

LEAH LAKSHMI PIEPZNA-SAMARASINHA

CARE WORK

DREAMING DISABILITY JUSTICE



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I have loved disabled people
life and am still amazed to do
our people, the more I remember
I remember that my ancestors
seeing each other in the unit
that asking after one another
what they need (what we might
access) was the only way to
best shot at staying alive. My
of vulnerability and how to
My ancestors knew joy. My
meditated on who they were
My ancestors became
—Stacey

To the beloved, I

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 tincture⁶ 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?⁷ 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 map⁸ 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?

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/>.

What does it mean to shift our idea of it's disability, childcare, economic as an individual chore, an unfortunate condition of the body, to a collective responsibility that we share?

What does it mean for our movement to be about Ourselves and our own lived experience?

What does it mean to wrestle with strength, vulnerability, pride, asking for help, and how are so deeply raced and classed and gendered?

If collective access is revolutionary, how do we learn to love each other? How do we build a collective care that lifts us instead of a system that keeps all the deep ways in which care is complicated?

This is an essay about care—about how people attempt to get the care and what it costs in terms, with autonomy and dignity. It's about some experiments that have taken place in and around disabled predominantly Black and Brown networks of care by and for us. It's about how we need to love and live, interdependent ways, without primarily relying on the support of families—the two sources disabled and Black people have been forced to rely on for care, sometimes with a lack of control. This is about some of the dream ways to access care deeply, in ways that are joyful, building community, loved, given, and not burn anyone out or abuse or underpay. It's about care for us and by us, and it is also for everyone, as able-bodied and normatively minded people. It's not always be, who the ghost of the ne

G COLLECTIVE ACCESS

*ati, I'm at the bus stop, I hurt so bad,
 borrow twenty dollars? Can you go
 're out and drop them off? Here's a
 munity acupuncture together? Hey,
 you repost this Facebook note? Can
 er to the city? If you come, you can
 tendant and you won't have to pay.
 you could bring over? I'm flaring.
 f I take your manual wheelchair and
 ll have food. Can you go with me to
 I talk to my doctor? Can I use your
 :kup? I'm just over the border into
 ve can afford ASI for the event. Do
 re's the list of accessible event spaces
 you be part of my mad map⁸ crisis
 get out, even if we live in the same
 food stamp office? Can you pick up
 the dispensary?*

for anxiety and panic attacks.

van service that operates in Berkeley, California.

he Icarus Project, a care plan used to describe
 what care they do or do not want. For more
 st/.

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 each other against huge odds. It is a sick and disabled communities of color also about the contradictions and the are about what stops us from being able from Black and brown communities been the ones forced to care for other what happens when sick and disabled not forget about each other, but we all I wrote this essay because I passionate stories—of the revolution work we do other, listen without judgment, share during a psychotic break, or lift each

I wrote this essay because I passionate and disabled QTBIPOC stories, and I witnessed and participated in over 10 of creating care are both a core part of work of making the next world, the post-fascist, postapocalyptic world. I stand at the crossroads, between both inevitable collapses of our work, and we and keep dreaming ways to build emerge that our work in creating the new world of us will become disabled and sick, but yet “community” is not a magic unicorn helps us do the laundry and be held the way we will do this is by being fucking the places where our rhetoric falls flat where this shit is genuinely fucking

I wrote this for my mother, a woman childhood sexual and physical abu

with fear, as what you want the most but

and disabled QTBIPOC stories that are
 at risk of being passed down, as the mediums where
 they are most accessible/safe (Facebook in the age
 of the smartphone 2.0). And I am also thinking of care
 that I know of through queer
 time, that I know of through queer
 that often get counted as disabled stories
 but themselves as disabled care stories but
 not. Like STAR House, the house
 for trans femme sex worker revolutionaries
 like Rivera, with the rent paid by hustling
 for space for trans people of color and street
 workers who help each other, and share hormones and
 gender affirmation; the AIDS activist
 groups of the '80s and '90s that shared safer sex supplies
 and helped prisoners to receive medical care; the
 creation of safe houses and sharing of both pills
 and ways of coming off meds safely;
 as well as harm-reduction networks like the
 ones that exist today where people share naloxone
 in their living rooms with folks who use
 it for themselves and offered healing and access to
 it.

And about what allows us to access
 care when we who have been taught that our care
 is a burden—to the economy, the state,
 and to share the bus stop with so we need
 to be as possible. It is an essay rooted in the
 experience of 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 often lose their voice and dignity. This is for all of us, Black and brown femme people, who have been both abandoned and police medical experimentation and den

This is for all the friends I know who desperately need care but will never ask for fear they or their children will be abandoned by everyone who has had to run away from police control—by family members who have meant control. This is for every group of stressed-out people you know, only three disabled people you know, who wait for other until it trails away into frustration. This is for those of us who have been isolated in our communities, who have and have not been in isolation. This is for everyone trying to get out of the psych ward, who sometimes get an actual professional who wouldn’t be able to help. This is for all the times I’ve relied on my friends, that changed my understanding of the world, that time I’ve succeeded and failed at caring for myself by moving forward, the dream future

HOW PEOPLE GET CARE (AND DON'T)

I’m not an academically trained disability studies scholar, I pretend that this next section fits (or doesn’t) academic standards. The history of disability and denied care and the ways our needs are met is vast, and there is no way I can do a very brief history of how

syndrome and no medical care, and mental racism, as well as DID and if ever able to access any form of care . who both neglected me medically onalization as a young disabled and l the absolute best and most common class survivor who trusted no system my younger self, a newly incredibly old, who made up ways to care for i disability community, from books, wrote this for everyone who has been tever they call state disability money ability accommodations for the first at "medical proof" of our sickness get anything the state begrudgingly isit, Access-A-Ride, state or federal mmodations at school or work. This ng our disability to keep everything to social acceptance and capital—all

not closet our disability, Madness, itnessable disability is just a fact of for violence, for attempts by police, us and lock us up. This is for all of us ol, that being disposed of—who still lack and brown who freeze, who feel it asking someone to do our dishes ess, because that is the work we or : or no money during enslavement, and racist poverty—and this is for d toilets and wiped asses for little or

Combating
of
2

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

to have care

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.⁹

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

⁹ Qwo-Li Driskill, personal conversation with the author, August 2011.

the United States from the mid-1700s, disabled people were "too ugly" to be seen in public, and disabled people from being able to work. Ugly Laws were interwoven with a mass of hospitals, "homes," "sanatoriums" where it was the norm for disabled people to be sequestered from able-bodied "normals."

These institutions overlapped with asylums, like residential schools, where Indigenous children were taken and stripped of their language and culture. People who were poor, brown, criminalized, trans, queer, and disabled were locked up for profit. People's fear of disability was everywhere. It came out of generations of people who meant being locked up, losing your freedom, and being subject to abuse. The specter of "totalitarianism" is everyone when we consider asking for better care.

One of the first and most passionate movements for disabled people's liberation was the independent living movement—how the disability rights movement was born. Black, Brown, and White Quads, the white, polio-surviving, disabled people radicalized while attending UC Berkeley. Black and brown power and free speech movements were in each other's company because they were all in the campus infirmary. How after the 1970s, independent living centers and push

¹⁰ For more about this huge disabled history, see *With a Little Help from My Friends: A History of Disability in America* (Durham, NC: Duke University Press, 2011), *Disability in Public* (New York: New York University Press, 2017), "The Ugly Laws," *The Baffler*, February 28, 2017, www.thebaffler.com/ugly-laws-taylor, and "I Want to Help the Handicapped," www.ju90.co.uk/help/eng/help1.

post-colonialism. (I am also aware of ability is limited to a white-dominated usage, and how inaccessible that is to disabled people who could potentially connect to both approaches.) But here always sick and disabled people have the centuries, and I don't have time never will say that in many precolonial stigmatized ways of being disabled that did or death. Disabled Cherokee scholar that in precontact Cherokee, there are different kinds of bodies, illnesses, and ailments; none of those words are negative words for people as defective or not as good as

pre-colonialism, things changed, and disabled Black, Indigenous, and people: enslavement, colonial invasion, and something as state-funded care. Instead, work, we were often killed, sold, or taken to a factory or plantation owners and neurodivergent people's care and needs: race, class, gender, and location, but not always able to evade capture and find ways to be cared for by our families, nations, or even brown communities to disabled people. The notion of legal and societal ableism plus that we were locked up in institutions is what "The Ugly Laws, on the books in

Interview with the author, August 2011.

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."¹⁰

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 infirmary. How after graduation, they started the first independent living centers and pushed for Medicare and Medicaid to

¹⁰ For more about this huge disabled history, see Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham, NC: 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.