

# Disability Visibility Podcast

## Episode 48: Care Work

Guest: Leah Lakshmi Piepzna-Samarasinha

Host: Alice Wong

Transcript by [Cheryl Green](#)

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

### Introduction

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

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

ALICE WONG: Hello, all you beautiful people! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host Alice Wong. My guest today is Leah Lakshmi Piepzna-Samarasinha, a writer, cultural worker, teacher, and trainer based in the Pacific Northwest. This episode is about care work, and it's also the name of Leah's new book that came out in October 2018 titled [Care Work: Dreaming Disability Justice](#). We talked last fall about the meaning of care work and disability justice and how people practice both in their everyday lives. Please note, throughout the interview, the term DJ refers to disability justice. Are you ready? Away we go!

[electronic beeping]

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

ALICE: Hey, Leah. I am so excited to have you back on the *Disability Visibility Podcast*.

LEAH LAKSHMI PIEPZNA-SAMARASINHALICE: Thank you. Alice, I'm so excited to be on it, and congratulations on your book. It's incredible. I really love that our books came out at the same time.

ALICE: I feel like it's been a big year for both of us.

LEAH: Yeah.

ALICE: And disability, I feel like all the universes, all the planets are aligning, and it's such a delight. You and Stacey Milbern were on this podcast in episode six talking about care work and the labor of queer disabled femmes. Do you mind, I guess, introducing yourself and just sharing a little bit about who you are for folks who are just learning about you for the first time?

LEAH: Sure. So, my name is Leah Lakshmi Piepzna-Samarasinha, and who am I? I am a queer disabled non-binary femme writer of Burgher and Tamil Sri Lankan and Irish/Roma ascent. And I'm a writer. I started off as a poet. I have three books of poetry in print, and I have a fourth one coming out this spring, 2019. And I'm also the author of the recent book *Care Work: Dreaming Disability Justice*, which is a collection of essays, and the memoir [Dirty River: A Queer Femme of Color Dreaming Her Way Home](#), which is my kind of disabled survivor, femme of color memoir. And with Ching-In Chen and Jai Dulani, I co-edited a book called [The Revolution Starts](#)

[at Home: Confronting Intimate Violence in Activist Communities](#). And I'm kind of giving most away. And then next year, I have a book coming out that my friend, Ejeris Dixon, and me co-edited called *Exploring Transformative Justice: A Reader and Toolkit*.

So, yeah, I'm a writer. I do performance art with Sins Invalid, which a lot of people know of as one of the places that disability justice really started and a really fierce, disabled queer people of color performance collective. And yeah, I also identify as autistic, neurodivergent, chronically ill, and physically disabled. And I live in Seattle, Washington.

### Leah's book, *Care Work*

ALICE: Great. Thanks for that. Today, we're talking about *Care Work*. And right now, as we're recording, it's December 2018. And your book, *Care Work*, only came out a few months ago. And I wanna know a little bit about the origins. How did this book, the idea of it, first come about?

LEAH: Totally. So, you know, I've been physically disabled and chronically ill since I was 21, which is 1996-1997. And right around the time where Sins Invalid and a lot of disabled Black and brown queer folks were starting to organize, like Patty Berne, Mia Mingus, Stacey Milbern, Leroy Moore, lots of other people, I saw this thing. And I was like, oh my god. This is the first time I've seen disabled, kinky, queer revolutionary Black and brown people doing writing and stories that feel like my life. And it's a long story short: I got involved with Sins. I started performing, and I was really present for a lot of moments of disability justice organizing and activism and cultural work in The Bay. And while I was there, there were just different places where I started writing different essays, some of which started off as blog posts, that really blew up. And some of which were really like tools that I wanted to share. So, I wrote this whole piece called [Making Space Accessible Is An Act of Love for Our Communities](#) that was like one part fragrance-free product list and one part talking about access as a form of love and cross-disability access, especially in communities of color that are disabled. And that really, that blew up on the Internet, you know. There were a lot of times I was really hanging out in a lot of parts of the disabled Internet and just writing stuff.

And then fast forward to 2016, I didn't think it was gonna be focused around disability justice at first. I just thought it was gonna be a little bit of everything that I'd written. But then when I started working on it, the more time I spent with it, the more I was like, oh, actually, yeah. There's a few essays that are not all disability all the time, but this is really a book of essays that's focused around disability justice in one way or the other. And that was the summer of 2016. And then Trump got elected.

[pensive music break]

We were all like, OK, so we're afraid that fascists are gonna round us up and kill us, or we're gonna lose the ACA, Medicaid, the ADA, like everything that allows us to stay alive on a right platform. So, we were all terrified, but then our whole sick and disabled QTPOC community and friends was like, "Let's get together. Let's talk. Let's build our network. Let's take care of each other." And we were just sitting in whatever accessible living room we had, being like, what are our resources to share with each other?

So, I was working on the book, and then there were some moments where I was like, is this really what I should be doing? Should I be leaving the country while I still can? Should I be going underground? And then I was just like, no. You know what? This would already be a useful book, but really at the core of why I wanna write this book, it's to me, I think of it as like a

toolkit that's both archiving a lot of moments of disability justice organizing and activism and just moments in time that I've been around for the past decade so it doesn't get erased when Facebook deletes all of us.

And also, I mean, Alice, before we started recording, we talked a lot about the idea of crip wealth. That instead of the deficiency model, as sick and disabled and neurodivergent and mad and Deaf people, we have all this wealth and all of these skills and all of this knowledge that able-bodied people have no idea exists. We've already survived so much shit. We have so many survival skills. And so, the book became like a compilation of like here's all this stuff. I wanna write a book that really lays out this is what it is, especially because Patty Berne and many other people have said, disability justice was invented by Black and Asian and working class and trans white people to be like, "We don't want a single-issue disability rights movement anymore." We wanna talk about how prison is a disability issue, Zionism's a disability issue. Police murder of Black and brown disabled people, that's a disability issue. We need all of our identities in there. We need leadership by disabled Black and brown people. We are sick of the whiteness and racism that's been too much in mainstream disability studies and disability rights. I wanna have something in print that writes down that record of this is who invented it. It is so important to know that Patty Berne and Leroy Moore and Mia Mingus and Sebastian Margaret and Eli Claire were the five people who sat down and were like, "OK, DJ. Let's talk about what this is. What kind of movement-building framework will it be?"

And I also was like, as we face incredible fascism and white supremacy—which, as we know has always had ableism at the core of it mixed in with racism and everything else and queerphobia—I was just like, I wanna have a toolkit where people can pick it up and be like, "Here's some crip tips."

### The publishing process

ALICE: I clearly see the value of a book like this. But I'm really curious about how you pitched it. And it was published by Arsenal Pulp Press. Can you tell me about, I guess, the process by which you approached publishers and also the response from, especially if you pitched it to more than one place, the response from publishers? And how did this book get greenlit?

LEAH: In some ways, I had a really lucky break because part of what allowed Arsenal Pulp to say yes was that— So, my book before this, *Dirty River*, had had a really, really hard time. I mean, I've always had a hard time getting published. *Dirty River*, which is this queer, chronically ill, survivor, femme of color memoir, I had been trying to get it published for four or five years. And it was like independent presses said no. Mainstream presses said no. People were like, "Oh, it's too experimental. It's not experimental enough." I absolutely ran into people who were like, "Oh, you know, it's too complicated a story. It can either be a disability memoir or an abuse survivor memoir. You can't have both." I had people who straight up told me, "Queer people of color don't buy books. No one is gonna care about this."

And so, when Arsenal Pulp said yes to *Dirty River*, they were kind of the last press on my list that I tried, and I was like, OK, if they say no, I'm gonna raise money and self-publish it. But then Arsenal, which has this wonderful, queer Asian editor, Brian Lam, at its head, he was just like, "I really love this book. I love the story. I don't wanna dumb it down. I don't wanna simplify it, rather. I love the voice." And he published *Dirty River*. And then it was a success, and then it was interesting. So, I was kinda like meandering along, working on the book, and it was February of 2017. And in the middle of all this February, winter, no-money moment, I got an email from somebody who worked at a major publisher in New York and was like a young queer person of color. They were like, "Hey, I really love your work, love *Dirty River*. I'm a huge fan."

I'm just wondering if you have any other books." And I was like, oh! I had given up on mainstream publishing ever publishing me. And I actually was like, "You know what? My role models are Gloria Anzaldua and Leslie Feinberg and people like that who never published on a major press, and they're giants of literature, and they changed the world. They changed the world, and they kept their integrity. So, I was like, you know. But when this person wrote, and they were POC and queer and all of this, and I was like, OK. And then we talked, and they were lovely, and they were really supportive.

I had to ask myself a lot of questions about just the ethics of doing that. Through the process, it became clear that basically, essay books don't sell. Basically, like major publishers are corporations, and what they care about is, is it gonna make them money? What I was told was that if you want an essay book to be published by a major publisher, you have to prepare to kind of posit yourself as an expert and the authority on this subject. That no one's ever talked about this before, and you're special. And I was just like, this is a collective movement. I do not feel—I think no matter who I was, I'd feel, no matter what my identities were—I'd be like, that does not feel ethical. I do not wanna become the star of DJ. That's fucked up. But I also was like, I'm light-skinned. I'm ambulatory. No. This is not feeling good. And I had conversations with other people in community. So, between that and just really wanting to resist the star system, I went back to Arsenal, and I was like, "I got an offer." And Brian was really sweet, but he was like, "Look. We will always keep your book in print. You can pick the cover. You can have creative control." These are things that a lot of writers don't get given. And I was like, OK. So, I'm gonna go with you.

As a disabled writer, when I talk to other disabled writers, when we are in anything but disability-specific space, we are running into a publishing world—even if it's social justice publishing world—that is just like everyone who reads books is able-bodied, you know! They're all normative. No one's ever thought about disability. No one's ever, like no one has any idea this shit exists. No one's interested. The only disability story you can think, that editor can think of like so many editors, is either an individual show and tell of like, you know, it's inspiration porn, it's tragedy, or it's death. Or it's somebody who's not us writing about us. So, the idea that we actually have communities and cultures is it's like speaking Martian to people!

[chill music break]

And I wanna be really clear. I do not mean this as any kind of "disability is the last acceptable form of oppression" bullshit because that's bullshit. And there is a similar assumption of universal abled-ness. It's all unconscious, but I was like, I am not writing as a disabled subject who is translating and explaining myself to abled people. I am writing for other disabled people of color first and foremost, and everybody else can listen in, and that's fine. But I am not going to change the language.

They showed me the cover, and they were like, "What do you think?" And I'm like, "Oh, it looks good except that subject thing that you have in the top left, it says, 'Social Sciences, Health Studies, LGBT'." And I was like, "I don't want it in Health Studies. I don't want it being next to some book on how to cure your gout." And I was like, "What about Disability Studies, Disability Activism, Queer Studies?" And I'm just like, right, like until there's a disability section, and until it's more than three white people, people aren't gonna, like— It's a chicken or the egg thing where people are gonna just keep drawing a blank about what is disability. So, there's a lot of that fighting.

And then I got out there, and what I'll say is that I just, I think every time I publish a book, you work on it for so many years in your office in silence and in isolation, and then it's getting ready

to go out into the world. And you're like, I don't even know if this is good anymore. Maybe it's a piece of shit. And you're also like, maybe people will notice, and maybe people won't. And so, in terms of getting it out there, it's been so interesting. 'Cause I did touring stuff, and now that I'm trying to be a middle aged crip, I'm like, no. You know, I'm really not getting to pneumonia for two months. I'm gonna really do it at my own pace. But it was really tricky to be like, I'm gonna do the tour on crip time, and I'm gonna take breaks, and I'm only gonna do so much. And people were like, "Can you come here? Can you come there?" And I was like, "I'm doing a total of three weeks of touring, and that's it. That is it. With breaks in between." And even then, it ended up being too much. I was just like, oh, I'll add on this. I'll add on this.

But then what happened was that every event I went to pretty much was sold out. I went to Western Massachusetts on a Monday, and there were 200 people. On a Monday. Packed. And I was like, I didn't necessarily expect this. And then the thing happened—and this is not a tooting my own horn thing—but the whole first run sold out in six weeks, which never happens! Which never happens!!

ALICE: Toot your horn! Toot it. Toot it.

LEAH: I'm gonna toot it! I'm gonna toot it. I'm gonna toot it. But the thing that's so interesting is that I wanna be a part of the historical record. I want it to be, I want it to be— I'm like, this shit. I'd love it if I get nominated for a national book award. As disabled writers, as disabled, intersectional writers, we should be, we're making history, and we should get all those big things, you know? But so, I didn't get most of that. I got like around halfway through the fall, I was like, oh shit. I've gotten no reviews. And then Autostraddle, Bani Amor, who's a really amazing disabled, non-binary brown writer did an incredible review that really got it, and that was great. And there's been a handful more, but I just.... I guess what I'm trying to say is that there's been this amazing response. And it's also been interesting because the book sold out partly because of touring, but also there were so many sick and disabled folks who could not make it to an event who just bought it because they're at home, and they wanna read a book about disability justice! So, it's kind of like the spoonie way of touring where you don't have to hit every city and every town because your readership is sick too, and they're not gonna come out necessarily 'cause they're tired! So, that was really interesting.

And I'm so proud of being in spaces like the Disability and Intersectionality Summit in Boston and Asian American Writers' Workshop, which long-time Asian community art space that just really threw down and is that rarity in New York. It's in an accessible space. They have an elevator, they have couches, they have good seating, they have a bathroom. It continues to heartbreak and amaze me the way in which non-disabled POC activists will just continue to ignore us, you know, and just completely be like, "Disability? What disability? Disability justice? What's that." It just really breaks my heart. And I'm like, you know, guys, we're running out of time. The whole West Coast was on fire for the past two years, and it's disabled people who were showing everyone else how to survive. You really need to listen to us. But you can only do what you can do.

[mellow music break]

ALICE: Yeah. You know, I try to post and promote stuff about your book.

LEAH: Thank you.

ALICE: And when I do put it on my Facebook group, the thread underneath, the comments are just like, "I love this book. This book is what I've needed all my life." I think we all have these

kind of moments in our lives where books will be like there's a certain book that'll just completely change our orientation.

LEAH: I hope so.

ALICE: And I feel like this is a book that's gonna have that affect for a lot of people. So, I was wondering if we could also talk a little bit about the actual term, "care work."

LEAH: Yeah.

### Defining "care work"

ALICE: So, how do you define care work? Because I think most people are familiar with caregiving, they're familiar with home care, but care work is something more. So, how would you kinda explain that to somebody?

LEAH: So, there's this theme of disability justice in general, and there's also this theme of care. I kind of saw it in my head at first, just like care/work. When I think about DJ, what is it? And I'm just like, well, it's the radical ways that we care for each other and that we fight to care for ourselves as disabled people, as disabled intersectional people. And that is work, you know. That is labor. That is work. That is real shit. And I don't know. I mean, I think in my head I just was like, when I think about the collective work of disability justice as a project, whether it's the performance art of Sins Invalid or three— You know, I always think of in Toronto where I think it was right after some of us had been in Detroit for Creating Collective Access, and there were like four disabled and sick femmes of color. And we were like, "Do you wanna get together, and maybe we can all be in bed on heating pads and have tea and talk about our lives?" And we were so tentative. I think about that meeting of four sick femmes of color talking about our lives.

Or I think about the one action I think of where there was a blockade of Oakland police headquarters, and there was a whole bunch of elders and disabled people. And there person in a power chair who was like, "I'm gonna lock down. I'm gonna lock myself down in front of the main entrance because it's gonna be a really bad optic if the cops are photographed beating up a white, maybe older looking powerchair user. I'm gonna use this." I just think of all those moments of disabled work where we are passionately caring for ourselves and each other and our future and how it's emotional, you know. It's not just a bunch of abstract ideas and politics and analysis. It's like, I mean, my friend Billie Rain, who was doing disability justice before it was a term. They were disabled and Arab and a ritual abuse survivor and living with lung tumors and MCS as a person of color and writing about it back in the early 2000s, like the really early 2000s. And I remember being on panels with them where we're always like, "What do you do to support disability justice?" And they were like, "Make a sick person soup! Make a disabled person soup. Bring someone lotion." I just think of all of that.

Going back to the stuff that me and Stacey were talking about, those little, huge moments of seeing each other and witnessing each other and showing up for each other and doing stuff. Like bringing soup to somebody is not seen as some hot shit activist whoo! "I led this rally of 10 million people" moment. But it's the kind of thing where we can't do the rally if we don't have the soup, and sometimes the soup is more important than the rally because I think it's a disability justice phrase to say, "To exist is to resist." Just by virtue of us living, we're resisting. And that's important.

So, this is kind of where I was coming from with the title, and then it was like, when I wrote my essay on fair trade femme of color emotional labor and care work, I was like, right. Some people were using emotional labor in this really kind of, I don't know, single-issue way. And I was like,

“No, no, no. You can’t talk about this without talking about disability. You can’t talk about this without talking about the ways in which Black and brown people have been forced to labor for free, whether it’s under slavery or indentureship or plantations or all the things, you know. And that led me to something I knew a little bit about, but the National Domestic Workers Alliance in the United States, their Hand In Hand campaign, where it was elders and disabled people who work with personal care attendants and the personal care attendants, the home workers all being like, “We need to be a united front.” Because personal care attendants need good money and paid vacation and sick leave and unionization. And disabled people and elders are like, “We need a Bill of Rights for ourselves so we are not abused by our care attendants. And we need the infrastructure to make it so that we can all access care attendants so that we’re not forced to pay subminimum wage because that’s what DHSS will pay, you know?”

I remember reading about it and being like, this is so powerful. This is a political organizing alliance around care, and it’s saying that feminized, disabled Black and brown labor is real fucking labor. And it’s real. So, there’s that way here, and I think that that’s a really important definition for me. Then I’ve also come to see that there’s been some academic texts that use the term “care work.” I’m not really embedded in academia, so I completely missed that. I apologize.

It’s all of that, and it’s also, I just, something that me and Billie talk a lot about are all the ways in which, as disabled people, and in particular, as disabled femmes of color, we are expected to do free labor and never complain about it and never be like, “No, I’m not doing that today. I am not explaining this, and/or I would like to be compensated in some kinda way, you know, even with a thank you.” Bringing soup, crisis counseling someone, or the way Stacey talked about the crip doulahood of being like, “OK, you’re a new powerchair user. Here’s how it works.” Or, “Oh, you know, you’re crazy, and you think you’re gonna go into inpatient. Cool. Here’s some tips.” Or like, “You just got even more unmobile, so here’s different ways that you can work with care attendants.” All of those things where it’s like yeah, it’s that work.

ALICE: I just wanna say that I appreciate that you’re writing about how one form of care work is protecting yourself. And you write this, and I’m just gonna quote you because I just love these lines so much.

LEAH: Thank you.

ALICE: So, you write, “It’s OK if you build in boundaries. It’s OK and good to build relationships where you are loved, not just for your labor. You are a renewable and also limited resource.”

LEAH: [chuckles]

ALICE: And I’m like, fuck yes! And you know, times infinity. Because you know what? We all have our limitations. We all feel this urgency to do what we can, especially under this current administration. I just wanna say how much I treasure you for who you are.

LEAH: Thank you.

ALICE: And I thank you for all that you do, not just all that you do, but just your spirit and who you are.

LEAH: Thank you. Alice, that means so much, truly. I feel the same way. I treasure you, the stuff that you’ve done with DVP the last few years. Thank you so much. I treasure you.

## Wrap-up

[hip hop]

ALICE: This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at [DisabilityVisibilityProject.com/Podcast](https://DisabilityVisibilityProject.com/Podcast).

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Thanks for listening, and see you on the Internets! Byeeee!!

♪ ...as low as you would if you were my sweatpants  
How far will they go?  
Oh yeah yeah  
How far will they go?  
Oh yeah yeah  
How far will they go?  
Oh yeah yeah  
How far will they go?  
Oh yeah yeah ♪