

MUSIC:

Disability Inclusion Required.

JUSTICE SHORTER:

Greetings everyone, and welcome back to the Disability Inclusion Required Podcast. The voice you're hearing now is not altogether new. I am Justice Shorter and I was with you a while ago on a previous episode. Today I join you as the host of this next season. Sincere appreciation to our phenomenal former host, Emily Ladau. We have so much in store for you in 2025, but before we get there, let's settle in right here because today I am joined by two wonderful guests, Nikki Brown Booker and Yolanda Vargas. Since October is National Disability Employment Awareness Month, we wanted to explore what it means to work while disabled in 2024. Let's get into it.

Yolanda and Nikki, thank you so much for joining us on the pod. Can you both give us an introduction and tell us who you are? By way of this question, what is the work you feel most called to do in this world and why? And we can start off with you, Yolanda, if you're comfortable.

YOLANDA VARGAS:

Yeah. Hi. My name is Yolanda Vargas. My pronouns are she or hers. The work that I feel most called to do ...A big chunk of my life has been focused on, and now that I'm in a better place in my life, I feel called to protect the people that I love and leave the world a little bit better for them after I'm gone. And that just leads me to take any avenue that hopefully helps me make the world a little bit better.

JUSTICE SHORTER:

And Nikki, how about you?

NIKKI BROWN-BOOKER:

Hi. I'm Nikki Brown Booker. I am the program officer for the Disability Inclusion Fund. And my pronouns are she/her. And I guess what calls me ... Such a good question. I really feel that I've had a couple of different callings in my lifetime, but the one thing that they all have in common is to actually really not only to try to make the world a better place, but to make sure that people with disabilities get what they need and really to try and give back to the community. So before I was in this position ... I'm actually a licensed marriage and family therapist, and I really felt really called to be a therapist early in my career because so many people with disabilities didn't have really good access to good therapeutic services that were actually appropriate to them and their needs. So I feel like that was one way that was a calling for me back then. And now in my current position, I feel like I'm really being called to service the community and find ways that I can really give back to the community that I've been a part of my whole life. And as a person with a disability and a person of color.

JUSTICE SHORTER:

Nikki, you have worked alongside folks at Hand in Hand and all of the phenomenal work that they have been doing over many years. I want to start off with these words from Hand in Hand. There is often not a clear distinction between caregivers and care receivers. Many disabled employers of domestic workers are also caregivers for family members, partners or members of their communities. Disabled employers also have a range of different relationships to attendant services into the care work industry. As do domestic workers. Honoring our intersections at the point of connections and who we are is a critical part of seeking Justice. Nikki, can you share a bit more about the importance of understanding care recipients as employers? And could you also explain how domestic worker rights are inextricable from disability rights?

NIKKI BROWN-BOOKER:

Yes. Absolutely. I love this question because I think that people don't often really think about care in this way. They often think about just the caregiver. But when you're the recipient of the care that someone is giving, you also are directing them into providing you appropriate care. And I've been an attendant care employer since I was like 18 years old and I'm 58 now. So this has been a really important part of my life. And so often as a recipient, we're not really taught how to actually supervise people and how to direct your care, and also how to really develop a strong relationship with your care provider. And I think that is so crucial to actually having a good relationship with the person who's providing care for you.

And domestic work is really ... You can't separate the work, honestly. So if my provider is giving me really good care and I want to make sure that they get really good benefits, that they get really good pay because if they are getting the things that they need, they're able to actually provide much better care for me. And also as a person with a disability, I deserve to get really good care and I deserve to get all the things that I need. And so I think the relationship is just so integral to each other. You can't really separate those relationships from each other. And I just think that people will try to separate they're a caregiver or that person is just receiving care. But that relationship is just so integral and I really feel that people really need to understand that. And domestic workers are not just providing care for people with disabilities, but they're also cleaning people's homes and taking care of people's children. And those are deep and important relationships and there's no way to really separate those two out from each other.

JUSTICE SHORTER:

Absolutely. And the reason why I started with that quote, the reason why I love it is because it acknowledges the overlap between the two. So often people with disabilities are also domestic workers. Many domestic workers have acquired disabilities along the way by nature of the work that they do, which can sometimes be very physically taxing on the body, but also mentally and emotionally taxing as well depending on the circumstances. And so it's really important just to acknowledge and echo precisely what you said. That they are connected and there's no way to separate or sever them. Unfortunately though often that work is erased or it is considered sometimes within the shadow economy, sometimes it is altogether invisibilized. And as a result

of that, I want to unspool that thread just a little bit in terms of talking about work that is invisibilized. Yolanda, I want to bring you into the conversation. Each day, disabled folks devote hours to crowdfunding and resource sharing in hopes of saving their own lives and the lives of those they love. Can you talk to us a little bit more about what funders could learn from such laborers of love?

YOLANDA VARGAS:

Yeah. I think a lot of funders don't realize how close most disabled people, especially those that are multiply marginalized ... In the community, we joke about constantly just sharing the same \$25 around so that people can buy groceries or cover their light bill or whatever or cover that overdraft fee. And I think funders come into it with a mindset that they have of like, oh, this is a mission. This is something that you should do for the love of your community. And it totally is you should be doing that. I hope people do feel that. But we also have to survive. So for every funder that's ever contracted somebody and been like, oh yeah, really vague on the details of how you're going to pay them, please be more upfront with that. But also uplift people so that when you give them opportunities to do input on your projects, that you're building connections with them and bringing them into different projects and building your network in that way and letting them recommend people because you're not hiring one person, you're hiring their community and every person that's touched and shaped their point of view.

So really consider investing into the communities that you're funding beyond just giving them money for projects. Like how can you uplift and help empower individuals and groups to continue doing that work when you're no longer a direct supporter is something that I would probably say to funders to help alleviate some of that feeling of always being on the edge of that financial cliff.

JUSTICE SHORTER:

There is so much creativity and ingenuity and resourcefulness embedded throughout the disability community, and we display that every single time one of us is going through a crisis or a disaster. Sometimes that's related to health. Sometimes that's related to an actual storm that's brewing somewhere. But often it's related to the everyday ramifications of discrimination and harassment and prejudice that we have to deal with. And so the web of support that we have developed and cultivated to quite literally hold each other up, keep each other housed, keep each other sheltered, keep each other with the medications that we need, it is a marvel to behold. I'm grateful and in awe every time I witness it. And we'll do a future episode ideally that focuses on some of the great work of mutual aid and how that has happened throughout our community.

Nikki, I'm going to come back around to you. I want to talk a more about cross movement organizing and more specifically collective bargaining. What can union organizers learn from disabled folks throughout the community? And vice versa, how can we continue to assure that disability issues are embedded into campaigns for worker rights, irrespective of the industry? Because people with disabilities are everywhere. We work in all types of industries. So how can

we make sure that whoever's formulating a union, whoever's pushing for worker rights, how can we make sure that they're learning from folks with disabilities, they're including us and vice-versa?

NIKKI BROWN-BOOKER:

Such a good question. With my work with Hand in Hand, we worked a lot with union organizers and what I've learned about that work is that we have to work together. I think that sometimes union organizers often get pitted against worker organizers because they're in some ways seem to be on opposite ends. But when you're trying to make sure that people get what they need, you have to really build community with all different sides of the issue. So I really feel like union organizers and disability organizers, sometimes it may feel like they're working at odds with each other, but they're really actually working for the same thing. They really want to see that that workers are getting everything that they need and in turn, the people that they're working for are also getting what they need. And I think it's really important that disability organizers are at the table with union organizers. I think it builds a really strong front to whatever industry that you're trying to ... If you're doing collective bargaining and you have people with disabilities and union organizers at the table together, it's much harder for the other side to try and pick you against each other. And I think that often happens. So try to leverage each other against the other group.

And when you're there together, you're stronger together. That whole idea that you're really building power with each other is so I think really important when you're doing cross-movement organizing. There is no you against me. It's really us together trying to get what we need and that when you're working together, that's going to be your key to actually get the things that you need.

JUSTICE SHORTER:

Absolutely. When I think about unions and I think about a lot of the worker rights issues that are on the table across many different industries, you'll see some commonalities there. You'll see people talking about the right to rest. Having time off, paid time off, talking about bereavement leave, talking about paternity leave and maternity leave policies as well. You have people coming together talking about when they're injured on the job, what is the process? You have people coming together to talk about not being overworked. So this mandate of having to work a certain number of hours under certain types of conditions that continue to wear on the body in ways that are really detrimental long term. So a lot of those worker rights have very serious and clear connections to disability justice works. I love that you made that connection. And that brings us into this discussion around retention and retirement as well. So often conversations around disability employment involves recruitment and basic accommodations, and these things are very crucial. But I'd like to delve a bit deeper by exploring how we can reach new heights to cultivate inclusive workplaces. Yolanda, Can you talk about the importance of equitable pay rates, promotions, and professional development for disabled employees? How can employers avoid the glass cliff phenomenon concerning disabled employees, particularly those who identify as women and as people of color?

YOLANDA VARGAS:

I think it's important for employers to understand where their employees are coming from, especially if you are a person with multiply marginalized identities, being born as a disabled person and a woman and a queer person who's also a person of color. I was raised to take up as little space as possible, to be as accommodating as possible, to be grateful for any scrap of anything that I was given. So I think a lot of people that are learning about the paid disparities for marginalized people and wondering, well, why don't they just ask for more? Or why don't they just step up and do these leadership positions or apply for these things? I don't think they realize how hard it can be to fail. We don't have the ability to fail. We don't have that grace when we fail. Internally we're always holding ourselves to such a high standard that trying something new and going out on a limb is really difficult. And I think employers might not realize that and might not understand that we've never been shown how to do certain things and be assertive and be in leadership positions before.

And so if employers really want to change that whole sticking at entry level when you have a disability not really helping people go farther, they need to recognize that they should approach people with that understanding of like, "Hey, let's start having this conversation. We're welcoming you into our organization now, but where do you want to be in 10 years, 15 years?" And even just between other coworkers, we should all be talking about how much we make. Talking about money is gauche, but it's not. It's how we understand our value within the system of working. And I think that's something that disabled folks don't talk about enough to make sure that we're actually being valued as much as our other non disabled co workers.

There's so many things that can empower us just through ourselves and talking to others that are in similar positions. I think when we think of networking, we think of it as a way to gain connections in the sense of maybe helping our organization and business. But finding somebody with a similar disability or similar life experience and being able to openly and honestly talk about what it's like to work in those positions or these fields can be extremely helpful in helping people grow their skill sets and their knowledge bases. Because those are the kinds of things that you can take with you anywhere. And I think more employers need to be fostering that communication and that positive and healthy networking to make sure that we're not just trying to hit these basic quotas of like, "Okay. We've hired five disabled people this year. Good for us."

How do we really foster meaningful systemic change where disabled folks are not only at entry-level positions, but leading the conversation and leading major businesses and things not related to disability? Because I think a lot of employers or organizations that disabled people apply to tend to be skewed towards disability because it feels safer. But I want disabled folks to be in positions of power everywhere. And I think that needs to be a conversation that everyone should be having. How do we make marginalized people feel supported and have the tools that they need to succeed instead of just feeling like we need to put somebody as a face of diversity in an overwhelming and often difficult situation and then be surprised that they fail? I think that pattern needs to change.

JUSTICE SHORTER:

I want to throw a spotlight on two gems that really shine and stick out to me based on some of the things that you said. One, I want to put an emphasis on your encouragement to folks to network across as opposed to just networking upward. So the idea that you should build amongst the people around you, people who are also on your level, also those who are on levels that you hope to reach one day. But hearing you say that absolutely reminds me of this very popular and viral clip of the great philosopher Issa Rae, who is a wonderful Hollywood powerhouse producer, director, writer. But she says something very similar in that the way that she came up, the way that she was able to get amazing projects off the ground to even be considered by Hollywood bigwigs was to work with the people who were surrounding her. Her friends, her colleagues, folks she went to school with. But creating those networks and moving across those different circles was really invaluable. And then the piece that you mentioned as you closed about setting folks up to fail.

Earlier in your statement you talked about the conditions in which people with disabilities are brought into an organization. And this is precisely what that glass cliff phenomenon is all about. Bringing people of color, bringing women into leadership positions under conditions of crisis and expecting them to work a miracle. And if they do not, it is somehow representative of the fact that see people with disabilities, people of color, women can't do it to begin with. We're going to only give you an opportunity when things are literally crumbling around us in an organization. Perhaps budgetarily, we're losing money, perhaps we're losing staff. Perhaps there has been a major scandal that has happened and instead of stabilizing the ship and giving you as much support as possible, we're going to put you in leadership and hope that you work a miracle. And those conditions are completely unfair and they do not create the type of foundation that we need to build wonderful policies and practices and programs off of. And so we want to make sure people with disabilities ... We're talking about inclusion. It's not just putting someone in a position of leadership when it is convenient and when nobody else wants the job. It is to put folks in leadership positions when we also know that we can provide them with the support and the resources that they need to succeed.

Nikki, I'm coming back over to you. Can you talk to us about some of the psychological stressors? Because being set up in a position when an organization is in crisis, it can be really, really difficult and hard on the mind and the body. So can you talk to us a little bit about the psychological stressors and strains? These implications, the psychological implications of working in an ableist work environment. How can disabled employees protect their body minds and how can employers root out and help resolve ableist practices and policies?

NIKKI BROWN-BOOKER:

As an employee who's worked at lots of different levels, I've been on the ground I remember my first job being in an environment in which I was the only person with a disability, and in fact, actually the only person of color, let alone a person with a disability. And those things they start to wear on you. When you don't feel like people really get you and understand you when you're in these environments that other people who are not disabled will often treat you as if ... One of

my big experiences in working field is being treated like a child, even though I am doing the same work or even doing work beyond the work that another person is doing and some other experiences that I've had working is that you just always have to feel like you have to be better than everyone else. You have to work harder than anyone else because for many employment places, you might be the only person that looks like you, that isn't in a wheelchair or a person of color, and you don't want to fail because you don't want your employer to then say, "Oh, well they didn't do it, so why should we hire another person with a disability? Or why should we hire another person of color with a disability if they can't handle it?"

So there's always that thing on your back where you're always trying to work harder, work smarter all the time. Just so you set the best example of what a good employee could be. And that really wears on your body. It wears on your mind. It's sometimes hard to go home and relax. You start thinking about your day over and over again. Oh, I should have did this. I could have did that better. They might see me differently because I wasn't able to complete that job faster than anybody else or meet that deadline. And we're workers just like anybody else. We have our own ... Nobody's perfect and nobody can be perfect. So it is one of those things where you have to tell yourself, I'm going to do the best that I can. And I think employers really have a responsibility to make sure that you get the things that you need. Sometimes it's really simple like just making sure that your desk is at the right height and that you have all the things that you can reach on your desk, which is a reasonable accommodation that employer can provide to make your work experience the best work experience it could be. But so many employers are still really resistant to actually building out the accommodations that people need. Those are all ableist policies and practices that really need to change.

And I feel like employers can actually ... You could partner with your employer and your employer should be partnering with you to make sure that you get what you need and that you can do the best job that you can do, that you have all the supports in place. And they should do that for all of their employees, let alone their employee with a disability. I feel like labor is, sometimes employers forget that their employees are really doing the work. They sometimes treat people, they don't count that they're not meaningful, and they forget that your employees are really the backbone of your workplace. And it's really just about the money and making money off of the back employees. And I think that as a disabled person, you really have to not take that ownership but actually put that ownership back on the employer to make sure that you're getting what you need in order to do the best job that you can.

JUSTICE SHORTER:

Giving people what they need. I mentioned before that we were going to focus a little bit on retention, but also retirement. Yolanda, how can funders invest in disabled retirees or disabled folks over 65 who still have budding ideas and new career goals? How can funders and how can we collectively continue to advocate for a world where disabled elders do not have to work until their last days because many people cannot afford to stop working?

YOLANDA VARGAS:

Yeah. Full disclosure, I am not an elder currently, but I had the privilege of having an old dad, which was something wild and wonderful to see and experience. So he really made me think about what my life would be like as I got older, even from the beginning because he was not a spring chicken, and I mean that in the best way. But he was a person that immigrated to America and started his own business and had a third grade education and had nine kids and was always working hand to mouth. And then he had a stroke. And I'm sure there are people out there listening to this that have their own business, but oftentimes when you have your own business, there is no safety net, there is no insurance, there is no 401k, especially when you're a mechanic with a third grade education.

So his life changed but I don't think he ever really wanted to stop working and he didn't. He worked up until his very last days. And I think that's something important to recognize. That everyone has something that drives them, that gives their life meaning and purpose, and all people deserve to experience that. And if that's working for them, they should hopefully be able to work because they want to and not because they need to survive. And I think that's a failing of society that so many people don't have the ability to save, and we're all just trying to survive. But yeah, my dad constantly loved work, but I wish he could have had a safety net. And it makes me think about disabled elders in particular where not only do they not have a safety net, they've never seen anyone like them live the life that they have the opportunities to live. Because their disabled elders were often institutionalized, barred from even having employment because of lack of accessible transportation, hospital settings that actually understand disability. All of these things that now make working until 65 and being disabled possible is so new to everyone. And now we have the opportunity to do what we want maybe in our golden years. That's such a wonderful thing for them, that in a lot of ways the world has changed for the better for disabled folks and also to employers.

It's important to note that maybe some older disabled folks don't identify as disabled themselves, and that's fine. They're just people that navigate the world differently to them and maybe they don't claim that title. But I think people need to realize that they're a driving force and they still have things they need to do and things they want to do. And how do we pull away from focusing on youth and planning for this whole life and how do we move to planning for older folks and uplifting them?

How do we support them? Because I often don't see a lot of early development leadership development geared towards older folks. It often has an age limit, which for the disability community in general doesn't really work because we all start the journey of adulthood ... And I'm using air quotes at different times in our lives because disability impacts how we see ourselves and how we navigate the world. So especially for older folks that have all of this trauma of being secluded and looked down on and now have the opportunity to live the lives that they want, how do we appreciate all of this passion that they have stored up into themselves? And I think it's just by giving them not only support but variety. Helping them find what their endeavors are. Maybe they finally get to delve into being more artistic or maybe they really actually loved math and wanted to be an accountant. Why not be 65 and start working as an actuary?

There's so many things that we can do, but as far as what we can do to help people that are soon to be retiring, it's hard because I think most of the information that we have around that is focused on the idea of planning for retirement when you're young, but not everybody has that luxury. So I think if I were to say to employers, how can you uplift this? Maybe have direct funding into helping people pursue their passions later in life. Take a chance on older folks, but also maybe create some additional benefits that would allow them to have a bit more savings in some way that you could trade off. But I think to discount the older community within the disability community is a mistake. And it's also something that makes me so sad because so many of our loved ones don't get to make it to 65. So I really want the people that do to have the best life possible.

JUSTICE SHORTER:

Likewise. Likewise. I am going to invite you Nikki to join in on this very question. It'll be the last question that I asked really before I invite you all to also do some collective future weaving with me as we close out today's episode. But before we do that, Nikki, you mentioned at the top of our conversation that you were 58, so you are closer to that threshold of retirement than Yolanda is as she mentioned. But I wonder if you have any perspectives on this and if you could perhaps link that to wider ideas that we have around deservedness and worthiness and entitlement and who gets the opportunity to work because they want to and who is expected to simply work until they can't work anymore? Any thoughts on that?

NIKKI BROWN-BOOKER:

Yes. I'm actually really thinking about this question really hard right now because of my age and starting to think about how am I going to be able to afford to live after I retire? Because one issue that we actually haven't talked about when you're talking about working is that for people with disabilities is sometimes they have to be really careful about not earning too much money because if they're on any type of Medi-Cal or benefits related to their disability, then there's a disincentive to make too much money so that you don't get thrown off of benefits. And so it's really hard to actually think about retiring if you're concerned about having the money that you need in order to retire.

And I don't know anybody who can live off of social security when they retire. It's so little, such a small amount of money that they receive, and you end up having people that are in their 70s and 80s literally having to decide whether to eat something that day or to pay a bill because they can't live off of their social security benefits. So my mother just turned 92 years old and she stopped working around 85 or so. But she continued to have to work in order to make sure she could survive, that she could eat, that she could have a place to live. Fortunately, she was able to get a housing subsidy so she could afford to do the things that she needed to do. But even so, my siblings and I supplement her income as an older retiree, and also as many people aged. They develop disabilities, so we have to make sure that she gets all the things that she needs and we supplement her income because she just can't live off of the social security that people get.

So when I'm thinking about retiring, I'm also thinking about how I can save money. And I think going back to the funder issue, I think funders could really help by doing some more research in this area and actually thinking about ways to build economic development for seniors and elders and for people with disabilities, that is so crucial that we don't really have an economic system for people who are older and disabled so that they can not have to make decisions like over paying a bill or eating. If you have made it to 70 or 80 or 90, like my mom, you deserve to be treated ... You deserve everything. Oh, you deserve all your flowers. You've really made it and you're doing ... And you have children, grandchildren, and you've contributed to society for so many years, and we need to really respect that and take care of each other when we get to that stage.

You are talking about this issue of deservedness and worthiness, I feel like in a lot of ways, our society does not really honor our elders, particularly our elders with disabilities in some ways. They just see them as almost as a drain on the system because they're going to need probably more care. And that's not a society that I respect and want to live in, honestly. So I'm always thinking about how we can take care of our elders better, and particularly our elders with disabilities and make them ... They deserve to be treated ... They are the queens and kings. They have lived to become the kings and queens. So you want to make sure that they get all the things that they need.

JUSTICE SHORTER:

Yes. Yes. Yes. Yes. As we dream into a future where people can get all that they need, I invite the both of you to do something that is a bit imaginative with me. We can do some future visioning here just a bit. I only want you all to just take one or two minutes, just one minute or so to help us drop into a scene. We're closing out today's episode, but can you help me complete the scene? You enter into a work environment that is free of ableist limitations. How does it feel? What do you experience? Who do you become when incited to let your gifts grow in such a safe and supportive environment? Yolanda, take just one minute or two to tell us your responses to that.

YOLANDA VARGAS:

Yeah. I think for me, I am in my home. It's working from home. And if I am traveling in abroad and out, it's having the support that I need to know that I'll be okay to do those things. But it's just everybody ... And if I do go into the office, everybody's wearing comfy clothes because you don't really need a blazer. You don't really need uncomfortable shoes. That's just something that we foist upon people to be more professional. And people have snacks by their computers and their emotional support animals, and people can take off days when they need it without feeling like a failure and just everybody's at peace. But also at the same time, their whole life isn't poured into their work. They have things outside of that work and their boundaries are respected. So when it's time to clock out, nobody hits them up for extra work outside of their hours.

JUSTICE SHORTER:

Nikki, do you want to add to this beauty, this beautiful scene that we're crafting?

NIKKI BROWN-BOOKER:

Yes. I envision a workplace where people are really enjoying what they're doing. That they are having fun with each other. That they're throwing ideas around, and everybody's like, "Yeah, that's really great," and everybody's working together towards whatever common cause that their job is as focused on. And that if you're a person with a disability, you have all the access needs that you need, and no one even bats an eye at that. And also that your coworkers are coming to you to hear what you have to say and that your expertise is really valued. To me, I feel like that would be such an amazing workplace. And that everybody is just really cares about each other and is wanting everybody to have a good work situation. That it's not just about one the boss having the best office. It's about everybody having the best space.

JUSTICE SHORTER:

Leah Lakshmi Piepzna-Samarasinh has a wonderful book called *The Future is Disabled* and Erica Alexander, a wonderful actress, has this quote that I always come back to. She says that the past is painful, the present is precarious, but the future will be free. And with dreams and visions like the ones that you all just shared, I have every reason to believe that it will be. Thank you all so much for joining us on today's episode. It has been such a pleasure. Thank you.

NIKKI BROWN-BOOKER:

Thank you.

YOLANDA VARGAS:

Thank you so much.

JUSTICE SHORTER:

If you want to keep your learning journey going, visit the Disability and Philanthropy form at disabilityphilanthropy.org. I'm Justice Shorter, and this has been another episode of Disability Inclusion Required. Thanks so much for tuning in and join us again next time.