

## **“The Future is Disabled”: Leah Lakshmi Piepzna-Samarasinha**

**LAURA FLANDERS:** The best of times, the worst of times, the COVID pandemic has been all that and more. I say has been because while our media and some of our politicians like to talk about returning to "normal", COVID's still with us in our hearts as well as in our daily lives. Like it or not, the virus is still out here. Many are still sick and dying, and the vulnerable, as we call them, are especially vulnerable. But didn't we all learn something about being vulnerable during the last few years? At the height of the pandemic, didn't a whole lot of us figure out how to make life safer, and even better, for our vulnerable friends and relations, and even for our vulnerable selves? What happened to all that we learned? It wasn't all bad. Dare I say, some of it was kind of wonderful. Leah Lakshmi Piepzna-Samarasinha spent her two COVID years of what she calls disabled isolation writing prophecies, love notes, and mourning songs, which she's now gathered into a book, "The Future Is Disabled: Prophecies, Love Notes and Mourning Songs". It came out at the end of 2022. "What if, in the near future, the majority of people will be disabled, and what if that's not a bad thing," she asks. What if disability justice and disabled wisdom are crucial to creating a future in which it's possible to survive fascism, climate change, and pandemics, and to bring about liberation for all? Leah is a writer, poet, disability and transformative justice movement worker. Her preferred pronouns are she and they. The book is published by Arsenal Pulp Press, an independent, queer-of-color-led press, and I am very glad it brings her back to our show. Leah, welcome to the program. I am so glad to see you again.

**LEAH LAKSHMI PIEPZNA-SAMARASINHA:** Thank you, Laura. It is always such a huge pleasure.

**LF:** Let's start with us describing ourselves.

**LLPS:** Right, so this is something that a lot of blind and low-vision people, and folks with other disabilities, have asked for for years, because if you're blind or low vision, you know, it helps people to be on an equal footing with people who are sighted, to know what they're seeing when somebody's talking or on screen, and it's just a really easy way of providing access.

**LF:** If I asked you to visually describe yourself, what would you say?

**LLPS:** Yeah, so I would say, "Hi, my name is Leah Lakshmi Piepzna-Samarasinha. I'm a mixed race, light brown skin, Sri Lankan and white, young-looking, middle-aged person with brown and purple curly hair on one side of my head and a very overgrown fade on the left side of my head. I'm wearing purple lipstick, rose gold metal glasses, a turquoise kind of crop top, and I've got a piece of artwork behind me by the artist Jen White-Johnson that says, "Create More Anti Ableist Spaces."

**LF:** I love it, all right, well, I am then a sort of whitish, blondish, 60-ish woman, and I'm in a room with a bookcase behind me and a Yoko Ono piece of art that says "Imagine Peace" on the back of my wall. For those who don't know, can you define the term disability justice for us?

**LLPS:** Sure, disability justice is a movement-building framework that was started in 2005 by people like Leroy Moore, Patricia Berne, Mia Mingus, Stacey Milbern, Eli Clare, and it basically builds on and exists in the cliffhangers of the disability rights movement. So, disability rights very much focus around laws, policy changes, things like that, really important. Disability justice is an intersectional movement that centers the lives and leaderships of Black and Brown and queer and trans disabled people, and that really changes what both our visions for the future are and what we understand is disability issues, right? Disability justice would say that, for example, police violence is a disability justice issue because, as I've said and as we know, 50% at least of folks murdered by the cops are both Black or Brown and disabled, deaf, chronically ill, autistic. So, we can't end police violence and murder without dismantling racism and ableism at the same time.

**LF:** I sometimes find it helpful to kind of center us in where we are and what we left before we came to this conversation. I have on my mind all the things I have to do. What about you?

**LLPS:** It feels odd to almost miss some parts of 2020. I don't miss most of them, but I'm going to say what a lot of people have said, which is that there was more of a mass sense of we look out for each other in 2020 and we're trying to work to protect each other, and where we're at now is what I and a lot of other activists are calling the great gaslighting, where there's tremendous pressure from the state and corporations to be like, oh, America, go back to work, go shopping, there's no pandemic here, except there's so many of us who know that that's not true. And for those of us who are, you know, disabled, high risk, immunocompromised, parents, elders, what have you, all of the above, we're like, wow, I'd love to go to the movies.

**LF:** There was some kind of wonderful things about the last few years that we've been through. Can you describe one that stands out for you?

**LLPS:** It is really kind of shocking to me when I read it, and I read from it, to be like, the stuff I'm describing that's from 2020, 2021, like massive mutual aids, like, things like, I'm thinking about Caremongering, which was a network started by Indigenous and Sikh women and Two Spirit people in Toronto, and it spread all across Canada. At its height, the Toronto Caremongering had 20,000 people, they didn't know each other, and it was a lot of people who did not have a huge community or family, but it was just people being like, "I made 40 packets of butter chicken and rice, and I'm in this neighborhood and anyone can come get it." "Do you need diapers? Great, I've got some extra ones." And the people who ran it really pushed back when people were like, "Ooh, well, do you really need those diapers?" They were like, "No, we don't question people." It's radical hospitality, and it was beautiful. It was really beautiful, and it kept so many people alive and joyful because they were like, "God, I've got food and love." I mean, I know so many people who felt more isolated prior to COVID. They were like, I've just been, you know, a single parent, sick, what have you, nobody cares, and wow, all of a sudden, there are these mutual aid societies that are coming through.

**LF:** One of the things you do in the book is describe what it takes to create community, community with disability justice front and center, and some of the descriptions are really simple, but, again, I think you break a lot of mystique about what it would be to create disabled community or community that doesn't leave disabled people behind. You talk about people like, you know, just making their lives inclusive and reaching out to you and others. Can you give us some examples for people who don't think of themselves as disabled? What can we do to make sure we're not missing out on the pleasure of being with you all?

**LLPS:** Sure, well, I want to say first of all that, I mean, I think the UN statistics are that 30% of the world is disabled. Disability includes physical disability, chronic illness, mental illness, neuro divergence, blindness, deafness, lots of stuff, and a point I really want to make that's, you know, in the title is that with COVID, we really are looking at a world that, if it's not majority disabled yet, it's going to be really soon. You know, care often gets talked about as the soup and the grocery drop-offs and that "let me give you a ride", and that's all really important, and what also counts as care is doing things like the massive campaigns that disabled people did and are doing. You know, what Alice Wong of Disability Visibility Project did with High-Risk California, which is a project she started when, early in the vaccine rollout, disabled people were not prioritized. And we were like, "We've been inside," and she was like, "I've been inside for a year,

literally," you know, and she and other people organized to get Governor Gavin Newsom and the public health departments to be like, "Okay, wait, no, we are not going to put you to the bottom of the list because we think your lives don't matter and you're going to die anyway." So, that kind of activism is care, you know, pushing to change the laws around personal care attendance and, like, making sure that personal support workers get paid above the minimum wage and get paid well. That's an act of care.

**LF:** And react when the Americans with Disabilities Act is weakened or when there are new threats to it, which I understand there are in the current Congress and the next one.

**LLPS:** Right, I mean, I would say with that, and I would say also with Olmstead, right, which is, you know, the legal challenge that was advanced by disabled people, including Lois Curtis, who just passed, who was a Black disabled warrior, disabled people in the South, who were living with intellectual and developmental disabilities, who've been institutionalized all their lives, who were like, "No, we want to live in our own homes," and they fought and they won that. And ever since Olmstead has been passed, the Right continues to push, to be like, "No, we want to lock you back up, we we want put you back in institutions like the old days," when not only is it inhuman, not only does it cut off our right to live beautiful, rich disabled lives in the world, but it's not even cost-effective. I mean, institutions are jails. They cost millions of dollars, right, much more than being able to live in your own apartment with somebody who comes in and helps you when you need it, right? So, being aware of the disabled issues that are out there, for people who are abled or who might not think of themselves as disabled, and talking about them, fighting for them, writing those letters, being at those demonstrations is important. The last thing I'll say is, and I cite this in the book, there's a lot of different initiatives led by disabled people being like, for God's sake, please keep virtual options, masking options, please don't act like it's gone, because, like, I mean, hi, what do we have to do? Like, the hospitals were at crisis standards. Kids can't get into the hospital. Everyone who goes is like, "I waited eight hours, there's no doctors anymore." There's so much sickness, masks work, and honestly, when people go, "Oh, they're such a pain," I'm like, "You know what's a pain? Getting sick and dying. You know what's a pain? Being disabled and never leaving the house again. That's a pain."

**LF:** Two things. One, we are going to have you read something in just a minute. I want you to introduce it. Two, I need you to define the title and talk about what you mean about "The future is disabled".

**LLPS:** First of all, I want to say that Alice Wong used it first as a phrase and generously gave me permission to use it as the title of my book. I mean, I think the bare bones definition is that in the near future, as I've said, most of us are going to be disabled, numerically, right? But what's also true is that so often as disabled people, we are told that there's no future for us. As Patty Berne and other founders of disability justice have said, there've always been disabled people. There's not one way to have a body or mind, right? And we can be angry at things, like war and colonization and environmental racism, that do fuel some disabilities, but that does not mean that as disabled people, we're the broken toys, you know, in the box, right, and that we're useless and we need to get fixed. So, when I say the future is disabled, I mean that as disabled people, number one, we are imagining, in the worst conditions, futures where not only do we exist, but we are thriving, we are in leadership, and we are sharing the tools that everyone's going to need to survive, and I'll give a couple of examples. You know, I lived in the West Coast, I've lived in the West Coast for 15 years of my life, and for the last five years, there's been intense wildfire smoke emergencies. If anyone's used a Corsi-Rosenthal Box, which is that hack where, if you can't afford a HEPA filter, you go and you get a furnace filter and you put it on your box stand. Disabled people invented that. Disabled people were the first people who were like, "Oh, there's wildfire smoke. Here's a mask, here's the different kinds of masks. Here's how you clean the air in your house. Here's how you take care of your mental health," 'cause it's very stressful when the sun is blood red, right, "and here's how you take care of each other," right? Everything from that to the kinds of radical shifts towards care that is abundant is stuff that we've been practicing, and it's stuff that more and more people, everyone's going to need that if we're going to make it.

**LF:** You say there's a connection between the future being disabled and our, I don't want to say epidemic because it's not a natural phenomenon, but our practice of mass incarceration.

**LLPS:** Oh, yeah, I would say definitely because I think that mass incarceration is disabling. If you're not disabled when you go in, and we know that so many disabled Black and Brown folks are either victim to police brutality or they're imprisoned, if you're not disabled when you go in, you get disabled inside, right? So, a future that's disabled is an abolitionist future because it's against prisons. It's also against all institutions, including the institutions that lock disabled people up.

**LF:** I'd love you to read a part from the book, and this is a piece that begins, "This potential revolution isn't just going to happen." In it, you talk about "crip doula-ing". Can you just tell us what that is in case people don't know?

**LLPS:** Like any doula during a birth, we know that when somebody's laboring alone to give birth, it's often a horrible experience. It's really hard, and just the presence of another person there, holding that space and being like, "We believe in you," changes the way that birth feels. Stacey Park Milbern, of beloved memory, invented the term "crip doulaing", and she was like, "That's what you do when another disabled person teaches you, this is how you drive a wheelchair, have sex, accept help, manage your care attendants, be a care attendant. This is how you work, this is how you write a whole book five minutes at a time for bed." This is how you live, and it's not a fate worse than death. It's actually awesome. This is also from the last chapter, and it's from a subsection called "Scaling Up Crip Doulaing". "This potential revolution isn't just going to happen. There will be, already is, a need for crip doulaing on a massive scale, linking newly disabled people living with Long COVID with people who've been sick and disabled longer, sharing our skills in living with chronic illness and fighting the medical industrial complex. In particular, there are people in chronic illness community, like folks living with chronic fatigue immune dysfunction syndrome and multiple chemical sensitivity and late-stage Lyme disease, who've done community research on post-viral syndrome that millions of people living with Long COVID desperately need access to. Our disabled histories of activism and survival skills are crucially needed, and most people outside disabled and chronically ill community don't even know that they exist."

**LF:** Thank you for that and for that reading. If we were to doula, perhaps, a new world into being, a lot of it would be bringing into being things that don't exist yet, but you mention in the book some things that do exist right now. Do you want to name a few? I'm thinking particularly of your library of things.

**LLPS:** Yes, so I wrote about when I was living in Washington. The public library system in Thurston County had these libraries of things, which included, they had libraries of adaptive devices. So, you could just go and check out wheelchairs, screen readers, augmented communication devices, things that you could use, like large playing cards. If you're low-vision, you can play poker. Adaptive video game controllers, and it was all free, and you didn't have to have a doctor's prescription, and they just trusted disabled people. They trusted that, like, hey, if you want to try this out, if you need this, go for it. And it's so different than the current system, where, you know, so many people I know can't even get a doctor's note saying, yeah, this person has Lyme disease or cerebral palsy, and they need this accommodation at school or at work, right, because of the way the medical system's set up, and that's in the public library system in Thurston County in Washington. I also know that in Ontario, in Hamilton, the Disability Justice

Network of Ontario started something similar, that was an adaptive device library, in their library system in a very working class, steel town in Southern Ontario.

**LF:** And you might walk into your own library and say, "Hey, they got one, why can't we?"

**LLPS:** Right, exactly, I mean, you know, when I went through a breakup, I was like, God, I can't, you know, I've got severe osteoarthritis, I don't really have a left hip joint, I'm 47 years old, and I was really used to my partner bending down and picking up things for me, and I was like, "God, what am I going to do," and then I was like, "Oh!" Like, my friend was like, "You can get a grabber. It's just, you know, you buy it online, and you reach down and you pick it up," and I was like, and honestly, that sounds like a small thing, but there's actually a lot of people who stay in abusive relationships because their partner is their caregiver, and they're like, "What am I going to do without them?" And if you don't know that there are adaptive devices out there, and so often, you know, I've been disabled since I was, yeah, oh, 25 years this year, and I've never had a rheumatologist or a primary care practitioner be like, when I've had a flare up or a situation where walking's been hard or I've been in pain, they've never suggested, why don't you get a walker, why don't you get a RollerAid, or why don't you try this? They've always just been like, well, Advil, or, you know, hopefully you'll get better someday, or lose weight, right? And, you know, there's a real hostility to adaptive devices and disabled technologies in the medical world, but it does not have to be that way, and when we reduce those barriers, it makes a lot of things much more possible for people.

**LF:** I remember my father, who was in a wheelchair, would try to communicate to people that he actually was able to do more things in the chair than he would've been able to do in a walker or crutches, or everything that people would try to do rather than be in a chair. For him, it was not ideal, as you say, but not the worst either. And he went on to have a big career and make me, so I'm very glad he wasn't disparaged or discarded, but it was war and disregard that lost him the use of his legs.

**LLPS:** Yep.

**LF:** Let's talk about sex and bodies. How can we begin to feel better in our bodies, and what does our ableism, how does our ableism hamper that?

**LLPS:** Well, you do the really easy questions, Laura, I've gotta say.

**LF:** I'm not asking you to take us through a sex show exactly, but how do we do this?

**LLPS:** Wow!

**LF:** How do we throw off our anxieties about perfection?

**LLPS:** I mean, you just said it. I think that one of the cornerstones of ableism is this idea that there is one perfect, ideal body and mind and that everything else is something that we're supposed to be ashamed of. It's one of the reasons why a lot of core disability justice organizations and projects actually have really directly talked about sex and bodies, like Sins Invalid, which is, you know, a foundational disability justice organization that I've performed with. Patty Berne and, you know, the other founders have talked really deeply about how our bodies are where our desires and our hopes and our dreams live, and if you live in shame, if you can make someone feel ashamed, it makes it a lot easier for them to feel that they can't demand things. So, I think, how do we, how do we undo it? I think that one of the gifts about being in disability community is you're like, wow, nobody's body is like the white, skinny, abled, cisgendered, masculine, you know, ideal, and people, it's not like people don't deal with shame, but people are doing really amazing things with their bodies, including things that a lot of able-bodied people might not be able to imagine. Every single disabled person I know is, like, is kind of a master at, like, really prioritizing pleasure. You go, no, I'm going to really, I'm going to make a beautiful life. I'm going to have clothes that feel great. I'm going to get really into makeup. I'm going to figure out how to have adaptive sex toys. I'm going to, like, go to the casino. I'm going to go and hang out with my friends. I'm really going to live when I'm alive.

**LF:** Let's have you read something that is on this very subject. It begins about being told you're a sad sack, a medical tragedy, with violins ready to play, and what you do instead.

**LLPS:** So, this is from my section that's about disabled pleasure activism. "It is a particular disabled Black and Brown femme politic, often fat, too, of loudness, excess and maximalism that I adore. It's an insistence of our right to joy and to take up space. It's resistance. It's a crippling of pleasure. It's freedom work, insisting that we deserve our roses, lilies, peonies, jasmine, orgasm, freshwater while we are still here, and that joy and pleasure are key parts of what both help to

make us make this disabled world to come that we're dreaming of now in this moment and what helps keep us going when the work is hard and heartbreaking."

**LF:** For all of the beauty and inspiration and storytelling that's in the book, there's also tools that you can use if you're holding meetings, if you're holding webinars, if you are recording for television or radio, or even if you're just inviting people over. I'm going to ask you to take us out with reading from Section 5.5, where you start by quoting our beloved June Jordan.

**LLPS:** So, this is a reading from my chapter "Loving Stacey: An Honor Song", which is in memory and honor of my friend and disability justice organizer, Stacey Park Milbern. "Black, queer feminist, maestro, poet, essayist, teacher, and thinker June Jordan once said, "Love is life force." I believe in the radical power of disability justice love as life force. It found me, the disabled divine, when I was sick and alone on a futon with no spoons and community, and it has stayed with me, something I am continuously learning together with Stacey and many other disabled kin, a rippling crip ribbon that weaves through all the moments of my crip life. I'm going to continue to shape my life around it because it's been what's brought me home. More than ever, even and especially as times get harder, I think this rigorous, messy learning and devoted disabled love will be what keeps us and leads us. I know that, like any kind of love, it will surprise me, shake me up, turn me inside out, scare me, and set me free. I believe it can be a piece of the disabled divine on earth. I invite you to join me and us in this practice and to witness the ways you are already doing it as real."

**LF:** I want to encourage people to check out the book, "The Future Is Disabled: Prophecies, Love Notes and Mourning Songs". Leah Lakshmi Piepzna-Samarasinha, always a pleasure to have you with us.

**LLPS:** Always a pleasure to be here.

**LF:** Identity or idea? What is disability exactly? Is it an identity that pertains to a certain group of people with clearly defined and definable characteristics, or a much more porous idea? As a group, disabled people have certainly been treated differently. In the workplace, for example, employers with certain special certificates can set up sheltered workshops, where disabled workers are paid much less than the federal minimum wage. In schools, teachers can constrain and seclude kids with disabilities in ways that wouldn't be allowed for other children. A case in

Florida was recently settled by the Justice Department that found that teachers had been locking disabled kids up in boxes for hours. And what about healthcare? Roe v. Wade or no Roe v. Wade, disabled people will tell you they've never had real freedom to choose. So, there's no surprise that disabled people today are coming out loud and proud and demanding to be seen and heard and listened to, but let's be careful how firmly we delineate the lines. The ADA, for example, the Americans with Disabilities Act, gets its power, in a sense, from the fact that it doesn't define who's covered under its umbrella. Instead, it puts the onus on society as it requires employers to make reasonable accommodations for all. Those very words are being used today to benefit all sorts of people suffering from Long COVID, or people that work better or prefer to work at home. So, let's think about disability, not as a prison, no, not as a prison ever, but as a prism on our lives. If you look at your life that way, how does yours shape up? I'm going to make it a practice, how about you? You can find my full conversation with Leah Lakshmi through subscribing to our free podcast, which you can find all about at our website. I encourage you to check it out. In the meantime, stay kind, stay curious. Thanks for joining me for The Laura Flanders Show. I'm Laura.

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