Disability Visibility Podcast

Episode 6: Labor, Care Work, & Disabled and Queer Femmes

Guests: Leah Lakshmi Piepzna-Samarasinha and Stacey Milbern

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE: What does it mean to hold space for one another? Why don't people recognize and value the care disabled people provide?

My name is Alice Wong, and I'm the host of the Disability Visibility Podcast, conversations on disability politics, culture, and media.

I read an essay for Bitch Media titled *A Modest Proposal for a Fair Trade Emotional Labor Economy* in July 2017. This piece really got me thinking and resonated with me deeply. The author, Leah Lakshmi Piepzna-Samarasinha, is someone I follow online, and I wanted to reach out to her about it. Several weeks later, my friend, Stacey Milbern, posted something on Facebook on the labor of disabled people. This seemed like a message from the universe that I had to do something on this topic.

In this episode, Leah and Stacey talk about the labor they perform as disabled queer femmes and the gifts we give each other in our community. Are you ready? [electronic beeping] Away we go!

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

ALICE: OK, great. So, I guess welcome to the podcast! Thank you, Leah and Stacey, for joining me. Stacey, why don't you introduce yourself first, and then Leah.

[bouncy music]

STACEY: I'm originally from North Carolina, and I'm living in the Bay now. I'm a queer, disabled, mixed-race woman of color. I've been doing disability justice work with Leah for, I think, at least a decade, maybe.

LEAH: Yeah, and I'm Leah, you, she, and they pronouns. So, my identities are mixed Burger, Tamil Sri Lankan, Irish, and Roma. 42 years old, born in North America, child of an immigrant, disabled, chronically ill, neurodivergent, survivor, working class. I'm a writer and performance artist, and I was super jazzed to be here, super excited about your work. And I love Stacey!

An essay centering disabled femmes of color

ALICE: You know, one of the reasons why I wanted to have this conversation is really based on a piece that you recently wrote, Leah, titled *A Modest Proposal for a Fair Trade Emotional Labor Economy* centered by a disabled femme of color, working class/poor genius. What prompted you to write it, if you don't mind me asking?

LEAH: Oh my god, my whole life [laughs]! One, I feel like I've been a part of a lot of conversations, specifically in femme communities, over the past couple years about the ways in which labor is gendered and queer misogyny playing out in the ways in which femme people in queer communities were really expected to do all of this work of emotional and care labor and how it wasn't often seen as "real work."

[doorbell]

ALICE: Side note: As a person who isn't queer or femme, I appreciated this description of femmes by Leah in her essay. I wanna share it with you. "Femme: A person who has one of a million kinds of queer femme or feminine genders. Part of a multiverse of femme gendered people who have histories and communities in every culture since the dawn of time. A queer gender that often breaks away from white, able bodied, upper middle class, cis ideas of femininity, remixing it to harken to fat or working class or Black or brown or trans or non-binary or disabled or sex worker or other genders of femme to grant strength, vulnerability and power to the person embodying them. A revolutionary gender universe."

LEAH: And a big part of, I don't know, just for me being me in disabled community, specifically disabled community that's filled with disabled queer, trans people of color, is seeing all the care labor and support we give each other that is so invisible to able-bodied people. They have no idea it exists. And as disabled people, we're so used to being seen as people who are just passive recipients of care, you know. We're these helpless cripples. We're burdens. Other people have to take care of us. And the able-bodied world has no idea of how much care disabled folks give to each other, right? So, it's femmes I know who feel really exploited as people who do care labor, emotional work, support work. And if care labor is so important to us as disabled people, what would it mean to create a fair-trade economy? What would it mean to have a world where care labor is this huge thing that's keeping us alive all the time, but where we don't feel ripped off? We don't feel like we're doing all this work, and we don't even get a thank you, and it's not seen as real.

[ambient music break]

Expected labor from disabled queer femmes and holding space

ALICE: As disabled queer femmes, what are some examples of labor that you've been expected to produce by the people around you and by society in general?

STACEY: My brain sometimes works a little bit in chronological order. So, I think about being a young girl, young femme person, and part of what I had to offer is doing a lot of emotional processing and holding space, and it doesn't get seen as labor, of course. But of course it is, and I think a lot of times, people with disabilities--especially femme people--get expected to do all kinds of emotional labor in exchange for access support. And it's not seen as interdependent or even something that we're offering.

This week, I had kind of a little bit of a crisis this week where one of my primary attendants, she quit on Monday without leaving any notice. And usually, to hire an attendant, it's like six weeks of me working really, really intensely. It's just been bringing up a lot around the labor it works to keep myself alive. And I had a really cool experience this week, where my community was able to hold that labor a little bit more. I think something that I was doing in isolation, that people were really holding the emotional weight of processing of a goodbye like that. It's a lot there too.

ALICE: So, Stacey, you mentioned earlier about holding space, but what does that mean to you in terms of what does it look like, and what are some examples of it?

STACEY: Yeah, so something Leah and I have been talking just in the last week is in response to all of these attacks on our community, just the psychological impact that it's really having on folks. I know for myself, I was in such a bad space the last few weeks if Medicaid programs are gutted, and people had to go into institutions. And I really think some of what is holding space is just really witnessing what it means to be disabled in a ableist society. I think what makes ableism so painful is that people are expected to manage impairments and navigate all of these huge systems in isolation and without talking about it, without anyone knowing. And I think one of the best things we have to offer, as disabled people to each other, is just being able to hold the heaviness around all of these complex things. Leah, did you wanna jump in?

LEAH: Yeah, no, totally. I'm really loving listening to you, and you always have such brilliant things to say. I super appreciate it.

But you know, Alice, jumping back to your original question about what are some of the demands that are made on us or that we do, or what is some of the work that we do, and kind of spinning off of what Stacey was saying about holding space too, I mean, I think what Stacey just said about how incredibly stressed out disabled folks have been. I feel like that's just one example of this invisibilized world of disabled labor that is going on all the time that's survival labor, you know?

Some of the places my mind goes are well, in terms of work that I've gotta do, there's the work I have to do to stay alive as my kind of disabled person, which is everything from I'm on Medicaid right now, I'm on Apple Health. And every six months, I've gotta requalify. So, that work that's what Stacey's talking about, it's really seen in ableism as like, oh, that's just this private thing you do; it's not political. But all the work I've got to do to prove that I'm still disabled and to prove that I still deserve access to health care. We have, as disabled people, all this brilliant knowledge about what our bodies and minds need, but we're always in this position of having to prove it to the medical-industrial complex to get the stuff that we need to survive, right?

So, I look back, and I'm like, shit! I've been navigating this world my whole life, whether it's lying about having suicidal ideation so I don't get locked up, or presenting my chronic pain in just the right kind of way where I don't get seen as drug-seeking. And then I think about, I would love to have a vaudeville routine called *Where's the Access Info*, where we're always-- You know, whether it's a supposedly social justice-oriented conference or community space or event, or whether it's a mainstream space, or whether it's even within disabled community, we're always going, "Hey, can you post the access info? Hey! What's the access info? Hey! So, when you say ASL, have you actually confirmed it? When you say it's wheelchair accessible, do you really know that, or are you kind of just making that up or going on what's on the website?" And managing people's feelings of defensiveness or anger or them crying when we ask these questions. Or their surprise and shock when, as disabled people, we get angry.

I'm sure you guys have faced this where there's an event, and X disabled person goes, "Hey, where's the access info?" And maybe the person putting on the event goes, "Oh, yeah! No, totally accessible! There's just four stairs. We'll carry you!" And then, disabled people go, "Hey, actually, that's not OK. That's not accessible." And then, there's a whole bunch of defensiveness around, "We're trying to learn! Why are you so mean?! Why are you being so harsh on us?" And they don't understand that we have gone through this a million times before, and we know that that's not accessible. And we know you can't carry somebody and their 500-pound wheelchair four flights of stairs. That's not access, right?

So, I feel like that's both crip labor and emotional labor at the same time. But I was like, let me just taking note of all the different emotional labor, care labor, and crip labor I do. It's like, text this person who's going through this situation. Text this other person, for this situation. Offer this access hack when I see somebody posting about an experience I share online. Post this fundraiser. Repost this fundraiser [laughs]! Suggest this thing.

You know, a friend of mine was like, "Oh my god. I didn't know I was chemically sensitive, and it turns out I am. I'm having to rewash all of the clothes my grandma washed for me in Tide." And I'm like, "OK, well, if you put in vinegar and baking soda, around a cup and a half, that's gonna help you detox your clothes." That's like 10 things already in half of one day! And then I just kinda gave up because there's just so many, you know?

And it's funny because after the essay came out, I saw a couple of people--I don't think directly in response to the essay--but just kind of talking about these conversations that are happening about emotional labor and care labor. I remember seeing someone be like, "You know, I think it's all bullshit! I don't think it's work to support a friend. That's just something nice that you do." And I'm like, you know, I kind of hear where that person might be coming from. That's the whole thing: It's not labor where you go, and at the end of the day you get a paycheck. You're doing it for free, for the most part. But I think it's very important and interesting when we start talking about it: It's actually work and skilled work. And these are skills that a lot of disabled folks have that able-bodied people don't necessarily have, that we've learned from our experiences of being sick and disabled, you know?

ALICE: Yeah, I think what you said earlier about emotional labor not being the same kind of labor, based on other people's readings of your article. I think that really ties to capitalism and this idea that if you can't quantify it, if you can't put a monetary value on it, somehow, it is not the same as skilled labor or what we think of as skilled labor. I think another example of just emotional labor all the time is this request for information. You know, so many times, as the one disabled person in a space or in any sort of meeting, you always ask, do you have to explain yourself or provide this free education that happens again and again and again? And then, when you dare to push back and say, "Oh, you know, by the way, I do work as a consultant," then I get crickets.

[crickets chirp]

LEAH: So, I think about stuff like that, and I think that when it comes to disabled folks, often there's also this crossover where the person who comes up to you and is like, "What happened to you," and wants to know your really personal story of disability. I see that happen a lot in the kind of interactions you're talking about, Alice. I feel like when we say, "Actually, no, I'm doing something else right now," or, "I don't know you," or, "Yeah, I could talk to you for 10 minutes, but after that, here's my consultancy rate," there's this particular merging of ableist anger and, I think, sexist anger when disabled femmes of color say no, where they're both like, "Who the fuck are you to say no?" And also, "You should be grateful that I wanna ask about you, little cripple! What do you mean you have something else to do with your time?! What do you mean that you get to have a limit, and you don't wanna tell me your personal story that's vulnerable and private?"

There's so many ways that you both know, ableism works in a way where disabled people are not allowed to have a private life; our bodies are public property to be examined by people on the street who stare, medical people, whoever. So, it's a real act of rebellion they're not expecting when you go, "Actually, I'm not gonna tell you 'what happened to me.' I don't have to do that."

[upbeat music break]

Disabled femmes and feminine people do care work and have super powers

ALICE: So, I would like to talk a little bit about care labor because a lot of non-disabled people only imagine disabled people as recipients of care, and they truly don't recognize how much care work is actually done by disabled people, in particular disabled people of color, including femmes and feminine people.

Leah, you wrote in your piece, you said--I'm gonna quote you--"Sick and disabled folks have many superpowers: one of them is that we often have highly developed skills around care." So, to both of you, what are some examples of care work that you're a part of or that you've witnessed that you find powerful and amazing?

STACEY: It's funny: My friend, Maddy, posted a photo of me in the ICU holding my cellphone, and I was coordinating access support for myself because I was in the ICU, but they weren't giving me the support that I needed, ironically. And so, I was coordinating people to come be with me at the hospital to make sure I would be OK. And it was really funny because I would try to coordinate their visits to be at the same time that I wanted people to meet. So, just that I think all of that is care work, whether that's connecting people to communities. Because a lot of friends, people are super isolated or sharing resources or helping someone problem solve or helping somebody get through a triggered experience or reminding them when something is like internalized ableism or racism and helping them find their power.

ALICE: How about you, Leah? I know you mentioned your list of things that you've done, but also just what are some super powers that you think you have?

LEAH: You know, my experience a lot of the time has been that able-bodied people--even able-bodied people who think they get it--really don't know how to be in it for the long haul with sick and disabled folks. They're still kind of in that place where they can wrap their heads around, "Oh, somebody broke their leg! Let's get a meal train together!" But with the understanding that this is gonna be a temporary condition, and then the person's gonna go back to being an able-bodied person riding a bike, right? But when it comes to somebody who's gonna be disabled or sick or neurodivergent for our lifetime, they just kind of fade away. They're like, "Oh, that's too much. I don't know how to be there."

I've had so many, I've seen so many, able-bodied activists be like, "Oh, shoot! That sounds...well, good luck!" But then I've seen disabled people literally get up from where they've been projectile vomiting for eight hours to be like, "You need 20 bucks? You need an Effexor? Great. Lemme just wipe this vomit from my mouth. I'm gonna get in my car, put my breathing mask on, and go and drop you off your pill and get you some takeout." So, I think in general, a disabled super power I see is that kind of way that we often are the ones who don't abandon each other, and where we're like, "Hey, you're not too much for me. Your bodymind is not too much. You're normal. We're normal. I'm gonna bring you soup, and I'm gonna clean your fucking sink and take your recycling out. Or I'm gonna ask somebody to do it. I'm gonna do all of this really not-glamorous daily labor that's gonna make your life possible." I think of it as like poor, working class wealth, and I think disabled wealth, how generous we can be with each other. We're just like, "Hey, crip! Yeah, I'm gonna go hang out, watch TV with you. That's great."

So, I think one of my super powers is taking part in networks like that. I really like cooking large amounts of soup and then freezing it and then bringing it to friends when they're sick. I'm a good cook. I would also say that one of our biggest super powers is I think that--I mean, I don't know a disabled person who doesn't still struggle with internalized shame and internalized ableism--but I think that there are a lot of us who've really fought our way towards undoing shame in our lives. And I think that that is a fucking gift we give each other, is that you don't have to be ashamed of your bodymind. As Stacey said, it's not your body; it's ableism. Right?

ALICE: Mmhmm.

LEAH: Our bodies and our minds are fine the way they are; they're amazing. I think that's such a super power that many, many able-bodied people don't know how to give to disabled and sick and mad people in their lives, of like, "You're fucking awesome." And not in a magic cripple way, but in a, "No, we're so amazing as we are."

[mellow music break]

Crip mentors and crip doulas

ALICE: Stacey, this makes a perfect segue because I do wanna talk about something that you wrote. In a recent Facebook post, you wrote, "...the work of supporting people rebirthing themselves as disabled or more disabled has a name. We are doulas. Crip mentorship/coaching/modeling at its best is disability doulaship. The fact that society doesn't even have language to describe this transition speaks to the ableism and isolation people with disabilities face in figuring out how to be in their bodyminds & in this ableist world."

So, talk to me about disability doulaship and how you kind of developed these thoughts. Because I think I was like, the minute I saw that post, I'm like, "Yes! Yes! Yes! Yes!"

STACEY: So, I was just noticing that people, disabled people, we go through so many, I feel like I've lived so many lives. Some of them are by choice, and then other plans are not by choice. Like, last year, I acquired a new disability, and it's changing the experience of my body. And I think we expect people with disabilities just to manage all of these transitions quietly. That's how you be a good disabled person, is not talking about your disability and not disrupting ableist, able-bodied, able-minded culture or not being a burden. Just doing it all well and gracefully and on your own. And that's just not the reality of the disability experience.

I think we have to acknowledge that there is some mourning and that there is a loss and that there also is really can be some beautiful experiences that come out of it as well, just like anything in nature or life. And I think just naming it, naming becoming disabled or more disabled as a transition that happens in life and that it can be a life-changing transition or experience is really important. Because most people, or all people, go through that at some time, and if we can figure out how to really show up for each other during these times, then I think we could change the social experience of what it means to be disabled.

LEAH: Something, to me, that goes along with the idea of, "Oh, disability, you're just supposed to manage that and not bother anyone with it and just keep it real quiet," is that most able-bodied people have--or in the ableist imagination--disability is not an expected thing that's gonna happen to you. It's, "Oh my god! Let's just really hope that you stay able-bodied till you die!" Which is so not reality! I mean, something that people say a lot is, "Well, everyone, pretty much, ends up disabled one way or the other." But there's so much embedded in mainstream community of like, "Well, it's just awful. Who would wanna be incontinent? Who would wanna be in a wheelchair? Oh my god! He can't even walk by himself anymore." And I just think how would it remake the world if instead, it was a community expectation that everybody's bodymind changes? There's so many ways that your bodymind alters, and it's not going into a deficiency. It's like, "Oh, yeah! You had a real normative mind, and then you got a TBI. And now you got a different kind of mind. There's a whole new library of knowledge to learn, being in that mind and to share. And there's spaces and doulas that will help you do that. You had one community, and now you have another." All of that.

ALICE: That's great. Yeah, and I do think that Stacey, what you said earlier about rebirthing, I think it's totally a new approach to thinking about this traditional linear process or the assumptions that people have about disability, where it's like a constant either downward trajectory, where it's really just about being transformed and evolving into a new kind of being.

[playful music break]

Wrap-up

ALICE: So, I guess I'm gonna ask both of you, how can people reach you if they wanna--not to say ask you for labor but--

LEAH and STACEY: [laugh]

ALICE: But! If they wanna learn more about you, follow you online, how can people reach you?

LEAH: Yeah, I can go. This is Leah. Probably the best place to reach me is--I'm a little old-school--on my website, BrownStarGirl.org. And my email on there is brownstargirl@gmail.com.

ALICE: So, Stacey, how can folks find you if you wanna be found?

STACEY: I don't really use Twitter, but people can contact me. My handle is @CripChick.

ALICE: Great. Well, thank you so much for talking with me, you two.

LEAH: Thank you so much for all that you're working on!

ALICE: All right. Good night, you guys. Thank you so much!

LEAH and STACEY: Good night.

ALICE: Good night! Thank you!

STACEY: Bye!

ALICE: Bye!

["Dance Off" hip hop song]

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All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

While you're there, you'll also find a link to Leah's essay and a video featuring Stacey with Patty Berne on ableism and disability justice.

The audio producer for this episode is Geraldine Ah-Sue. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening, and I'll see you on the Internets!

♪ Rock it to the blast off

Stop drop dance off ♪