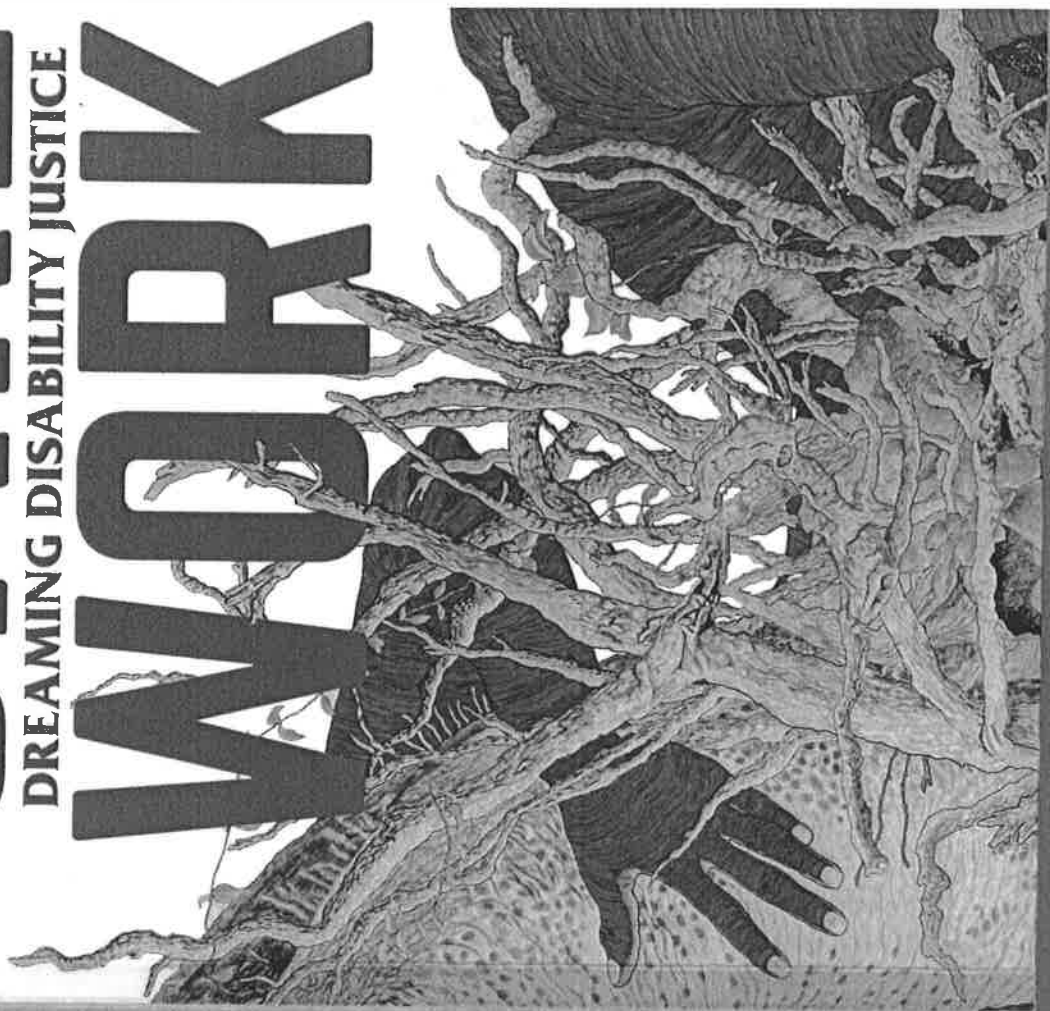


LEAH LAKSHMI PIEPZNA-SAMARASINHA

CARE WORK

DREAMING DISABILITY JUSTICE



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HIS COLLECTION OF ESSAYS, Lambda Literary Award-winning writer and activist and performance artist Leah Lakshmi Piepzna-Samarasinha explores the politics of disability justice, a movement that centers the lives and leadership of sick and disabled, trans, Black, and brown people, with knowledge and gifts for all.

Care Work is a mapping of access as radical love, a celebration of the work that sick and disabled people of color are doing to find each other and to build power and community, and a tool kit for anyone who wants to build radically resilient, sustainable communities of liberation where no one is left behind. Powerful and passionate, *Care Work* is a crucial and necessary call to arms.

—after page, Leah Lakshmi Piepzna-Samarasinha documents the necessity, power, and sheer force of disability justice. Be prepared for her words, stories, and political thinking to shake up what you know about care and access, revolutionary dreaming, and present-day resilience.”

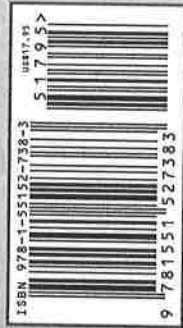
—Eli Clare, author of *Brilliant Imperfection: Grappling with Cure and Exile*

A brave and brilliant book that captures the messy gestation and wildly liberating vision of disability justice. With passionate integrity, Leah tells the collective story of a movement that arms the idea of care into a force capable of unraveling all the braided injustices of our lives.”

—Aurora Levins Morales, author of *Medicine Stories and Kindling: Writings on the Body*

Reading this book allows you to live inside the gorgeous, uncomfortable, emergent, compassionate, and disabled femmes of color have been making all along. Leah cares for us all with this work, not in the apologetic, default, mommy mode you may be trained to expect. This care is the self-sourced, survivor-accountable, salty-sweet truth-telling we need to (guess what?) SURVIVE.”

—Alexis Pauline Gumbs, author of *M Archive* and *Spill*, co-editor of *Revolutionary Mothering*



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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

A MODEST PROPOSAL FOR A FAIR TRADE EMOTIONAL LABOR ECONOMY

(CENTERED BY DISABLED, FEMME OF COLOR,
WORKING-CLASS/POOR GENIUS)

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. Often complicated remixes that break away from white, able-bodied, upper-middle-class, cis femininity, remixing it to harken to fat or working class or Black or brown or trans or nonbinary or disabled or sex worker or other genders of femme to grant strength, vulnerability, and power to the person embodying them.

The thing about being a working-class or poor and/or disabled and/or parenting and/or Black, Indigenous, or brown femme is that people are going to ask you to do stuff for them. Oh, are they ever.

They're going to ask you to listen, do a favor, do an errand, drop everything to go buy them some cat food or crisis-counsel them. Manage logistics, answer feelings emails, show up, empathize, build and maintain relationships. Organize the childcare, the access support, the food. Be screamed at, de-escalate, conflict resolute. They're going to say, "Can I just pick your brain about something?" and then send you a five-paragraph email full of pretty goddamn complex questions. It'd be real nice if you could get back to them ASAP. They're going to ask if you can email them your powerpoint and all your resources.

Some of them will be people who are close to you; some of them will be total strangers. *Do you have a minute?*

For free.

Forever.

And you know what's going to happen? You're going to do those things. Because you do, indeed, care. Because it's the right thing to do. Because you're good at it. Because you want to.

And because: your life as a working-class or poor and/or sex-working and/or disabled and/or Black or brown femme person has taught you that the only damn way you or anybody survives is by helping each other. No institutions exist to help us survive—we survive because of each other. Your life is maintained by a complex, nonmonetary economy of shared, reciprocal care. You drop off some extra food; I listen to you when you're freaking out. You share your car with me; I pick you up from the airport. We pass the same twenty dollars back and forth between each other, building movements and communities as we go. It's maybe what hippies mean when they talk about the gift economy; it's just a million times more working-class, femme, Black and brown, and sick in bed.

We live in a white, capitalist, colonialist, ableist patriarchy that oppresses in many ways. One of them is that femininity is universally reviled. Patriarchy, racism, transmisogyny, colonialism, ableism, classism, and whorephobia come together to dish out hate to folks who are femme or feminine in extra fun ways. In the queer communities I have been a part of since the 1990s, I have witnessed over and over how femmephobia, sexism, and transmisogyny act together to view femininity and femmeness as weak, less than, not as smart or competent, "hysterical," "too much," and not as worthy of praise or respect. Forget femme invisibility; the thing most femmes I know are impacted by is lack of femme respect. Femmephobia and transmisogyny infuse queer and mainstream cultures in a million ways, from the

ways in which femme genders are seen as inherently less radical and more capitalist/assimilationist (assuming money spent on makeup and dresses is somehow more capitalist than money spent on bow ties and butch hair wax) to the ways in which, as writer Morgan M. Page notes, “any minor slip of language or politics and [trans women] are labeled ‘crazy trans women’ by cis people while trans men nod knowingly in agreement,” resulting in trans women being shunned and expelled from community.

Generations of femmes of many genders have written and organized about misogyny and transmisogyny in queer and trans communities, and I’m able to suck in a deep breath of air now and then because of this work.

But I remain, with many other femme and feminine people, harmed by misogyny—where endless free care work and emotional labor is simply the role my community and the world has for us. We are supposed to wipe the asses of the world without ceasing. As a newly physically disabled, working-class femme of color in the 1990s, I often felt how the queer and radical prison justice communities I was part of looked down upon my gender, especially when I was disabled and broke and surviving abuse and needing support. Then I really sucked—I was just another needy, weak *girl*, huh? The one place femme people could receive respect in those communities was if we were tough, invulnerable, always “on,” and never needing a thing. I know I’m not alone, and I know this experience has not ended.

The working-class and poor femmes, Black and brown femmes, sick and disabled femmes, parenting femmes and sex-working and rural femmes I know hold it the fuck down. We pull off shit—from organizing complex marches and transformative justice actions to the life-support work of making sure people are fed, don’t die, and don’t get evicted—on no sleep and low spoons and a quarter tank of gas, over and over again.

Our organizing skills in these departments are incredible, and often not valued as much as masculine or charismatic leadership, or indeed seen as skills. I want our skills and competency to be respected and rewarded. What I think is a problem is when this labor both becomes the *only* way femmes are rewarded in community and isn’t seen as a choice but as what you’re just supposed to do (because you’re femme, right?). This expectation can be voiced as a veiled or direct compliment—*You’re so competent, right? You’re so good at this, of course we wanted to ask you*—but it doesn’t make the work itself less, well, a gendered demand to work a whole lot. When you’re in this gendered situation, you’re also presumed to be endlessly available and interruptible. People ask you for help or labor, and “no” is nowhere in their conception of what your response might be. Far too often, the emotional labor we do as femmes or feminine people is not seen as labor—it’s seen as air. It’s that little thing you do on the side. Not real organizing, not real work, just talking about feelings and buying groceries. Girl stuff. Femme stuff. Disabled and sick stuff, not a real activist holding a big meeting stuff. Thanks, though! That was really helpful!

Before I go any further, I want to be really clear about a few things: I don’t think that only femme or feminine people offer care labor, or can. I know femmes who suck at this stuff. And I know many masculine and other-gendered people who do care labor, and I want all genders of people to be receiving and providing that labor in our communities. I’ve heard masculine folks talk about ways the gendered nature of care labor affects them—from being expected to always be physically super-able-bodied and strong to being expected to be “the rock” that will always be there, without having needs of their own. From Black and brown and working-class and poor men and masculine people being seen through a racist, classist lens that is surprised when they are loving and caring, parenting, and doing care work to disabled masculine people

being impacted by complex ways that disability is feminized and denied disabled bodily autonomy. What I want to tease out and focus on are the ways that misogyny, femmephobia, and transmisogyny come together to royally screw over femme people of many genders; how misogyny, femmephobia, and transmisogyny are part of global systems of gender that extract a hell of a lot of labor and energy from femme and feminized people, from parenting and caretaking being considered “free labor” to sexist assumptions of femme perma-availability being made in queer and trans communities. Also, the gendered wage gap is real. Cis and trans women really do get paid less than cis men, and women and femmes who are racialized, disabled, imprisoned and institutionalized, trans, rural and poor/working class get paid extra bad.

Second, I’m not against care work existing. I love the care and mutual aid we give each other in queer, trans, sick and disabled and working class and queer and trans Black, Indigenous, and people of color (QTBIPOC) communities. As a sick and disabled, working-class, brown femme, I wouldn’t be alive without communities of care, and neither would most people I love. Some of my fiercest love is reserved for how femmes and sick and disabled queers show up for each other when every able-bodied person “forgets” about us. Sick and disabled folks will get up from where we’ve been projectile vomiting for the past eight hours to drive a spare Effexor to their friend’s house who just ran out. We do this because we love each other, and because we often have a sacred trust not to forget about each other. Able-bodied people who think we are “weak” have no idea; every day of our disabled lives is like an Ironman triathlon. Disabled, sick, poor, working-class, sex-working and Black and brown femmes are some of the toughest and most resilient folks I know. You have to develop complex strengths to survive this world as us.

I love how working-class, femme, and disabled this care labor is. I just want it to also not be seen as an automatic expectation of

any femme at any time! I want some rules so we don’t feel drained, exhausted, and fucked over. I want it to be a choice. And I want its next-level genius of skill to be recognized. This is skilled labor!

So I would like to advance the radical notion that providing care is work. By work, I mean it’s just that: *work*. I mean that the care work we give is essential to building movements that are accessible and sustainable. We are building and maintaining movements when we’re texting to make sure someone is okay, talk on the phone for hours, talk shit on the couch, drop off a little care. Those things are not a sideline or an afterthought to our movements. They *are* our movements. And I have seen some of the most femme movements and communities—disabled ones, sex-working ones—organize very differently because they are fully centered around feminized, sick survivor care labor.

I tried an experiment recently. For one week, I logged how many times I was asked for care labor or support, and what I noticed about who was doing the asking, and how. My findings? Every single—really—femme person who hit me up started their requests by asking me how I was doing and prefaced their requests by saying things like, “Hey, if you have time,” “Do you have the capacity to give some support?” or “When and if you have time ...” They also were more likely to offer to buy me lunch, trade me for something, run an errand, or pay me. And they were more graceful and heard it the first time when I said, “Hey, I’m so sorry, but I can’t right now.”

Masculine and non-femme friends, however, were much more likely to just hit me up and say, “Hey, could you ...”: pray for them, hook them up with a publisher, tell them what doctor they should go to, listen to them vent about an intense transformative justice process gone wrong, be a reference, or answer a question. It was not uncommon for these requests to come from someone I had not heard from for months. There was no, “Do you think you have the

wages and work conditions and for state health and social services departments to raise pay rates allowed for care support workers. I think about how little people working in “pink-collar” fields that are highly feminized like cleaning, caretaking, childcare, waitressing, and service work get paid. I think about my mom, a former waitress, explaining to me when I was seven years old how waitresses are legally paid far under the minimum wage and are dependent on tips to make any kind of money (tips that depend on the femme emotional labor of being seen as sexy, nice, and cute), and how you should either be ready to pay twenty-five percent *minimum* as a tip or you shouldn’t go out to eat. (The current minimum waitress wage in Massachusetts is \$2.66 an hour. She made a hell of a lot less in the 1960s.) And I think about Black, Indigenous, brown, working-class women’s and femme bodies being forced to work for free or for pennies—as enslaved people on plantations, in Export Processing Zone factories in Sri Lanka and many other Global South countries, and beyond. I think about disabled and Mad people locked in nursing homes and institutions working for well under minimum wage in “sheltered workshops,” and I think about people in prison working for pennies an hour. Finally, I think about the rage and oppression many sex workers face for having the gall to actually charge for sexual, emotional labor! It’s impossible to think and talk about emotional labor, care work, and gender without talking and thinking about all these intertwined histories and realities of oppression and resistance. All of this has started me thinking about what the solutions might be. If care labor is, well, labor, and we participate in an emotional economy all the time, what would a just care labor economy look and feel like? What would I want to get paid (in money or care labor or appreciation), and how? What would I want the conditions of my labor to be, to feel that my work was in safe, compensated conditions that had my worker’s rights at the center?

time or spoons to do this?” no suggestion of “I could offer X thing in return,” and no “If you don’t, it’s totally okay.” There was also no, “How are you doing?”

This pissed me off. I also knew I was far from alone. My conversations with other femme people are full of us describing our care labor—and of us bitching about how exploited, unappreciated, and exhausted we often feel when that labor isn’t recognized. The sexism and femme oppression in these dynamics loom huge. Disabled, white, working-class femme poet Tara Hardy recently remarked at *ADEPT*, a sick and disabled queer performance at Gay City, Seattle’s queer theater, “Femmes get objectified two ways, one sexually, the other as Mommy.” In the sexist world, Mommy does a million hours of unpaid labor a week without anyone asking them.

There’s been a huge amount of writing about emotional labor in the past few years—everything from the oft-reposted Metafilter thread on gendered emotional labor that is now fifty single-spaced pages long to essays by queer and trans writers of color like Kai Cheng Thom and Caleb Luna to Ada Hoffman’s wonderful essay about autistic practices of emotional labor to a million conversations I’ve seen and taken part in with friends and comrades. In thinking about the roots and histories of unpaid and unrecognized labor by feminine people, I don’t know how to capture their enormity. But I think about movements like Black Women for Wages for Housework and others who fought for the audacious demand that people should get paid wages for the labor of homemaking and parenting the WSCCAP conceives of as “naturally” being unpaid. I think about movements like the National Domestic Workers Alliance’s Caring Across Generations campaign, where elders, disabled people, and the personal care workers who support them—many of whom are immigrant, Black, or brown people performing the feminized labor of personal care support work—are organizing together for fair

This is what I've got. This is just the beginning, but every revolution has to start somewhere. These thoughts are an experiment and a work in progress. Feel free to add your own.

Fair trade emotional economics are consensual. In a fair trade femme care emotional labor economy, there would be no unconsensual expectations of automatic caretaking/mommying. People would ask first and be prepared to receive a yes, no, or maybe. I ask if you can offer care or support; you think about whether you've got spoons and offer an honest yes, no, or maybe. In this paradigm, it's the person offering care's job to figure out and keep figuring out what kind of care and support they can offer. It's the person receiving care's job to figure out what they need and what they can accept, under what circumstances. Both folks might need some support and rumination to figure this out. You can negotiate: You can say, "I can't do that, but I could offer this." I can say, "I appreciate that offer, but I think I need someone who can just listen right now." And, most of all, no is okay. I can say, "Honey, I wish I could, but I'm tapped out right now—is there someone else you can talk to?"

Fair trade care webs draw on sick and disabled knowledge about care. Sick and disabled folks have many superpowers: one of them is that many of us have sophisticated, highly developed skills around negotiating and organizing care. Many sick and disabled people have experienced receiving shitty, condescending, "poor you!" charity-based care that's worse than no care at all—whether it's from medical staff or our friends and families. Many disabled people also face receiving abusive or coercive care, in medical facilities and nursing homes and from our families and personal care assistants. We're also offered unsolicited medical advice, from doctors and strangers on the street (who are totally sure carrot juice will cure our MS) every day of our lives. All of those offers are "well meaning," but

they're also intrusive, unasked for, and mostly coming from a place of discomfort with disability and wanting to "fix" us.

The idea of consent in care labor is radical and comes from our experiences receiving these kinds of clusterfucks of so-called care. On sick and disabled internet gathering places I hang out in, it's a common practice for folks to ask before they offer advice, or to specify when they're not asking for solutions or tips—or, when they are, what specific kinds of information they're open to. For many, it's mind-blowing that disabled and sick people get to decide for ourselves the kind of care we want and need, and say no to the rest. Ableism mandates that disabled and sick people are always "patients," broken people waiting to be fixed by medicine or God, and that we're supposed to be grateful for anything anyone offers at any time. It is a radical disability justice stance that turns the ableist world on its ear, to instead work from a place where disabled folks are the experts on our own bodies and lives, and we get to consent, or not. We're the bosses of our own bodyminds. This has juicy implications for everyone, including abled people.

Fair trade femme disabled care webs are reciprocal. Recently, my friend Chanelle Gallant commented on Femme Secret Society, a Facebook femme community-building and support group, "Sometimes when I get hit up for advice & support from folks I'm not already friends with, I prefer if they offer me something in exchange. If we are in the same city & what they're asking for will take me hours [to do], I might ask them if they can make me a meal." She asked femmes in the group what kinds of things—including cash—they had asked for as compensation for requests of our free labor. And femmes talked about asking for food, services, pet care, tarot readings, personal services, or bodywork in exchange for emails from strangers that began, "Can I just pick your brain for a minute?" or big, complicated requests for emotional support.

Hearing Gallant and other femmes talk about asking for something in exchange for our emotional labor was a game changer. I had rarely considered asking for something in return for the endless stream of requests for information, mentoring, and support that came into my inbox. Informally, especially in disabled and femme communities I was part of, there was certainly often an unwritten rule that if you gave care, you got some back—it was just good manners. In many Black and brown communities, this all seemed to go along with the concept of good manners or just how you were raised to treat people, what some folks I know call home training. I picked my friend up from the airport and he slept on my couch when he was on tour, and when I was on tour in his city, he offered me the same thing back. But sometimes I just gave a lot and was left exhausted without getting anything back. Not even a thank-you.

Many, many things shifted in my life when I started to think of my care labor as labor, not just “the right thing to do” or “I’ll just answer their question, it’ll only take a minute.” When I started thinking about how much free work I could afford to offer, and if there might be some things I’d like in return.

Everything doesn’t have to be fifty-fifty all the time. I think that’s especially important for folks who need a lot of care to survive, who may not be able to offer a ton back all the time. But I would argue for a general bend towards offering something back, even just a thank-you, a “Hey, I see the work you just put in” or a “I’m too sick to do anything right now, but I can offer this when I can.” Shit, I had someone give me a ten-dollar jar of fancy kraut they’d shoplified the other week to thank me for something! It’s not good manners to always take and never give back.

Reciprocity of care labor is also a disabled practice. In disabled communities, we talk about the idea that we can still offer reciprocity to each other, even if we can’t offer the exact same type of care back. For

example: if my disabled body can’t lift yours onto the toilet, it doesn’t mean I can’t be reciprocal—it means I contribute equally from what my particular body can do. Maybe instead of doing physical care, I can research a medical provider, buy groceries for you when I’m out shopping, or listen to you vent when one of your dates was ableist.

Fair trade care labor is not a one-sided, femmephobic, sexist shit show. Masculine and other genders of people can notice feelings and offer to listen and do childcare too! I swear to fucking god, these are learnable skills!

Fair trade care economics could be kinda like ... permaculture?

The more systems are not a monoculture, the more sustainable they will be. The more there are a lot of different kinds of folks giving and receiving different kinds of care, the more there’s room for boundaries, ebbs and flows, people tapping out, and people moving up. Crips and nonnormative people have a lot of different gifts to offer, and normals and ableds often assume not only that we have nothing to offer, but that we can only be (patronizingly and abusively) cared for. But care doesn’t have to be one way. It can become an ongoing responsive ecosystem, where what is grown responds to need.

Vacation, time off, sick time, weekends, and time and a half could be part of the deal. Maybe not exactly the way they are when you work at Target but ... some kind of way? A fair trade disabled femme working-class emotional care economy would give people doing emotional labor time off. We would get to have limits to our hyper-responsibility. We would get to have lives that are more than bouncing from crisis response to crisis response.

Because we deserve joy and rest. And while crisis and extreme states are common parts of human experience when we have just gone through a really hard slog—being there for someone who is suicidal or negotiating an intense death in the community—in this economic system, it’s not just okay, it’s accepted and normal to not run to the

next crisis after we've just finished one but, instead to ask someone else to move up and take the baton.

Disabled femme fair trade emotional economics receives a thank-you. Our work is seen as work. Our emotional labor is respected. We are not just asked to labor, and then asked to labor again. We get—dare I say it—appreciation cards and bonuses? I'm not talking about Starbucks gift cards at Christmas, necessarily, and I'm not talking about the kind of forced gratitude that is demanded from many of us in return for care. I am talking about a culture of appreciation, respect, and thank-yous for care that doesn't have to do with groveling or bullshit. I am talking about what many of us already do: notice, thank, and witness the work being done.

Imagine how free we could get if instead of femme labor being an unpaid, demanded mommy tap, we could be thanked and compensated for our work, and then kick back and put our feet up, smiling. Imagine if it was compensated and the labor conditions were fair—maybe everyone would want to do it more. Imagine if we were not only respected for our care labor but also allowed to be more than our care labor.

Imagine how much we could win if there was more than enough care to go around.

PREFIGURATIVE POLITICS AND RADICALLY ACCESSIBLE PERFORMANCE SPACES

MAKING THE WORLD TO COME

If, as the African revolutionary leader Amílcar Cabral described it, culture is the “collective personality of a people,” then the arts are its collective dreamlife. In the absence of coercive control, the arts, like dreams, are naturally drawn to the deepest hopes, fears, and truths that are suppressed in daily life ... art becomes conscious dream-telling, responsible creation with the potential to affect the life of our people.

—Ricardo Levins Morales

Prefigurative politics is a fancy term for the idea of imagining and building the world we want to see now. It's waking up and acting as if the revolution has happened. It's, for example, building a sliding scale community acupuncture clinic that is affordable and centers disabled and working-class/poor and Black, Indigenous, and people of color instead of writing reports about how the medical-industrial complex is fucked up. (Though that can be important too.) I think of it as akin to the Allied Media Conference principles of “We spend more time building than attacking” and “We focus on our power, not our powerlessness.”

The higher education programs where I studied writing and performance taught basically zero about creating accessibility in making performance art, theater, and spoken word. The focus was almost always