

BoggsCast Episode 1: Emily Ladau

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JAIME ZAHID: Welcome to BoggsCast, where faculty and staff at The Boggs Center on Developmental Disabilities explore best practice, showcase success stories, and help listeners envision possibilities for innovation through interviews with state and national experts.

Part of Rutgers Robert Wood Johnson Medical School, The Boggs Center is New Jersey's University Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental Disabilities program.

I'm Jaime Zahid, Community Supports Educator at The Boggs Center. I'm joined by Charlotte Borgersen, who is a student at Rowan University and a Partners Graduate from the class of 2021. In this episode, we'll be discussing topics related to disability allyship and storytelling to connect about disability with Emily Ladau. Ms. Ladau is a passionate disability rights activist, writer, storyteller, and digital communications consultant whose career began at the age of 10, when she appeared on several episodes of Sesame Street to educate children about her life with a physical disability.

She serves as the Editor in Chief of the Rooted in Rights blog, a platform dedicated to amplifying authentic narratives on disability experience through an intersectional lens. Her writing has been published in outlets including The New York Times, Self, Salon, Vice, and HuffPost. And her first book, Demystifying Disability is being published by Ten Speed Press, an imprint of Penguin Random House in the fall of 2021.

Emily has spoken before numerous audiences, from the US Department of Education to the United Nations, and has been a three-time presenter for New Jersey's Partners in Policymaking program here at The Boggs Center as well as a Developmental Disability Lecture Series presenter. Central to all of her work is a focus on and harnessing the power of storytelling as a tool for people to become engaged in disability and social justice issues.

Charlotte, do you want to start with some of the questions that we have prepared for Emily?

CHARLOTTE BORGENSEN: Do you mind if I say something before I get started on my questions?

JAIME ZAHID: Absolutely. Go for it.

CHARLOTTE BORGENSEN: Emily, I wanted to tell you, you're the reason that I started sharing my story more since you came to talk to us at Partners, and it's really helped me get through and not be emotional with telling my story.

EMILY LADAU: Charlotte, I love that so much. And I would also say sometimes it's OK to be emotional when you're sharing your story because it's so deeply personal, and it's something that you live every day. You wake up in your body, and you live each day as a person with a disability, right? And so sharing your story is something that can have a lot of emotion behind it. But I'm so excited that you're sharing your story more, and I think that is my ultimate goal, to make sure that people feel more comfortable with opening up and making connections with other people. So that's amazing. Thank you for telling me that.

CHARLOTTE BORGENSEN: You're welcome.

JAIME ZAHID: For those that don't know, Charlotte heard from Emily for the first time this past September as part of the Partners in Policymaking program. And Emily was one of our first presenters for the Partners Class of 2021 and really empowered many people, including Charlotte, to be able to tell their story and to tell it in a meaningful way that really gets the point of advocacy across to those who are listening.

And Charlotte, I think it is important, as Emily said, to retain some of that emotion when you tell your story because without that emotion, the story is kind of just words, right?

CHARLOTTE BORGENSEN: Mm-hmm. Alright, so we'll get started with questions. Alright. What advice would you give to individuals with disabilities who are pursuing disability advocacy? Where should someone start?

EMILY LADAU: I think that's such a good question, and we actually touched on some of my advice already. Hold on to that emotion and that passion that you have. When you have a disability, it's not as though you can separate yourself from that part of you or that part of your identity. And so recognizing that you are sharing a part of yourself with someone else is a very powerful thing.

And I know it can seem really scary and overwhelming to tell your story to a room full of strangers, but nobody said that you need to start there, right? Advocacy starts wherever you're comfortable. And so for me, it looked like having conversations with friends, and it looked like having conversations with family. And then eventually, yes, I did move on to larger platforms, but that's not the kind of thing that happens overnight.

I think that advocacy starts at home. It can start with changing the mind of one person. It can start with speaking up for yourself because you feel that your needs are not being met in the way that you would like them to. It can start with communicating in whatever way works for you to let other people know that you are the one who is experiencing the disability. You are the one who should be shaping what your life looks like.

And so I think that we have this idea that advocacy needs to create these big, sweeping policy changes or these big shifts in culture. And that's ideal, but that doesn't happen if we don't start with one person at a

time. And so I am all about having those individual conversations, sharing your story in any way that makes you feel comfortable, and just building up from there. Remember, if you've changed one person's mind, that has a ripple effect. So never think that starting with one conversation is not enough because that's actually a huge step in the right direction.

JAIME ZAHID: And I found that statement, Emily, that you just made, "advocacy starts wherever you're comfortable," to be so empowering. And I feel like it's empowering beyond disability advocacy. I feel like it's any type of advocacy, and certainly disability advocacy. But as a person who experiences disability sort of second hand, as you know, I don't identify as having a disability. It is important for me to remember that people need to start with where they're comfortable.

So as I work with self-advocates, I think I'm going to make sure that I really keep that in the back of my mind, or actually, the front of my mind, that the person I'm working with, or speaking to, or hearing from needs to be comfortable in order for the words to have true meaning.

So moving on. I know this sounds-- it's sort of a deep question, and I feel like it can be related to advocacy or otherwise, just getting to know Emily a little bit. So what keeps you up at night?

EMILY LADAU: Well, honestly, I think my answer to that relates back to what we were just talking about. I am so often kept up at night by situations or scenarios that I have encountered where I feel like I could have handled it differently, or I feel like I could have advocated for myself better, or I could have been a better ally to someone else.

And so I probably lose way more hours of sleep than I should thinking about what I could have said in the moment or how I could have responded that might have made a different impact when it comes to disability advocacy. And sometimes that actually requires me to push myself out of my comfort zone. And I'll be totally honest. Despite the fact that I joke around that I am a professional disabled person in the sense that not only do I have a disability and it is part of my life personally, but it's also very much a part of my life professionally, I also find myself feeling like I still have a lot to learn. And so I'm often up at night thinking about the ways that I can better support the community and ways that I can educate people. But at the same time, meeting people where they're at is so important to me. So I'll often be awake at 3 o'clock in the morning writing something in my head, because I want to make sure that I get the words just right so that I don't alienate anybody in the process of my advocacy. Because it goes back to what we were talking about regarding emotions, right?

I feel very deeply because disability is part of me. It's part of who I am. I don't take it off when I go to bed at night, and so when I wake up the next morning, I really want to make sure that I have it right, that I know what I'm going to say, that I feel prepared. But the reality is that doesn't always happen, and so then it keeps me up the next night while I'm thinking about how I could have gone about things in another way. So having any kind of marginalized identity, I think, is something that will end up keeping someone up at night just because there's so much going on in the world that we have to think about and figure out how to

navigate. So that is probably what I'm thinking about if you find me posting on social media at 3 o'clock in the morning because I can't fall asleep. [LAUGHS]

JAIME ZAHID: Awesome. You mentioned in that response the word "disability allyship." I'm hoping that you can tell us a little bit more about what does that mean? What does that mean to you? What does it mean to the disability community?

EMILY LADAU: That's a great question, and I think we need to understand that allyship is a verb. Being an ally as an action. Being an ally is not a title that you give to yourself. It doesn't look like, "oh, I held the door for someone with a disability. What a good ally. Or oh, I used language that I felt was correct, so I'm a good ally," right? It's more about diving into a meaningful learning process about disability and understanding that if you do not have a particular disability, then you're not the expert on that disability. So I always say if you've met one person with a disability, then you've met one person with a disability. And that means that even though I can talk about disability, I can really only talk about my own in a way that I am 100% confident, because I can't presume to speak for someone who, for example, is a non-speaking autistic person, right? Because I have a physical disability and communicate verbally. And I can't speak for someone who has a mental health disability that I may not have because I don't experience that. But what I can do is be an ally in the sense that I'm continuing my learning and I'm continuing to understand that the best thing that I can do is know when to support and amplify. And when it's time for me to move forward, to step up, to be a support system where I can.

So allyship looks like many things. And I know it's hard to pin down an exact right answer, but the most important thing that you can do is be open to constant learning and conversation about how you can best support people of a whole range of marginalized identities. And it's going to be an ongoing process. It's not something that happens overnight, but that's OK. That's a good thing, right? That's how we form connections. That's how we create change.

JAIME ZAHID: Excellent. And your response to that comes a little bit full circle for me, anyway, back to what Charlotte was speaking about when we first started. And it seems that your allyship back in the Partners program really empowered her, and I think it's part of why she's joining us here on this podcast today.

Your words also were very thought-provoking, and I'll have to admit, I've actually stolen your words on a number of occasions, your phrase of, "if know one person with a disability, you know one person with a disability." And I do try and channel that thought when I'm speaking with people with disabilities, and with other professionals, and just even friends and family about disability topics.

CHARLOTTE BORGENSEN: Mm-hmm.

EMILY LADAU: Steal away. If it benefits you in conversation, by all means. I was by far not the originator of that, I'm sure. But I know that I've learned from many wonderful disabled people before me, and so I just want to keep that knowledge and keep that passion for remembering that we're all individuals really

going.

JAIME ZAHID: Absolutely. And again, that goes beyond disability.

EMILY LADAU: Absolutely.

JAIME ZAHID: And so it's something that's so important for us all to remember, so thank you for that. I think, Charlotte, you might have had the next question for us?

CHARLOTTE BORGENSEN: Yes, I do. What are your long-term goals related to advocacy?

EMILY LADAU: For me, advocacy is really kind of cyclical. So if I have achieved a goal in one area, there's a good chance that my work is not done. And I don't mean that to sound overwhelming, but it's the reality. There are so many people in this world that it's simply impossible to reach all of them. And so my goal is to reach as many people as I can in ways that feel good and in ways that feel right.

And so my long-term goal is really to be doing exactly what I'm doing now, but just to continue to grow, and to continue to advocate on a broader scale. And also, to focus on really knowing when it's not my turn to speak, and when I need to pass the mic to other people. And recognize that the best long-term goal that you can have for advocacy is giving the spotlight to other people whose voices may not necessarily be heard in the conversation.

So my goal is not so much to amplify my own words forever, but rather to provide jumping-off points for other activists, especially people who are multi-marginalized, to have a platform, to have the spotlight on them to really give them the support that they need to share their story.

And I'm lucky to say that I do a lot of that already, especially through my work as Editor in Chief of Rooted in Rights because I support disabled writers of all different types of identities to share their story. And so that's an incredible privilege that I have to be able to do that. And longer term, I just hope to do more of that and to spread that even more broadly.

JAIME ZAHID: I love that response. And the fact that-- if I could encapsulate your response into one sentence-- your long-term goals with advocacy are to pass the baton to other advocates, and I think that has such deep meaning.

Why is there such a stigma around disability? And what do you think that we all can do, particularly those of us who don't have disabilities? What can we do to contribute towards reducing that stigma?

EMILY LADAU: Stigma comes from a lack of understanding and a lack of connection. And so that's why I'm such a big proponent of storytelling, because I believe that you can present a fact to somebody like, 1 million disabled people worldwide, right? That's a fact. That's the statistic. But you can also tell a story about one person with a disability or one group of people with disability, and that story is far more likely to resonate than statistics. And so removing stigma starts with telling stories and forging human connection.

But unfortunately, that's kind of something that needs to work both ways. People also need to be receptive to those stories. And that becomes challenging when we live in a society where we are so steeped in stigma of disability that we're afraid to really engage with disability. It's something that makes us nervous and uncomfortable, and we don't really want to be around disabled people because we're unfamiliar with it. We're afraid we're going to say the wrong thing. We're afraid that we might somehow end up disabled as well.

There's all kinds of concerns that we have because of the way that stigma is such an entrenched part of the world. And so we somehow need to bridge those gaps, and break down those barriers, and start opening up the lines of communication, but that job shouldn't necessarily belong only to people with disabilities. That's a lot to ask people with disabilities.

And so my request is that as much as people with disabilities can open up and talk about their experiences to help break down stigma and to help make people more comfortable, I really also ask that people without disability open themselves up to hearing about it, open themselves up to having those difficult conversations, to learning more, to recognizing that they're probably going to make mistakes and that that's OK, as long as they learn from those mistakes and don't repeat those mistakes. And so stigma is something that we solve only if we recognize it as a two-way street.

JAIME ZAHID: Very Good. Charlotte, I'm curious to hear from you. As a young lady who has a disability, do you feel like you experience stigma in society, whether it be at work, amongst friends, at school?

CHARLOTTE BORGENSEN: Well, I'll tell you this. It reminds me of a biology class I took quite a long time ago or semesters ago. I came in a power wheelchair, and my professor thought I couldn't get out. So as soon as I got up and walked across the floor, his eyes opened wide and was like, what? Like, thinking, oh, my! He had students before me that are in wheelchairs who can't get out.

And then also, I also now use a white cane, so he was also just curious about that, too. So we started talking, and he actually talked with me. I talked to him. I told him that I can walk. It's just I use the chair for long distances, or things to help me carry certain things, and so forth. And so yeah, no. I've surprised most people in my lifetime with things. Yeah, no.

Even going back to when I was little, I had people telling me I wouldn't walk and so forth. And I just keep on surprising people as I got older, so.

JAIME ZAHID: Very good.

EMILY LADAU: Charlotte I'm so glad you brought that up because I think that people also have very specific ideas in their head about what disability looks like. And so the fact that you were able to have that conversation with your teacher, I think, is really important. And I'm glad that you felt comfortable doing that.

CHARLOTTE BORGERSEN: Mm-hmm.

JAIME ZAHID: And you might have just in one person-- But again, that ripple effect that Emily referenced. In one person, you might have changed some of his perceptions, which is awesome because then maybe he's at a dinner party a month later talking to somebody about disability, perhaps. One can only hope, right?

CHARLOTTE BORGERSEN: Mm-hmm.

JAIME ZAHID: Emily, onto your book. So you're being published in the fall. That's so exciting. Tell us a little bit about your book and what inspired you to put pen to paper-- or probably fingers to keyboard. It's 2021, after all-- and become a published author.

EMILY LADAU: I'll tell you, it was definitely pen to paper before it was fingers to keyboard. I have notebooks for everything, and writing by hand actually helps me think things through before I type it out. So it was definitely pen to paper before fingers to keyboard, but I'm excited to talk about it.

So yeah, I have a book coming out in September. It's called *Demystifying Disability: What to Know, What to Say, and How to Be an Ally*. And the reason I wrote it is because I felt like there was a real gap in basic conversation around disability in a way that feels friendly and approachable.

So often it's either personal memoir or a textbook, and I found myself wondering where that in-between point is, where we can begin to learn about disability. For example, language, and etiquette, and disability in the media, and how to be a good ally. Those are all things that I think people have a lot of questions about, but they aren't really sure where to start.

And so I got very, very lucky that I actually recorded a podcast a few years ago. And a literary agent heard that podcast and reached out to me. And she said, hey, have you ever thought about writing a book? And I suppose I had, maybe, in the back of my mind. But it ended up turning, with her guidance, into this project to really fill that gap and create that approachable guide so that people have a starting point to learn about disability.

JAIME ZAHID: Wow, that is an awesome story. And it really goes to show how you want to take every opportunity you can in life. You recorded a podcast years ago, and it helped a dream come to fruition. Oh, and Charlotte, I think you have the next question we prepared.

CHARLOTTE BORGERSEN: Yes, I do. What are some ways that you feel society can be more accessible? And when we use the word accessible, are we talking about physical accessibility such as doorways and ramps, or is there more to it?

EMILY LADAU: Charlotte, I think that's a great question, and I have a couple of different answers. So first of all, accessibility is definitely not just about doorways being wider or there being ramps to enter, right?

Because you can make a place physically accessible. But if once you enter that place it's not welcoming to someone with a disability, then it's not really accessible.

And so accessibility isn't just about physical location. It's also really about attitudes and recognizing that being inclusive doesn't mean that there's a ramp leading up to the door. It means that once you get in the door, you're also part of what's going on inside.

And so I always ask people to consider that when they say we're accessible, you need to understand that that doesn't just mean how is the physical environment built. Because if you have a ramp, if you have a way to get inside the building, great. But once you're inside that building, as I was just saying, how are you being treated?

Are you part of the activities that are going on inside there? Are people being sensitive and respectful in their language? Are people ensuring that you have your needs met in terms of, maybe you need the lighting changed at some point, right? Or maybe you need access to a bathroom, right? So it doesn't really matter what happens on the outside of a building. It matters that you feel welcome when you get inside that building.

And the other thing is that accessibility works for everybody. There is something called the curb cut theory or the curb cut effect. If you have a curb, it's a step up, but not everybody can use that. But if you have a curb cut, everybody can use that. That works for everybody. And so yes, that is an example of physical accessibility.

But when it really boils down to the main concept, what that actually means is that accessibility benefits everyone. Accessibility is more welcoming for everyone. And so yes, physical accessibility is important, but it's really recognizing the impacts of that accessibility and shifting attitudes and perspectives that's going to make society a more accessible place.

CHARLOTTE BORGERSEN: Mm-hmm.

JAIME ZAHID: Awesome. Thank you, Emily. Do you feel like we missed anything?

CHARLOTTE BORGERSEN: No.

JAIME ZAHID: Can you--

EMILY LADAU: I really don't. This was great.

JAIME ZAHID: Because I feel like I know-- I actually feel so proud to say this. I want to brag and say I know you well enough, so I bet there's so much more we could have talked about.

I know that you grew up with a mother who experiences disability firsthand. How what was that an impact on your life and your journey to self-advocacy?

EMILY LADAU: So many people think that the fact that my mother and I have the same disability is a tragedy because it is a genetic disability, and so she passed it on to me. But I have never seen it that way. I've always seen it as being incredibly powerful that I grew up with somebody who showed me that it's possible to grow up with a disability and showed me that there are challenges in navigating, but that those challenges can so often be figured out.

And I have an incredibly strong bond with my mom, and I'm so lucky for that. And my deepest wish, quite honestly, is that all disabled people had someone in their life, whether it be a parent, or a family friend, or a sibling, or some kind of role model with a disability who shines a light, and paves the path, and leads the way.

And I know that sounds so cheesy, but I think that I benefited immensely from having someone with a disability in my life at all times. And so I truly wish that for other people with disabilities, that they have people who can guide them, and mentor them, and support them, and offer advice and a shoulder to cry on because my mom was all of that and more for me. And I think that really helped me become who I am. But in a world where disabled people don't always see themselves reflected back at them, having someone who is a direct reflection back to you is a really powerful thing.

JAIME ZAHID: Awesome. And so two things come to mind as you responded to that. One, sort of going back to the beginning of our conversation around stigma, I got a knot in my throat when you said that people think it's a tragedy that you have the same disability as your mother, and that goes back to the idea of stigma, I think, anyway, where people think that disability is such a tragic thing. And it's truly-- I mean, I can't speak for people with disabilities. But from what I hear, it is not a tragedy, and that's part of the stigma that we need to erase.

And then secondly, what I heard from your response was that you had representation firsthand in your life, in your home growing up. And we hear a lot of that phrase lately about people, perhaps, people of color having representation in politics now that Kamala Harris is our Vice President. And so that representation obviously had such an impact on your life and such a positive impact.

EMILY LADAU: I'm glad you brought both of those things up because I think that without representation, forming a sense of self becomes more challenging. And so having representation in very public spaces like public office, for example, is a huge step in the right direction. And having better representation in media, a huge step in the right direction.

And it's absolutely true, unfortunately, that disability is so often viewed as a tragedy. And the thing is that we can't forget the nuance and all of that, which is that disability can be very difficult. Disability can have tragic moments. Disability can be hard, and it can be exhausting, and it's not all sunshine and roses.

But at the same time, we don't need to look at it solely as a difficult and tragic thing. We need to understand that there is joy, and community, and culture. There's reasons to celebrate. There's reasons to be proud of who you are. And if we don't understand and recognize that balance, then I think that we're missing out on a whole lot of richness that disability adds to society.

JAIME ZAHID: Thank you for that response, Emily.

CHARLOTTE BORGERSEN: OK. What's one question that I didn't ask you but you think I should have?

EMILY LADAU: You know what, Charlotte? I actually think that you and Jaime asked me so many questions that I couldn't possibly come up with another one. And I think that if I thought about it long enough, I'm sure there is a whole lot of nuance. We could talk about education. We could talk about employment. We could talk about dating. We could talk about so many things because every issue is a disability issue, because disabled people are impacted by every issue.

But I think that for the purposes of this conversation, I'm really excited by how much ground that we've covered. And I think it was so great to be able to engage on so many different topics with you. But I don't think that there's anything else that you could have asked that we could have crammed into this incredibly rich conversation.

JAIME ZAHID: Awesome. Thank you, Emily. And Emily, I have to. I'm sorry. Maybe this is unprofessional. You mentioned dating. How is it going with your boyfriend?

EMILY LADAU: [LAUGHS] It's going quite well. We've been together for 3 and 1/2 years now, so yeah, it's been a while and he's pretty good. No complaints there. And hey, I think that professionalism is not always super needed when talking about disability because we have to remember that disabled people are real people like anybody else, and dating and relationships are part of conversations that we have. And so I'm glad you asked. We're good.

JAIME ZAHID: [LAUGHS] I'm glad to hear that. I can't believe it's been that long.

EMILY LADAU: Yeah, it's been a while. [LAUGHS]

JAIME ZAHID: So congrats.

Thank you to Emily for participating in today's podcast, and thank you to Charlotte for assisting me in the interview. Thanks for listening to this episode of BoggsCast, a podcast by The Boggs Center on Developmental Disabilities. A full transcript of this episode can be found at theboggscenter.podbean.com. Be sure to subscribe to this podcast on your favorite streaming service to stay up to date with the newest episodes. To learn more about The Boggs Center, visit our website at rwjms.rutgers.edu/boggscenter and follow us on Facebook at [TheBoggsCenteronDevelopmentalDisabilities](https://www.facebook.com/TheBoggsCenteronDevelopmentalDisabilities).