

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 COLLECTIVE ACCESS

In the face of systems that want us to have been finding ways to care for ourselves. As Vancouver’s *Radical Access Mapping* people: if you don’t know how to do it, you’ve been doing it for a long time, usually good at it.” Sometimes we call them care webs, we call them “my friend that helps me,” or we don’t call them anything at all—care webs.

The care webs I write about here challenge attendant care as the only way to access care. The model of charity and gratitude, the desires of the disabled people running the webs, a mix of abled and disabled people to help each other in “crip-made access”—access made by turning on its head the model that says you receive care, not give it or determine if you are disabled only or involve disability. We still work from a model of *solidarity* rather than other in mutual aid and respect.

I first learned of the term “mutual aid” in books like Ursula Le Guin’s *The Dispossessed* that quoted white guy theorists like Kropotkin and many other anarchist and anti-capitalist to mean a voluntary reciprocal exchange for mutual benefit. Mutual aid, as opposed to the moral superiority of the giver over the receiver, invent the concept of mutual aid—n

11 *Radical Access Mapping Project*, <https://raa.org>

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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*¹¹ 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 “crip-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,

11 *Radical Access Mapping Project*, <https://radicalaccessiblecommunities.wordpress.com>.

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
seen in too long!*

How you can help:

*I use a wheelchair and I a
help with my personal care ne
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yourself up with a friend. Twc
and yay for safety! :-) It does
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bed. I usually pee at 12ish, 5i
bed and wake up. If you don't
shift would be so extremely he*

*If you are interested let me
else who might be interested,
(I appreciate people of all gen
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preciated. Thanks soo much ..*

*Can't wait to see/meet you
Loree*

Interviewer: "Your model of colle
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inities have complex webs of exchanges
 sense of white anarchism as one of the
 ideas of mutual aid, it doesn't surprise
 me that the collective care I encountered was
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CARE COLLECTIVE

Let me know I am Loree Erickson,
 a former academic who now lives in
 Leesburg, VA and lived in
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 embodiment, and desirability. As
 a former academic, I love care relationships
 and support structures. I also love sun,
 justice. I am coming to DC to
 teach and by young women
 at a University. Then, of course
 I see my people (as well as eat
 safe).

I am around 11ish and am around
 130lbs. I am heading to Richmond
 traveling with a friend who can
 help, but I am in need of friendly
 people so 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 ap-
 preciated. 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."¹²

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

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>.

care attendants because of her not to past fifteen years, her care collective non-disabled friends and community to help her with dressing, bathing, and do all the care work herself: she has friends of emailing, scheduling, and training travels away from her home base of and teach workshops, or to visit friends ask, via Facebook and email, for people of her care team. In recent years, Loree fundraisers to purchase adaptive equipment shifters who are poor/low income for as Loree gets older, and her community.

Loree's care collective is not just her the care she needs; it's a site of collective where many people learn about disability (the nitty-gritty) in action for the first time that upon moving to Toronto, her care collective political space. "It was more like meeting new people, I was connecting with friends that collective care functions as anti-people were becoming radicalized and participating in the collective. "It's lectures from the bathroom, but you of our lives and so that's part of the

In Loree's care collective, her something she both needs and does community, hang out with Loree, and

13 Muna Mire and Mary Jean Hande, "'The Action Speaks Louder: OPIRG-Toronto's Field 2013, 8-9.

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head] "Yeah, it really is. It's too bad as to be radical."¹²

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er & Crip: Sexing Up Disability Is a Way of Life 9, 2009, <https://www.dailyxtra.com/young-hot->

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."¹³

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

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.

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 I'm glad Loree's model works for her, but when I don't show up for a shift, I can't be being liked or loved by the community when I want to."

I think that all of these things a care collective is still an incredibly important part of accessing care that has made more possible for me and others to dream.

CREATING COLLECTIVE ACCESS DETR

We know that for many of us it comes to traveling, navigating buildings, sidewalks, public spaces, the bathrooms, the places to go, the cost, the crowds, the door and so so so much more.

Would you like to be co-organizer and our allies/comrades who help with collective access?

What is collective access? How do we intentionally create collective access?

Most of the time, access is not available. It is up to you to find it, sometimes, up to you and your support (PA) or random friend. It is not just about collective commitment and it is not just about being relegated to an afterthought.

Access is complex. It is not just about getting disabled folks/crip

ways care is thought of in the world, task that is never a site of pleasure,

writing of what care means, of what means of mutual aid and crip-femming fundraising video for the collective, the toilet with the help of a care shifter and care shifters trading gossip and seeing the video, one participant in it is really mind-blowing for me to see so intimate, without shame, and with so much time."

is a deep possibility model, not a one who needs care. Her collective is a broad network of friends and life where people know her and are helping many people, especially sick, socially isolated to be able to access. I have learned a lot from watching it, a million collectives for low-income disabled, or chronically ill people in myself and Black and brown friends and people who are willing and able to spend many years, especially when that care is that may not have a resolution. I wish to offer emotional caregiving to those whose extroversion and neurotypicality are necessary to access an abundance of care—factors

show who want and need the distance and 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?¹⁴

Creating Collective Access (CCA) was a crip¹⁵-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, 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

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.

by thousands of people talking ab-panic attack or suicidal ideation 2 usual supporters' access hacks? In: away from the crip survival skills to feeling that our disability exper not to be spoken about—especial in non-disabled social justice corr bring those feelings on even mor

But in 2010, some of us can disability justice organizing. W and trans people of color, talki intersectional lives, and talkin would mean that didn't leave an rooted in a ground of other disa who were finding each other th Story (a closed online portal for color, through the cultural, po Disability Justice Collective, t meetings in crip-of-color hallw call, Stacey, Mia, and I had a pro have to choose between handli crossing our fingers that the come through to take care of u together and caring for each ot a space that centered Black and by disabled queer femmes of c people begrudgingly "helping" We didn't know, but we knew much existing disabled spaces and their casual and overt racism we were always on hold with ac

't stop. It is hard and even when possible to figure out alone. The mutual aid between crips and whether we can create a culture of trying this out! would you like at this could look like? do you comrade who wants to help out

I was a crip¹⁵-femme-of-color-made her in the summer of 2010. You can go to collectiveaccess.wordpress.com, but it opened because three disabled queer people called to plan the workshops we were going to at the Access Conference (AMC) and US Social Justice gathering bringing tens of thousands of people together to imagine a revolutionary future—and we talked out about how we were going to

my experience: getting ready to go travel and freak-out about how badly the whole world at the airport break your wheelchair? Will the accessible van or wheelchair material just not be there? Where will it be? Will you be 1,000% overstimulated

¹⁵*Live Access*, June 2, 2010, <https://creatingcollectiveaccess.com/detroit>.

In disabled communities as a fuck-you, in-your-face manner similar to how queers have reclaimed the word "queer" people have complex feelings about it, and it's not surprising I coined the term "Krip" to avoid using a term that meant economic organization.

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 ma orders and walked the food back to

Being less isolated helped us that were effective because they ca not just one individual crip writin The AMC ordered in fragrance-fr Detroit back then didn't have an stocked Dr Bronner's unscented. Th we built also helped us survive the challenges (like, no wheelchair-ac on all the promo material, and wh person we talked to was like, "Can ask about the shuttle?" and didn't we can't, because we can't physica texting, "I am spooning out, I ne passed out at one end of the con there as fast we could, and them s roll up made all the difference.

We didn't just survive the confer Committed to leaving no one behi in a big, slow group of wheelchair people. Instead of the classic able-t us were used to, where able-bodie rate and didn't notice we were twol as slow as the slowest person and r got out of the way. Instead of goi chose to stay in, and ate and sharec us, it was our first time doing that

CCA changed everyone who who just heard about it. It was jus their communities transformed.