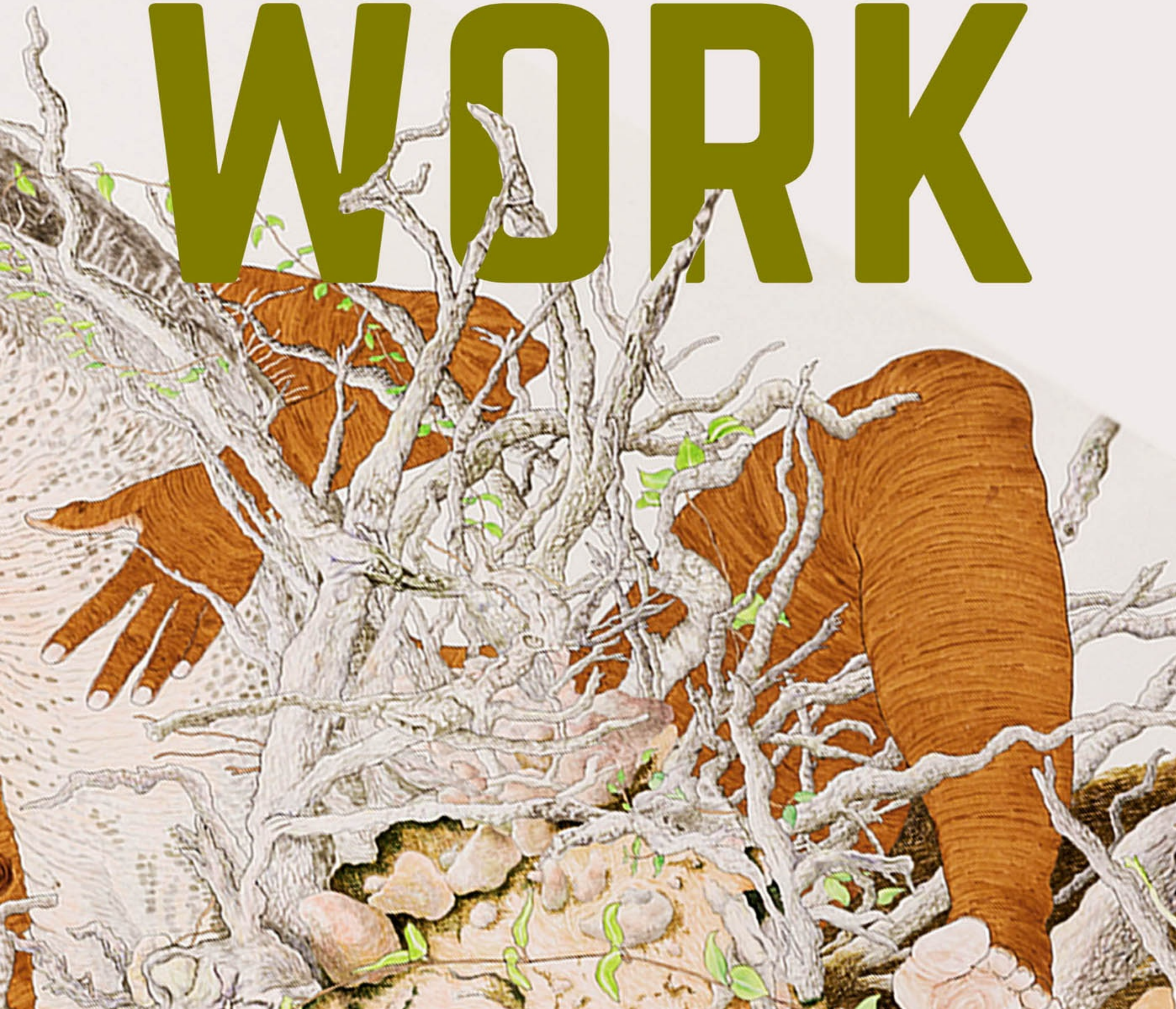
LEAH LAKSHMI PIEPZNA-SAMARASINHA

CARE WORK

DREAMING DISABILITY JUSTICE



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I have loved disabled people of color my whole adult life and am still amazed to discover that the more I love our people, the more I remember where I come from. I remember that my ancestors found each other out, seeing each other in the unseen. My ancestors knew that asking after one another and making sure folks had what they need (what we might understand as collective access) was the only way to be together; together, the best shot at staying alive. My ancestors knew the power of vulnerability and how to hold each other in dignity. My ancestors knew joy. My ancestors made mistakes and meditated on who they wanted to be in community. My ancestors became those people.

—Stacey Milbern

To the beloved, kindred, needed

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IV

CRIP EMOTIONAL INTELLIGENCE

Black queer femme writer Kim Katrin Milan created the phrase "femme science"[19] to mean femme skills, technologies, and intelligences. For me, it was revolutionary to hear someone state that femmes had actual, particular skills, talents, sciences, and cultures. I'm not sure when I started hearing and using the terms "crip skills" or "crip science"—probably roughly around the same time. But it meant something. It meant something to name and talk about all the crip skills I was seeing and learning that I and other disabled folks had. It meant something because, well, the deficiency model by which most people view disability only sees disabled people as a lack, a defect, damaged good, in need of cure. The idea that we have cultures, skills, science, and technology runs counter to all of that. In a big way.

Naming that also means having to field some able-bodied blank stares. Able-bodied people are shameless about really not getting it that disabled people could know things that the abled don't. That we have our own cultures and histories and skills. That there might be something that they could learn from us.

But we do, and we are. So here are some things I've noticed as hallmarks of crip emotional intelligence, skills we use within our cultures and with each other.

- Crip emotional intelligence means not taking it personally sometimes, when another disabled person is short with you, is fumbling for words, is frustrated. Instead, you might assume that they just threw up for eight hours, have been fighting suicide for a week, have cellulitis in one of their legs again, have five giant fibroids and are struggling to decide what treatments to try. I'm not talking about excusing verbal abuse; I'm talking about the ways in which we cut each other slack. I'm talking about the ways we start from the assumption that someone might be dealing with a lot of pain, or facing a seven-layer cake of ableism and impairments, or struggling to use verbal language. I'm talking about the gift we give each other of seeing what the able-bodied imagination refuses to see: that sick, disabled, Mad, Deaf, and neurodivergent lives, and the stress we hold from places where ableism rubs up against them 'til they chafe, are normal. This is the norm, the default we assume is happening, rather than being oddballs who don't fit into an abled norm and have to apologize for it. Crip emotional intelligence is also not always losing it when someone doesn't use precisely the right word. It's knowing the difference between someone being a fucker and someone who has a brain injury, aphasia, extreme social isolation, or just didn't go to Oberlin.

- It's also figuring out how to communicate using smaller words, not academic words, different words than you just tried, writing. It's waiting for someone to be done finishing spelling out a sentence on their augmented communication device before responding. It's using text. It is not assuming that audist and academic ways of communicating are the smartest or the best.
- It's not assuming. Anything. It's always asking: if you can touch, what you call your body or your sick, what you need, if you even want suggestions for your issue or if you just want listening. It's understanding that each disabled person is the expert on their own body/mind.
- Crip emotional intelligence is understanding isolation. Deeply. We know what it's like to be really, really alone. To be forgotten about, in that way where people just don't remember you've ever been out, at meetings and parties, in the social life of the world. How being isolated, being shunned, being cut off from the social world of community is terrifying because you know that it can literally kill you. And that being alone also does not always have to be killing; it can also be an oasis of calm, quiet, low stimulation, and rest.
- Crip emotional intelligence is not taking it personally when someone cancels and continuing to invite them to things. To not forget them.
- Is not shaming someone for precut vegetables or wet wipes or going to the drive-through or using a car. Including an SUV, because it's big enough to fit a chair.
- Is understanding that disabled people have a full-time job managing their disabilities and the medical-industrial complex and the world—so regular expectations about work, energy, and life can go right out the window.
- Is understanding the terror of ODSP or SSDI reviews, the food stamp office lines, that you never miss a specialist appointment, that going to the doctor is not usually the first response, that if you leave your disabled parking pass somewhere it's incredibly stressful, that so much of your money goes to pills or co-pays or therapy or supplements.
- Is noticing and showing respect for all the ways we push ourselves past our spoons all the time—when someone counsels someone in the middle of panic or blows their wrist spoons typing out resources. It understanding that we are in a constant dance of negotiating how to work while disabled or sick or in pain.

- Is sharing resources and showing up, and having a spoken or unspoken rule that acknowledges that you both (the two crips in the situation) have stuff going on. You will offer what you can. You will stop when you have to. You will accept “no” to your offer without taking it personally.
- Is the ability to read someone’s face, body language, and energy to tell that they are in pain or struggling. Is being fluent in the skills of noticing pain, fatigue, overwhelm, and trigger.
- Is knowing that phrases like “Hope you feel better soon!” or “Awww, that succcccks!” are dirty words when they come from abled people after you describe your disability.
- Is understanding that if you find an accessible way to exercise for your body, that’s great. But if you spent the day on the couch—because there is no way of exercising that doesn’t cause pain, or because you can’t move much, or because you just want to—that’s just fine too. Understanding that it’s a sacred task to not shame each other for being in bed in a world where completing the Ironman or going to Zumba is shoved down everyone’s throats with no understanding of how “healthy” can hurt.
- Is understanding that beds are worlds. Houses are worlds. Cars are worlds.
- Is understanding that there are a million ways to be sexual (if one is sexual), and some of them live in phones, don’t ever involve genitals, happen once a year. Is understanding that all movement is movement, and counts, including when someone can only move three fingers and part of their forehead. All sex is sex.
- Is understanding that when someone says, “I feel like shit/I’m feeling sick,” the automatic reply shouldn’t always be, “Oh, stay home/don’t do it/let me do that for you!” That instead, you can say, “I’m sorry,” without trying to fix it and say, “What feels possible today?”
- Is understanding that everything will break, everything will take longer than you think, the elevator will be broken at the BART station and Paratransit will be three hours late. And that these are not surprises. These are deliberate acts in a world that doesn’t value or fund access.
- Is offering to do laundry. Is offering to do it again. Is knowing you will probably have to offer help a million times before another disabled person takes you up on it.
- Is offering what you can. Is asking if you can offer. Is saying when you can’t.
- Is understanding that when someone does something themselves, even when it looks like it’s full of struggle, that’s not always them “being passive-

aggressive.” Sometimes, this is just us, hauling the groceries up the stairs, the way it looks like when we do that. Sometimes, we don’t want to a pat on the head. Sometimes, we have learned not to depend on people who then fail to show up and complain about how hard it is to help a disabled person.
- Is knowing that offering miracle cures is a dirty word. Is knowing that cure is not mostly the point. Is knowing that our bodies don’t need to be cured or fixed into normalcy to be valuable.
- Is tending to give each other the benefit of the doubt. We have been thrown away by so many people. We try not to throw each other away. No matter how unpopular or shitty the opinions expressed may be.
- Is knowing the algebra of pushing past and/or massaging your limits so that you can drive home, accompany someone at the hospital, perform a daily task, cook, eat. Is knowing that “Just do self-care!” is well meaning but totally inadequate. Is knowing we do more than we can all the time. Is knowing that “limits” is a negotiation.
- Is never assuming. Anything.

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