Emily:

Hello, hello everyone, and welcome to another episode of Disability Inclusion: Required. Today's episode is one that I am so excited about because we are going to be pushing past stereotypical ideas of disability and instead celebrating it. And I often encourage people to recognize that even though we have been socialized to perceive disability in a negative way, it's actually a beautiful culture and a community and an identity. And so that's what we're going to talk about today in honor of Disability Pride Month, which actually takes place every July. And it lines up with the anniversary of the passage of the Americans with Disabilities Act, which happened on July 26th, 1990. So joining me for this conversation are two absolutely incredible people. I'm so thrilled to have them both with me, Ryan Easterly and Justice Shorter. So let's get to it. And I would love to start off by inviting both of our guests to share a little bit about yourselves. And Ryan, let's start with you and then Justice, you can jump right in.

Ryan:

Well, thank you Emily, and I'm so excited to be in conversation with both you and Justice. Hi, everyone. My name is Ryan Easterly. I serve as executive director of the WITH Foundation. I'm also co-chair of the President's Council for Disability Inclusion in Philanthropy. I'm also a Black man with mixed race lived experience. I'm gay and I have disabilities. My disabilities are cerebral palsy, as well as I have a mental health diagnosis. I grew up in Alabama and I always appreciate a good glass of sweet tea.

Justice:

That is a wonderful way to kick us off. And your voice is wonderful and it reminds me of sweet tea, so that is a good deal. Hello everyone. This is Justice Shorter. My point of center when it comes to pride is now and will always be my people. So if I'm introducing myself to you today, I have to start off by saying that I am the granddaughter of two remarkable grandmothers, Leola Daniels Carter and Danny Jahari. I am the daughter of Lily May Carter and Michael Demetrius Shorter. And I show up in this space having been shaped my entire life by Black women with disabilities. And I know this now, but I was unaware of it then at the time because the word disability, it wasn't commonly considered as a multiverse vessel that was kind of capable of carrying the wholeness of who they were and all of their color, their wisdom, their creativity, all of the ways that they showed up.

I'm happy to be in conversation today because we're talking about how the word disability has ballooned and blossomed over the last several years to be more inclusive and incorporating the entirety of who we are. I am a Black blind lesbian woman. The work that I do sits at the intersection of disability, justice, racial justice and disaster justice issues. I go about doing that work in a way that focuses on curation. I curate trainings. I'm a facilitator. I'm a composer of written works. I am a director and dreams caper when folks ask me to come in and to vision a project and to see it through its implementation and its production. So in that way, I have found many nuanced and eclectic opportunities to get out there and to do the work that makes my spirit sane and that more often than not is centered around people of color with disabilities.

Emily:

I think that both of you are going to bring so much richness to this conversation and I really cannot wait to dive in more. But first, I think it's really important for me to recognize and acknowledge that the journey of identifying with disability is very different for every person who is disabled. And so I identify as disabled, but I also exist at this nexus point of privilege and marginalization because I am a white straight woman, but I am also disabled. And so these facets are all very deeply intertwined and impact how I experience the world and how the world perceives me.

I like to remind people that if you've met one disabled person, then you've met one disabled person. And none of us can speak for anyone but ourselves. And so on that note, I think it's really important to uplift each of your journeys. And I'd love to know, I'll go to you first, Ryan, and then Justice, you can jump in again, was there a pivotal moment in your life when you came to embrace disability as part of your identity, when you began to find yourself feeling proud of who you are?

Ryan:

I think for me, I frankly don't remember a time where disability wasn't a part of me. I remember it being discussed in foster care and kind of being teased about by folks in the community and was always very aware of how I was perceived. But I think for me, when I think about pivotal moments in regards to my experiences, I was able to participate in a leadership program in high school called the Alabama Governor's Youth Leadership Forum. That leadership program was specifically for students with disabilities. I think it was through participating in that program that I really began to understand how I could help other folks with disabilities get the support and resources that we needed to survive and thrive. So I think it was at that point that I not only understood disability as part of my identity, but really embraced my role as a disability advocate.

Justice:

Well, I think for me, I started to embrace my disability when I realized that I could not run for myself anymore. When you are faced with a truth that you have previously thought was something that could just be avoided, that could just be maybe tucked away because it is difficult and it is painful, I think if we are going to talk about pride. That is not a conversation. That is the void of understanding what pain and grief looks like because that is so true for many people in terms of their journey towards pride, right? A lot of times people think that it is just a quick leap that you go straight to a position of being celebratory of this new identity that you have. And for many of us who come from various communities that have been historically habitually marginalized, oppressed, that journey is a little bit different.

And for me, it was not something that was readily available, language, nor was it a readily available community for me to tap into. As I said before, I've always been surrounded by individuals who, if I looked back on it today, I would say, "Oh my God, that person had a disability. That person. This person." All of these, I was surrounded the entire time by disability, but the language was not looked upon lovingly, right? It was not something that you lovingly leaned into. It was not until I got older and I realized that I could not avoid it and I started to understand that I had to love this piece of me if I wanted to love me and my totality. And then I started to learn and dig more into disability. And to be quite frank, I didn't see as much as myself represented there because I started learning about the traditional disability rights movements and spaces.

But my goodness, when I broke into the golden chest, that is all of the literature and frameworks around disability justice, that is when all of the colors started to stream in. That is when I truly became a person who was so proud to have a disability because then too with the understanding and the learning came community, right? Because we also can learn in community, "Hey, have you read this book?"

"No, I haven't. Well, what is that about? And then who else do you know and who else is working on these types of issues?" when the community was created. When I also started to connect with other young Black, vivacious, amazing, fun, loving young people like myself at the time with disabilities, that is when things truly started to take shape for me in such a beautiful way. And I have to shout it out because Care Work: Dreaming Disability Justice by Leah Lakshmi Piepzna-Samarasinha, that book was absolutely pivotal for me. I have been steadily making my way along the edges of my journey for many years before that, but that book shifted something deep inside of me and has kind of continued me on my journey. It's a wonderful point of reference for people. If you have not already read it, please feel free to dive in. There's so many great works out there now, and that in and of itself is just simply wonderful. It's just wonderful in every respect for it.

Emily:

Justice, I'm so glad that you shouted out Care Work. I think that it's really crucial for people who are listening who may be at different points on this journey of understanding disability as an identity and as a community and as a culture to have a reference point, and I can honestly think of no better one. And also so much of what you named really struck me in the sense that I also was surrounded by disability growing up, and yet I didn't have that language of what it meant to be proud and to embrace it as part of who I was. And it wasn't until I started connecting with other disabled people and realizing that this is not something to hide away, to push away from myself, that I made this transition, if you will, into respecting myself. It's not always loving the experience because definitely you named that there's pain there, but also understanding that I am allowed to be proud of myself in a world that doesn't always give you that permission.

Justice:

Absolutely. Absolutely. And I'll let Ryan chime in and then I'll come back in with an additional thought on that point in particular.

Emily:

Ryan, you're welcome to add any thoughts that you might have. Otherwise, I have many more questions for you too. I know you have so many insights to share.

Ryan:

Go right along. I'm just thinking a lot about disability culture and kind of the role it also plays in embracing disability identity. I think for me, if it's okay, I'm just going to share kind of what I'm thinking.

Emily:

Please do.

Ryan:

I think when we think about culture, it's important to understand that disabled people are more than the rights we fight for. And when it comes to culture, that really it is disability culture that allows us the environment to embrace our identities and also understand that we're more than using ramps or having access to interpreters or communication and devices. It's really about those environments where we can be our full vibrant selves and come into community and have spaces where we have an understanding and our appreciation for the long legacy that people with disabilities have in being innovators in the ways that we impact our communities, our families, our loved ones. Really disability culture is where we use our lived experiences to create beautiful work, whether it's artistic or otherwise, and really where we enhance communities and also develop lifelong friendships. So many folks I know like Justice and like you, Emily, you continually challenge me to do more, to grow an understanding of myself and to support others in helping to understand themselves. And that's really... You can only have those environments when you engage in discipline culture. That's what's-

Justice:

I agree with this. I agree with this. As I'm listening to Ryan, I am thinking of all of the different ways that we capture and we chronicle culture. And I even think about that from the perspective of oral histories because I tend to lean towards things that are audible. It is my medium of choice, but I think about all of the oral histories, and it is a project that I'm really eager to work on at some point in the future.

But I think about all of the everyday stories, the stories that aren't necessarily heralded in history books or in documentaries already, but the everyday stories of people like my mother and my grandmother, people like my aunts and my uncles, all of the different folks who have their own survival stories, all of the folks who have their own strategies for how they have made it through. I think that that has to be captured as a part of the story because you might look at it and think that, "Oh, that's just Black culture or that's just Latinx culture." But understand that none of us are just any one singular issue, which of course disability justice focuses on as well, right?

None of us live single-issue lives as Audrey Lorde would say. And so because of that, I'm interested so much in understanding and unpacking and amplifying the experiences, the oral histories of Black people, of Latinx folks, of Asian folks who you, again, just you would never know, you would never know their names, but they have raised the generation that we are now or the generation that raised us. I think that it's just so important to understand the majesty and the magic that is within the stories that they hold, the strategies that they have devised. They matter as well, right? That is also a part of this culture.

And as Ryan was just mentioning, sometimes we get really rigid in the right space. Like if we're not pushing for a specific piece of legislation, then it's not worthy of conversation. If we're not pushing for a particular policy, then it's not worthy of us focusing in on it. That's not necessarily disability culture. But my grandmother figuring out how to raise six kids in Chicago when she came up during the Great migration and not being able to read, that to me is a story that I want to hear about. You know what I mean? That is a story that I want to focus on. Her body enduring all types of disabilities because of the labor, the physical labor that she had to do in order to support those children. That is what matters to me. I have never known my grandmother without some sort of disability.

I want to hear those types of stories because that matters. It may not have led to a particular piece of policy or legislation, but it birthed me. I am here because of her, and that matters. And that's also a part of the culture. So if we're having any sort of conversation about culture and it leads to or commands or conveys that we have to erase people like that, then that's not a conversation that I'm going to be in. And so I love more rich and robust and nuanced discussions like the ones that we're having today because I think it will fully encompasses what we are striving to be as a community.

Ryan:

And Justice, I want to just echo that I want to hear more of those stories as well, and I so appreciate this conversation. I do want to take a moment to uplift some of the oral history work that Alice Wong with the Disability Project has done in collecting some of those stories.

Justice:

Absolutely.

Ryan:

But the more we can uplift the experiences of people bringing all their identities, talking about their full experiences, the better I think we are as a society. So I can only say amen to everything you've just said.

Justice:

We need as much as we can get. And this is so true. Alice Wong has paved the way in so many extraordinary ways, and it's simply spectacular. Absolutely. And lifting up the work that she does. And I agree. Just as much as we can, I sometimes think about this in terms of other communities and other groups out there. Sometimes when I talk to someone, they'll say, "Well, there's this one project out there." And I'm like, "Yes, but there should be many. There should be many. There's so many of us. There's so many entryways that we can go through. There's so many different rabbit holes we can climb into and explore. There's just so much out there." The success of what Alice Wong has done should only be a additional evidence and proof that there's just so much more to do. It has already been done in a way that is exceptional. It has shown the world, because our work is known worldwide, what this community is made of and the importance of oral histories. And I look forward to the continuation of that work and in any shape or form, absolutely.

Emily:

As somebody who is also very passionate about the storytelling aspect, I am just excited to hear you both so jazzed about that because I think that is really the crux of culture as you both named. We're so quick to reduce disability to diagnosis, to barriers to stereotypes and stigma. And we forget that there's so many beautiful stories of each person's experience as someone with a disability. I think that the culture exists within the nuance. So I'm grateful to both of you for talking more about that.

And I also want to make sure that we are uplifting the concept of what's known as disabled joy. As we are celebrating disability pride month, we need to talk about what it means to experience joy within disability culture, within the disability community. And disabled joy is a concept that Sandy Ho, who is the program director of the Disability Inclusion Fund, talks about really, really often. And I think it's such a beautiful concept. So I'd love to know, and I will turn it first to you, Ryan, and then to Justice, what does disabled joy mean to you? I'd love to know how you seek it out, but then also how do you navigate the moments that may not feel so joyful?

Ryan:

I want to start by just acknowledging that I feel like I'm on my own journey in regards to disabled joy. As someone who's led the life that I have who's multi marginalized, there aren't many times where I don't remember being in some kind of struggle trying to meet some kind of challenge. So I acknowledge that I am more of a person who can be a little bit of a pessimist, can wait for the other shoe to fall. So it is something that I'm on my own personal journey regarding.

But I think for me, the things that I find helpful are thinking about disability joy as those opportunities to be in community with other disabled folks to share closeness and kind of have that open, honest, frank discussion as well as more recently understanding that sometimes when we think about joy and think about concepts like self-care, we think of it, I need to do this. But sometimes disabled joy and self-care is giving yourself the permission to do nothing, to just rest. Our bodies need rest. Our value is more than what we produce. So it's allowing myself the opportunity to fill the joy in the moments that I don't have to produce. But I'm very curious to hear Justice's thoughts and I know being around Justice helps me feel more joy.

Justice:

I appreciate you so, so much, Ryan. I think first off, when you talk about rest, I have to lift up the work of Tricia Hersey. If you have not already, folks listening, checked out her book Rest Is Resistance, I highly encourage you to do so. She really goes deep into all of those different layers that people sometimes consider and sometimes don't when it comes to resting and how much of that is a requisite in order for us to survive and live into the lives that we want. So I'm so happy that you mentioned rest, Ryan.

I get joy in a lot of ways. I get joy by having conversations with organizations and getting them to agree to making sure that other people of color with disabilities are going to be prioritized and going to be a part of the conversation. I get joy out of making sure that the budgets are in alignment in ways that are going to pay people for their contributions. That gives me joy because I also get calls and I'm in conversations with the people who are on the receiving end of that, and they are just so jubilant about the fact that someone is continuing to support and to serve as a buffer so that they don't have to do it because it can be exhausting to have to constantly advocate that you get paid to contribute to something that everybody else who's on the project is also already being paid for, right?

So the partnerships and the participation is a key thing for me, and I'm always advocating. And that is a practice of interdependence for me, which is another principle of disability justice. So if I'm entering into a new partnership with a client or organization, one of the things that I'm always curious about is what other pathways will exist for partnerships with other individuals or other organizations? And then also what do those pathways look like for people who will contribute their participation to the initiative? Because again, much of my work centers on communities of color, so I have to always be thinking about that. And when I succeed, oh my goodness, the seeds of joy are just blossoming all over the place and I am ecstatic about it.

I think about joy and I think about this in terms of pride because I just concluded a wonderful Black Pride celebratory weekend not too long ago in Washington DC. There was so much pride in simply dancing with my fiance. There was so much pride in listening to wonderful poets and finding out that there's sign language interpreters who are up on the stage. But with that pride, there was also a pairing there that took place because it was paired with a bit of pain in the sense that when I asked multiple times, "Were there other people with visible disabilities present?" the response that I received was, "No."

Now hear me clearly. That does not mean that other people with disabilities were not there, but visible disabilities were not present as much. A lot of the locations were inaccessible. And that is something that propels me a bit. It fuels me because one thing that I am also hoping, again, I kind of dream my projects into it existence, so I put it out in the atmosphere. And one of the other things that I'm hoping to work on in the near future is to connect with these groups who do pride work, to make sure that they understand that accessibility is not just sign language interpreters, right? It's also making sure that we have accessible games if there's going to be a recess event, that there are alternative options for people to participate who can't physically show up to the space.

COVID is still a real issue. A lot of events took place outside, but some of these locations we're just fiercely inaccessible. So making sure that there's some alternatives, there's some additional access, accommodations that are provided, and that information is readily available that people do not have to go dig through every single event to hopefully find a contact that will hopefully have the contact information for somebody else who can point them to where they can receive additional assistance. The atmosphere is so communal, the atmosphere is so loving. The seeds are there. We just need to continue to provide them with nourishment and nutrients so that hopefully we can grow additional access into those spaces. That really matters to me.

So I think a lot of that, it kind of encompasses my joy, kind of understanding where my passion points are, understanding how we can continue working with each other and community, how we can do, as Dr. Angelou once said, "I come as one, but I stand as 10,000." So when I come into a space, it's not just me. It's the people who will come after me. It's the people who came before me, and it's the people who are right beside me, my peers. All of that matters and all of that gives me so much joy.

And I can go on and on and on about this. Before we wrap, I may come back around to the joy point again, but I do want to be mindful of your time. But there's just endless, I think, outlets of joy for me. And that does not mean that there are not also several critical points of pain and grief. I have to be very clear about that. But these things are not mutually exclusive. They exist on the same plane for many of us. But the existence of pain does not mean that there is no pleasure that is present. And so Ross Gay, who is a wonderful poet who I love, says that grief is really the metabolization of change. And I love that because so much has changed for so many of us over these last several years. So many of us are grieving in so many ways, and so we are grieving as we also grow into our joy. And that's important to acknowledge.

Emily:

I want to thank both of you for acknowledging the complexity of what disabled joy looks like. And I think that so often when we are talking about these big, broad concepts, we can fall into the trap of being very reductive, but joy does not exist in a vacuum and pain does not exist in a vacuum. And so often these emotions are deeply, deeply intertwined when it comes to the disability experience and when it comes to the experience of holding multiple marginalized identities. I think that as we seek out joy, we also need to recognize that there is still so much inaccessibility and so much ableism that is prevalent and pervasive. And we need to call that out and we need to take action on that and recognize that none of us are perfect and we're all still learning and growing and doing the best that we can, but there's so much more to be done.

And so I'd love if each of you could touch upon what you think needs to happen, particularly across the philanthropic sector to ensure that we are moving in the right direction, not just towards disability inclusion of the nice concept of the buzzword, but really towards embracing disability pride, disability culture, moving towards disability justice. What message, what call to action would you like to leave our listeners with in reflecting on Disability Pride? And Ryan, I will start with you. And I'd love if you could also touch a little bit on your role in philanthropy and your connection to that and also to the work of disability and philanthropy specifically. And then I'll turn it over again to you, Justice, to close us out.

Ryan:

I think for me, when I think about the message that I'm hoping our listeners will leave with today, I'm hoping that our peers and philanthropy will be aware of the pitfalls of the charity model associated with disability. You've heard today a lot about the variety of experiences that we as disabled people, especially as disabled BIPOC people have, and we need to move beyond just the charity model of disability and truly move towards embracing a disability justice framework. I'm hoping that my peers in philanthropy will move towards supporting the good work that is happening by and for disabled people, especially BIPOC disabled people, find ways to fund the work that is already happening. It's happening in your communities right now. You've heard from myself, Justice and Emily, and we are lucky today in that we have ways to share our experiences and share our stories. But there are plenty of Ryans, Justice, and Emilys in communities that don't have the platforms, but that doesn't make their experiences and their stories any less powerful. So know that this work is happening, others are doing it. You just need to support it.

And lastly, I would say that in addition to doing this work in terms of our funding priorities and our funding practices, I hope we're also doing the work internally so that we're making sure that as funding organizations, we're allowing people to feel comfortable in sharing their identities and experiences in the work, and that we as funders can move towards if you happen to be a funder that has ever said, "I don't do disability, or we don't do disability," that that stops because there's no aspect of any issue, identity or community that we as funders care about that disability doesn't touch on. So hopefully, in addition to all the great things you take away that that's among them. But again, I want to turn it over to Justice because she is such a powerful advocate, and I'm sure will say much more important things than I shared.

Justice:

Not a chance. You and I are both equally dropping things that are on our heart, things that we've been holding in our hands and in our minds. So I am so deeply appreciative of you and the conversation that we've had today.

Listen, if I'm going to leave folks with anything, I would say this, invest in people with disabilities, being outside and being a part of nature and being a part of this world. There are so many nature and eco kind of environmental projects and initiatives. And again, people will say, "Well, there's a few" different disabilities specific organizations that focus on environmental issues and getting people out to enjoy nature in the same breath that we're trying to preserve it, but also out there to enjoy it, simultaneously enjoy it. And I for one, just, I want more. I want more because I'm moving in the spirit of abundance.

And for so many of us, we have been restricted to one or two options. "Well, if you live in this city, you might be able to get these resources. You might be able to get these benefits. If only you went to that school, that one school may be in your county or in your district that had that service, that had that person on staff who could really help, maybe you would be in a different position or maybe you would be so lucky." And I completely move against that type of mentality. I want there to be an abundance of options, especially for communities of color, many of whom are dealing with the worst in terms of all of the residual impacts of environmental inequities and racism and ableism, so on and so forth.

And so really, a huge push around the disaster justice, environmental justice work that I do is focusing on, yes, we need to be addressing these issues systemically because they are structurally violent in terms of the impact that they have on these communities, but we also need to be making a concerted effort to make sure that we are creating spaces for people to enjoy nature as well in an accessible way. Because goodness, we deserve to [inaudible 00:35:30] amongst the flowers. We deserve riverboat rides. We deserve to touch waterfalls as well. We deserve to sit in the serenity of trees. We deserve that as well. So I cannot echo that enough.

If we're talking to funders, my message is simply this, invest in disabled dreams and do that without strengths. If you are going to do anything, do with my friend Ericka Reil says. She works with me on the National Human Trafficking and Disabilities Work Group. She says we should be doing check-ins, not checklists. So if we're going to fund a group, fund the group, fund the individual, fund the dream, but let people have the space to grow into whatever it is that they are working on. And if someone is not as successful as envision themselves being, do not label that as failure. Do not completely crush their enthusiasm by saying, "You didn't meet this benchmark. You didn't meet that benchmark." Because we are all trying.

And I guarantee you, if you look at some of the track records of many of our large national, international organizations, you will see that many of them also struggle despite being very well-resourced and well-staffed, right? So we need to not hold small groups, sometimes even informal groups or individuals or smaller organizations to these unrealistic expectations that they have to constantly be seeking out perfection, right? We are all in practice. So if you are an individual listening to this message, my goodness, my message to you is to continue your practice, continue your practice, because as Mariame Kaba tells us, hope is a discipline and we are all in the steady practice of it every single day.

I hope to join you in practice in some way, shape, or form. I hope that our contact information will be available. So if there's ways that we can support the wonderful work that you all are doing, do not hesitate to let me know because that is what it is all about. Thanks so much.

Emily:

I wish I could just end it right there and not even have to wrap it up because everything you said was mic drop after mic drop. Truly both of you, I'm so grateful. And yes, we will make sure to share in the show notes ways that people can connect with both of you and also learn more about the vital work that you both are doing.

I just want to wrap up by saying that what I heard so powerfully from both of you is that disabled people belong everywhere and every issue is a disability issue. We have just as much of a right to take up space and to experience joy and to celebrate the experience of being alive as much as anybody else. And so I couldn't think of a better group to have a conversation with than the two of you to talk about Disability Pride. I am so grateful for your time. I'm grateful to everyone who took the time to join us for this conversation today, and I wish you a fantastic Disability Pride Month. I'm so grateful that you took time out to listen to this episode of Disability Inclusion: Required. And to keep your learning journey going, you can visit disabilityphilanthropy.org. Until next time, I'm Emily Ladau. Thanks so much for listening.