



A conversation with Emily Ladau

Voice Over:

(singing).

Barry Whaley:

Hi, everyone. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, I want to welcome you to “504 at 50.” I’m Barry Whaley. I’m the project director of the Southeast ADA Center. “504 at 50” is a special interview series created in recognition of the 50th anniversary of the signing of the Rehabilitation Act of 1973.

In our series, we speak with leaders of the disability rights movement who advanced the cause of equal rights through their tireless work. On today's episode, we welcome Emily Ladau. Ms. Ladau is a passionate disability rights activist, writer, storyteller, digital communications consultant whose career began at the age of 10 when she appeared on several episodes of Sesame Street to educate kids about life with physical disability.

She's also the co-host of the “Accessible Stall” podcast. She is an author; her most recent book, “Demystifying Disability: What to Know, What to Say, and How to Be an Ally.”

Emily, we're so pleased to have you with us today and we're also pleased to welcome as our host for today's conversation, Jonathan Martinis. Jonathan is the senior Director of Law and Policy at the Burton Blatt Institute at Syracuse University, and no stranger to being an author either. So I will turn it over to you, Jonathan.

Jonathan Martinis:

Thank you, Barry, and thank you so much for joining. I promise you, we are going to discuss far more important things, but as a child of Generation X who sat on his



mother's lap while she turned the UHF dial, the first thing I have to ask is: what was it like being on Sesame Street?

Emily Ladau:

It's a fun question to start out with, and I'm glad to be here in conversation with you today. And being on Sesame Street was something that I think I have recognized the power of more so in hindsight than I did at the time, because I was only 10 years old. In those moments, I knew that there was power in being able to share my story and in being the disability representation that I had wanted to see in the books that I was reading, in the TV that I was watching. And that was an incredibly powerful thing.

But looking back on it, I realized that it was a launching pad for me to feel like my story matters, to feel like my story could make a difference, and that's not something that I take lightly or for granted. And sure, it was fun to hang out with Elmo and Big Bird and Oscar and just feel like a part of the neighborhood, but really what it comes down to is that disabled people absolutely belong in the neighborhood. They're absolutely a part of all of our communities.

And so being part of that broader conversation is something that has really carried through my entire career. I have never, ever forgotten what it felt like to be told that one person being representation for someone else can have a ripple effect and can make a difference.

Jonathan Martinis:

Thank you for that. I really like what you said about representation and ripple effects. How did you build on that, that desire to create those ripples to become such a prominent disability rights advocate?

Emily Ladau:

I have always been someone who is really passionate about connecting and educating and having conversations with people, but I never thought that I would choose advocacy as a career path until I got to college and I knew that I wanted to be a high school English teacher, but suddenly I found myself leaning further and further into the world of advocacy and realizing that it wasn't just personal, it was political. It was about more than just one person. It was not just about me.

And so I wanted to do what I could to advocate, but I had no idea what that meant, truly none. I just had a bit of a quarter life crisis one day, and I told my family, "I



think I'm going to leave the teaching program and be an advocate." And they said, "Oh my goodness, okay, we don't know how you're going to make a living, but we support you. Go for it."

And from there I realized that the lived experience that I had could be a jumping off point for broader conversations about disability issues. And so after college, I began to really dive into learning about the disability community and I did an internship program through the American Association of People with Disabilities. And it was there that I finally had that bubble popped of, "Oh, you were one of few disabled people doing this work." Absolutely not. Not at all. That was really my first opportunity to understand that there's a whole ecosystem of advocates who are doing this work, that my identities and my experiences are one among more than a billion.

And so my growth as an advocate has really come from connecting and engaging with so many other people who are part of the disability community who have been doing this work and learning about the fact that there is a history, that there is a culture, that I am part of something bigger.

When we say "504 at 50," that means 50-plus years of disability history right there. And no one ever taught me about that history when I was younger. But once I immersed myself in that, once I started to realize that I am a part of a community so much bigger than myself, that was what really pointed me down the path of becoming an advocate and recognizing that I can be someone who can throw stones in that ocean and have that ripple effect and change that one mind at a time.

Jonathan Martinis:

What is your favorite, or if that's a poor use of words, the most significant issue on which you've advocated?

Emily Ladau:

To be honest, I feel like it's hard for me to choose a particular issue because I recognize that every issue holds a different level of importance to different people in different moments. What I am most passionate about is often media representation because I believe that the media that we consume very much shapes how we think and how we perceive disability. And so that in turn creates a cycle where how we think about disability impacts the media that we create.



And so when we're part of a cycle where we're not breaking down the ableism that we are perpetuating both in how we think about disability and how we represent disability, that then has an effect on how we think about and communicate about every other disability issue. Because we're only seeing, in so many cases, these very one-dimensional depiction of disability in the media. And when things are so reductive in that way, we're really missing the bigger picture of disability. We're really missing the full depth and breadth and humanity of disability.

And so I am particularly passionate about advocating for more robust and accurate disability representation in all forms of media because I think that's really a pathway to expanding understanding and acceptance and access. And I recognize that it's just one aspect of advocacy among so, so many issues, whether we're talking about healthcare, whether we're talking about voting rights, whether we're talking about physical access to environments, you name it. But my passion really lies in being able to expand understanding of the disability experience through media.

Jonathan Martinis:

Your passion for focusing on the bigger picture, especially in media and popular views of people with disabilities, is a great lead in to discussing your book. You've written a book called "Demystifying Disability: What to Know, What to Say, and How to Be An Ally." As you mentioned, we're here 50 years after the Rehabilitation Act and over 30 years after the Americans with Disabilities Act.

Can you tell us what still needs to be demystified about people with disabilities and whether it's discouraging that we still have to demystify?

Emily Ladau:

I certainly can understand how it might feel discouraging when the disability community has been fighting and fighting and continuing to fight, and changes have been made, and yet we're still here having basic conversations about disabilities. But I think so much of that stems from a fear of the unknown and an uncertainty because we don't learn about disability in school curricula. We don't talk about disability as the world's largest minority. We don't think about disability as anything more than a niche issue if we think about it at all. And the lenses that we look at it through are so often pity and charity and helplessness, and we don't stop to talk about disability as just a natural part of the human experience.



And so my goal in writing, *Demystifying Disability*, was to offer people a foundation so that when we start to have conversations about disability, we're not afraid of saying the wrong thing. We're not afraid of making mistakes because I think that inaccurate representations of disability are so rampant that a lot of non-disabled people just have not been exposed to disability, just don't know any better.

And so what I'm asking them to do is meet me where I'm at and I'll meet them where they are, and we'll have a conversation about some of the basics around disability, like the fact that it's okay to say the word disability for starters, because sometimes we can't even get past that word. And then how are we going to have a more in-depth conversation? And once you have some of that foundational knowledge, you begin to recognize it's not so scary. It's just part of diversity. It's part of what makes us who we are.

And so the book, for me, has been an offering to non-disabled people and disabled people alike, calling upon them and saying, "Hey, we can all do better. We can all learn a little more. We all have ways that we can improve on how we are allies to each other and to the disability community."

And I always acknowledge that I am only one person, and that the experiences that I have, that shaped how I wrote the book, come from the fact that I am a white woman with a physical disability who communicates verbally, and I do have privilege in those areas. And so in having that privilege, and in recognizing that privilege, my goal is really to use the book to just begin conversations.

I'm not the start and the end. I'm one point on a broader journey of learning. And I hope that that is what people will take away from this conversation, that no matter who you are learning from, who you are listening to, there's always more learning to be done. There's always more that you can do to expand your knowledge about disability. And for me, I'm here to make that process, hopefully, a little bit easier and more approachable.

Jonathan Martinis:

So how do you have the conversation with the person or people whose sole experience or sole view of people with disabilities comes from popular culture that might be at best well-meaning caricatures or seen through the lens of so-called inspiration porn? How do you talk to people like that and bring them a better viewpoint?

Emily Ladau:



It can be challenging at times because there's this inclination that people have to assume that when I'm pushing back against those narratives of disabled people being inspiring or tragic, that I am somehow being bitter and that I'm not really appreciating the warm fuzziness of the story.

But the reality is that I'm not here to be anybody's warm, fuzzy feeling. I'm a person, like anybody else. And so I have to strike a balance when I have these conversations where I let people know that, yes, it is okay to appreciate and admire what somebody else has done but ask yourself if you would feel the same way if that person did not have a disability that was apparent to you.

I think we need to remember that we can flip our scripts when we're thinking about disability. So often, we're looking at disability as the other. We're looking at disability as something that we really shouldn't talk about. We push it into a corner. It's taboo. We're all delicate flowers. But no, we are part of the human population.

And so I try to get people to understand that, statistically speaking, you or someone you know has a disability, this is relevant to you. And don't you want to be part of a world where it is more welcoming and accepting and accessible, so that one day if you become disabled, you will also be welcomed. You will also feel like you have access.

And so it's really about introducing the conversation to people in a way that doesn't feel overwhelming or intimidating. And I know that that can get tiresome at times. People can feel like, "Oh, we've been having these same conversations for years and years and years, and we're still doing the work of educating." And I agree. I get tired too sometimes, but meeting people where they're at has had a really powerful effect on changing minds, and that's how I try to approach every conversation.

Jonathan Martinis:

Thank you. So recently you were the editor-in-chief of the Rooted in Rights blog, highly recommended, by the way, to listeners. Can you give us a little background on what that was about and what you feel were some of the really significant areas that you addressed?

Emily Ladau:

Absolutely. So I started working with Rooted in Rights back in 2016, and I felt the blog from the ground-up pretty much with the goal of creating a space to amplify the voices of the disability community and the perspectives of the disability



community, especially multiply marginalized disabled people whose perspectives were so often left out of mainstream media. And there were so many gaps in conversation around so many different issues. And to be able to offer up a platform for writers to fill those gaps and to express their truth and to talk about their lived experiences was really, really powerful and something that I feel lucky that I was entrusted to be able to do.

So many people came to me with stories that other outlets were unwilling to publish, that they didn't feel safe publishing in other outlets, that they felt like were missing from other outlets. And we were able to give those words a home. And now I have stepped down from that role and passed it on to a new editor-in-chief, who is bringing their perspectives to the work because I'm a big believer in shifting power and creating space where you can.

And so my time at Rooted in Rights taught me so much about how we can address everything from healthcare to voting, to dating and relationships, to the COVID-19 pandemic. You name it, we talked about it. And now with another incredible editor at the helm, new perspectives are being shared. And I think it still remains an incredible resource for learning about disability, right from disabled people.

Jonathan Martinis:

Thank you. You also now co-host the podcast, the "Accessible Stall," also very highly recommended. If you haven't checked it out, what are some of the focuses you've had on the podcast and what are some of the issues you've addressed there?

Emily Ladau:

So I have co-hosted the Accessible Stall with one of my best friends, Kyle Khachadurian, since 2016. And our goal in creating the podcast was quite simply to keep it real about disability. And at the time, there was not a ton of disability representation in the podcast space. And over the past few years, we have seen it grow and grow, and it's really been an incredible thing to witness, but we felt like there was a gap there, and we wanted to be a part of the efforts to fill that gap and just to have conversations about what it's like to be two disabled people in the world and what it's like to navigate the world as disabled people.

And so we've talked about everything from environmental issues to media representation to physical pain, how we're feeling in our bodies, what it's like to be out and about with a disability. Over the years, it's just been a place to have those



conversations, and to hopefully help other people feel seen and less alone, and also to educate along the way.

Jonathan Martinis:

As you mentioned, we're approaching the 50th anniversary of the Rehabilitation Act. In fact, that's the subject of this series of interviews. Without question, there has been progress in 50 years. In 1973, people with disabilities weren't necessarily even allowed in schools. So there certainly has been progress. Can you tell us what you think is the most significant progress in these years?

Emily Ladau:

I think it can be easy to take on a defeatist attitude sometimes when we realize, as we were talking about earlier, that sometimes, we are having these same conversations over and over again, even though laws were passed so many decades ago. But I also feel like the progress is in the fact that I am here having this conversation with you right now and the fact that we are creating and continuing to create our own culture. We are continuing to document our own history.

It's true that there have been legal improvements and there's also much room to grow. It's true that despite the fact that we have these protections in place, there are still so many violations of those protections. And yet the fact that disabled people are becoming more visible, more prominent, part of these conversations, engaging in these ways, making our own media, directing our own media, putting ourselves out there, I think that's an incredibly empowering thing for the community and something that I want to uplift and to celebrate.

Jonathan Martinis:

Thank you for that. The fact that there has been progress also just highlights that there's so much more to do. I have a friend who says that "One of the biggest problems we face is that states are trying to meet 1990s AERO standards in the 2020s."

So if you were able to solve one problem, one overarching issue facing people with disabilities, with the wave of your hand, what would it be?

Emily Ladau:

I've thought about this quite a bit, and I think that transportation is an issue that I would love to see focused on so much more than it already is by so many incredible



activists who have been tirelessly doing the work because transportation is really at the hub of everything else that we do.

So if we do not have access to transportation that disabled people can use, public transportation, then how do we get to healthcare appointments? How do we go out and socialize? How do we go to work? How do we go to school? How do we go exercise our right to vote? How do we go grocery shopping? And so I think that by fully fixing access to public transit, again, if I could wave a magic wand and do that, we would vastly improve quality of life and access for so many disabled people who right now aren't able to safely and securely get out and about to do what they need to do.

And in recognition of the fact that we have such an accessible public transportation system, and also that it's not safe for people to go places right now necessarily because of the ongoing pandemic, I would also add to that, I know you said one issue, but if I can add just one more, I would say creating more virtual access, more hybrid option, enabling people to access telehealth, to go to school virtually, to work remotely, to attend events on Zoom.

Focusing on solutions that are practical in the face of the fact that we still need a transportation infrastructure overhaul. And right now it may be a little bit easier to create access in a virtual world.

Jonathan Martinis:

Thank you. And I cannot agree more. I often say that there's a difference between community integration and community inclusion. One is where you live, and one is how you live. So thank you so much for being an advocate and for using your voice and your platform to advocate for how people should live. And with that and with, again, my thanks, I'll turn it back to you, Barry.

Barry Whaley:

Thank you, Jonathan. And Emily, thank you so much for being our guest for this interview's, really engaging, thought-provoking. I really appreciate your time.

Listeners can access this interview and other interviews at the Section 504 at 50 website. The web address is section504at50.org. This series is produced by the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and is a collaboration with the Disability Inclusive Employment Policy Rehabilitation



Research and Training Center. Again, thank you for listening and we look forward to seeing you at our next interview.

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