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S3 E5: Self-Advocacy with Lindsey Massengale, Ph.D.

Rebecca Hines

University of Central Florida, rebecca.hines@ucf.edu

Lisa Dieker

University of Central Florida, lisa.dieker@ucf.edu

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Transcript

Lisa Dieker

Welcome to Practical Access. I'm Lisa Dieker.

Rebecca Hines

And I'm Rebecca Hines. And Lisa, tell us a little bit about what to expect in this episode.

Lisa Dieker

So, we're really excited. We have a great guest with us today that can talk about a lot of topics. We have with us Doctor Lindsey Massengale, who is an instructor of virtual tutor, and we have to thank her for being a military spouse and thank her husband for a service to this county. Lindsay also was very open about having her own unique mobility talents in life, and she's going to highlight some of those for us. So, Becky, you want to start us off with a question? Welcome, Lindsay. We're glad you're here.

Rebecca Hines

Hi, Lindsey. So, I'm wondering, you know that I have a nephew with cerebral palsy, and he has significant mobility issues and lots of, you know, communications issues, et cetera. So as a family member you know, it's always interesting to me to hear the stories of others and kind of the kinds of considerations as you navigate, a world that wasn't necessarily designed for people with mobility differences, and I thought maybe you could share with us a little bit about what you've encountered along the way, both here in the United States. But I know you have an international background as well. Can you give us an idea of kind of navigating things in our society?

Lindsey Massengale

Well, first and foremost, with my experience, I navigate with my eyes before I really go to navigate and a lot of times I will go test out something before I actually have to engage in that area, whether I'm by myself or with a trusted friend or family member in case I run into uh-oh I need help. In the United States, it's pretty easy and I know how to use my voice to go hey this is a big access point for everyone, no matter your ability. Where else can somebody get in the building? For example, there was a handicap access to a university I taught at, but it was all the way on the side that I said. Yeah, I don't want to use that access because it's too far. So, I have learned to say, hey, I need to have access somewhere. Can you do one of the things growing up is, during fire drills, which is a huge thing for me. Not only do I not like the noise, where am I going? Let's practice without any sound now I'm fine with it being a teacher, you're just used to it, and the school actually had a code where they kind of come and nod and say and I'm like, why are you twitching? And then I realize she's nodding towards the alarm. So, I knew ok, it was going to go off. Prepare yourself so you can prepare your kids. But when I was in middle school, we realized that my exit for fire drills did not have a curb cut out for me to safely cross the street. It took the entire year, the entire year! For my family to get them to cut out a curb cut out so I could safely do fire drills with my class because the fire department said let a child walk by themselves to go find the curb cut out and then circle back and find their class. Not going to work. And then, but overseas, I've always had to have a buddy, either with me or meet me there. Now as a child overseas, I had a one-on-one aide that actually lived with us. Once I got into the school environment. I knew where I was, and I crawled

around before I learned how to walk. My teachers knew me, so I was pretty much ok, but she was there to help me navigate the halls and the stairways and everything like that because I couldn't do it independently. Now when I traveled for trips. I've had a buddy with me be or meet me there because I could navigate the airport with wheelchairs, but what do I do to get out into the parking lot and the language barrier, and I don't like it when somebody grabs when you're not falling.

It's just basically the language barrier, but really looking at how to get around and not only getting around, but it's also really understanding that there were third world countries see me as somebody who, why are you even out in society?

Rebecca Hines

So, there's a big difference just in in not only in the architecture and design for people with differences. There's difference internationally, but also just in terms of beliefs and understanding and inclusivity, I'm sure yeah. And so, you mentioned you know that you that idea of using your eyes first to really to come up literally with a plan for being mobile. And I think that's a great take away for teachers or parents that idea, you know the extra level of planning that that's needed and helping kids start to think about that.

Lindsey Massengale

That was not something that came up with just me, that was actually something I learned Becky in PT. They would set up different, let's just say obstacle courses because a lot of things are obstacle courses to me that you might think are a walk in the park and then they'd say ok before you move around. How are you going to navigate? Tell me what you're going to do before you do it.

Rebecca Hines

That's awesome.

Lisa Dieker

So, one of the things I know is you've had some unique as you said, being out in society, looked at a little differently. Do you have any unique stories because one of the things I know about you, you're a three-time UCF knight and we're very proud of that fact. Having got your doctorate here, you don't lack the ability to advocate. I would say that your parents created the lion for advocacy. Not only is that what you write about, and you do. But what are some examples of times that you had, or maybe a couple personal examples of where you really use your advocacy skills, or you really were perceived differently and kind of use that as an opportunity of learning for you.

Lindsey Massengale

Well, one of the things starting from the very, very beginning, before I even realized that I was different because I was not raised as a different individual as we were. I don't remember which trip to Russia it was. My dad was only supposed to be there for two years, but then they couldn't find anybody to replace him, so they asked him to stay for two more. And yeah, that was fun. And I was really young, we were there between my ages of four and eight. But we were going through airport security at the time. I've never heard of a wheelchair. They had a gigantic mesh stroller for me. Just think stroller but think huge and we are going through the security checkpoint and the security officers say wheelchair coming

through. I don't realize they're talking about me right away. So, they do their whole thing, we get to our gate, I say to mom, what is a wheelchair? It was at that moment that mom and dad had to explain to me the best that they could that hey I don't know the tools that I'm using because to me they are normal. So, to hear somebody use it because we just called it a stroller. And learning what is a wheelchair and that first exposure of yes, you are different, but we your family don't treat you any differently unless it's to help you succeed.

Lisa Dieker

Yeah, and that's who you are. So that's kind of taking you not only through 4- to 8-year-olds, but let's fast forward to today, you are an advocate, you do virtual tutoring, you teach online. What is your message to others that maybe aren't as comfortable with who they are because you may be the most comfortable person, I've ever met in accepting your differences as a strength and as an asset, what is your advice to somebody else who's like, gosh, I don't know how to disclose or to advocate. What's your suggestion to them?

Lindsey Massengale

First and foremost, my suggestion is disclose when you feel that it is absolutely necessary. I look at it as a need to know basis. Even at the school that I taught previously, my principal didn't know until I shook his hand. And then he literally goes woah, so it's a need to know and it's also I have to remind myself it's a need to know for your own safety. Do they need to know because ok, I'm going mountain climbing and I'm off balance, and I'm going to need help with something. Is it a need to know for your own safety and is it a need to know, let's just say is it I need to know for your benefit and to benefit them.

Lisa Dieker

What if somebody were discriminating against you, that's something I know about you. Let's take the bus loop that doesn't work. What is your first step of action that you recommend people do?

Lindsey Massengale

For discriminating?

Lisa Dieker

Yes.

Lindsey Massengale

I would have a friendly conversation say hey, this is how you have made me feel. This is what I would rather you do. Because each there is a society's eyes and the society's voice. But then there's the individual's voice. It is your instinct, but then it is you the individual's preference. Like I know I've had some conversations with you that you've learned some different things of stepping in and helping and when and when not, but yes help, but help when the individual is ready. Unless there is immediate danger in the way.

Rebecca Hines

Well, I think that's actually great advice and to kind of start to transition into some areas that are actually your expertise and your interest. I know that your mom actually wrote a book, *My Daughter*

Taught Me to Walk and I believe that she actually told some of the stories and some of the struggles and you know, different encounters that you've had along the way, but let's kind of transition a little bit into your professional interest that interest of literacy and writing and you know, so tell maybe you could tie a little bit, you know, what did your mom's book mean to you, but you could also take it as a work of literature, you tie that together for us.

Lindsey Massengale

My mom's book was I did not know she wrote the book until it was almost finished because she had some questions for me. They had every name that you used, and you had to get permission to use and reading through the book after it was published, learned a lot because I didn't realize I knew my parents fought for me, but I didn't realize the advocacy that they did for me to get me to where I am today. So, it was a learning experience for me, and it's also I mentioned it to really good friends that I know because I want them to accept it for the stories that it is and not just read it as another book. And then they asked me questions about it because it sparks where we've been all over the world. One of my friends has had similar stories to what's in it, so that was a really neat common ground with it. I learned a lot from it and my mom taught me actually how to write, from a very, very, very young age, and I've fallen in love with writing ever since probably elementary school. I was always writing something.

Lisa Dieker

Well, and I think you've really taken that passion for writing and advocacy that's in your mom's book and kind of made it your professional career share with us advice of how families might use writing, whether their child has the ability to write, maybe they need to use speech to text. How do you see writing as a way to advocate and to communicate for people with a range of needs, including those with cerebral palsy?

Lindsey Massengale

I see writing as first and foremost an outlet. If you can't say it with your voice, write it down. I have always one of the phrases I started using with my students is you always have a voice. In this classroom, your voice might be your voice, and your voice might be your pencil. Especially if you were taking a test and they wanted to raise their hand and shout out the answer, they said nope, your pencil is your voice, so you always have your voice. Just what is the modality of your voice? Write it down. I even tell my students, I'm not, not paying attention to you, but I'm writing something down, so I don't forget later on. Even to go as far as the most common is journaling. Write something down so you remember to tell somebody. Write something down to say, hey, this was a struggle today, but maybe in a week you're like, wow, I've overcome. Writing helps set goals and lets you see where you are and where you're going.

Lisa Dieker

And as a classroom teacher and this is kind of my last question Becky if you have any other wrap up questions. As a classroom teacher how do I give voice to kids who maybe are silent in both writing and in speaking in my classroom? What are some of your tips? Practical tips to give kids a voice.

Lindsey Massengale

I would say drawing is still a voice. I would say if they wanted to act something out. I had a specific student who could hear you if his hearing aids were in, but if he forgot his hearing aids, he'd mime for me. And I got used to understanding that there is always a way. I've had kids use different hand motions, even if it's not true sign language, you get to know your students. One of the teachers would tease me and say you're proficient in Anthony because it was the name of the student. Because it's like getting to know your own children, you get to know how they interact and what they need and how they're trying to express it to you. So, reading and writing the actual acts that we think that they are. They can be done in a lot of different ways. We just have to figure out what is that unique way for that student.

Rebecca Hines

And Lindsay, as we wrap up, I'm just curious, I know that you have a PhD. I know you have experience in the classroom, and I know you've lived a military wife experience at this point, but what's next? What's next for you?

Lindsey Massengale

You what's next is, I am actually in the midst of getting ready to launch my own online website business that will let me be a listening ear or voice and continue tutoring for others. It's called journeying through learning and it's not it by phrasing with it is let me meet you where you are and let's journey together. So, I want to be with whatever I'm doing it's always what do you want to do now? I'm still thinking about it. I always want to be that helpful hand that if I don't have the answer today, let's team together and figure it out.

Lisa Dieker

So, I did say I was done but I really do have one question I want to ask you now that I think about it, sorry and it really will be my last question, I promise. What do you think it means when a kid walks in and sees your unique challenges as you said, and they can be hidden on camera. But when I walk in a room? I see kind of some of the physical mobility challenge. What do you think that means to students when they see you as a teacher?

Lindsey Massengale

I actually, Lisa, have a story to that one. It was the end of the year, my last year at the school that I was previously at, and I said to the students what is something you learned this year? And I'm expecting them to say adding, subtracting animals, the typical first grade answers one of my students stood up and said Dr. Massengale you taught us it is ok to be different. I had to take a minute and go whoa, that came from my first grader. But I think they see the difference and yes, they're curious about it. I love all the questions. It's how you ask the question depends on how I answer it and if I answer it. But their curiosity is necessary because I may be the only one, they run into like this. I may be one of many that I want to be the role model for them and have them not be afraid of working with being around somebody who is different. Because in a way we are all different, but what is your difference?

Lisa Dieker

Well, with that, I think I'll leave it at that. Well said as always, we're very excited that you're our colleague, our friend, and a role model for advocacy in the field. And we thank you for joining us on

Practical Access. Please post questions or comments on our Facebook page and send us a tweet @AccessPractical. Thanks Lindsey.

Lindsey Massengale

Thank you.