilities experience in the workforce. Many of us are grateful and thankful to have been given the opportunity, and we don't want to do anything to mess it up. So that means we might not take risks, we might not push ourselves. We're going to try to stay in this little box that we perceive as safe, that has been carved out for us. And ultimately when we do that, we and our employer misses out. And so it doesn't just go for those of us with disabilities, it goes for everyone, but it goes double for us. When an employer can create an environment and atmosphere where people with disabilities feel that they can strive and fail forward and learn, then you're going to get the best from us. And we're going to bring something that the rest of your workforce might not necessarily have, it's our point of view, it's our perspective. And what I've seen in my 25 years of working is companies are valuing that more from people with disabilities today, Mindy, than they did when I got started a quarter-century ago.

Mindy Henderson:

You spoke so much wisdom in that answer that you just gave me, and I think that there's two sides to employment. There's hiring, and I would love to know your perspective because you work in the thick of this day in and day out at Disability:IN, but I feel like we've heard a lot in the years leading up to present day about inclusive hiring and hiring of people with disabilities, but there's the other side of the coin, which is really that inclusion or belonging piece once you do make the hire. And I feel like that is a side of the coin that the conversation is maybe just getting off the ground and beginning to evolve, which maybe is indicative of the fact that, like you said, the numbers and some of the statistics that we've seen around hiring of people with disabilities, I think we've seen the needle move a little bit, maybe not as much as we would like, but maybe that's indicative of having more people in the workforce with disabilities. And I think

that it's equally important to work on the aspects of your culture once people are in the doors and boots on the ground with you to making sure that they feel safe to be who they are, like you said.

Russell Shaffer:

Absolutely. I think particularly drawing on some of my past work in the private sector, to me the simplest definition of culture is the things we all do. And the fact of the matter is that you can have an inclusive culture or you can have a non-inclusive culture, it is your culture. And so for me, I've always felt like inclusion is an action verb, belonging is a reaction verb. And so what are you as a leader, or as a peer, as a colleague doing in your everyday behaviors to try to put forward an inclusive environment for the people that you work with, the people who work for you, even the people who you work for in some instances? There's so much that we can do.

Deloitte published this great study a few years ago that they called the Six Signature Characteristics of Inclusive Leadership. And for Ease, they all start with C. So they make it really easy to remember, but are you committed to this work? Are you committed to inclusion? Do you have the courage to challenge the status quo, to speak up when you see things that aren't right? Are you curious to expand your learning, to be able to create spaces for conversations that are going to help you grow? Are you cognizant of your own bias? Mindy, on that webinar we did earlier, you talked about bias. We all have biases, even ourselves, even those of us with disabilities, and we have our own internalized biases of.

Mindy Henderson:

Course.

Russell Shaffer:

So be cognizant of those biases. Are we culturally competent, taking steps to learn language, to learn new ways of thinking, new ways of behaving? Are we collaborative? Are we willing to work with others to source ideas? So all of these things are indicators of inclusive leadership that we can practice in our own behaviors. And then ultimately, and the data shows that the more of these behaviors that are present, the higher likelihood that an employee is going to feel like they belong. And so for those of us with disabilities, do we have a leader who's willing to stand up and say, "You know what? This meeting, it's not captioned. Let's make sure that we've got captions on this." Do you see that your company is committed to disability inclusion by having an employee resource group present? Do you see your colleagues are curious because they engage you in conversation and they want to understand how they can be more inclusive? These things are indicators of an inclusive culture.

It doesn't happen by accident. It is truly an intentional. And I think one of the things that we see at Disability:IN is there are a lot of companies who are really, really committed to figuring out how to do this right and to be able to create the type of culture inside of their organization where their employees with disabilities can perform at their level best and can feel psychologically safe, and moreover that they are able to attract more employees with disabilities to join

their organization because they see the value that a diverse, inclusive workplace brings.

Mindy Henderson: Yeah, truly. And of course, any time you include people, give people a seat at the table with different lived experiences, their perspective is going to be different and they're going to be able to think of things that you may not have. And so I love just the conversation about diversity and inclusion itself. And those six things that you mentioned, I think are a great list to work from for any company that might be listening that is wondering how they get started. And I think that too, it's important to mention, and I get this question all the time, is, "How do I even begin? What's the first step that I can take to creating that inclusive culture?" And I think it's important to tell people that they don't have to boil the ocean, so to speak. Just like you so eloquently said, I think you do one thing at a time and take one step at a time. And those things in aggregate become a beautiful organization where you are more competitive and more successful, and your employees really enjoy being there and can lean into who they are.

So the Disability Equality Index that Disability:IN is famous for really, I mean, among other things, but that's one of them, it's become a key benchmarking tool for corporate disability inclusion. First of all, I would love for you to talk about it, and for anyone who may not be familiar, help them understand exactly what it is, but also how you've seen it evolve, and maybe what some of the promising trends or examples are that show that companies are moving that needle.

Russell Shaffer: Absolutely. Been fortunate to have been involved with the disability index since its inception. When I worked at Walmart, Disability:IN was one of my external partners that I worked closely with. And I remember Disability:IN coming to me and saying, "We want to stand up this benchmark to help companies better understand corporate disability inclusion policies and practices. Is this something Walmart would help support?" And so at the time we did, we were one of the founding sponsors of the disability index and participated in the index in its first year in 2015 along with 79 other companies, there were 80. Participation now a little more than a decade later has grown by more than 6X, 70% of the Fortune 100 who participated-

Mindy Henderson: Wow.

Russell Shaffer: ... in the disability index. And so it really has grown and evolve, but fundamentally it is intended to be an objective forward-looking, reflective third-party assessment of disability inclusion policy and practice across the enterprise, from culture to leadership to enterprise-wide access, benefits, recruitment, retention and advancement, accommodations, community engagement and supplier inclusion. We are actually retooling the index for 2026, totally revolutionized and simplified the question sets, the recognition, the scoring for 2026, and we'll be opening the index for next year on January 7th. And we'll be sharing a lot of details in the coming week. So anybody who's interested, please

stay tuned to our website, disabilityin.org for a lot more details on the future of the index. But I think the thing that I will say there is that one of the great evolutions of the index over the past few years is that we've evolved it from being a US-centric benchmark to a truly global benchmark pilot with seven international countries in the past two years, Brazil, Canada, India, Germany, Japan, the Philippines, the United Kingdom, taught us a lot. And now for 2026, regardless of where a company is in the world, can take the disability index. So it is truly gone global.

But I think, Mindy, back to the prior question, it's interesting, before we got started you talked about having a little magic in our conversation. And it's funny, as we were talking about culture on the last question, one of the things that we found with the index that we affectionately refer to as the magic formula, and what we've found is that culture and leadership really drive disability inclusion. And what I mean by that is companies that have a disability-focused employee resource group and have a senior leader within two levels of the CEO who is active and visible as an ally for disability inclusion or themselves a person with a disability, those companies are much more likely to have inclusive hiring practices, accommodations, and accessibility strategy and plan, and many of the other downstream policies and practices that are key contributors to a disability-inclusive environment for their employees. But it really starts with that culture. Are you prioritizing that employee network and resource sharing through ERGs? And do you have a leader who's outspoken and vocal about championing disability inclusion? And so a lot of times companies will want to look at practice or policy as indicative of results. And that's important, but they're usually an indicator of something that can often go overlooked, and that's that leadership and cultural commitment.

Mindy Henderson: Interesting. So I think I know the answer to this, but I'm going to ask it anyway, but to be listed in that index, is that a set of questions that any company can go in and answer the questions and get their scoring, their evaluation and be listed on the index?

Russell Shaffer: Any company that meets eligibility for the index, yes. So eligibility is pretty simple, are you a non-governmental organization with 500 or more employees? If that is the case, then you are eligible to participate in the disability index wherever you operate in the world.

Mindy Henderson: Great. And I love that you shared with us the top two things that you see in the trends that move that needle. What challenges do you currently see, and what kinds of things does Disability:IN do to help companies overcome those hurdles?

Russell Shaffer: I think that one of the things that we're seeing become an increasingly high priority for companies is accessibility and digital accessibility. And I think there are so many reasons for that, just digital transformation in society in general, but what we talked about earlier with more work being done virtually and at distance, I think prioritizing accessibility and our virtual meeting platforms and how we set up virtual meeting spaces is really, really critical, but then just the

proliferation, Mindy, of artificial intelligence. And AI can be such a powerful tool for accessibility and inclusion, but only if it's designed in a way that supports that. And so companies are just now trying to figure out, "How do we use AI in general for our business operations and productivity across the workforce? And then how do we use it as a lever to drive disability inclusion? How do we ensure that it's accessible?"

And so that's one of the things that we've been seeing over the past several years with the disability index, is we've seen a gradual click-up in the adoption rates of accessible practices across our participating companies. So the companies that have an accessibility policy for their organization has crept up from under 50% five, six years ago to now about 2/3 of companies. And similar progression in the number of companies that indicate that they audit their internal employee-facing products for accessibility. And so the more companies prioritize these things, the more they realize and recognize that they need support to understand how to operationalize that. That's one of the things that we at Disability:IN are very fortunate to be able to help the companies that we work with be able to move forward on in their journey.

Mindy Henderson: You put on a conference every year, Disability:IN does, and I had the good fortune of attending this year over the summer. And it was an incredible conference for disability inclusion, and the companies that I saw participating and in attendance at the conference was really impressive, but I learned things about Disability:IN that I didn't know prior to attending that conference, probably one of the takeaways that you hope people would leave that conference with. But I want to talk about two of those things in my next couple of questions because I thought they were really fascinating, and I'd love to know more about the work that you do. The first one is Disability:IN's Supplier Diversity Program, which helps connect disability-owned businesses with major corporations. What progress have you seen in supporting these entrepreneurs? And what again, can organizations do to expand those opportunities?

Russell Shaffer: Yeah. No, thanks for that question, Mindy. That's a program that's near and dear to me. It was actually one of our first signature programs at Disability:IN, our Supplier Inclusion Program turns 15 this year. We are the leading global third-party certifier of what we call disability-owned business enterprises or DOBEs, and that includes service-disabled-veteran DOBEs as well. At the time that this goes live, we will probably have crossed the 1,000 certified DOBE threshold. We are sitting at about 993 as we record today.

Mindy Henderson: Wow.

Russell Shaffer: Yeah, so not only will we celebrate 15 years this year, we'll celebrate 1,000 certified small businesses. And most of these know DOBEs that we are working with are small businesses. They meet that qualification of a small business, and they're working on a whole host of things. More than 90% of them are doing B2B type of work, goods not for resale or professional services, training, marketing, legal consulting, et cetera. We do have some of our DOBEs who do

consumer products. And we publish a DOBEs gift guide each holiday season. As the holidays are coming up, keep an eye out for that on our website and shop disability owned. But most of our DOBEs are looking to do business with government contractors, with the private sector, and bring a whole host of skills and expertise and products to bear for businesses. And so any procurement professionals out there, anyone who works in talent development inside of companies, please look at our DOBE database, reach out to us at Disability:IN through our website, or to me, russell@disabilityin.org, love to get you connected with these DOBEs.

And these business owners collectively have a tremendous economic impact. Those 1,000 DOBEs we are publishing this month, our 2025 DOBE impact study, Mindy, where we found that collectively those 1,000 DOBEs account for nearly \$3 billion in total revenues [inaudible 00:31:55].

Mindy Henderson: Wow.

Russell Shaffer: 21,000 individuals across those 1,000 DOBEs. And moreover, as one would expect, to be disability-owned business enterprise, 51% owned, operated and managed by a person with a disability. And so people with disabilities, we are more likely to employ other people with disabilities. Our DOBEs, 82% of them employ people with disabilities at a rate higher than the median for disability employment, which is 4%.

Mindy Henderson: That's fascinating. What is the process like to become a DOBE?

Russell Shaffer: A certification process. And so usually it takes anywhere between 30 to 60 days, entails completing an application that includes operating documents, articles of incorporation. Because we are certifying you as a disability-owned business, we do ask for documentation about your disability as well as other business documentation. And then we've got a certification committee that reviews all of those documents and makes recommendations on whether to certify or not to certify. Our certification rate is well over 95%. Most of our companies who get through the application process for certification do get certified. If this sounds like you out there, if you're an entrepreneur with a disability, and your business is 51%, so majority owned, operated and managed by you and/or co-owners with disabilities, come our way. We'd love to help certify your business and expand your market.

Mindy Henderson: I love it. I love it. And obviously these are companies that are doing exactly what we're talking about here today. The next program that I want to talk about, I also thought was very cool when I heard about it at the conference, the NextGen Leadership Program is helping young professionals with disabilities launch successful careers. When I was starting my career six months ago... No, a little longer than that ago, I had great role models in business and things like that, but I didn't have anyone who told me how to be a disabled professional, and how to thrive in that environment with the stigmas and things that I was going to come up against. And so I loved hearing about this program. Is there a

story that comes to mind that captures the spirit of this program and the change that it's driving?

Russell Shaffer: Yeah, this is another one of our programs that means a lot to me. This one has been around, the NextGen Leaders Program, for more than a decade, 12 years now. And Walmart, once upon a time when I was there, helped fund the NextGen Leaders Program through the Walmart Foundation. So it's a program I've been tracking for a very long time. The first year of the program we had 20 NextGen Leaders. This year we had a record-sized class of 438.

Mindy Henderson: Wow.

Russell Shaffer: And so yeah, each of those 438 individuals are a college student or recent graduate with a disability, all types of disabilities. And they have educational and career-aspirational backgrounds from business to finance, STEM, communications and more, but a lot of STEM. And that's really driven by what our disability and corporate partners are looking for in employees. So each one of those 438 individuals is matched with a mentor from one of our disability and corporate partners, and they have a six-month virtual-mentoring relationship. And the goal is to help get them job ready, to get them ready to enter the workforce with the durable skills that they need to be able to get that first job and to succeed once they do.

And Mindy, I think you're absolutely right. As I shared at the outset, I've been in the labor force for about 25 years, graduated college in 2001, viewed myself as part of that first wave of post-ADA people with disabilities entering the workforce. And yeah, I didn't have role models with disabilities to look up to and to ask questions of, to get counsel from on how to navigate the workforce as a person with a disability. I would've loved for something like the NextGen Program to have existed when Josh and I were in college and coming out of college, it would've made a huge difference, but today, we're able to provide these talented young people with that mentorship and that access to employers.

You asked for a story. We are right in the midst of recruitment for our 2026 NextGen Leaders Program right now. And so please check out our website if you are a college student or recent grad with a disability, or you know somebody who fits that bill, we're accepting applications through December 5th for our 2026 program, which we'll launch in January. And looking at our collateral for this year's program, I was reading a story of one of our recent program alums who got plugged in with the program in 2024 as a NextGen Leader, came to our conference as part of our NextGen Talent Accelerator, met a recruiter from one of our disability and corporate partners and was hired for an internship that concluded this past summer. And at the end of that internship, they were invited back for that company's development and fellowship program in 2026.

Mindy Henderson: Wow.

Russell Shaffer: And so countless stories like that. We have tracked more than 100 job offers to NextGen Leaders and NextGen alums this year alone and counting, more than we tracked last year. And that was more than we tracked the year before, which I think goes back to what we talked about before, many companies are committed to hiring talent with disabilities. And when we create opportunity for access and for application and for recruitment, these talented people are doing the rest. They're landing the jobs and they're crushing it when they do. And so the NextGen Leaders Program is one where we just love to see those success stories each and every time, because it changes the trajectory of somebody's life and their career.

Mindy Henderson: Incredible. And I think it's really powerful to think that you have that many people also, not just the new professionals that are up and coming as part of this program, but that you have that kind of volume of organizations, companies, people wanting to be mentors to the 400 people that you talked about. I think that that's really incredible.

Russell Shaffer: I mean, yeah, to have 438 NextGen Leaders, that means we need to have 438 corporate mentors doing these one on one. And yeah, those 438 mentors are coming from nearly 200 different companies, Mindy.

Mindy Henderson: Wow, that's incredible. You should be really proud of that, that's incredible. Accessibility is one of Disability:IN's core pillars. How are you helping organizations see accessibility as more than compliance, helping them see it as an innovation opportunity that really benefits everyone?

Russell Shaffer: Yeah, absolutely. I think this is one, for me as somebody who's blind, there is no inclusion without accessibility. And so we like to say at Disability:IN that accessibility is at the intersection of everything, and accessibility technology can be a barrier or a bridge to inclusion depending upon how it's developed and deployed. Accessibility is how we can navigate the barriers on that bridge to a more inclusive workforce. Accessibility really unto itself is innovation, but it unlocks innovation, and it opens up the market. We often like to talk about universal design as a way in which we can ensure that all people have equal access and are afforded opportunities to participate in the physical or the digital space. And we like to point to the curb-cut effect as an indicator of that. So when we think about those sidewalk curb cuts that everybody is familiar with, I think, Mindy, the residents in the MDA community especially is we know that those curb cuts were originally put there specifically for individuals in wheelchairs, to help them navigate city streets effectively and safely. But today, they're used ubiquitously by anybody who's operating something with wheels, a bicycle, a scooter, a baby stroller, a dolly, a piece of luggage. They benefit anyone and everyone who's using something on two wheels, but that's not who they were created for.

And so when we design intentionally in a way that includes people that have historically been marginalized or left out, we create a demonstrably better experience for everyone. One person's access is another person's convenience.

And so similarly with websites, repeated studies have shown that the user experience for all users is increased on websites that are accessible and designed in a way that is inclusive of people with disabilities, that takes into consideration web content accessibility guidelines. And so when we shift left in our design-thinking organizations, and ensure that the edge cases are no longer on the outside looking in, but they are considered in every facet of the design process, and people with disabilities are involved in product development and testing, we're going to get a better, more inclusive product that's accessible for people with disabilities. But moreover, we're going to get a product that is going to be more applicable and utilitarian for all users, all consumers, regardless of disability.

Mindy Henderson: Well said.

Russell Shaffer: When you say that to a business, it's, "Where do I sign?"

Mindy Henderson: No kidding.

Russell Shaffer: Because they recognize the market reach and potential value of what they're creating goes up.

Mindy Henderson: Yeah, and boy, I love that you mentioned universal design, because man, I don't understand why universal design is not more of a prevalent factor in so many ways in our built environment and product development and in a lot of different ways, there are ways to design to include everyone that don't detract from anyone else's experience. For me, it's a no-brainer that this would be the way that organizations, companies, city planners, you name it, architects, would operate. And I know we're getting there, but I love that you mentioned it.

Russell Shaffer: Absolutely. What I would say too, to put a fine point on that, Mindy, your prior question was like, "What is the case beyond compliance?" And so I'll just kind of circle back to that. Compliance is a very real and tangible thing that businesses have to consider. And so when you do not prioritize universal design, and then compliance comes a knocking, you've got a retrofit after the fact. And that costs money. It costs on average 10 times more to retrofit something, to make it accessible after the fact, than if it was born accessible from the outset. And so not only do you get all of those benefits that we talked about before with universal design, you circumvent compliance come a knocking and having to retrofit, which is going to cost more to the bottom line than if you would've just prioritized accessibility in the first place.

Mindy Henderson: So very true. I'm glad you followed up with that. I seriously could talk to you for the next six hours, you have such great knowledge and advice. It's rare to have a conversation like this where I think the people who are listening can take away very tangible ideas for how to transform what they're doing. Beyond numbers in terms of DEI and measuring inclusion and belonging, what metrics matter the most, do you think, in creating sustainable progress?

Russell Shaffer: I think that there are metrics that every company can measure, many do, not necessarily metrics that we at Disability:IN measure, but that we would encourage our companies to look at. And at the end of the day when we're talking specifically as it relates to disability inclusion from an employment perspective, as it is National Disability Employment Awareness month, what are your employees saying about their experience? And almost every company is doing employee engagement, whether it's annually, whether it's quarterly through little pulse surveys, what have you, but paying particular attention to employee engagement and sentiment, and then segmenting that by disability, which requires you to know who in your workforce is a person with a disability.

And so to again circle back to our webinar from earlier, that means you've got to have a self-identification campaign. You need to have your employees confidentially and voluntarily self-identifying that they are a person with a disability. And then ultimately you need to enrich that sentiment and engagement data with that disability-representation data to understand what is the employee experience of your employees with disabilities, and what are those drivers telling you? So what is their intent to stay? What are they telling you? Are they telling you they are actively looking for another job at a rate above, below, or similar to the rest of your workforce? What's their referral behavior? Are they telling you that they are more inclined, less inclined to recommend your company as a place to work for their family and friends?

And so these are really clear, high-fidelity indicators of the health of your organization at large, but specifically when you put that disability-inclusion lens on there. Listen to your employees, they're going to tell you how you're doing. And if it looks like that employee engagement amongst your employees with disabilities is lagging, then reach out to your employee resource group, presuming you have one, create listening sessions, do some more targeted focus group and listening to understand where the disconnect is from policy and process and practice. But your employees are going to tell you how you're doing, you just need to listen.

Mindy Henderson: So true. We're almost out of time, but I have two more questions that I would love to ask you. You've spoken candidly about your own experience with retinitis pigmentosa and how it's shaped your approach to leadership. What insights have you gained about adaptation, resilience and purpose through your own journey?

Russell Shaffer: Yeah, there's a lot. We might chew up a lot of those six hours that you mentioned a minute ago, Mindy [inaudible 00:49:23].

Mindy Henderson: I have the time if you do.

Russell Shaffer: I do. I think what I will say is perhaps something that's your listeners might not expect me to say, is we're recording this podcast, we're a few days removed from World Mental Health Day. I think when people meet me or learn about me and my disability, I think the presumption is, oh, I'm engaged with this work

because I'm blind, because I lost my vision. And that is predominant, but there are other reasons. There's my relationship with Josh that I mentioned earlier, but both my parents had disabilities. My mom lived with epilepsy my whole life, and my dad was diagnosed with type 2 diabetes when I was still in school. And so I saw a disability from a different perspective with them.

But for me, there's so many of us who have acquired disabilities or disabilities progress over time, physical, sensory disabilities, there is a mental health component to that. To be told at 10 years old that you're going to go blind one day, and then for that diagnosis to come true later in life, to discount that there's going to be a mental health component to that is really discounting the human experience overall. And so for me, to tell people, Mindy, the most disabling thing that ever happened to me wasn't losing my vision, it's what losing my vision did to me emotionally and psychologically. So we've talked about it a lot here with accommodations, with accessibility, for my disability in particular, whether it's a light cane or whether it's a service animal, whether it's a screen reader, whether it's some other piece of assistive tech or technology, there are so many things that exist today that help us close the productivity gap as people with disabilities. But ultimately, none of those things matter if you don't want to get out of bed in the morning and face the world.

And I found myself at a point like that in my life as I was losing my vision much more rapidly and aggressively than I expected to. Doctors told me when I was a kid, I'd go blind in my 40s or my 50s. I went blind in my late 20s, early 30s. I knew I was going to go blind, I just wasn't prepared for when I did. And I didn't have the tools and the training that I needed in order to be able to navigate the rest of my life. And it just so happened I was smack dab in the early stages of my corporate career, I was newly married, and my wife and I had just welcomed our first child. And so there was so much that I was challenged by and struggling with that compounded my mental health.

And so fortunately, I worked at an employer that prioritized supports. I was able to leverage an employee-assistance program and speak to a mental health counselor, and be able to get the support that I needed to be able to proceed with my life and live it to the fullest. So any and every opportunity I get, I don't ever want to discount the mental health part of my experience, but recognize that for many of us in the disability community, our disability identity begins and ends with mental health. And so the more we can do to break the stigma around mental health, to normalize comments like those that I just made, and ensure that it's okay and safe for people to be able to say those sorts of things to me, it's not a hyperbole to say it can save lives.

Mindy Henderson:

100%. And it's such an important component for so many of us in this community, I'm so grateful to you for sharing that. As we wrap up, what is your message to employers, educators, and community leaders this National Disability Employment Awareness Month? How can each of us contribute to a future where disability inclusion is woven into every aspect of work and entrepreneurship?

Russell Shaffer: Yeah. So for me, Mindy, it's what I like to call the three L's, listen, learn, and lead where you're at. So create spaces where people with disabilities feel psychologically safe to share, to disclose. You'll be curious, appropriately so. Don't tokenize someone or put them on the spot or expect them to speak on behalf of anyone and everyone with a disability or their particular disability. Give them the space to speak from their own experience. And then listen actively and respond with empathy, and with action when action is merited. And then take action yourself to learn. Back to biases, bias is all a result of our experience and our exposure. And the great thing is we can retrain our experiences and exposures time and time again. So if disability is not a part of your knowledge base or lived experience, then go read a book or listen to a podcast that features a person with a disability. Watch dramatized shows that accurately, authentically and affirmingly portray disability. And learn through consuming media that is created by or appropriately represents people with disabilities in a variety of environments and settings, including the workforce.

And then finally, lead where you're at. So often we want to make the big, grand gesture, and we don't know how, or we don't have the opportunity. As a baseball fan, my Cleveland team went out, but I love to talk about baseball. And so the analogy I use is don't swing from the fences when a single will do to get the runner in from third. So put another way, I had a leader who used to talk about tiny noticeable things, or TNT, just like a stick of dynamite, it's small, but it has a big impact. And collectively, if we all do little things, incrementally they'll add up to one big collective impact. And so lead where you're at. Take the opportunity to learn and listen wherever and however you can.

Mindy Henderson: Well, that's about the best note I can think of to end things on. Russell, thank you so much for your time and for sharing your wisdom and your experience with us. We're going to put all of your information in the show notes so that people can connect with you and keep an eye on Disability:IN, and potentially participate in some of your programs. Thank you for being here with me today.

Russell Shaffer: Thank you so much for having me, Mindy. I look forward to seeing you at our Disability:IN conference, your second one, in Dallas next July. And anyone, everyone, come one, come all, we'd love to have 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. If you enjoyed this episode, we'd be grateful if you'd leave a review, go ahead and hit that subscribe button so we can keep bringing you great content, and maybe share it with a friend or two. Thanks everyone. Until next time, go be the light we all need in this world.