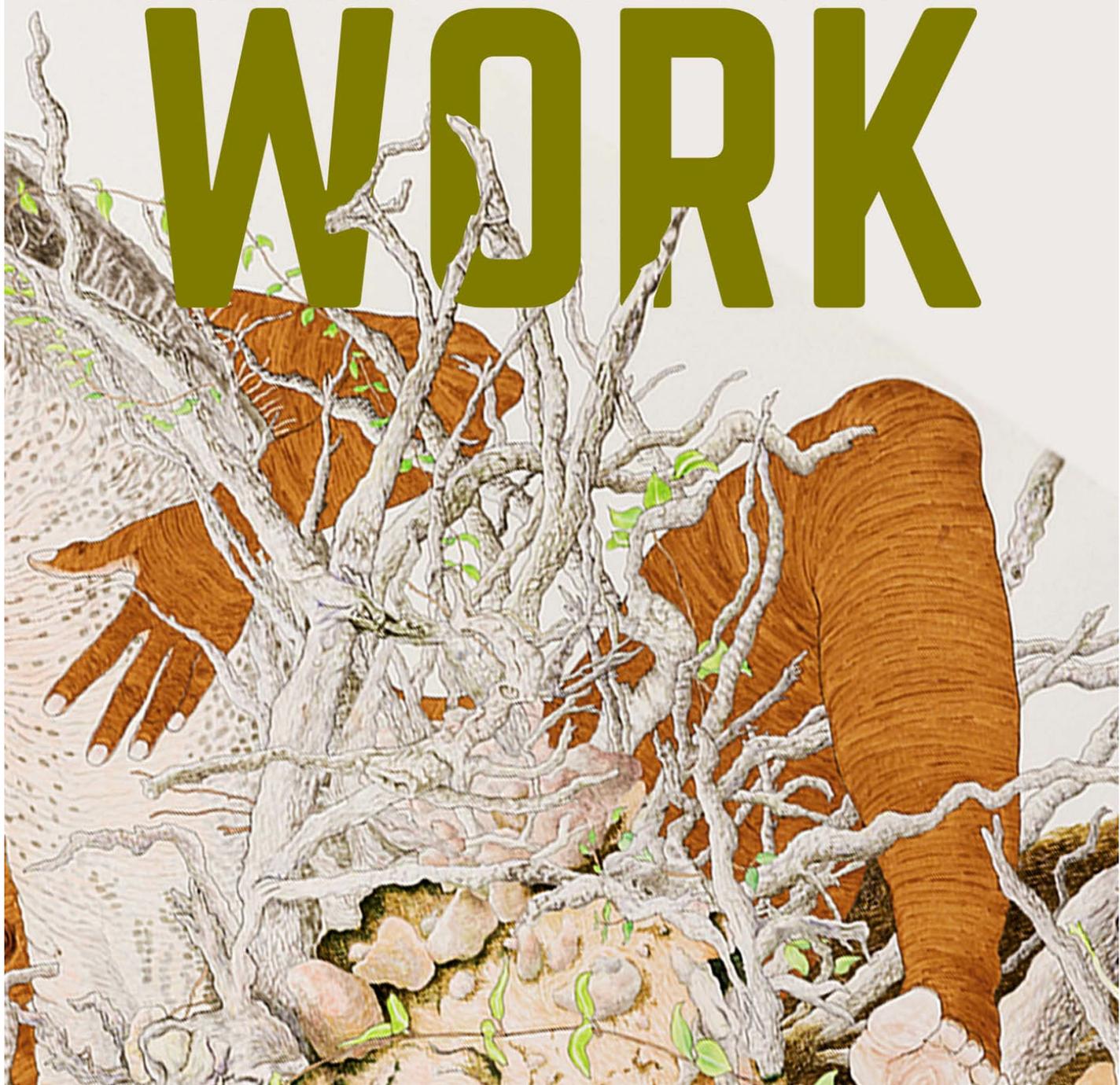


LEAH LAKSHMI PIEPZNA-SAMARASINHA

# CARE

DREAMING DISABILITY JUSTICE

# WORK



**LEAH LAKSHMI PIEPZNA-SAMARASINHA**

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WORK**

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**ARSENAL PULP PRESS  
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CARE WORK

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# CARE WEBS

## EXPERIMENTS IN CREATING COLLECTIVE ACCESS

*Do you have the car today? Hayati, I'm at the bus stop, I hurt so bad, can you pick me up? Hey, can I borrow twenty dollars? Can you go buy groceries for me when you're out and drop them off? Here's a list. Do you want to go to community acupuncture together? Hey, B. needs more care shifters, can you repost this Facebook note? Can we share the access van ride over to the city? If you come, you can say you're my personal care attendant and you won't have to pay. Do you have anemone tincture<sup>6</sup> you could bring over? I'm flaring. Holding me would be good too. If I take your manual wheelchair and load it up with takeout, we'll all have food. Can you go with me to the clinic and take notes while I talk to my doctor? Can I use your address for the Easy Does It pickup?<sup>7</sup> I'm just over the border into Oakland. Let's pass the hat so we can afford ASL for the event. Do you have the interpreter list? Here's the list of accessible event spaces we made on Google docs. Can you be part of my mad map<sup>8</sup> crisis fam? Wanna Skype if you can't get out, even if we live in the same city? Wanna go with me to the food stamp office? Can you pick up an eighth for me when you go to the dispensary?*

What does it mean to shift our ideas of access and care (whether it's disability, childcare, economic access, or many more) from an individual chore, an unfortunate cost of having an unfortunate body, to a collective responsibility that's maybe even deeply joyful?

What does it mean for our movements? Our communities/fam? Ourselves and our own lived experience of disability and chronic illness?

What does it mean to wrestle with these ideas of softness and strength, vulnerability, pride, asking for help, and not—all of which are so deeply raced and classed and gendered?

If collective access is revolutionary love without charity, how do we learn to love each other? How do we learn to do this love work of collective care that lifts us instead of abandons us, that grapples with all the deep ways in which care is complicated?

This is an essay about care—about the ways sick and disabled people attempt to get the care and support we need, on our own terms, with autonomy and dignity. It's specifically an essay about some experiments that have taken place over the past decade by sick and disabled predominantly Black and brown queer people to create networks of care by and for us. It's about our attempts to get what we need to love and live, interdependently, in the world and in our homes, without primarily relying on the state or, often, our biological families—the two sources disabled and sick people have most often been forced to rely on for care, sometimes, well, often, with abuse and lack of control. This is about some of the ways we are attempting to dream ways to access care deeply, in a way where we are in control, joyful, building community, loved, giving, and receiving, that doesn't burn anyone out or abuse or underpay anyone in the process. This is for us and by us, and it is also for everyone who thinks of themselves as able-bodied and normatively minded, who may not be, who will not always be, who the ghost of the need for care still dances with as deepest fate-worse-than-death fear, as what you want the most but can't even let yourself speak.

It is an essay full of sick and disabled QTBIPOC stories that are well known in certain activist

disabled QTBIPOC circles but at risk of disappearing or not being passed down, as the mediums where we find each other become less accessible/safe (Facebook in the age of Trump) or fade away (Web 2.0). And I am also thinking of care webs that have existed through time, that I know of through queer legend and myth, that do not often get counted as disabled stories and may not have thought of themselves as disabled care stories but still shared access tools, meds, and care—STAR House, the house started by Black and brown trans femme sex worker revolutionaries Marsha P. Johnson and Sylvia Rivera, with the rent paid by hustling and street sex work, as a safe space for trans people of color and street trans people to be free, be with each other, and share hormones and other supplies for healing and gender affirmation; the AIDS activist prisoner networks in the 1980s and '90s that shared safer sex supplies and AIDS drugs and fought for prisoners to receive medical care; the mad movement's underground safe houses and sharing of both pills and alternative treatments, as well as ways of coming off meds safely; the underground, often criminalized, harm-reduction networks like the New England Drug Users Union today where people share naloxone and fentanyl testing strips in their living rooms with folks who use opioids. We have found each other and offered healing and access to each other before and will again.

It is an essay full of questions. About what allows us to access care, as sick and disabled people who have been taught that our care needs are a pain in the ass and a burden—to the economy, the state, our families, the person we have to share the bus stop with so we need to take up as small a space as possible. It is an essay rooted in the stories I know, live, and witness, as a working-class, disabled femme of color—of all the ways our people have saved and continue to save each other against huge odds. It is an essay about the miracles that sick and disabled communities of color make for each other, and it's also about the contradictions and the cracks. Some of the questions are about what stops us from being able to ask for care when we come from Black and brown communities, for example, who have always been the ones forced to care for others for little or no money. Or about what happens when sick and disabled people are the only ones who do not forget about each other, but we all are extremely, extremely tired. I wrote this essay because I passionately believe in the power of our stories—of the revolution work we do when we cook a meal for each other, listen without judgment, share meds, hang out with each other during a psychotic break, or lift each other onto a toilet or a scooter.

I wrote this essay because I passionately believe in recording sick and disabled QTBIPOC stories, and because I believe the stories I have witnessed and participated in over the past decade of building ways of creating care are both a core part of disability justice work and the work of making the next world, the world we want, the post-Trump, post-fascist, postapocalyptic world. I wrote this because I believe we stand at the crossroads, between both the gifts and the unexpected, inevitable collapses of our work, and we have the opportunity to dream and keep dreaming ways to build emergent, resilient care webs. I believe that our work in creating the new world depends on it—because all of us will become disabled and sick, because state systems are failing, yet “community” is not a magic unicorn, a one-stop shop that always helps us do the laundry and be held in need. I believe that the only way we will do this is by being fucking real, by not papering over the places where our rhetoric falls flat, where we ran out of steam, or where this shit is genuinely fucking hard.

I wrote this for my mother, a working-class survivor of severe childhood sexual and physical abuse, a disabled Irish and Roma woman living with post-polio syndrome and no medical care,

and then cancer spawned by environmental racism, as well as DID and complex PTSD, who was rarely if ever able to access any form of care or support for her disabilities, who both neglected me medically and shielded me from institutionalization as a young disabled and neurodivergent person, who did the absolute best and most common thing she could do as a working-class survivor who trusted no system and few people. I wrote this for my younger self, a newly incredibly sick, isolated twenty-two-year-old, who made up ways to care for my disabilities in isolation from disability community, from books, prayers, guessing, and dreams. I wrote this for everyone who has been denied SSI, SSDI, ODSP, or whatever they call state disability money where you live, or “official” disability accommodations for the first or fourth time, who can’t get that “medical proof” of our sickness or disability and who thus can’t get anything the state begrudgingly offers us—that discounted transit, Access-A-Ride, state or federal disability benefits, welfare, accommodations at school or work. This is for those of us who are closeting our disability to keep everything from health insurance and jobs to social acceptance and capital—all of which we need to survive.

This is for those of us who cannot closet our disability, Madness, Deafness, and illness—whose witnessable disability is just a fact of life that becomes a bullet target for violence, for attempts by police, doctors, and families to murder us and lock us up. This is for all of us evading that capture and control, that being disposed of—who still have need. This is for everyone Black and brown who freeze, who feel we could never, ever think about asking someone to do our dishes or clean our toilet or help us dress, because that is the work we or our families have done for little or no money during enslavement, colonial invasion, immigration, and racist poverty—and this is for those of us who have both cleaned toilets and wiped asses for little or no pay and respect and who too need and deserve care with respect and dignity. This is for all of us, especially Black, Indigenous, and brown femme people, who have kept our communities alive after being both abandoned and policed by the state, and in the face of medical experimentation and denial of health insurance.

This is for all the friends I know who have needed care but also needed to evade Children’s Aid and foster care. This is for everyone who desperately needs care but will never let a care worker in their house for fear they or their children will be taken away by the state. This is for everyone who has had to run away from accepting care because care meant control—by family members or partners or workers or strangers. This is for every group of stressed-out QTBIPOC friends who are the only three disabled people you know, who are doing all the care for each other until it trails away into frustration, stress, yelling, and breakdowns. This is for those of us who have been forgotten and left behind by our communities, who have and have not survived that abandonment and isolation. This is for everyone trying to keep themselves or their friend out of the psych ward, who sometimes want more than anything for some actual professional who wouldn’t be messed up and who would actually help. This is for all the times I’ve relaxed into the miracle of being cared for well, that changed my understanding of what was possible, and every time I’ve succeeded and failed at caring well. This is for the road we make by moving forward, the dream future of autonomous care we deserve.

**HOW PEOPLE GET CARE (AND DON’T) AND WHAT CARE MEANS**

I'm not an academically trained disability scholar, and I'm not going to pretend that this next section fits (white-dominated) disability studies academic standards. The history of disabled people accessing or being denied care and the ways our needs have been policed and profited off of is vast, and there is no way I can do it justice in one essay—but I wanted to offer a very brief history of how care has and has not been offered to us in North America pre- and post-colonialism. (I am also aware of how so much writing about disability is limited to a white-dominated disability studies field and language, and how inaccessible that is to the vast majority of sick and disabled people who could potentially use it—so there are pros and cons to both approaches.) But here goes: There have been a million ways sick and disabled people have accessed the care we need over the centuries, and I don't have time to go over them. A light once-over will say that in many precolonial contact communities, there existed ways of being disabled that did not mean stigma, shame, exile, or death. Disabled Cherokee scholar Qwo-Li Driskill has remarked that in precontact Cherokee, there are many words for people with different kinds of bodies, illnesses, and what would be seen as impairments; none of those words are negative or view those sick or disabled people as defective or not as good as normatively bodied people.<sup>9</sup>

With the arrival of white settler colonialism, things changed, and not in a good way. For many sick and disabled Black, Indigenous, and brown people under transatlantic enslavement, colonial invasion, and forced labor, there was no such thing as state-funded care. Instead, if we were too sick or disabled to work, we were often killed, sold, or left to die, because we were not making factory or plantation owners money. Sick, disabled, Mad, Deaf, and neurodivergent people's care and treatment varied according to our race, class, gender, and location, but for the most part, at best, we were able to evade capture and find ways of caring for ourselves or being cared for by our families, nations, or communities—from our Black and brown communities to disabled communities. At worst, a combination of legal and societal ableism plus racism and colonialism meant that we were locked up in institutions or hospitals, “for our own good.” The Ugly Laws, on the books in the United States from the mid-1700s to the 1970s, stated that many disabled people were “too ugly” to be in public and legally prevented disabled people from being able to take up space in public. The Ugly Laws were interwoven with a mass creation in the 1800s and onward of hospitals, “homes,” “sanitoriums,” and “charitable institutions” where it was the norm for disabled, sick, mad, and Deaf people to be sequestered from able-bodied “normal society.”<sup>10</sup>

These institutions overlapped with other prison/carceral systems, like residential schools, where Indigenous children were stolen, abused, and stripped of their language and culture, and prisons where Black, brown, poor, criminalized, trans, queer, and sex working people were locked up for profit. People's fear of accessing care didn't come out of nowhere. It came out of generations and centuries where needed care meant being locked up, losing your human and civil rights, and being subject to abuse. The specter of “the home” and lockup still haunts everyone when we consider asking for or needing care.

One of the first and most passionate demands of the disability rights and mental patients liberation movements of the 1960s and '70s was for independent living and deinstitutionalization. It's an often-told crip story—how the disability rights movement started with the Rolling Quads, the white, polio-surviving, physically disabled men who got radicalized while attending UC Berkeley by both witnessing Black and brown power and free speech movements and being sequestered in each other's company because they were only allowed to live in the campus

infirmiry. How after graduation, they started the first independent living centers and pushed for Medicare and Medicaid to pay for state-funded personal care attendants to allow them to live in their own apartments and get help with dressing, using the bathroom, and transferring from bed to chair.

Yet some/many of us live in the “cliffhangers,” as Patty Berne puts it, of the disability rights movement—the spaces where a white-dominated, single-issue, civil rights approach that depends on the ability to use lawsuits to achieve disability liberation leaves many of us behind. Some of us are disabled folks who are able to access care attendants to help us live that are paid for by the state, Department of Health, or Social Services. Some of us are disabled people whose disability the state never approves of—so it’s not “real.” Some of us fear that letting anyone in to care for us will mean we are declared incompetent and lose our civil rights, so we guard the houses where we can be sick. Some of us know that accepting care means accepting queerphobia, transphobia, fatphobia or sexphobia from our care attendants. Some of us are in the in-between of needing some care but not fitting into the state model of either Total and Permanent Disability or fit and ready to work—so we can’t access the services that are there. Many of us are familiar with being genuinely sick as hell and needing some help but failing the official cripp exams because we can still cook, shop, and work, only slowly and when there is no other choice. Some of us are not citizens. Some of us make twenty bucks too much. Some of us will lose our right to marry if we go on state disability, or our access to work or housing. Some of us belong to Nations that will not accept state money. Some of us—always, and especially post-Trump, with the rise of fascism calling for the end of Medicaid, the ACA, and the ADA in the US, and socialized medicine and human rights legislation throughout the world—are continuously worrying about what happens when our precarious right to state-funded care goes away, and what our survival strategies will be then.

## MOVING PAST NIGHTMARE TOWARDS STRATEGIES FOR THE FUTURE OF COLLECTIVE ACCESS

In the face of systems that want us dead, sick and disabled people have been finding ways to care for ourselves and each other for a long time. As Vancouver’s *Radical Access Mapping Project*<sup>11</sup> says, “Able-bodied people: if you don’t know how to do access, ask disabled people. We’ve been doing it for a long time, usually on no money, and we’re really good at it.” Sometimes we call them care webs or collectives, sometimes we call them “my friend that helps me out sometimes,” sometimes we don’t call them anything at all—care webs are just life, just what you do.

The care webs I write about here break from the model of paid attendant care as the only way to access disability support. Resisting the model of charity and gratitude, they are controlled by the needs and desires of the disabled people running them. Some of them rely on a mix of abled and disabled people to help; some of them are experiments in “cripp-made access”—access made by and for disabled people only, turning on its head the model that disabled people can only passively receive care, not give it or determine what kind of care we want. Whether they are disabled only or involve disabled and non-disabled folks, they still work from a model of *solidarity not charity*—of showing up for each other in mutual aid and respect.

I first learned of the term “mutual aid” as an anarchist teenager, in books like Ursula Le Guin’s

*The Dispossessed* and in a lot of zines that quoted white guy theorists like Kropotkin. All of these writers, and many other anarchist and antiauthoritarian writers, use the term to mean a voluntary reciprocal exchange of resources and services for mutual benefit. Mutual aid, as opposed to charity, does not connote moral superiority of the giver over the receiver. White people didn't invent the concept of mutual aid—many precolonial (and after) Black, Indigenous, and brown communities have complex webs of exchanges of care. However, given the presence of white anarchism as one of the biggest places that talk about ideas of mutual aid, it doesn't surprise me that one of the first examples of collective care I encountered was dreamed up by a white Southern disabled queer femme anarchist whose politics brought together disability and mutual aid.

## THE PREQUEL: LOREE ERICKSON'S CARE COLLECTIVE

*Hello Lovely People ...*

*For those of you who don't know me I am Loree Erickson, a queer femmegimp porn star academic who now lives in Toronto, ON but grew up in Leesburg, VA and lived in Richmond for 8 years. My work tends to focus on the intersections of radical queer, disability and sex/uality bringing together personal experience, creativity (through video and photography), and theory to explore issues of explicit sexual representation, embodiment, and desirability. As well I theorize around personal assistance/care relationships and create alternative support structures. I also love sun, sparkly things, and social justice. I am coming to DC to present at a day long seminar for and by young women with disabilities at American University. Then, of course I have to come to RVA and see my people (as well as eat biscuits and gravy at 821 Cafe).*

*I arrive in DC Friday, around 1ish and am around until Monday morning. Then I am heading to Richmond till Wednesday eve. I am traveling with a friend who can help out with some of my care, but I am in need of friendly recruits to help as well. Plus it's an awesome opportunity to meet fabulous and friendly people/see friends I have seen in too long!*

*How you can help:*

*I use a wheelchair and I am looking to recruit folks to help with my personal care needs (fancy words for getting into/out of bed and going to the bathroom). No experience needed (I am really good at talking folks through it plus what I need help with is pretty straight forward) and ya only have to be sorta buff. I [weigh] around 130lbs, but it is not as bad as it seems. If you're worried about lifting I might be able to buddy you up or maybe you can buddy yourself up with a friend. Two people makes it way easier and yay for safety! :-)* It doesn't take that long (around a 1 hour—usually less—to pee and a bit more to get into/outta bed. I usually pee at 12ish, 5ish and then when I get into bed and wake up. If you don't have a lot of time, even one shift would be so extremely helpful.

*If you are interested let me know or if you know anyone else who might be interested, please send this their way (I appreciate people of all genders helping me). I need to know as soon as possible so that I know how stressed out to be. Plus we are coming soo soon! :) Also if you can send me your availability that would be amazing.*

*Help with any part of this would be awesome and forwarding it to other nice people is also very much appreciated. Thanks soo much ...*

*Can't wait to see/meet you and your friends!!!*

*Loree*

**Interviewer:** “Your model of collective care includes disability as part of our social understanding of mutual care. What you are doing is helping to shift our collective social understanding of care. It’s profoundly political.”

**Loree Erickson:** [Nods her head] “Yeah, it really is. It’s too bad that taking care of each other has to be radical.”<sup>12</sup>

Encountering Loree Erickson’s artwork, and then learning about and witnessing her care collective, changed my life. Her artwork and disabled community organizing were some of the first places where I saw a femme disabled person talk about disability, femmeness, and desirability, or the concept of interdependence, or collective care as a thing that could exist in the world. Her queer femme anarchist disabled white Southern art, organizing, and self were everyday parts of my political reality in Toronto in the mid-2000s and had a huge impact on the city’s activist communities. For many people in Toronto and beyond, her care collective has been both a groundbreaking model for alternative dreams of care making and a place to be brought into disability activism and culture.

Loree began her care collective in her twenties in Virginia as a survival strategy: the state’s refusal to fund attendant care adequately (as is true most of the time with state social service) meant that the amount of money she got to pay attendants was below minimum wage. And often, when she was able to hire an attendant with DHSS money, they were homophobic and unsupportive of Erickson when she was watching queer films or hanging out with other queer friends. In response, Erickson fired her attendants, had a meeting with her friends, and came up with the vision to experiment with collective friend-made care together.

Her care collective continued when she moved to Toronto, partially because of her lack of ability to access state-funded home care attendants because of her not being a permanent resident. For the past fifteen years, her care collective has been filled with disabled and non-disabled friends and community members who work shifts each week to help her with dressing, bathing, and transferring. She doesn’t have to do all the care work herself: she has friends who take on the admin work of emailing, scheduling, and training potential care shifters. When she travels away from her home base of Toronto to conferences, to lecture and teach workshops, or to visit friends and lovers, she or supporters ask, via Facebook and email, for people in that region to help and be part of her care team. In recent years, Loree and allies have planned small fundraisers to purchase adaptive equipment and compensate some care shifters who are poor/low income for their time and care work, especially as Loree gets older, and her community gets more disabled themselves.

Loree’s care collective is not just a practical survival strategy to get her the care she needs; it’s a site of community and political organizing, where many people learn about disability politics (both the theory and the nitty-gritty) in action for the first time. In one interview, she notes that upon moving to Toronto, her care collective became a more explicitly political space. “It was more like mobilizing a community. I was meeting new people, I was connecting with folks, and I started to see the ways that collective care functions as anti-ableism training for folks,” she said.

People were becoming radicalized around care and disability through participating in the collective. “It’s not like I’m giving workshops or lectures from the bathroom, but you know, we’re talking about both of our lives and so that’s part of the way that the education happens.”<sup>13</sup>

In Loree’s care collective, her need for access is posited as something she both needs and deserves, and as a chance to build community, hang out with Loree, and have fun—not as a chore. This is drastically different from most ways care is thought of in the world, as an isolated, begrudgingly done task that is never a site of pleasure, joy, or community building.

This is radical. It is a radical rewriting of what care means, of what disability means, taking anarchist ideas of mutual aid and crip-femming them out. I’ve shown people Loree’s fundraising video for the collective, where shots of her transferring to the toilet with the help of a care shifter are interspersed with footage of her and care shifters trading gossip and dating advice over breakfast. After seeing the video, one participant in a workshop on care I gave said, “It’s really mind-blowing for me to see someone accessing care that’s very intimate, without shame, and with everyone laughing and having a good time.”

Loree’s care collective model is a deep possibility model, not a one-size-fits-all solution for everyone who needs care. Her collective working relies on her having access to a broad network of friends and acquaintances, a social and activist life where people know her and are interested in helping her out, something many people, especially sick, disabled, and mad people, are too socially isolated to be able to access. Although I admire her collective and have learned a lot from watching it, I also think about how there aren’t a million collectives for low-income Black and brown autistic, physically disabled, or chronically ill people in Toronto. I think of the challenges myself and Black and brown friends and acquaintances have had finding people who are willing and able to do care for a week or a month, let alone years, especially when that care involves pain or mental health crises that may not have a resolution. I think about the ways Loree’s willingness to offer emotional caregiving to her care shifters, her whiteness and extroversion and neurotypicality are factors that aid her in being able to access an abundance of care—factors not available to everyone.

I also think about the people I know who want and need the distance of having someone they don’t know care for them. As a wheelchair-using, physically disabled Black femme friend of mine remarked to me, “I’m glad Loree’s model works for her, but if someone drops me, if someone doesn’t show up for a shift, I can die. I don’t ever want to depend on being liked or loved by the community for the right to shit in my toilet when I want to.”

I think that all of these things can be true at the same time. Loree’s collective is still an incredibly important example of a crip-created way of accessing care that has made more worlds of care possible for myself and others to dream.

## CREATING COLLECTIVE ACCESS DETROIT, JUNE 2010–JUNE 2012

*We know that for many of us, access is on our minds when it comes to traveling, navigating the city, movement spaces, buildings, sidewalks, public transportation, rides, the air, the bathrooms, the places to stay, the pace, the language, the cost, the crowds, the doors, the people who will be there and so so so much more.*

*Would you like to be connected to a network of crips and our allies/comrades who*

*are working together to create collective access?*

*What is collective access? Collective Access is access that we intentionally create collectively, instead of individually.*

*Most of the time, access is placed on the individual who needs it. It is up to you to figure out your own access or, sometimes, up to you and your care giver, personal attendant (PA) or random friend. Access is rarely weaved into a collective commitment and way of being; it is isolated and relegated to an afterthought (much like disabled people).*

*Access is complex. It is more than just having a ramp or getting disabled folks/crips into the meeting. Access is a constant process that doesn't stop. It is hard and even when you have help, it can be impossible to figure out alone.*

*We are working to create mutual aid between crips and beyond! ... We hope that together we can create a culture of collective access. We are just trying this out! would you like to join us in practicing what this could look like? do you have ideas? are you an ally/comrade who wants to help out or be on call?<sup>14</sup>*

Creating Collective Access (CCA) was a crip<sup>15</sup>-femme-of-color-made piece of brilliance that came together in the summer of 2010. You can read much more about it at [creatingcollectiveaccess.wordpress.com](http://creatingcollectiveaccess.wordpress.com), but in my version of the story, CCA happened because three disabled queer Asian femmes were on a conference call to plan the workshops we were organizing at the 2010 Allied Media Conference (AMC) and US Social Forum (USSF)—an enormous social justice gathering bringing tens of thousands of people to Detroit to imagine a revolutionary future—and we were completely fucking stressed out about how we were going to survive those conferences.

This is a very common disability experience: getting ready to go travel to a conference and having your freak-out about how badly the whole thing will fuck up your body. Will the airport break your wheelchair? Will you get sick from a fragrance exposure? Will the accessible van or ASL promised in the conference material just not be there? Where will the food be, and is it stuff you can eat? Will you be 1,000% overstimulated by thousands of people talking about intense things? What if you have a panic attack or suicidal ideation 2,000 miles away from home and your usual supporters' access hacks? In short, how will you negotiate the world away from the crip survival skills you have where you live? We're used to feeling that our disability experiences are private, embarrassing, and not to be spoken about—especially crips who may be working mostly in non-disabled social justice communities—and conference and travel bring those feelings on even more so.

But in 2010, some of us came together at a nascent moment of disability justice organizing. We came together as disabled queer and trans people of color, talking, sometimes haltingly, about our intersectional lives, and talking about what disability organizing would mean that didn't leave any part of ourselves behind. We were rooted in a ground of other disabled queer and trans people of color, who were finding each other through online portals like the Azolla Story (a closed online portal for disabled queer and trans people of color, through the cultural, political work of Sins Invalid and the Disability Justice Collective, through our own blogs and chance meetings in crip-of-color hallways, coming and going. And on that call, Stacey, Mia, and I had a profound moment

of clarity. We didn't have to choose between handling our access needs on our own or crossing our fingers that the conference and the airlines would come through to take care of us. We could experiment in coming together and caring for each other. What would it be like to create a space that centered Black and brown disabled people, that was led by disabled queer femmes of color, where instead of able-bodied people begrudgingly "helping" us, we were doing it for ourselves? We didn't know, but we knew it would be the polar opposite of so much existing disabled spaces that were dominated by white crips and their casual and overt racism, so much mainstream space where we were always on hold with access services. We didn't know what we were doing, and we knew what we were doing. We knew we were creating something revolutionary.

So we did it, and we did it quick, in the last three weeks before we had to go to Detroit—threw up a quick WordPress site asking for other sick and disabled queer, mostly Black and brown, people to find us, for us to find each other. We knew we couldn't create access for thousands of people, but we wanted to see what we could do with the resources we had.

And it worked: sick and disabled queer people of color found us, through email and Facebook posts and friends of friends, and, once we got there, through running into us on-site. It came together in that effortless-feeling way that happens sometimes when something's time has come. There was so much creativity, hustle, and fun—and disabled queer of color brilliance. One member of CCA drove up from North Carolina to Detroit with two other disabled POC and her personal care attendant in her wheelchair-accessible van. That van legally fits four people, but I have photos of thirteen crips crammed into it and driving through Detroit, laughing our asses off. We shared information about why fragrance-free body care products are important and shared the actual products, especially those for Black and brown hair and skin, with each other, including with people who'd never heard of "fragrance-free" before but were down if it meant we were able to be together. We booked a few accessible dorm suites so we could sleep and hang out with each other.

CCA was one of the first places I ran into what I would later call cross-disability solidarity, and more than that, the reality of our different disabilities not being a liability, that there could be ways we supported each other. One person selectively used some "poor, cute cripple" skills to charm the dorm staff and get them to unlock the fourth-floor kitchen so we could cook and store groceries. One neurodivergent person who didn't have mobility problems walked a mile to the closest restaurant to load up someone else's spare manual wheelchair with our shawarma orders and walked the food back to everyone who couldn't walk that far.

Being less isolated helped us make group demands of the AMC that were effective because they came from collective disabled power, not just one individual crip writing a request on a registration form. The AMC ordered in fragrance-free soap for the washrooms because Detroit back then didn't have any supermarkets, let alone one that stocked Dr Bronner's unscented. The relationships and collective power we built also helped us survive the USSF, which had some major access challenges (like, no wheelchair-accessible shuttle, even though it was on all the promo material, and when we called to ask where it was, the person we talked to was like, "Can you come to the conference site and ask about the shuttle?" and didn't quite get it when we were like, "No, we can't, because we can't physically get there"). I remember someone texting, "I am spooning out, I need crip love" from where they were passed out at one end of the conference center, and all of us getting there as fast we could, and them saying that just watching us walk and

roll up made all the difference.

We didn't just survive the conference—we made powerful community. Committed to leaving no one behind, we rolled through the conference in a big, slow group of wheelchair users, cane users, and slow-moving people. Instead of the classic able-bodied conference experience most of us were used to, where able-bodied people walked at their able-bodied rate and didn't notice we were two blocks behind, or nowhere, we walked as slow as the slowest person and refused to abandon each other. People got out of the way. Instead of going out to inaccessible party sites, we chose to stay in, and ate and shared about our disabled lives. For some of us, it was our first time doing that. People cried, flirted, and fell in love.

CCA changed everyone who was present for it and a lot of people who just heard about it. It was just four days, but people went home to their communities transformed. We were no longer willing to accept isolation, or a tiny bit of access, or being surrounded by white disabled folks as the only kind of disability community we could access, or being forgotten. We talked about how it had been for us to be with each other. We threw queer disabled femme of color brunches that were maybe just us and the three other sick and disabled femmes of color we knew, but we sat in bed and talked and talked about our lives. We tried out starting crip hangouts and zines and performance nights. We started thinking about what it would mean to have our own care collectives, on a permanent basis. We came back less willing to accept ableism from conferences and community spaces, because we knew it could be different—and if CCA could happen in someplace with scarce physical resources like Detroit, it could happen anywhere. Being part of that wild pack of slowness, talking tentatively about our disabled lives in ways we'd never said out loud before, changed everyone's lives.

## AN ASIDE: STORY THREE: THE CRASH-AND-BURN EMERGENCY MODEL

In many able-bodied activist communities—QTBIPOC and mostly-white punk—I've been a part of, I've been witness to another form of care web that is very different from the ones I've written about so far. They're the emergency-response care webs that happen when someone able-bodied becomes temporarily or permanently disabled, and their able-bodied network of friends springs into action. When the friend gets hit by a car when they're on their bike or gets pneumonia, there are emails and calls and care calendars set up, and (mostly able-bodied) people show up to the hospital. (Mostly able-bodied) people cook food and throw benefits. There's a sense of urgency! Purpose! Action! OMG, someone is sick! We must come together as a community to help them. (Many disabled people roll their eyes at this moment: *Wow, when it's your mountain-climbing friend who gets hit riding their bike, you care, huh? For me and the other folks who are always disabled, not so much, huh?*)

The urgent care calendar care web lasts for a few weeks, a month. And then ... people trickle off. People think that the person's all better. It isn't a fun cause of the moment anymore. People think: *Wow, you're still disabled?*

These models have a lot to learn from disability justice models of centering sustainability, slowness, and building for the long haul. They tend to come from people who don't know, well, that disabled people or community or activism, um, exists. Since they don't know (or have been

firmly ignoring) that we exist, they often reinvent the wheel(chair). I'm not the only crip who's felt bitter when I've seen calls for benefits and care earnestly sent out for someone who's been able-bodied up to that point and now has an acute, sudden need, when I've watched myself and my friends who have chronic disabilities, have been disabled since birth or live with chronic physical illness or dance with madness/mental health, struggle to get responses to our everyday and acute asks for care and support.

These emergency-response care webs often really fall apart when and if the person they're for becomes disabled in a long-term way, and the members realize that the "issue" isn't an individual problem that their buddy has—that beyond needing care, their friend is being impacted by the ableism of both the everyday world and much queer and activist space. Clubs they used to hang with aren't wheelchair accessible (they notice for the first time); fighting with insurance companies and the access van take hours. Huh! Is this a thing? The emails start coming in to the one crip they know: "Hey, do you know where so and so can find accessible housing? Seems like it's kind of hard to find." It's not that I don't want folks to access what they need—but I also have to roll my eyes that these folks are noticing ableism for the first time. I want them to understand that the struggles their friend is facing are not new or unique to them, that although I'll usually share my knowledge, so many of us have been using (limited) spoons<sup>16</sup> to fight these fights for a long time.

If these care webs are going to keep working, a paradigm shift needs to occur in those friends' heads. They need to see the disabled people they've blanked out on listening to for years when we've been trying to talk about access or our lives. (An apology might be cool, too.) They need to understand that their friend isn't a special cripple, cooler than the rest—that the problems they're facing aren't individual ones but systemic struggles that face all crips and need collective solutions. They need to ask themselves why they have systematically refused to value or take in what disabled folks around them have been and are saying. They need to listen and learn from the care work and skills disability communities have been doing for years—and maybe offer some compensation for that knowledge. Or at least say thank you.

## STORY FOUR: CCA BAY AREA

In the fall of 2010, some of us who'd been in Detroit came back to the Bay Area where we lived or moved there for the first time. And it occurred to us: Why didn't we try and do something similar here? What would it mean to take the temporary experiment in crip-of-color-made access that had worked so beautifully during the four to ten days we'd be in Detroit to our homeplaces, in a long-term way?

We dove right into the modest, wildly ambitious plan of attempting to create a Bay Area care collective by and for disabled queer and trans people of color.

We came together with a lot of hope and a ton of longing, a longing for a community we had been wanting for most of our lives. We came together with so much need and so much fear, like icebergs, where most of the mass lies below the surface.

When we sat down at our very first meeting, I thought I knew exactly how it was going to go. When I thought about what I might need in terms of disability care and support, I could name it right away: I could sure use some help driving my best friend to acupuncture and the grocery store

and the mosque twice a week—I loved helping them, but between supporting them, supporting myself, and working two to three jobs, plus working on two or three unpaid collectives that were each like part-time jobs, I was exhausted. And, in a smaller tone of voice that didn't reach outside my head, *I could use folks who could help me do some stuff too.*

This project turned out to be a little more complicated than I'd thought it would. Everyone had a lot of questions. Should CCA Bay be open to white folks or just POC? Just crips or non-disabled QTBIPOC allies? Some argued that some of us had white crips in our “pods” of people we shared care with already, so it wouldn't make sense to exclude them. Other folks felt strongly that white disabled people always dominated crip space and did not want to risk creating a space where we would have to fight to continue to center people of color. Some felt that including non-disabled BIPOC folks could help develop seed organizers who could work to make the non-disabled QTBIPOC community less ableist.

But before we jumped into Google calendar, one member pulled out a flip chart. She said that before we did anything we needed to talk what would allow us to give and receive care. Most of us, she pointed out, had received shitty care, abusive care, care with strings attached. Most of us, she guessed, would want to give care, and then shrug and say, “I don't know, I'm fine” when asked what we needed. We went around: What made it possible for us to receive care? What was bound up with that act of reception? Under what conditions could we be vulnerable?

These, it turned out, were very deep and necessary questions. Hard to answer ones. The crip \$64,000 questions. That friend was right: all of us were eager to offer care; receiving care, not so much. It was so much easier to offer care to other people than to ask for what we needed, for so many reasons. Many of us had been raised as immigrants and/or women or femmes of color to always jump up and feed people first, do all the dishes, and help without being asked, while serving ourselves last. For many of us, care had been something that was forced on us—something abusive family members or teachers or health care workers did, whether we liked it or not. Or care had been something it wasn't safe to say that we needed—because there was no care out there for us, no health care, no therapist, no parent with time, no safe parent who actually cared. Maybe as disabled people, if we wanted to have any kind of independence, we had to deny that we needed any help at all—in order to stay in mainstreamed classes, go to college, or date, we had to say that we didn't have any needs. I can remember my mother clearly telling me in high school, when I first thought I might be neurodivergent—it was decades before I would know that word, but I was still really fucking clear that my brain and cognition and my ability to navigate space were very different from most people around me—that it was unsafe for me to say that I might need a tutor—tutors and accommodations, newly allowed under the brand new ADA, were for the rich white boys; I just had to be twice as smart and keep up if I wanted to get a scholarship. I couldn't afford to look “stupid.”

And finally, some of our needs were so vulnerable, so embarrassing, so complicated to ask for that it was much easier to just not admit we needed them. In that go round, when I silently thought, *I could use some help too*, one of the first things I thought of was that when I was sick, I often needed help with housework—making my bed and doing dishes, chores, and laundry, buying groceries, and cooking food. But as a working-class femme, raised by an ex-waitress mom who taught me to always bus my own table, and as someone who'd cleaned houses for a living, I had a strong working-class ethic about always doing my own housework. I couldn't imagine asking one

of my friends to clean my toilet or do my dishes without feeling like an asshole—even though I regularly and happily did chores for friends when they were sick.

We met an average of twice a week for a year. A lot of our time was spent building relationships, hanging out, and supporting each other in different ways, from physical care to emotional care during breakups. And we faced some challenges that many groups like ours have faced and will face again. We realized that even though we were all queer and trans disabled people of color, we didn't automatically know each other's access needs cross-disability. People who were physically disabled didn't automatically understand the needs of folks who were Mad, and vice versa. Sometimes, we thought of those misunderstandings as betrayals, instead of opportunities to own our mistakes or ask each other to teach us.

Mia Mingus's often-quoted words, from her essay of the same name about committing to crip community, "Wherever you are is where I want to be"<sup>17</sup> got put to the test when access needs weren't complementary and we couldn't physically be in the same space. When someone needed help moving out of their house up two flights of stairs, even though the call for help said, "Come if you can help move and lift boxes! Come by if you just want to lend moral support! Bring food to share" (suggesting that helping physically move boxes, bringing food, and offering moral support were all equally legit ways of supporting)—but if I was too fatigued to get out of bed and too broke to bring food, did that mean that I wasn't being a good community member? We were running into a similar challenge Loree had once talked about with an earlier care web she'd been involved in: What happens when chronically ill folks—who often have fatigue, lack of physical strength, and a need to shift and cancel schedules as we get sick—try to assist physically disabled folks, who often need folks to be able to lift heavy things, and who may have pretty scheduled lives (e.g., chair users who have PCA care shifts when they pee scheduled every four to six hours)? We weren't always great at sitting with those contradictions with kindness and curiosity, an "Okay, that didn't work—what would?"

Often, instead, we experienced the places where interdependence didn't just magically work out as betrayal, letting each other down. We had so many hopes for each other, so much belief that we could be everything to each other, effortlessly and automatically, through shared identity. And we'd been betrayed so many times before, by white disabled people and non-disabled people in our lives, so we hoped that since we'd finally, finally found that beloved BIPOC sick and disabled community, we'd never fuck up (or be tired), always know the right thing to do, and be able to do it. It turned out that, like every time I've come together with people I've shared an identity with, there was bliss and also heartbreak when we assumed that that bliss would be easy and forever.

As romham of RAMP Vancouver writes:

If interdependency is in our DNA, what does it mean when we fall out of whack with it? How do we handle the realities of our bodies and minds that need what they need when they need it? What does it mean when I can't support you in the ways you're supporting me? Does interdependency mean we do the same for one another at all times, as though there's even such a thing as "the same" when it comes to this stuff? Is it a gentle ebb and flow? What if my ebb will never match your flow? What if it's sometimes a torrential downpour and one of us is drowning? What do we do then?<sup>18</sup>

There were more questions. Like, what happened when some of us could hang together more because we had fewer mobility needs—we could make it into a car, could deal with exposures—and some of us couldn't? How did we make things feel fair when some of us got tired and sick and needed to cancel, and others—maybe folks who practiced “sucking it up” and working through pain more, maybe just folks who didn't have pain and fatigue—were left feeling like they were doing all the work? What about those of us who felt more comfortable going to non-disabled events together so got to spend that time and get that visibility, and those of us who felt more overwhelmed or had more anxiety about being stared at?

And, maybe the biggest disabled community question of all: What happens when a lot of people who have always been the only one, are no longer the only disabled queer of color in the room? How does that affect how we work together, build community, and work out conflict? Sometimes, because we were used to being the only revolutionary crip fighting ableism in a sea of able-bodied obliviousness, it was hard for us to hear that we weren't always right, to understand differences of opinion or approach or experience as other than wrong, or attack, or threat.

After a year, our group broke up, from all of these pressures and hard spots and a web of interpersonal conflict. It was a hard breakup. I felt like my dream sick and disabled QTBIPOC crew had fallen apart, that a community I had passionately believed in and given much of my limited energy to had failed.

I didn't know that one group falling apart didn't have to mean that was it—for the idea of building a care web, for the movement. I wish we could've known that the struggles we hit weren't failures or signs of how inadequate we were but incredibly valuable learnings. I wish I'd known then what I do now—that all this stuff is the \$6 million crip question, that we were by far not the only disabled queers to struggle with them, and that our struggle to figure these questions out is at the heart of our movement work. CCA is another worthy, imperfect model in my body's archive, one I build on as I build care in my life now.

## STORY FIVE: AN ONGOING, VIRTUAL CARE WEB: SICK AND DISABLED QUEERS

Disabled Mizrahi genderqueer writer and organizer Billie Rain started Sick and Disabled Queers (SDQ), a Facebook group for well, sick, and disabled queers, in 2010. Billie started SDQ as an experiment in building an online community open to all sick and disabled queer people that would center sick and disabled queer people of color and other folks who had traditionally been marginalized from mainstream disability rights spaces, that would also be accessible to the many sick and disabled queers who were isolated, homebound, or had limited energy or ability to travel physically to an in-person meeting. Mostly, Billie wanted a place where a lot of sick and disabled queer people could hang out in bed, online, and chat with each other. Over the eight years of its existence, SDQ blew up into a virtual, North America-wide community that both offered a hell of a lot of practical care and support—shared knowledge about diseases and doctors and disability hearings, people witnessing each other and fundraising for rent and medical bills and accessible vans—and became a locus of disability justice thinking, relationship building, and organizing.

It is impossible for me separate the care work SDQ members did from the theories we made, from how we shared tools, wrote poetry, and created friendships. SDQ folks regularly mailed each

other meds and extra inhalers and adaptive equipment. We shared, when asked, information about what treatments worked for us and what didn't and tips for winning a disability hearing. We crowdsourced money for folks who needed to replace stolen wheelchairs, detox their houses, get living expenses together for rehab, or get out of unsafe housing situations. People sent care packages and organized visit teams for members they might never have met in person who were in the hospital, rehab, or the psych ward. We cocreated an evolving, amazing cross-disability best practices/community guidelines document that helps folks learn about the disabilities that aren't ours—from captioning videos to neurodivergent communication styles. At its height, it was everything good that social media made possible—instant connection with a million people with shared identities and interests, who could listen to you when you were in crisis or answer a disability question that no one near you knew the answer to. It was a structure that broke two of the biggest barriers most disabled people face—isolation and shame.

SDQ felt like a hot spot of disability justice in practice. Some of the smartest DJ thought happened here, and mostly, it felt free of “activist stardom” but filled with collective disabled intelligence. Instead of a few Special Crips, it felt like a place where a lot of folks, often especially folks who were deeply isolated and excluded from systemic power and the world, got to think and talk with each other, take and share pictures of ourselves in bed, share tips about hypermobility and sex, diagnose each other way faster than the free clinic could—and also ask big questions about disability, art, sex, activism, and life. SDQ at its best functioned as a big, sustainable, pretty damn cross-accessible care web powered by members who were homebound, not working a lot, isolated, on disability, and who had time to throw down support, prayers, and connection via text, the internet, or phone. Because the format was text based, it was Deaf accessible and accessible to folks for whom voice and in-person communication is hard. It was and is a more challenging/less accessible format for folks who are working, anxious, or overwhelmed by a lot of internet, or EMF sensitive so that being on the computer is hard or impossible.

SDQ had a community value of people responding how they can, as they can, with no shame if they didn't have capacity. SDQ is also a model of what we mean when we try to explain that disabled people know how to do sustainability. SDQ was inherently very sustainable because it wasn't just you trying to ask your crew of six local people for help—you could reach out to thousands of people across the world, and someone would always be up, someone would always have cash or capacity or energy to talk you through whatever it was. SDQ grew from a community with one moderator to one with six, so there was always someone to step in if someone else was sick or spooned out. SDQ felt like a living example of what sustainable organizing looks like, led by people who are pushed out of 99% of able-bodied mainstream activism and are told that we aren't capable of doing any kind of organizing or political activity.

I remember a heated debate on SDQ where a new member said they liked the space, but it “didn't seem like there was much activism going on here.” People got really heated. We talked passionately about how what we were doing on SDQ—the talking and the meds-sharing and the scheming and the life support—absolutely counted as activism, was a way we were transforming traditional notions of what activism was to make it over in our own crippled-out images. And that without the life support we were giving each other, we wouldn't be able to stay alive to do activism, or life, at all.

## CARE FUTURES

As I write this, Trump is in his second year. We've withstood his government's attempts to destroy the ADA, the Affordable Care Act's access to health care for disabled and sick people, and Medicaid's funding of paid home attendant care. Everyone I know is a mix of on edge, permanently wondering what shit will hit the fan next, trying not to be stuck in reactivity and panic, and sometimes, absurdly hopeful and passionate about building the futures we need.

I am ten years in to these wild experiments with collective access and care, and I am both grateful for the stories under my belt and full of the knowledge of how much I still don't know. I continue to live a life supported by a practice of being able to call on kin in emergencies and everyday need and being able to respond to need. I am a veteran of many emergency care circles and GoFundMes that have come together when someone is facing a disability crisis—eviction, medical bills, emergencies, mental health crisis. I know some things about how to organize a circle of people who can offer care, stop by with food, send money, and text people back.

Yet as I move forward in this life of creating and receiving care, I am continually impressed by how we find ways to keep each other alive when the state is fucked, and community can be fucked and inadequate too. I love seeing how friends and strangers seem to be more and more used to crowdfunding care and setting up care shift Google docs. I also see the burnout and exploitation of often femme and disabled labor that happens, and also what happens when people plain run out of energy, money, and time. I think about the needs I have that I am still too ashamed to let anyone see, let alone take care of.

I also think about friends and strangers who have plenty of needs but not enough friends or strangers willing and able to come through to care for them. The community is not a magic utopia, just like our families weren't, and we don't all just magically love each other, or even like each other, let alone agree on every political issue. I think about people I know who are mean or angry or bitter or "hard to like"—and disabled—and how that confluence is not a surprise or an accident, because many of us are indeed in a shitty mood, mean, or bitter from withstanding decades of ableism and the isolation that it brings. I think about the people I know who I don't want to die lying in their own piss, but I don't want to be the one who changes their diaper either. I think about the things I still can't ask friends to help me with—cleaning the house when it's incredibly nasty after I've been in pain for weeks, dealing with shit or blood. I think about my friend's statement that she shouldn't have to rely on being liked or loved to get care.

I recently realized I was hitting caregiving burnout—something I was familiar with as a concept but never thought would happen to me—with a loved one after many months of chronic illness and mental health crisis on both our parts. After a Google search connected me with a caregivers' website for my county and I sent an email, I got a nice phone call back from someone from who told me that we would be eligible for twenty-four hours of emergency respite care—someone would be paid by the county to show up, pick up the meds, do the dishes, cook some food, and listen. She tactfully said, "Many people find they have an easier time with someone who is being paid, well, to do the work, coming in and helping than asking a friend to clean and cook." When I told my friend that this existed, not only did they agree, they exclaimed, "How come all our friends aren't using this, instead of just burning each other out?" I know the answers—shame, lack of access to the web, thinking that it doesn't exist or the actuality that it really doesn't exist or

we won't be eligible or we'll have to jump through rings of fire to get it. And it made me see more possibilities.

I don't think there is any one single answer to the need for care. I just want, to echo my friend Dori, more care, more of the time. I want us to dream mutual aid in our postapocalyptic revolutionary societies where everyone gets to access many kinds of care—from friends and internet strangers, from disabled community centers, and from some kind of non-fucked-up non-state state that would pay caregivers well and give them health benefits and time off and enshrine sick and disabled autonomy and choice. I want us to keep dreaming and experimenting with all these big, ambitious ways we dream care for each other into being.

## SOME TOOLS AND PITFALLS TO WATCH OUT FOR, FOR FOLKS DREAMING CARE WEBS

**Crips supporting crips! Only! Ever!** Crip-on-crip support is awesome! Often, after a lifetime of ableist able-bodied people providing shitty or abusive care and assuming that we're not able to do anything ourselves, disabled people caring for each other can be a place of deep healing. Many, if not most of us, have good reasons not to trust that able-bodied people will actually get it, will actually come through on their promises of care or support. Lots of disabled folks I know who are well versed in this experience also understand that it's mostly only other sick and disabled folks who actually show up for each other. We can be projectile vomiting and we'll still send you a supportive text from the side of the toilet.

However, moving together as disabled people, in my mind, has some important caveats. Solidarity with other crips also means the realities of an inaccessible world and cross-ability access. If I am chronically ill and don't have the energy/strength to lift you onto the toilet, that doesn't mean I am a bad ally. There's also the reality that sometimes we all need care, simultaneously. I've often seen crip-only spaces fill with feelings of betrayal and hopelessness when we cannot fulfill some of our friends' needs. Instead, I believe it's possible to build a model of experimenting and seeing how it works out, then adjusting. We can try, knowing we may fail and things may turn out to be more complicated than we expected.

I also think that recruiting non-disabled folks who actually have their shit together (or can be trained to) can be a great option for some care. And what about paying some folks, in cash or work/skill trade, some of the time for spoons or energy-demanding labor? How about valuing a system of people contributing as they can, not necessarily "equally" or "always"?

**Assuming that as crips we intrinsically understand each other's access needs, or that access intimacy (even when we have the same kind of disability) is automatic.** Or that even if we really get each other's shit at first, our needs don't change over time.

**Not paying attention to the gendered/raced/classed dynamics of care**—a.k.a., are the poor and working-class disabled femmes doing all the work all the time? Care is feminized and invisibilized labor. Care is something that many (not all) poor/working-class folks do like breathing—we got time! It's just the right thing to do, right? What's going on with race and entitlement? Who feels comfy asking? Are the white queers, the pretty queers, the middle-class, relatively happy, skinny, normal queers getting much care? How many masculine-gendered people have I cared the ass off for, with no reciprocity? Talk about this stuff! It's really important!

Disrupt it! Get the masc, pretty, abled people to put in time!

**Doing all the admin work yourself!** So often I've seen sick and disabled folks do everything—all the caregiving, all the resource buying, and all the emailing and filing. Get some eager able-bodied person to manage the damn calendar!

**Assuming there is one right way to do “it”—it being the ways we offer or organize care—and that a way that works for a while won't change.** The circle of six people who come together at first may not be able to keep doing everything forever. The one person who was so great at doing the admin/organization end of things may get really sick of doing it, especially if they're holding all the notes in their head. Build capacity. Share the tools someplace everyone can access them. Switch out roles. Plan for people giving care to have our own crises. Having only one person with the skills and capacity to coordinate stuff is a recipe for burnout.

**Assuming that care webs have to be huge or that someone else somewhere is the “expert.”** We're so used to disabled care being professionalized, to assuming that medical and therapeutic professionals are the only ones qualified to intersect with our terrifying bodies. But the first CCA was created on three weeks' notice. Collective care, like transformative justice, can be so many things—a “crip your hangout” hangout, an ASL meetup, a Lotsa Helping Hands calendar, a hangout where I bring you food and we smoke high-CBD weed.

Sometimes it's not perfect. Often, disabled folks are (surprise) isolated. Some people have a big community to draw on; many of us don't. But just like some access is better than none, some (good) care can be better than none—and can be built on.

## **QUESTIONS TO ASK YOURSELF AS YOU START A CARE WEB OR COLLECTIVE, AND KEEP ASKING**

- What is the goal of your care web? Who needs care? What kind?
- Who's in it? What are their roles: caregiver, care receiver, both, admin person, fundraiser?
- How are you resisting the charity model in your work?
- What are best practices that allow the people receiving care to receive care well?
- What are best practices that allow the people offering care to offer care well?
- What physical tools (A van? Scent-free cleanser? A car? A smartphone?) do you need to make the access work? What money or other resources do you need to make it happen?
- How will you celebrate and make it fun?
- How will you build in time off and times when people are sick and you need a plan B?
- What meeting structure do you need to check in, talk through issues, and keep things on track?
- Are you building in ways for disabled folks to offer care, instead of assuming that only able-bodied people are the “care-ers”?
- What's your plan for dealing with conflict when it happens?
- How are you going to document your work? Do you need a place to keep receipts, a log of who does what hours?
- Do you have a plan for checking in and making sure funky dynamics aren't creeping into your care? This could be anything from pity, martyrdom, guilt, or difficulty negotiating boundaries to the ways gender dynamics (women or femme people doing more care than masculine people and receiving less, expectations that many genders of people are supposed to “have it all together”), race dynamics (universalization of white experience, racism creeping in when Black or brown people are doing cleaning or physical care for white folks), class dynamics, whorephobia, internalized ableism, or cross-disability dynamics (for example, the differences between the experiences of more visibly/apparently disabled folks and those whose disabilities are invisibilized). (These are just some examples, not an exhaustive list.) It helps to view these issues coming up as part of the work and to have a proactive, scheduled time to check in about them.

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- 6 Anemone is an herb that can be used for anxiety and panic attacks.
- 7 Easy Does It is a wheelchair accessible van service that operates in Berkeley, California.
- 8 A “mad map” is a term invented by the Icarus Project, a care plan used to describe what madness looks like for a person and what care they do or do not want. For more information, see <https://theicarusproject.net/>.
- 9 Qwo-Li Driskill, personal conversation with the author, August 2011.
- 10 For more about this huge disabled history, see Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham, NA: Duke University Press, 2017); Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2010); Sunaura Taylor, “After the Ugly Laws,” *The Baffler*, February 28, 2017, <https://thebaffler.com/blog/after-the-ugly-laws-taylor>, and “I Want to Help the Handicapped ... According to the Charity Model of Disability,” [www.ju90.co.uk/help/eng/help1](http://www.ju90.co.uk/help/eng/help1).
- 11 *Radical Access Mapping Project*, <https://radicalaccessiblecommunities.wordpress.com>.
- 12 Elizabeth Sweeney, “Young, Hot, Queer & Crip: Sexing Up Disability Is a Way of Life for Loree Erickson,” *Daily Xtra*, September 9, 2009, <https://www.dailyxtra.com/young-hot-queer-crip-12141>.
- 13 Muna Mire and Mary Jean Hande, “‘The Pace We Need to Go’: Creating Care Culture,” *Action Speaks Louder: OPIRG–Toronto’s Field Manual for Those Who’ve Had Enough*, Fall 2013, 8–9.
- 14 “Crips Visiting Detroit!” *Creating Collective Access*, June 2, 2010, <https://creatingcollectiveaccess.wordpress.com/2010/06/02/crips-visiting-detroit>.
- 15 “Crip” is a word used by many people in disabled communities as a fuck-you, in-your-face reclaimed word, short for cripple—similar to how queers have reclaimed the word “queer.” Not everyone likes it or uses it; people have complex feeling about it, and it’s not great for abled people to use it. Leroy Moore coined the term “Krip” to avoid using a term that also is the name of the Crip gang/street economic organization.
- 16 “Spoons” is slang created by sick and disabled communities to describe units of energy and capacity, specifically within a sick and disabled context of having a limited amount of energy because of chronic illness or disability (thus having to make decisions about which tasks to do and which to let slide, moving at a slower pace/“on crip time,” etc.). The concept was created by Christine Miserandino in her essay “The Spoon Theory,” posted on her website, *But You Don’t Look Sick*. In her essay, a chronically ill woman attempting to describe what it’s like to live with chronic illness pulls out a handful of spoons and uses them as units of energy, relating what it’s like to have to carefully count how much energy you expend on daily tasks many abled people take for granted.
- 17 Mia Mingus, “Wherever You Are Is Where I Want to Be: Crip Solidarity,” *Leaving Evidence*, May 3, 2010, <https://leavingevidence.wordpress.com/2010/05/03/where-ever-you-are-is-where-i-want-to-be-crip-solidarity/>, accessed July 2, 2018.
- 18 “What Happens When We Can’t Live Interdependency All the Time?” *Radical Access Mapping Project*, November 9, 2015, <https://radicalaccessiblecommunities.wordpress.com/2015/11/09/what-happens-when-it-feels-like-we-cant-live-interdependency-all-the-time/>.