



Episode 33: Wheelchair Barbie Talks Advocacy & Inclusion

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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.

Today's guest is so impressive, and as someone who I am proud to call a friend. Madison Lawson is a journalist, model, and disability rights activist. Her written works have been featured in publications including Vogue, Glamor, Teen Vogue, Allure, and more. Not too shabby.

Lawson's advocacy work has gotten her featured in campaigns with brands like Sephora, Pretty Little Thing, and Olay, just a couple little brands you may have heard of.

Her greatest inspiration is the work and legacy of her late friend and the mother of the disability rights movement, Judy Heumann, who laid the groundwork for disabled people around the world to be better integrated into society.

Madison hopes to give representation to her younger self who never saw people who looked like her shown in a positive light in media; and to be one of the many voices pushing the needle of inclusion forward for people with disabilities.

I mean, Madison, I don't know that we need to say a whole lot more other than that. You're amazing.

Madison Lawson: Oh. Thanks, Mindy.

Mindy Henderson: I'm so excited to have you here. Thanks for joining me.

Madison Lawson: Thank you for having me. I'm so excited. I love your podcast. I love everything [inaudible 00:02:14]. Your work is so important. And I am also just so very honored to get to call you a friend. So, thank you.

Mindy Henderson: Thank you so much. So, I want to start just with some basics. We learned a lot about you in that intro that I just read. Of course, the podcast's primary audience is the neuromuscular disability community.

So, I'd like to paint a little bit of a picture for people who may be listening and hearing about all of these magnificent things that you've done. And also, to better understand just how your neuromuscular disease manifests and how it affects you and impacts you in your daily life. Do you mind talking a little bit about that first?

Madison Lawson: Yes, for sure. So, my journey with getting diagnosed and all of that has been complicated as it is for a lot of people with neuromuscular diseases. I have, well, what they're calling it right now is Ullrich congenital muscular dystrophy.

Genetically it presents that way, but I also have some traits that make it similar to spinal muscular atrophy. And spinal muscular atrophy was my original diagnosis. They thought I had what's called non-chromosome 5q SMA, which means my SMN gene wasn't affected, but my nerve conduction test is identical to that of somebody with SMA. And nerves aren't typically as affected with Ullrich congenital muscular dystrophy.

So yeah, it's a little weird. They're calling it Ullrich's right now, but it could be my own kind of form, and diagnosis isn't always super cut and dry. There's so many different forms of MD and it manifests in so many different ways.

For me, I started showing signs pretty quickly after I was born. I was always kind of low muscle tone. I walked later than most kids do. I was able to walk until I was about eight years old, but I never walked the way that a non-disabled person walks. I walked anguine.

Mindy Henderson: Aw. Adorable.

Madison Lawson: But I was born with hip dysplasia, and they thought that's what was causing all my issues. But it turns out people with my disease typically are with Ullrich's, that's very common. But also, it's common with SMA to have-

Mindy Henderson: Yeah.

Madison Lawson: Yeah. After they did a couple surgeries, I wasn't healing properly, and walking was always very difficult until it was impossible. And so, I've been in a wheelchair since I was about eight.

My life has been painted from a seated position, and clearly that's the way that it was supposed to be. And I feel very lucky to get to look at life through a lens that not everybody gets the chance to look through.

I've found so much power in my community. I feel so lucky to be a part of a community that I get to learn and grow from every single day and get to meet people like you.

Mindy Henderson: Aw. I could listen to you talk all day. I love the lens that you look at things through and your positive attitude and it's not something that comes naturally for a lot of us.

So, I guess to that end, has this always been sort of your natural attitude about things or did it take some work and some intention to get to be this way?

Madison Lawson: I think that self-love is a journey for everybody, and it's not always linear. In fact, most of the time it isn't. So, I definitely have days where positivity isn't at the forefront, and that's fine. A part of life is feeling those big feelings, the highs, the lows.

I think when you have a neuromuscular disease, you kind of have to find the light and you have to find the things in life that are important to you quickly and go after that with everything. Because in my opinion, I'm just kind of like, what do I have to lose?

So yeah, I mean, I definitely don't... I'm not always positive. I'm not always happy and joyful, but I try to find the good in everything, and I try to find the things that I was put on this earth to do and focus on those things; and not as much on the things that maybe I wish I could do or may be [inaudible 00:06:38].

Mindy Henderson: Yeah.

Madison Lawson: Sometimes in life, we have situations or things happen to us that we never would've chosen for ourselves if it was up to us. But everything points you into the direction of growing into the person you were supposed to be.

And for me, being disabled is something that I would be an entirely different person without, and I really like the person that I've become, because I fought to become her.

Mindy Henderson: Yeah. You give me goosebumps. I love it. So well said. Well, you are, as a lot of people who are listening probably know, you're widely known as Wheelchair Barbie on social media. Tell us how that came about and just sort of what that name means for you, what it symbolizes. Where did all that come from?

Madison Lawson: So, when I was in middle school, I was shopping one day and this old woman at Macy's came up to me and said, "Oh my gosh, you look like a little Barbie in your wheelchair." I loved that. I thought that was so cute. And I was like, "Hmm, I should roll with that."

Mindy Henderson: There's something there of that.

Madison Lawson: And so, I made that my handle. Social media is so powerful in the way that it's really the only thing where you can kind of control the way that you're looked at.

Mindy Henderson: Oh, that's interesting.

Madison Lawson: I feel like when you're disabled, you don't have a lot of autonomy on the way that you're viewed. People will just come up as you know and ask the most out-of-pocket questions or have the most wild assumptions about what your life looks like, without even having a clue of what that genuinely looks like.

And it's not their fault. The media hasn't always portrayed us in a light that is positive. I feel like for so long, the only way that you saw disabled people is through this lens of inspiration porn.

Mindy Henderson: Yeah.

Madison Lawson: And so, people like us, that's our purpose, to inspire them or make them feel better about their lives. Social media was a tool I used to actually not just be looked at, but to be seen. I would share little anecdotes and stories about things that I'd been through or funny things that people would say, funny things that I would think.

Then I got really tired of comments like, "You are pretty for a girl in a wheelchair." "You're really funny for a person in a wheelchair." And I just didn't want the ables to infiltrate the way that I looked at myself.

So, I created a page that was for disabled people because I just thought about little me. And I was like, "What did I need to see? What would it have meant a lot to me to watch somebody that looked like me say or to," you know.

So, I wanted to be authentic and I wanted to show my experiences and share that with somebody that might be going through a similar thing. So, I feel like when you have a neuromuscular disease, there are a lot of us, but we're kind of spread

out. And so, things can feel isolated, especially when you're young and when you don't see people that look like you every day. So, I want that to be a tool where I could bring people together and connect and find community.

I've been so fortunate to be able to do so, and I've met so many people that I never would've met without social media, people like you. And to make the most meaningful connections in life.

I feel like disability is something that does bring people together and it's such a niche experience. But it's such a big minority, and you don't realize how many people it affects, because it can feel so isolating when you're just in your own world by yourself.

But once you share those experiences and people relate to it, it's such a different connection when you find somebody that not only feels empathy for what you're going through, but who's like, "Me, too. I understand what you feel." And that just means so much.

Mindy Henderson: That's amazing. So how old were you when you got on social media and created Wheelchair Barbie and started putting the messages out there that you're putting?

Because when I was... I'm a little bit older than you. And when I was the age that I'm thinking you might've been when you started, I wasn't nearly that self-aware, to be able to identify this idea of the world and what they see me as, and what I really am and all of those things. It took me a little bit longer to get in touch with those kinds of things. So, were you really young?

Madison Lawson: I was in middle school. I was in seventh or eighth grade when I started sharing my journey on social media. And middle school is that awkward phase that everybody is awkward and weird and just feel so lonely no matter if you're disabled or not.

I remember for the longest time just wanting to fit in so badly and wanting to just blend in with everybody, and realizing at that time, I never really would.

Mindy Henderson: Uh-huh.

Madison Lawson: During that time, that was really empowering for me because that was a time that I started seeing other people on social media that looked like me, that would be able to connect in ways that people would say things that were just outrageous. Like, "You're so funny for somebody that's disabled," and things like that. I felt like, "Okay, they're trying to be nice to me, but why do I hate it?"

Mindy Henderson: Right.

Madison Lawson: I just kind of decided that it didn't really matter what I said or did. Those people were always going to feel that way or they would have those views of disabled people. And so I just decided all I can do is share my truth and show that the way they perceive disability is nothing like it is.

Mindy Henderson: Yeah. I love it.

Madison Lawson: So, I just decided I want to create content that is solely for disabled people. And if able-bodied people see it and they learn something or it changes their perspective, cool. But I create content for our community to feel heard and understood. And I just always want to be there for all the little disabled people out there that are feeling lonely. I remember exactly what that felt like. And that's my heart and soul.

Mindy Henderson: That's beautiful. And again, so well said. And I'm thinking about myself when I was in middle school. And not only was I not self-aware enough to be able to go on a crusade like you are on, to change people's minds about things. But I think about on top of that, what it would've meant for me to have someone like you to look up to.

That was definitely something that was missing from my life, so much so that I almost kind of went in the opposite direction that you went. Instead of setting an example and speaking out about things, it's hard for me to explain this, and it's going to sound really weird when I say this. But I almost tried to hide the fact that I have a disability. And that's a really hard thing to do when you live your life from a wheelchair.

You can't hide a wheelchair, of course. But I tried to blend and be as much of a chameleon as I possibly could when I was that age because I so desperately wanted to fit in, and to look like everybody else and be like everybody else, because I didn't have the examples of people who looked like me to know that that was actually okay. And it could be pretty great.

Madison Lawson: And I feel like, I mean, we have a little bit of an age difference, but I feel privileged to be in the generation that I'm in.

Mindy Henderson: True.

Madison Lawson: Because I feel like for a long time, we didn't have any media perception of us that was accurate. In a way, it felt like, "Are we ever going to see that?"

Mindy Henderson: Yeah.

Madison Lawson: And me as a kid, I didn't know if we were going to see that. And I remember feeling so invisible, but it was weird. It's not that people don't see me. People are constantly looking at me, but nobody sees me.

Mindy Henderson: Right.

Madison Lawson: And it just felt so [inaudible 00:15:49]. I felt very privileged to, I had a couple examples of some little crumbs of representation. I mean, once we started seeing people in film and things like that. A lot of times they weren't actually played by a disabled person, but it still was crumb of like, yeah, "Oh, there is some tiny representation." I feel like for you, a lot of your life, that was never, ever a thing.

Mindy Henderson: It wasn't.

Madison Lawson: And I just feel like, I don't know. That's why I feel so empowered by people like Judy and all the people that worked so hard to start rights for us, when for so long, so many people were told no.

So, I try to track my privilege in that way because that's something that the generation before me, they had nothing. They didn't have any representation. They had to fight for every single little right that I was born with.

So yeah, I definitely, I feel like if you were born to my generation, you would've been very similar to me.

Mindy Henderson: I would love to believe that. I hope that that's true because I can't think of a better role model. And you mentioned Judy Heumann, and we mentioned her in the intro for you.

I actually had the absolute privilege to have her on this podcast about a year before she passed. And what an amazing person. I mean, I know that you think very highly of her and the roads that she paved for us were absolutely incredible.

I can't imagine that there will ever be anyone like her again. She was just fearless and had a way of speaking to people that you couldn't help but listen. She was incredible.

Madison Lawson: She really was. And she was so intentional.

Mindy Henderson: Uh-huh.

Madison Lawson: She just made space for every single person, no matter what. How to meet you on your level. And she didn't just meet people, she genuinely wanted to help every person that she met. And I don't know that we'll ever have another Judy.

Mindy Henderson: I know. I know. She had such a servant's heart and yeah. So, from Judy Heumann to the Barbie movie. Let's switch gears and talk about that a little bit.

I saw the Barbie movie a little while ago, a couple of weeks ago, and it was so different than what I was expecting. I'm laughing about it just a little bit, but it's actually, it's one of the smartest movies and one of the most empowering movies for women in particular that I've ever seen.

I mean, the monologue that America gave towards end of the movie, my jaw dropped, and I couldn't believe what I was hearing. It was so amazing.

I set out initially, and I hope that this doesn't come out the wrong way, but I really wasn't interested in seeing it because I'm a grown woman, I'm not into Barbies anymore, and I thought it was going to be a kid's movie. And then I started to hear rumblings that it was actually a lot more than a Barbie movie, and

it so was. It was just this girl power to the extreme. And there was a Barbie in the movie who used a wheelchair.

What impact, if any, do you think the Barbie movie will have on the broader topic of disability representation in the media?

Madison Lawson: I felt like disability was something that this time wasn't as much of an afterthought, which is really... I mean, I know when it comes to representation for us, the bar is kind of in hell, so we're [inaudible 00:20:12] thing.

But I really felt happy to see not just, there was a Barbie that had a prosthetic limb, there was other disabilities represented in it. And it was just to even be on screen in that way in Barbie Land.

Mindy Henderson: Yeah.

Madison Lawson: It's like, okay, even just 20 years ago, there wasn't a wheelchair Barbie.

Mindy Henderson: No.

Madison Lawson: That is major. That's a big deal. And I felt so joyful because even as a grown 26-year-old woman, when I go in the Barbie aisle, on my wall behind me, I have six Wheelchair Barbies on my wall.

Mindy Henderson: I love it.

Madison Lawson: The original Becky that was just made for people with disabilities, the Becky school photographer, all the way up to the modern Wheelchair Barbie. And how a lot of people don't even know the original story of Becky or that she even existed.

Because in 1997, there was a young woman, I'm going to say her name wrong, it's Kirsten. I don't know how to say her last name, but she was playing with her Wheelchair Barbie and realized that the wheelchair did not fit in an elevator. And wrote Mattel, "Hey, can we modify the elevator so that my Becky can fit in there?"

Well, instead of fixing the elevator, they just discontinued Becky.

Mindy Henderson: Oh my gosh.

Madison Lawson: That's so parallel to the way that [inaudible 00:21:43] treated in society. When I look at Wheelchair Barbie, knowing the backstory, knowing everything, I relate to her so much because I feel like she fought to be represented.

And although we never saw a resurgence of Becky, we did see Wheelchair Barbie, and this time it was Barbie in a wheelchair. So that is really cool to see that.

When I was a kid, when the original Wheelchair Barbie came out, people didn't, I guess that society wasn't ready to see Barbie in a disabled woman's image.

Mindy Henderson: Yeah.

Madison Lawson: And as terrible as that is, that's where they were at that time, unfortunately. But to know we are seeing strides in that way; and to know that little girls can go down that Barbie aisle and feel that excitement that I feel even still as a grown woman to see that. That just fills me with so much joy.

And yeah, I feel like the Barbie movie was such a powerful representation of womanhood in general. And so many [inaudible 00:22:53] in that film and just what it feels like to be a woman and navigate all the barriers, and then add the barriers of disability on top of that. There's just so much.

I would've loved to see Becky in the film. They were going around with Midge and Allan and telling their stories, and I loved that they kind of got to roast Mattel a little bit.

Mindy Henderson: Yeah.

Madison Lawson: I would've loved to see Becky roast Mattel a little bit. I think that her time is coming.

Mindy Henderson: If there's a sequel.

Madison Lawson: And her story is... Yeah, yeah.

Mindy Henderson: Yeah. But you're right. I don't think her story is finished being told. And I hope that Mattel is listening right now and that they will bring Becky back, bigger and better than she ever was with a wheelchair that fits the elevator.

And the Barbie movie really sends a message of empowerment to people to embrace who they are, instead of feeling pressured to conform to what society wants you to be. The theme throughout the movie is this idea that everyone thought that Barbie was just something pretty to look at, but in actuality, there were like 50 Barbies in this movie. And Barbie is an astronaut, Barbie is a CEO, Barbie is Black, White, disabled. Everything that you can possibly imagine. And like we've been saying, this is such an important message in the disability community.

What are your thoughts on stepping out and really being your own person? How can we all sort of rally and fight against falling subject to who society really says that we should be?

Madison Lawson: I've heard a lot of this conversation surrounding the Barbie movie in terms of as kids, we kind of have all these hobbies and things. But then when it comes to turning into a woman and growing up, women are kind of expected to forget about their hobbies and focus on the way that men perceive us.

I thought it was how even in a world where women are in power and they're kind of highlighted, it's not a patriarchy, men still were not harmed.

Mindy Henderson: Right.

Madison Lawson: Spoiler alert. When Ken was leading Barbie World, he was obsessed with the patriarchy. And women were kind of objectified even in Barbie Land, and women were made to see, "Okay, how can you serve men?"

I think the biggest thing we can do as women is really just support each other in our hobbies and in the things that bring joy to us. And focusing on we all experience the hardships of womanhood and what that's like to navigate how you feel about yourself and how society perceives you. It's hard. It's very hard.

So, the best thing we can do is just uplift each other, be a girl's girl, be there for your fellow sisters and their struggles. And focusing on being a supporter and not a competitor is the best thing we can do as women. And I think, yeah, just especially as disabled women, there's so many layers and so many layers that not every other woman experiences.

And so just recognizing that and being there to support other women that look like you. And even, yeah. That's the biggest thing. We just got to, I think, embrace our hobbies. Embrace the things that bring light to your soul.

I don't believe that people are drawn to things by accident. Just running with what sets your soul on fire and going after with everything in your heart and supporting other people and their pursuit of their happiness as well.

Mindy Henderson: I love that you came at the answer to that question from the perspective of not just embracing who you are but encouraging and supporting each other. And I think that because as we're growing up, as we're becoming women, maybe not every single one of us, but a lot of us really, really seek approval from one another. And to not get that approval, to not get that support, or heaven forbid, to be told that you are wrong or something about you is wrong or something that you like or are wearing or whatever is wrong, it's so damaging.

So, I love your answer for that reason. I think that in today's day and age, we are fortunate because there is a conversation that's happening, and we have made progress thanks to Judy Heumann and so many other people. We've made progress for the disabled community, and we're going to continue to make progress.

There's still work to do, of course, but that one of the most important things that we can do apart from using our own voices and speaking out against the things that we think are wrong in the world for people with disabilities, I think next in line, the next most important thing is supporting each other and loving our differences and accepting our differences and letting them be okay.

Madison Lawson: Yeah. If you are a person in the world that loves yourself, that's a radical act of rebellion there.

Mindy Henderson: Ooh.

Madison Lawson: The world wants you so badly to hate yourself, wants you to need other things, want you to seek approval from people.

And so, you deeply loving yourself, I feel like that's the only way to break this cycle. And it's hard, like we talked about here. And it's a journey and some days are better than others.

I thinking recognizing that that's a journey we're all on, and being there for each other to help people navigate that, I think that's the best thing we can do in life is just uplift each other. We rise by lifting others. And in our case, a lot of times that can be literal.

Mindy Henderson: Right. It's true.

Madison Lawson: Yeah, in life we should always strive to help other people become the best version of their selves. We're all just trying to figure it out.

Mindy Henderson: Yeah. Amazing. Amazing. I want to move us along to some other topics. But before we leave this topic, you went to the Barbie movie premiere, which is super cool.

Did they just find Wheelchair Barbie on social media and be like, "Exactly, we're inviting her." Or how did that invitation come about? Did you meet Ryan Gosling and did you give him my phone number? Those are my final Barbie movie questions.

Madison Lawson: So there is a coalition called 1IN4, and they focus on encouraging every part of Hollywood to be more inclusive of people with disabilities. So, you guys should all follow 1IN4 on Instagram. They're incredible. The work they're doing is so important.

It's led by a lot of people that have disabilities themselves, which is the most important thing in terms of representation. And that needle forward is actually allowing us to lead.

And this amazing girl named Caitlyn reached out and was like, "Hey, we can't have this Barbie premiere without the Wheelchair Barbie. You're the one that came to our mind first when we were asked to find people to come." So that just meant the world to me.

Mindy Henderson: Wow.

Madison Lawson: Sometimes when you're posting on socials, it can feel like screaming into a void. And [inaudible 00:31:29] on the other end, that are right there with me supporting me in my journey. And especially people that look like me, and that means everything.

Mindy Henderson: Yeah.

Madison Lawson: So yeah, it was an honor to even be invited. And the whole time I was like, "Is this a scam? Is this real?" Even leading up to it, I was thinking, "What if I came all the way out here and it's not even real?"

Mindy Henderson: I probably would've thought the same thing. "Is this real though?"

Madison Lawson: Yeah. And then I didn't get to meet Ryan Gosling, unfortunately. He was on the stage. I never saw him up close. But Margo Robbie walked past me, and it was weird seeing her as a human. I don't know, goddess being in my head. And so, I was like, "Wait, she's just a person? What?"

Mindy Henderson: Yeah.

Madison Lawson: So that was cool. I didn't get to say anything because she was surrounded by bodyguards. But yeah, that was cool. And Kate McKinnon walked past me as well.

Mindy Henderson: Oh and love her.

Madison Lawson: She's so tiny.

Mindy Henderson: Oh my God, really? Oh my gosh.

Madison Lawson: Yeah.

Mindy Henderson: That's so funny.

Madison Lawson: That was really cool. And I am sorry I failed you as a friend.

Mindy Henderson: I was wondering why he had not called yet, so I'm glad to hear that it was not an actual snub.

Okay, well, let's move on. I want to talk about, you've got so much cool stuff going on. And I know that you have an Education Policy Fellowship with New America.

Can you talk a little bit about New America for anyone who may not be familiar with them and what this fellowship is and what you're doing with them?

Madison Lawson: So New America is a think tank located in DC. They deal with all kinds of different policy. My specific area that I'm working in is education policy and specifically disability education policy.

I'm working on a blog series about navigating the special education system, incorporating voices all throughout. So that's students, parents, teachers, what that system looks like, the complexities within it, the flaws within it. And it's actually been a really interesting experience. It almost feels like therapy in a way.

Mindy Henderson: Yeah, I bet.

Madison Lawson: I'm looking at the elements of the special education system that I was too young to remember exactly how that got started. And in some ways, it's great because I am getting to learn all these new things. But in some ways, it makes me sad because I realized there's so many people that don't ever get access to things that they needed.

It's because of how intentionally complex those policies are written. The only people that have access to them are the ones that know how to navigate it. And it's really complex.

So, you add barriers, like language barriers, or even if people's parents are uncomfortable with disability identity, that kind of can prolong people's struggles because they don't want to identify their kid that way. And then the kid looks at disability as something bad and something they shouldn't want.

And so yeah, it's been kind of a roller coaster of emotions because it's like seeing exactly where that internalized ableism stems from. And I think in general, society kind of has this negative view of disability. And if anyone doesn't believe that, just ask somebody to say the word disabled. There's just an inherent discomfort in saying it in that way.

For a lot of us that have grown up with disability, it's never been something we've thought of as being negative. Or it's never been something that... Inherently disability isn't a bad thing. It's just the way that society connotes that word that makes it feel like a bad thing.

So, it makes me sad that I'm going to have to unlearn so many things that I see exactly where that comes from. And I see it's a lot of deconstructing. And I remember going through that myself, and I remember not wanting anything to do with disability as a little kid.

And then once I did embrace it, and once I did find that community, that was when I found my power. That was when I came to light with who I am. And I didn't care anymore about how non-disabled people perceived me because I thought, "Oh, I can change it. One day they're going to respect me. One day they're not going to feel this way about me."

No matter what you do, you can't really control how other people feel about you. All you can do is control the way that you feel about yourself.

Mindy Henderson: Yes.

Madison Lawson: The best way to feel empowered is by surrounding yourself with people that look like you and that are dealing with those same barriers. There's something so refreshing about disability humor, and maybe I'm a little [inaudible 00:36:48].

Mindy Henderson: Oh, I am too. Yeah, I poke fun at myself all the time.

Madison Lawson: I mean, disability humor is peak humor. Nobody's funnier than us.

Mindy Henderson: It's true. I feel that. Yeah.

Madison Lawson: And that's just what I want for everybody. My biggest advice to parents when they have a kid that gets diagnosed or when they find out their kid has some type of a disability is just let them find their community. Let them be embraced by it, because we are waiting to love them. We are waiting.

We're a big, huge powerhouse and we know how it feels to be rejected for being who we are, and we never want anyone else to feel that way. So just letting your kids be loved by the community, that will give them life.

Mindy Henderson: So true. I love it. I love it. And you're so right. We're here with open arms.

One of the really beautiful things about this community is that so many of us have had to work so hard. I am using kind of air quotes, "to measure up." And we feel like we've had to work harder, do more, be better and all of these things. When in fact, we were all of those things anyway, we were fantastic. We just didn't realize it.

Now that we're making progress, and there are so many people in this community, I mean, so many people who are insanely successful and powerful like you said and have really figured some things out and can show other people, other up and comers the way. I think it's a great thing.

Madison Lawson: When you see people that look like you succeeding, [inaudible 00:38:50] don't think you can succeed without that. But it just makes it easier to picture yourself succeeding. And you're like, "Okay, well, somebody's done this before. I'm not paving the way."

A lot of times disability can feel like such an individual journey, and in a lot of ways it is. But there's ways once you see someone that looks like you doing what you want to be doing, it's like, "I don't have to reinvent the wheel. I can [inaudible 00:39:15] the wheel."

Mindy Henderson: Yeah, exactly. And that's a lot of what we try to do at Quest Media. We try to really spotlight a lot of the people in our community who have figured it out, who have overcome the barriers and the obstacles and things. And we try to put examples in front of the young people in our community so that they can see all of these amazing examples of people who've done what they would like to do, but maybe don't believe that they can yet.

So, the fellowship, the blog series that you talked about with New America, I'm very excited. I can't wait to read it. Can you tell us anything about when it will be available to read or where people can read it?

Madison Lawson: Yeah. So New America's website. One of them is already published.

Mindy Henderson: Oh, [inaudible 00:40:07].

Madison Lawson: Yeah, I'm just still in the process of putting them together. And as soon as they're ready, they'll be uploaded every couple of weeks. So yeah, it'll be on New America's website.

Mindy Henderson: Oh, fantastic. That's really great. So, I am going to switch gears again, and I want to talk to you a little bit about Hill Day with the MDA advocacy team.

That's where you and I met in person for the first time. I had followed you for a long time and I was so excited to get to meet you there. But we were all there, us, and I don't even know how many other advocates, a number of other...

Madison Lawson: I think 31 of us?

Mindy Henderson: Yeah, you're about right. Yeah. We were there to talk to legislators about the FAA reauthorization and getting accessibility language written in for people with disabilities. What was your impression of that day? And do you feel like you accomplished what you were there to do?

Madison Lawson: I feel like that day was such a rollercoaster of emotion that [inaudible 00:41:13] about how some of it was unexpected. And I don't know. I feel like air travel is something that we've encountered so many obstacles dealing with, and we've talked about it openly and publicly.

It felt different though, being in the presence of the people that can actually make a difference. Kind of realizing that we in that moment have to make them care. And if they don't, nothing changes.

Mindy Henderson: Right.

Madison Lawson: The gravity of the situation just felt very intense in that. And every minority can relate to that in terms of having to make people care so that you can have the same rights that everybody else is already given. That's just kind of a minority experience in general.

But I remember being lost in my emotions a little bit and surprised, because it takes a lot to make me cry. And I cried in my meetings, and I was a little bit... Not that I didn't know that it made me upset. Obviously, I'm very passionate and upset. But it was just, I didn't expect to react in that way. And it made it even more intense. I definitely just felt like I don't know what's going to make them care if they don't care about it after hearing our stories.

I don't think I will feel fulfilled until it's passed. So, I felt grateful to be there amongst... So many people could have been there in my place. I didn't go there saying anything that other people haven't experienced. So, I definitely felt privileged to get to share my story and to be there with a functional wheelchair.

Mindy Henderson: Yeah.

Madison Lawson: So, I was trying in the moment to be positive and count my blessings. But also just, this has to get passed because if it doesn't, we're going to have to wait another five years before we can do anything about it.

Mindy Henderson: Right.

Madison Lawson: I felt like I gave it everything that I could, but we'll find out in September if it was enough.

Mindy Henderson: Yeah, no. Well, and I've seen clips of you in your meetings talking to people, and I think that you were very effective. So, I don't want you to sell yourself short at all.

You also made an incredible video that I want to talk about in a second, but that you're right. And I cried too in my meetings. And it surprised me just like it surprised you. It kind of crept up on me.

But my situation, I hadn't flown in 14 years before I went to do that Hill Day to go talk to lawmakers. And the whole experience start to finish, getting to Washington, DC for that event was humiliating. That's the word that I keep coming back to. And I sat in their office trying to, like you said, trying to make them care that I had been utterly humiliated the day before. And all of the emotion that came out.

I was looking at them thinking to myself, "I can say these words, but do you care?" And it was just the gravity, like you said, of the moment and the frustration of having just lived the experience and then sitting in their office and wondering if it even mattered to them.

It was a lot. But that my own personal assessment is that you and I cared a lot about what we were there to do, and we took the responsibility very seriously. And hopefully they felt that from us.

Madison Lawson: I have a lot of time to sit and think, so I analyze everything. But I felt so empowered. In that experience, what made me the most empowered was honestly the first night when we were all together.

Mindy Henderson: Oh, I know.

Madison Lawson: And just how... I don't know if it was like a trauma bond or what, but we all just shared our stories organically. But it was in a way that it wasn't... We didn't even have to fully explain it to be understood.

Usually when we're talking about these things to the general public or to non-disabled people, they're like, "Oh my gosh, that's ridiculous." But to be in a room full of people where you can joke about it, and they get it, and they actually know it.

And that was just, I could have stayed in that room with you guys all night long. We stayed till... We had to get up so early the next day.

Mindy Henderson: I know.

Madison Lawson: We were dying laughing. Wasn't it like one by the time we got out of there?

Mindy Henderson: Well, I'm not going to lie. I actually did leave earlier than most. And I went up and went to sleep because I'm not as young and fresh as the rest of you. I have to work a little harder for my beauty sleep.

Madison Lawson: I should have done that. I was five minutes late to breakfast because I [inaudible 00:46:58]. So, I told myself, "No matter what happens tomorrow, I'm here for these people and it's worth it." Even just that night, just getting to bond with everybody.

Mindy Henderson: Oh, I know. It was such an amazing experience to all be there for a common reason that we all live and know and understand. You don't get that every day. It was absolutely amazing.

We're running out of time, so let's talk about the video that I alluded to a minute ago. You and I had similar experiences. We had cameras go with us to Washington, DC to actually show people what the process is like and what we have to navigate and put up with when we are going to fly on a plane as wheelchair users.

My video has not been released yet. It's going to be out in September. Your video was released. It is one of the most powerful things I have ever seen in my life to speak to an issue like this. And it's had over a million views.

Tell me just what the experience of filming the video and people's reaction to it, if there has been one, where people have said things to you personally. Talk a little bit about the video for me.

Madison Lawson: So, Ryan did an incredible job. He was so fun to work with.

Mindy Henderson: He was amazing.

Madison Lawson: He was down for anything. Up so early when we went to the airport. And it's horrible to say this, but I was actually very glad that everything that could have gone wrong was going wrong.

Mindy Henderson: Yes.

Madison Lawson: Because I mean, if you're going to show that, that's honestly the most powerful thing. I was like, "Watch nothing happen. Watch everything..."

Mindy Henderson: Right, exactly. It's like taking your car to the mechanic. It doesn't make the noise for the mechanic.

Madison Lawson: It was like every little thing that could go wrong was going wrong. And I was just kind of like [inaudible 00:49:10] to say, but no. You're like, "See? I'm telling the truth." It's the only way for people to understand is if they see it. Because any normal person that watches somebody deal with this will be horrified.

The normal reaction to something like that is, "That's ridiculous." That is absolutely inhumane the way that we are dealt with and treated. And anybody would be disgusted by that experience.

Mindy Henderson: Yeah.

Madison Lawson: And so, I felt very grateful to have Ryan there. And I heard screaming while they were loading my chair. I couldn't see what was going on, but luckily Ryan could film it.

Mindy Henderson: Oh my gosh.

Madison Lawson: As I'm getting manhandled onto this flight, I always stay very positive and kind to everybody doing all the work.

Mindy Henderson: Exactly.

Madison Lawson: Because I understand that it's not just miserable for me. It is miserable for every single person involved.

Mindy Henderson: Yes.

Madison Lawson: And I feel for them just as much as I feel for myself in that moment. And I know everybody's doing their best. So, I stay making jokes while I'm getting loaded. When they put me in the aisle chair, I was like, "Have you guys ever seen Silence of the Lambs?"

Mindy Henderson: Yeah.

Madison Lawson: Clarice in the chair [inaudible 00:50:40]. That's literally how it feels to be transported and strapped into this little chair. And it is genuinely horrifying to deal with every time. And I have to emotionally just kind of turn off my feelings and get from point A to point B and then have my breakdown later. Have my moment of being upset once it's over with. Because if I break down in the moment, I just can't.

Mindy Henderson: Right.

Madison Lawson: I understand your position of not wanting to fly. That's a hundred percent valid and a hundred percent I get where that comes from because yeah, it is horrifying. And I'm lucky to still be young and feel invincible and doing things.

Mindy Henderson: Yeah.

Madison Lawson: Even now, the last time I flew, I went to California for the Barbie premiere. And when I was flying home, they didn't switch me from the Nile chair into a regular chair, and I had a connecting flight, and they were taking too long because nobody was bringing the transport chair. So, they transported me in a Nile chair, which is illegal. I ended up being in that for so long, then I got a bedsore. And so, it's just so frustrating and dangerous.

The feedback that I got from the video though was overwhelmingly what I wanted. It was [inaudible 00:52:02] positive. Everybody in the comments was mostly talking about solutions that they thought of. They're like, "Why don't they just do this? Why don't they just..."

Mindy Henderson: Right.

Madison Lawson: And it was people that had never thought about it before that were starting to [inaudible 00:52:15] things. And that was the overall goal, I think, just to get those conversations circulating.

There were some trolls in the comments that are like, "Well, disabled people just shouldn't fly." Or "Disabled people just shouldn't..."

Mindy Henderson: Oh, wow. Hope you never break your leg.

Madison Lawson: Yeah, well, exactly. And that's when I just feel sad for those people because-

Mindy Henderson: Yeah.

Madison Lawson: And imagine feeling that you don't deserve rights if you don't meet a certain criteria. And I hope that if those people ever become disabled, that nobody ever treats them the way that they decided we should be treated.

But I feel like if they do, they'll quickly learn.

Mindy Henderson: Yeah. And as I've heard you say, "It's a club that anyone can join any day of the week."

Madison Lawson: No one's exempt.

Mindy Henderson: Yeah. Exactly.

Madison Lawson: You have no matter what race you are, no matter... We are the minority that encompasses all the others, so is actually excluding everybody.

And also, do you think that elderly people just shouldn't be able to participate in society? Or if it's not you, it's very likely to be one of your loved ones.

Judy always used to say that people are temporarily non-disabled. And I think that's so true. Even if you're only disabled for a portion of time, nobody's exempt

from experiencing it or having a loved one experience it. And you're highly likely to experience it in one way or another.

Mindy Henderson: Absolutely. It's in all of our best interests to fix these problems. It really, really is. And so, I'm glad though that the vast majority, it sounds like, of the comments and the responses were constructive and compassionate. So, I am glad to hear that.

But the name of the game is awareness. And I don't want to put words in your mouth, but that's why you and I both agreed to put we out there on display and show what actually happens. Because it wasn't fun for me. I suspect it wasn't terribly fun for you either.

Madison Lawson: Ryan even said while he was filming, he was like, "Maddie, if there's anything that is too [inaudible 00:54:33] or too much, you just tell me not to film it. I'll take it out."

Mindy Henderson: Yeah. He said the same to me.

Madison Lawson: And I told him, "Film everything."

Mindy Henderson: Yeah.

Madison Lawson: I said, "Because if we don't film it, we still have to go through it and it's already humiliating enough. So, I want them to see how humiliating this is."

Mindy Henderson: Yeah, that's true.

Madison Lawson: So, he filmed everything, and he sent me the draft and was like, "Is this okay? Is there anything that is too much?" And I was laughing. I was like, "Well, dang, Ryan. You made me cry about my own [inaudible 00:55:11]."

Mindy Henderson: Yeah. Well, you know what was interesting is they sent me mine to look at, the first draft of it. And I watched it, and it actually made me nauseous to watch my own video.

I wanted to give constructive feedback about any changes that I wanted them to make. And I genuinely, it took me days before I could go back and make myself watch it again. And it was my own video. But it is, it's hard to watch. And it's the brutal truth of what actually happens. So yeah.

Madison Lawson: I mean, even there was a comment that I remember somebody was like, "Well, why do you pretend you can't hold your head up when you're in the seat, but then in your wheelchair you can?" And I'm like, "That's the whole point is now I'm holding my head up when I'm outside of my wheelchair."

Mindy Henderson: Exactly. Because you have a headrest, right? You've got features in your chair that take care of that for you.

Madison Lawson: Yeah. The chair is set up so that I can function. The plane seat is not. That is what happens to my body.

Mindy Henderson: Yeah.

Madison Lawson: The trigger.

Mindy Henderson: Oh, my goodness.

Madison Lawson: So funny. Because it was like, "They're so close to the point, but they're not quite right."

Mindy Henderson: Right. Just take one more step.

Madison Lawson: Yeah. And people that were saying it were nurses. I'd go on their account, and it would say, "Nurse." God. And I would say, "Eeeee."

Mindy Henderson: Yikes. Well, that's surprising. But like I said, I hope that it opens eyes to things and that everyone really rallies around this piece of legislation that is hopefully going to get voted on in September. So, fingers crossed, and we'll wait and see what happens.

We're going to put in the show notes, there's a link that anyone who's listening can go to. And we will make it very easy for you to reach out to your lawmakers and express your support for language in the FAA reauthorization for accessibility.

So, I am so, so sad because we are not just out of time. We are over time. But this happens every time you and I talk because you're amazing and I love talking to you.

But I just want to ask real quickly again, you do so many things. You're a writer, you're a model, you're a journalist. What's next for you? What else do you have going on that we may not have touched on, if anything, that you want to mention?

Madison Lawson: Well, I'm always working on projects. I am currently dabbling in a different thing than I've ever done before, and I'm really excited to explore it. It's in the avenue of writing and media in inclusion of disabled people.

Mindy Henderson: Well, that's a teaser if I ever heard one.

Madison Lawson: Yeah. That's all I can say without saying it. It's one thing I'll go after.

Mindy Henderson: Okay.

Madison Lawson: I can't talk about it. But there's just so many ways to get involved in the community and so many things that need to be done. And I just feel like our work is never done. That needle is always [inaudible 00:58:57].

So if you're listening and wondering how you can contribute, I think just doing what you are drawn to do and reaching out to your community and letting us love you and loving us. I think that is what you're meant to do.

And if you ever need anybody to talk to, if you ever need someone to help you navigate travel or flying, and if you need someone to yell at anybody for breaking your wheelchair, hit Me or Mindy up. I'm sure we would be both willing to do that.

Mindy Henderson: Totally. We've got you.

Madison Lawson: Yeah. We're ready for you and we're waiting with open arms. And Mindy, it's always such a privilege to talk to you. You're like my big sister. And I have somebody that understands everything and someone that is wiser and older than me that I can ask questions about literally anything.

I love you to pieces. You are such [inaudible 00:59:53] and I feel so honored too to be here with you.

Mindy Henderson: Oh, thank you. We're such a Hallmark card. I swear. Every time we talk, it's like, "I love you." "No, I love you more. I love you more." But thank you. That's incredibly nice of you to say. And I have so much respect for you and am just in awe of the person that you are. And again, I can't thank you enough for sharing your time with me today.

Madison Lawson: I love you, Mindy.

Mindy Henderson: I love you more.

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Thanks, everyone. Until next time, go be the light we all need in this world.