Emily Ladau: Hello everyone, and welcome to Disability Inclusion Required, a new podcast led by the Disability and Philanthropy Forum. I am so excited to be welcoming my guest today, Maria Town. I cannot wait for our conversation about one of my favorite topics, which is Disability 101. And I think it's really important to acknowledge the fact that everyone who's tuning into this podcast is at their own point of their journey when it comes to learning about disability. And a really big value for me is to be able to meet people where they are. So, part of that, I recognize, is offering some foundational information about disability, so when we are engaging in deeper conversations, we can expand that shared understanding and ultimately have better communication around disability. So, when I was reflecting on who I wanted to invite, Maria came to mind pretty immediately, because so much of the work that she does encompasses this really broad and diverse range of disability issues. And so, without further ado, let's kick it off. And, Maria, I'd love if you could share a little bit about yourself and your role with our listeners.

Maria Town: Sure. Well, Emily, first, thank you so much for having me, and I'm truly honored that you thought of me to be on this podcast. I have such respect for you and all of the different work that you do. So, a little bit about me, I serve as the president and CEO of the American Association of People with Disabilities. AAPD is a national, cross-disability civil rights organization that seeks to increase the political and economic power of the more than 61 million disabled people across the United States. And I come to this role with a deep personal and professional background in disability.

I have cerebral palsy. I very proudly identify as a wobbly person. So, I've been disabled my whole life. And reflecting on my experiences, I can acknowledge that I've been a disability advocate or at least a self-advocate my whole life, even if I didn't understand that that was what I was doing. Prior to AAPD, I spent a lot of time working in government at different levels. Let's see. Outside of work, I am cat mom. I have two cats with my wife. And I'm originally from Southern Louisiana, so if you hear me say y'all during this podcast, I will never stop saying it.

Emily Ladau: I was waiting for the cat mom part, because obviously that's the important thing here, is that we love cats.

Maria Town: Absolutely. Yeah.

Emily Ladau: And I am so jazzed, honestly, to get into this conversation with you, and I think it would be helpful for a little disclosure of my own. AAPD is really near and dear to my heart because, what feels like a million years ago, but was really only a decade ago, I did the AAPD Summer Internship Program, which is how I really began to dive into the world of disability. And it was my own crash course in a lot of information about disability that I had not previously been exposed to, because it's not something that's taught in history curricula in schools, and it's not something that you see nearly enough of in the media. And so, I now really prioritize ensuring that other people have access to that 101-level conversation, because that was what I needed to really get my start. And so, I think the first thing that we should do is back up a little bit and actually make sure that we are starting at the ground level.

I'd love to talk about the word disability. I want to know both what it means to you, but also if you could tell us a little bit more about what it means beyond the definition that we might be thinking of from a legal perspective. And also, for that matter, is it actually okay that we're even using the word disability here?

Maria Town: Okay, so those were three very big questions.

Emily Ladau: No pressure.

Maria Town: Yeah. And I want to start actually with the second one, which is, what's a basic definition of disability? And Emily, one of the things that you said was beyond the legal definition that we might be thinking of. And I want to say, let's actually start with the legal definition, because I think, in my experience, people assume that it is one thing when it is really something else altogether. So, the definition of disability in the Americans with Disabilities Act, which is a comprehensive non-discrimination law around disability, it says that a disability is any mental or physical condition that impacts an activity of daily living. Now that definition itself, for me, it's like, well, what do all these words mean? What is an activity of daily living? And that's really anything you would do in a day. Eating, drinking, reading, communicating, walking, getting yourself dressed, talking on the phone, right? Texting. And so, if you have a condition, whether it's physical or mental, apparent or non-apparent, that impacts your ability to do something in a day, that's a disability. And that's a disability that can be protected by law.

In my work, probably one of the most frequent questions I'm asked is, "What do you actually mean by disability?" And people ask that because there are assumptions and stereotypes about what disability means. A lot of people think it means wheelchair users, or people with mobility impairments like you and I have. Some folks might also think it includes blindness and deafness, when really, it's everything from cerebral palsy and intellectual disabilities, developmental disabilities, to depression, anxiety, chronic health conditions, cancer, long COVID, and all of the above. It's this incredibly broad umbrella of experience and identity.

So, getting into the first half of your question, what does disability mean to me? That's what it means to me. It's this diverse set of experiences and identities where there's something about your environment or our society that was not designed for how your body and mind engage in the world. Disability to me is also a community that is vibrant, that is complicated, and it is an identity that people can claim. And just because you claim it doesn't mean you have to feel great about it, and we can get into disability pride and concepts like that later. But that's how I understand disability. And to answer the last part of your question, I think it's actually a very good thing to use the word disability.

Emily Ladau: I think that you've actually set us up nicely to move into the next part of this, which is not only is it okay to say the word disability, but how do we refer to somebody who has a disability? And much like you, I understand disability as an identity. I see it really as a natural part of the human experience. And so, I embrace the term disability and I call myself a disabled person. But the question that I come across so often from people who really want to do right by the disability community is, "Should I be saying disabled person or should I be saying person with a disability?" Is there actually a right answer here?

Maria Town: No, there's not. I don't think there's a right answer. And I think it's important to understand the history of people-first language, which refers to people with disabilities, person with a disability. That is a language construction that was first started by self-advocates in the intellectual and developmental disability community, as a way for them to assert their personhood and humanity. And honestly, Emily, it hurts my heart so much to think about and to say out loud the fact that people in the disability community generally have to think about ways to get people in power, to get others in their community, to even consider themselves human. And so, that's how person-first language got started, as an advocacy tool by people with intellectual and developmental disabilities, or IDD, to say, "We are people. Treat us like humans. We have rights and we have a voice." And I want to acknowledge that in the broader disability community, a lot of times, folks with intellectual disabilities do not have space and are not centered in those conversations.

So, that's where people-first language comes from, and I actually continue to use both person-first and identity-first language in a way to honor that history. More recently, there's been a discussion of what's called identity-first language or disabled person, where people acknowledge that disability is a part of my personhood. It is a part of who I am. I would not call myself a person with femaleness or womanness, or a person with bisexuality. I would call myself a bisexual person, right? I would call myself a bisexual woman. In fact, I would call myself a disabled bisexual woman, to acknowledge that all of those things are a part of who I am. And so, that's how identity-first language works. And I think that one of the things that we really need to do is accept people where they are on their own journey, and how they want to identify.

We've begun to talk about these two different ways of referring to disability, but as you know, there are all kinds of euphemisms. And honestly, if somebody is using person-first language, I think that's a big win, because they're not saying people of determination, or differently abled, or unique abilities, right? And I think it is so important that people actually use the word disability, because disability is the language of rights. It's not the Americans with Abilities Act. And guess what? That law doesn't even need to exist, because people who are non-disabled don't experience the same kinds of discrimination. And so, if we want folks to be able to understand their rights, to be able to understand the, again, communities that they can be a part of, it's important to create opportunities for folks to really own the word disability.

Also, often when I say that I get some pushback, right? "Dis, it's negative. There's got to be something else." And I actually don't think it's a bad thing for people to feel a little bit uncomfortable. Having a disability, being a disabled person, is not easy. We have to put up with a lot of stuff, whether it's, I can't get into this doctor's office because it's not accessible, or, I can't access this information that I need in order to do my job or to file my taxes, because it is so confusing and there's not options for it to be screen reader-accessible. These are just small examples. And one of the things that I personally like about the word disability is that it indicates to other folks the discrimination and barriers that I face on a daily basis, that something like a euphemism, like unique abilities or special needs, just does not communicate at all. Yeah. I'll stop there.

Emily Ladau: I am over here just nodding my head so vigorously, like, "Yes, yes, keep going." You are so spot on. I mean, I suppose I'm a little biased because I already knew coming into this that our views are fully aligned here, but I think it's always really helpful to hear someone articulate what disability means to them, and the importance of understanding that language is not one size fits all, and the importance of understanding that we have to honor different ways of identifying, and we also have to recognize that disability itself, even though it is attached to such negativity, and it's really taboo in a lot of ways to use that word, there's nothing wrong with saying it. There is power behind using the word disability. And if there's one thing I hope people take away from listening to this, it is that. I hope that they understand that disability itself is not a bad thing, but the world is not designed for disabled people.

And so, I think that naming it and saying it, and using that word is really, really powerful. But I also would be entirely remiss if I didn't acknowledge that despite the fact that I am someone who holds multiple marginalized identities, I am a disabled woman, I am a Jewish woman, I'm also a cisgender white woman who has not experienced things like housing insecurity or food insecurity. I am someone who comes to this work at the nexus of privilege and marginalization. And so, I think it's really crucial that we talk a little bit more about the fact that we can't discuss disability without addressing how it cuts across different identity groups. And so, I'd love your take on this, if you could speak to this, and tell us why this is so important to acknowledge.

Maria Town: Where do I start, Emily? I mean, I agree so much with what you said, and I think that for disabled people, there are some experiences that can be cross-cutting, but truly, everyone's experience of disability is not only informed by their specific diagnosis and the maybe tools they use to navigate the world, but also informed by their socioeconomic status, their experiences with poverty, the state that they live in, their race, their gender, their sexual orientation, their gender identity, their family structure. Because disability occurs in every community, as you said earlier in the podcast. Disability is a natural part of the human condition. In the disability community, we have this saying that every issue is a disability issue, and that is absolutely true, but every disability issue or every issue is a disability issue also, again, looks very different depending on your context.

And so, I think when we silo these issues, one of the things that happens is we can pit communities against one another. And that is something that I think our broader sort of civil rights and social justice movements have suffered from. We have, intentionally or not, oftentimes segregated ourselves from opportunities for solidarity. And I think about something like the Equality Act, which is a comprehensive non-discrimination bill surrounding LGBT identity. That still has not passed. So, across the United States, there are a lot of people who could be fired for being gay, or be kicked out of businesses for being a lesbian. And when I think about myself, because of my age, because I was born after the AADA passed, I have always had the right to be disabled in public and not be discriminated against. But my job at AAPD is really the first job I've had where I have been out because I have very keenly understood the risk of employment discrimination for me as a queer person. And I don't just show up as one, right? I show up as both all the time.

The other piece to this is, historically, and you and I are a reflection of this, historically, the disability rights movement has been, I think, really dominated by white disabled people, specifically white people with physical disabilities. And, in reality, communities of color experience disabilities at higher rates. Sometimes those disabilities are a direct result of state violence. And one of the reasons that we have to talk about how disability shows up in all different kinds of ways across the world is so that we can acknowledge the different ways that people are impacted by disability, and how it informs their own opportunities and abilities to advocate for themselves and to get the resources they need to survive.

Emily Ladau: I think you named so many important things in that answer, and I definitely want to underscore what you were saying about how you don't just show up anywhere in the world as one part of yourself. It's not an either/or. It's a both and. And that is something that I think people forget. We can't look at any particular issue in a vacuum or in a bubble, and we also cannot silo ourselves from the work of other social justice movements because that is what disability rights work looks like. And so, I think that's really important to grounding our conversation. And I also think that it's a good segue into the concept of ableism, because you can't talk about disability at that 101 level without really understanding the discrimination that disabled people experience. And I often think about it as disability being on the margins of marginalization in so many ways.

Ableism is often the forgotten ism. And I want to bring it to the forefront and talk a little bit both about how you experience it day to day, but also if we could talk about it more broadly and systemically, I think it would really help people to have an understanding of what exactly we mean when we're talking about different types of discrimination, and for that matter, how they intertwine with discrimination beyond ableism.

Maria Town: So, I want to think about something you said, Emily, and tell you I disagree a little bit. I don't necessarily agree that ableism is the forgotten ism. I think in order to forget something, you have to know about it in the first place. And a lot of people I meet on a regular basis have never heard the word ableism.

Emily Ladau: I think that's a fair point. I think not forgotten, but actually just not even recognized in the first place sometimes. So, I appreciate that perspective quite a bit.

Maria Town: So, ableism is a system of prejudices against disabled people. It's a system that prioritizes people with certain abilities and certain kinds of minds and bodies over others. And one of the things that I think is most important to understand about ableism is that we are all harmed by everybody, whether it's disabled people or non-disabled people. And the reason I say that is because obviously disabled people are harmed by ableism in so many ways, whether it is the lack of accessibility and inclusion in our built environment or our programs, or assumptions that disabled people literally just would not be out and about in a community, because why would we ever leave our homes? But also, ableism creates ideas about disability and desirability, or these ideas that life must be so terrible as a disabled person, that for non-disabled people, when they become disabled, or when they encounter disability, they often have no other way to think about their lives as anything but tragic, and it's terrible.

Ableism contributes to these ideas that it is a bad thing to ask for help and to ask for support. It's connected to this sort of dominance of the idea of being independent, when in reality, we are all interdependent. Ableism also reinforces other forms of prejudice like racism and sexism. When I think about the history of prejudice against Black people in the United States, ableism has been weaponized against Black people to systemically diminish perceptions of intelligence and competency. When I think about hysteria being used as this sort of diagnosis for women who had opinions, and maybe didn't agree with what their husbands or their fathers or their communities were trying to force them to do, that is ableism literally being used by our medical profession and our government to silence women. We still see that today when we're talking about people who are marked as other.

I experience ableism all the time. When I am traveling with a family member or a friend or my partner, people who we interact with, maybe at a restaurant or in the airport or just on the street, will talk to my family member, who they perceive as non-disabled, instead of talking to me about me. I once got into a cab and the cab driver just said, not, "Good morning," not, "Hello," not, "How are you?" But, "You make life look hard."

Emily Ladau: I think that you have pointed to such a broad range of ways that ableism can show up in our day-to-day lives. And I think a lot of people don't think about it. And so when you start to point out that ableism is pervasive in employment spaces, in education spaces, in transportation spaces, in healthcare spaces, you name it, then I think we can begin to recognize that there is work to be done to dismantle it, and to really create a world that is actually equitable for disabled people. And I want to just take the pulse from you right now of what issues you think people who are just learning about disability should be paying attention to. I mean, in my ideal world, the answer would be every issue because, as you've brought up before, every issue is a disability issue. But if there are a few things that people who are newer to this space could really focus in on, what would that look like for you?

Maria Town: That's such a great question, and I'm going to go back actually to the previous one, because, I don't know how this example wasn't top of mind, but especially right now as we are still in the COVID pandemic, we're in the fourth year, we have seen such rampant ableism. And honestly, Emily, I think the reason it wasn't top of mind is because I've had to compartmentalize so much so I can continue getting up and going to work every day. But when we see people like the Center for Disease Control director say, in an interview with Good Morning America, "Oh, the death rates from COVID are low, and we're really seeing that the primary death rate has been with people who've have preexisting conditions, but that's okay. They were ill anyway." And that's not the direct quote, but it was something like that. It is just, to me, the epitome of ableism to think that the lives of disabled people are disposable, and we have seen that day in and day out during the COVID pandemic, and we will continue to see that.

And to bring it into your next question, instead of focusing on issues, I want to encourage listeners to interrogate their own assumptions, because I think when you start doing that, you can begin to connect disability to a wide variety of issues. So, when you think about disability, do you automatically think, "Oh, that must suck"? Or, "That must stink"? Or, "It must really bother them," right? Is that your first reaction? Is your first reaction, "Oh, I would never want to live like that"? Ask yourself why. Is it because of the disability, or is it because the systems that we have created, that we require disabled people to engage with, are hostile to our very being? When you think about disability, do you think that it would be better for people with disabilities to live in communities where they can be safe rather than living in homes with our families, who we love? Why is that? Ask yourself why. Is it because of the disability, or is it because we have created a world where it is so hard for people to thrive? And if that's your realization, how do we change it?

Emily Ladau: So, I think that this beautifully ties everything together, but I want to know, if you could boil it down to one or two sentences, recognizing that there is still so much that needs to happen globally, but also, for the sake of this podcast, within the philanthropic sector, to really ensure that we're moving in the right direction to a more equitable and inclusive and accessible world, do you have a final call to action.

Maria Town: Specific to the philanthropic community, my call to action is fund disabled people and fund work that advances disability rights and justice. Direct service work is incredibly important, and that needs to be continually funded. But if we do not also have funding that advances rights, community organizing, movement-building, and the pursuit of social justice from a disability lens, we will never remake the direct service systems that have dominated the disability space for so long.

Emily Ladau: We are going to, as we get further into the episodes of this show, dive into a lot of the conversation around disability rights and disability justice, and understanding the importance of funding disability, and why it is so essential to acknowledge the ecosystems in which disabled people exist and receive care and support, and acknowledge that interdependence that I know you were talking about before. So, I think that that is a crucial call to action. Fund disabled people, and also fund the people who are doing the care work, who themselves can also be disabled.

So, there's so much to unpack there, but not to worry, because that will come later on in the pipeline of episodes. But in the meantime, I really just wanted to say thank you to you, Maria, for taking the time out to have this conversation. I knew that it would be really, really wide-ranging and expansive, and I appreciate all of the insights that you shared into so many different aspects of the disability experience. And I'd love to know, before we wrap up, where can people find you on social media, and AAPD, so that they can keep their learning going?

Maria Town: Sure. Thank you so much, Emily, for that opportunity. So, people can follow me on social media, on Twitter. I'm @maria\_m\_town. I'm also on Instagram and Facebook at @Mariatown. You can also follow me on LinkedIn. And then, AAPD, you can go to our website, www.aapd.com. @aapd is our Twitter handle, and you can also follow us on Facebook and Instagram.

Emily Ladau: Amazing. Thank you so, so much. And I also want to remind people that disabilityphilanthropy.org, the Disability and Philanthropy Forum, is a publicly-available resource where you can access tons of information about disability issues and the ways that they overlap with other social justice issues. We offer all kinds of primers and insights and guidance, so you are not alone on this journey of learning about disability. And I thank you for taking the time out to listen to this conversation. And once again, I'm Emily Ladau, and this has been another episode of Disability Inclusion Required. Thanks so much for listening.