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“Crippling the Apocalypse: Some of My Wild Disability Justice Dreams”

from “Care Work: Dreaming Disability Justice”

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EVERYONE LOVES DISABILITY JUSTICE; NO ONE WANTS TO DO IT

Sick and disabled and neurodivergent folks aren’t supposed to dream, especially if we are queer and Black or brown—we’re just supposed to be grateful the “normals” let us live. But I am the product of some wild disabled Black and brown queer revolutionary dreaming, and I am dedicated to dreaming more sick and disabled queer brown femme dreams in 2018.

It’s been thirteen years since the original Disability Justice Collective—made up of activists Patty Berne, Leroy Moore, Mia Mingus, Sebastian Margaret, and Eli Clare, a group of disabled people holding a variety of Black, Asian, white, queer, and trans identities—came together to coin the term “disability justice” and lay the groundwork for a movement-building framework of intersectional, revolutionary disability politics.

And right now, we’re at an interesting moment in the history of disability justice. It’s one where white disabled people who are the reason we invented disability justice because they’ve ignored or actively excluded disabled Black and brown people for decades are saying, “Hey, that’s a fun term” and slapping “disability justice” on their all-white crip conference or panel. It’s also a moment in which, as Sins Invalid cofounder Patty Berne said in 2015, “In recent years, on websites and new media locales, on flyers and in informal conversations, I’ve witnessed people add the word ‘justice’ onto virtually everything disability related—from disability rights based services and access audits to disability scholarship—while doing nothing to shift either process or end goal, thinking that the word change alone brings that work into alignment with disability justice.”³⁸

I agree. I’ve noticed tons of abled activists will happily add “ableism” to the list of stuff they’re against (you know, like that big sign in front of the club in my town that says “No racism, sexism, homophobia, transphobia, ableism”) or throw around the word “disability justice” in the list of “justices” in their manifesto. But then nothing else changes: all their organizing is still run the exact same inaccessible way, with the ten-mile-long marches, workshops that urge people to “get out of your seats and move!” and lack of inclusion of any disabled issues or organizing strategies. And of course none of them think they’re ableist. Kicking cripples down the street? They’d never do that! They’re just totally clueless about what disability justice is or, indeed, what disability is, and that it’s not bad. They still silently believe that they’d rather die than be us, think of disabled, sick, or crazy people as “flaky” or “inspirational” but also pathetic and gross, don’t know any disabled history, and are still running shit the exact same way that makes or forces most of us to stay home.

Many abled Black and brown activists I know remain ignorant of the fact that sick and disabled Black and brown people are doing critical organizing and cultural work on issues from protesting the police murders of Black and brown disabled people to not being killed off by eugenics, killer cops, and medical neglect, from fighting the end of the Affordable Care Act, Medicaid, and the Americans with Disabilities Act to claiming the right to exist as we are.

No matter how much shit I post on Instagram about it, they seem to remain ignorant of the fact that we have histories and cultures and skills and visions, and that if we're going to survive the Trumpocalypse and make the new world emerge, our work needs to be *cripped the fuck out*. Our work needs to center disability justice and the activists at the core of it, where being sick, disabled, mad, neurodivergent/autistic and/or Deaf is at the heart of our radicalism.

THE CRIP ART OF FAILURE: BASED ON REAL-LIFE EVENTS

Recently, on a conference call, a totally well-meaning able-bodied person asked me: "We just have one question! Uh ... What is disability justice? Like, how do we do it?"

I said something diplomatic, like you do when you're trying to keep a gig you need. But in my head, I laughed my ass off. In my head I was like, *You wanna know how you'll know if you're doing disability justice? You'll know you're doing it because people will show up late, someone will vomit, someone will have a panic attack, and nothing will happen on time because the ramp is broken on the supposedly "accessible" building. You won't meet your benchmarks on time, or ever. We won't be grateful to be included; we will want to set the agenda. And what our leadership looks may include long sick or crazy leaves, being nuts in public, or needing to empty an ostomy bag and being on Vicodin at work. It is slow. It's people even the most social justice-minded abled folks stare at or get freaked out by. It looks like what many mainstream abled people have been taught to think of as failure.*

Disability justice, when it's really happening, is too messy and wild to really fit into traditional movement and nonprofit industrial complex structures, because our bodies and minds are too wild to fit into those structures. Which is no surprise, because nonprofits, while created in the '60s to manage dissent, in many ways overlap with "charities"—the network of well-meaning institutions designed on purpose to lock up, institutionalize, and "help the handicapped." Foundations have rarely ever given disabled people money to run our own shit. Nonprofits need us as clients and get nervous about us running the show. Disability justice means the show has to change—or get out of the way.

It's so easy to look at a list of disability justice principles and nod your head. But the real deal is messy and beautiful and real, as messy and beautiful and real as our bodyminds. And it's always something I can't quite get across when abled folks ask me what the hell I'm talking about. It's more like:

You and your friend are stressed out about Trump so you plan a show about how our disabled Black and brown ancestors survived fascism. They have a traumatic brain injury, and dealing with forms and email is hard for them, so you write a successful grant to the city arts commission in six hours with your ND hyperfocus brain. You get overwhelmed and

aphasic by multiple people talking at the same time, but they don't, so they're the one who takes the lead on doing tech and preshow production tasks. The gay theater's staff are nice but pretty overworked, and you end up doing a lot more of the production work than you bargained for. Artists are interested, but it's like herding cats to get some of them to respond to your emails inviting them to be in the show. When you talk with them, it turns out that a lot of them feel huge impostor syndrome about being disabled intersectional artists, are terrified they aren't "real artists" and need a lot of support. Your co-coordinator has a really hard time getting the ASL interpreters to write back and then books them for all four nights. When you get the bill, the ASL rate is three times as high as you budgeted because the agency refused to give a quote. The livestream dies halfway through, and someone gets pissed on Facebook because they're homebound and can't see the show now. You blow out an ovarian cyst on day two and are in a lot of pain but still have to emcee the show, but you ask for help and people come through. Despite this, at the end of it all, you and your friend still love each other and everyone says the show was amazing. And also, when you are \$1,200 short on the ASL, a) a former DJ collective that went bust due to internal drama gives you some money that's leftover in their bank account and b) a community member wins a huge settlement against SSDI and gives you \$250 in cash from the ATM outside their building, because you helped them stay housed last year by passing the hat at the last show.

Disability is a set of innovative, virtuosic skills. When abled people fuss about how hard it is to make access happen, I laugh and think about the times I've stage-managed a show while having a panic attack, or the time the accessible van with three wheelchair-using performers and staff inside broke and we just brainstormed for two hours—*Maybe if we pull another van up and lower their ramp onto the busted ramp folks can get out? Who has plywood? If we go to the bike shop, will they have welding tools?*—until we figured out a way to fix the ramp so they could get out. If we can do this, why can't anybody?

And this innovation, this persistence, this commitment to not leaving each other behind, the power of a march where you move as slowly as the slowest member and put us in the front, the power of a lockdown of scooter users in front of police headquarters, the power of movements that know how to bring each other food and medicine and organize from tired without apology and with a sense that tired people catch things people moving fast miss—all of these are skills we have. I want us to know that—abled and disabled.

DISABILITY JUSTICE IS ABOUT BUILDING RELATIONSHIPS

Over the past decade, I've seen many a well-meaning abled person or organization read a bunch of shit on the internet, follow the access guides, and do all the right things—get the accessible space, book an ASL interpreter, and ask people to be fragrance-free—and then be surprised and also kind of miffed when disabled, Deaf, sick, and mad folks don't show up en masse.

It shouldn't be so hard to figure out why this is: the abled people in question don't know any actual disabled, Deaf, neurodivergent, or Mad folks, or think that they don't, that "they" (us) are somewhere out there. Ableism and audism structurally separate disabled and Deaf people from abled and hearing folks. Literally. It's hard to make friends when the bar you always go to has a

flight of stairs, you're meeting until two a.m., and/or you don't know the language of the person you're trying to talk to.

When abled people get ASL and ramps and fragrance-free lotion but haven't built relationships with any disabled people, it just comes off like the charity model once again—*Look at what we're doing for you people! Aren't you grateful?* No one likes to be included as a favor. Inclusion without power or leadership is tokenism.

When I see disability justice flourishing, it comes from years of relationship building and building trust, from fucking up, making repair, learning from mistakes, and showing up for each other. In Toronto, hearing disabled people and Deaf people built relationships with each other for years, including creating community-controlled queer ASL classes so hearing crips could communicate with D(d)eaf and Hard of Hearing queers, resulting in powerful community connections. That didn't happen by accident. It happened because disabled and Deaf people organized together, showed up at each other's protests. When hearing disabled people learn ASL so they can communicate with Deaf folks, we are creating the rock-bottom tools we need to talk, laugh, hang out, disagree, organize, break isolation, and fall in love. And that is the opposite of a well-meaning but relationshipless access provision.

ABLED PEOPLE: TIME'S UP. ESPECIALLY BECAUSE YOU WILL EVENTUALLY BECOME US

It would be easy for me to write the same article that many sick, disabled, Deaf, and mad/neurodivergent folks before me have written to the abled—asking the abled to get it the fuck together and stop “forgetting” about access and disabled demands. It would be easy for me to write because it's still so needed: non-disabled activists of color continue to “forget” about basic access at events and meetings until someone disabled bugs them about it—or they remember for a few months after a workshop, or a year, and then the issue fades in importance again.

It breaks my heart every time, but besides not wanting to grieve being forgotten, at the end of the day, I'm practical: I want to win! If movements got it together about ableism, there is so much we could win—movement spaces where elders, parents, and sick and disabled folks (a huge amount of the planet) could be present—strength in numbers! We could create movement spaces where people don't “age out” of being able to be involved after turning forty or feel ashamed of admitting any disability, Crazyness, or chronic illness. We could create visions of revolutionary futures that don't replicate eugenics—where disabled people exist and are thriving, not, as often happens in abled revolutionary imaginations, revolutionary futures where winning the rev means we don't exist anymore because everyone has health care.

So, I will say, once: I want abled people to get it together in 2018. Stop forgetting about disability and access. Read some of the many brilliant, made-by-disabled-people access guides out there. Normalize access and disability. Learn about disabled cultures and histories. Look at the histories of disability in your own family and communities. Ask how you are fighting ableism in every campaign you do. Don't forget about us. Realize you are or will be us.

WILD DISABILITY JUSTICE DREAMS AND UNPACKING SHAME

My wild dreaming has me longing to go deeper than just getting basic access. As my friend and comrade Stacey Milbern recently posted on Facebook, “Sometimes I feel impatient about how much ableism has forced us to emphasize accessibility ... [But access] is only the first step in movement building. People talk about access as the outcome, not the process, as if having spaces be accessible is enough to get us all free. Disabled people are so much more than our access needs; we can’t have a movement without safety and access, and yet there is so much more still waiting for us collectively once we build this skillset of negotiating access needs with each other.”

Going deeper than basic access in our disability justice revolution as Black, Indigenous, and brown people isn’t simple. It means unpacking our deep histories of scarcity and shame. Sometimes when disabled people of color bring up access needs, I see able-bodied comrades of color’s faces turn stony and shut down. This often does not just come from a casual hatred of sick and disabled people, though that exists too. But sometimes, a person who’s angry and defensive about an inaccessible space is flashing back to their mom who died poor and alone, their uncle’s polio or schizophrenia no one would talk about, the way the only survival story many Black and brown communities have had is to deny our needs, work sixteen hours, and suck it up. Many of us hold stories about how our families survived enslavement, colonization, and other forms of violence’s grueling physical labor by not being disabled. Disabled people in those stories didn’t make it—they got killed. Many of us were taught from a young age that care, softness, and healing were for other people, and we needed to just make it work. We sit in legacies of scarcity, survival, and deep, unpacked grief that sometimes make people bitter and enraged when they see someone asking, as if they have a goddamn right to, for a chair, a moment, a bathroom that works.

I’ve also worked with many organizations—hell, I’ve been a part of them—where having no money was both the norm and something we prided ourselves on knowing how to make work and look beautiful. We could make a twenty-four-city action happen on a quarter tank of gas and no sleep. We didn’t have money to pay ourselves for the hundreds of hours of work we did; every space said no to us, so we made do with the one queer bar or APIA community center space we had. And when someone showed up pointing out that the space was up a flight of stairs, or asked if there was ASL, or wanted some kind of fragrance-free product, we often met them with a mix of bitterness and rage. *We’re not even paying ourselves and you want what??? My grandmother worked in the fields all her life; she never had an “access need.”*

There is grief mixed in with the rage, and survival, and a belief that you must be spoiled or entitled to ask for what you need. It reminds me of survivors who stubbornly insist that their parents beat them and they came out just fine. I honor the survival skills of denying need and getting the fuck by have been things that kept us alive. But I believe our beloved dead want us to do more than live on one cracker and an inaccessible building, forever. I also believe that we have other lineages of sick and disabled Black and brown ancestors, and non-disabled ones other than “The cripples got left to die; only the strong survived.” Before colonization, enslavement, and disaster, we had cultures where disability was a normal part of human existence, where we were honored and valued. As Black disabled queer writer and organizer Cyree Jarelle Johnson

remarked to me, “Harriet Tubman had seizures and narcolepsy because a slave owner threw a weight at her head. While on trips she likely had to sit down, lay down, move slowly and rest. Her comrades didn’t abandon her then, and we can figure out how not to abandon each other now.”³⁹

We have ancestral shame to heal. We have disabled lineages to honor. Let’s get to it.

LET’S LIVE LONG, BEAUTIFUL, CRIPPED-OUT LIVES

I know more than one genius organizer—usually a Black or brown sick or disabled woman or nonbinary person who doesn’t have a ton of disability community—who’s casually told me that they’ll be dead by the age of fifty. I respect that crip years are like dog years, and sometimes we live really huge lives in short amounts of time, but I can’t help but think that it doesn’t have to be that way. We’re soaked since birth in narratives that we will die young, that our lives aren’t worth living, and that we’re up against everything from insurance denials to police trying to kill us who want to do the same damn thing.

But as I hear my friends talking about how they’re sure they’ll die young, I wonder if changing the narratives around care might change their expectations of dying young. I think about what it would take to continue to build communities of care, where caring for each other is something we actually practice and build the structures to hold. I think of Loree Erickson’s mutual aid care collective and how it is both a model of being cared for when the state fails and a place so many people in Toronto get brought into disabled community that is deeply joyful, sexy, and fun in a way that many people don’t think of when they think of care. When I try to explain the care collective to folks outside Toronto, there’s a silence—it’s because they can’t quite imagine someone asking for and receiving help, including help that sees you naked and helps you with intimate acts, without shame and with joy. And I wonder—how would our belief that we could live rich, long disabled lives worth living change if we created more mutual aid collectives?

And I also think of the complexities of receiving care. I love collective care—but I would be lying if I said that it was simple, or the sole answer. I think about the many people I know and love who have a really hard time receiving care because “care” has always been conditional, or violent—the invasion of social workers or Child Protective Services or psychiatrists with the power to lock you up. I think about the need for care that can be accessed when you’re isolated, disliked, and without social capital—which many disabled people are. I think about how power dynamics and abuse can creep into the most well-meaning care collectives of friends, and of my friends who need twelve to fifteen hours of care a day, which is difficult to impossible for most unpaid friends to provide. I think about the person I was lovers with who was an asshole about thirty percent of that time, who I still send twenty bucks every now and then because they are seriously disabled and can’t work. I do this because they are a queer and trans person of color who grew up working class who’s pissed off a lot of people, and they still don’t deserve to die alone in their own piss. I think about my friend who said, “I never want my ability to go to the bathroom to be dependent on how liked I am.” I think about how relieved I was to discover that the state I live in offered twenty-four hours of emergency respite care to caregivers—someone well paid by the state who could come in and pick up meds, do some home care, and fold laundry—that my partner and I could access if one or both of us had a medical crisis. I think of

the disability networks where friends and total strangers on the internet bring each other soup and share meds and send money and how lifesaving that is—and what happens when someone is kicked out of that Facebook group.

Recently, Stacey Milbern brought up the concept of “crip doulas”—other disabled people who help bring you into disability community or into a different kind of disability than you may have experienced before. The more seasoned disabled person who comes and sits with your new crip self and lets you know the hacks you might need, holds space for your feelings, and shares the community’s stories. She mentioned that it’s telling that there’s not even a word for this in mainstream English. We wondered together: How would it change people’s experiences of disability and their fear of becoming disabled if this were a word, and a way of being? What if this was a rite of passage, a form of emotional labor folks knew of—this space of helping people transition? I have done this with hundreds of people. What if this is something we could all do for each other? How would our movements change? Our lives? Our beliefs about what we can do?

CRIPPING THE APOCALYPSE WE’VE ALREADY SURVIVED THE END OF THE WORLD

2017 felt apocalyptic. One place I felt the apocalypse was in the wildfires that covered the Pacific Northwest. One morning, I went outside and the air was dark gray. Something gray was sprinkling from the sky. Was it ... ash?

At first, the people on the news were optimistic. It should be over in a day. Then a week. Then maybe next week we’d have breathable air.

The news reports trickled in: fueled by climate change, giant wildfires in British Columbia had spread to cover most of Washington State. Fires started in the Columbia River basin near Portland. Then fires came to Santa Rosa and Southern California. Everyone was coughing and stressed out. I canceled a planned writing retreat in Northern California because I was scared of driving through fires circling the highway.

And when the texts started to come in—*Hey, is anyone else feeling like they can’t breathe, like they’re sick from all the smoke? Am I making a big deal out of nothing, or is the smoke making me feel super foggy?*—who were the people who already knew about masks, detox herbs, air purifiers, and somatic tricks for anxiety?

Yeah, you guessed it. Over and over, it was sick and disabled folks—particularly folks with chemical injuries, environmental illness, asthma, and other autoimmune conditions who had been navigating unsafe air for years—sharing the knowledge that being sick and disabled had already taught us. We had comprehensive information about where to get masks and respirators and about the right herbs to take to detox after exposure to air pollutants. We knew to go to libraries and other air-conditioned places to get an air break. We knew about HEPA filters and how you can make one with a furnace filter and a box fan. We knew it was normal to feel fatigue, confusion, and panic, and we knew to hit inhalers and take antianxiety herbs. Lightning Bolt,⁴⁰ a disability justice activist group formed in the wake of Trump to do community-based trainings

around access and community safety without the police, led a successful Masks to the People campaign, crowdfunding money to buy masks that they distributed to people living in tent cities in the Bay Area, since people living outside walls are extremely vulnerable to toxic smoke.

Since Trump got elected, many people in my community have been talking about how Octavia Butler was a prophet and how her books *Parable of the Sower* and *Parable of the Talents* eerily predicted the climate change, wildfires, and fascism of our current world. Many people in movement spaces have taken Butler's words as prophecy and text. (I'm not hating on that conversation: full disclosure, as one of the writers in *Octavia's Brood*, a wildly popular anthology of visionary social justice science fiction in the lineage of Octavia Butler, I've been a part of it.)

But what is often missing from these discussions is how Lauren Olamina, Butler's Black, genderqueer teenage hero who leads her community out of the ashes and founds a new spirituality that embraces change as god, is disabled. In the book, she is called a sharer: someone with hyperempathy syndrome from her mother's use of the Einstein drug, a popular drug that heightened intelligence. She feels everything everyone feels, and it's often overwhelming in a way that reminds me of some autistic and neurodivergent realities. It gives her impairments and also gifts.

To me, Butler's *Parable* books are a Black disability justice narrative. Lauren often struggles with her nonnormative mind, but it also gives her Black disabled brilliance. Her hyperempathy makes her refuse to leave anyone behind, even when they are a pain in the ass or she disagrees with them. It allows her to innovate, making her survival pack filled with seeds, maps, and money when everyone else thinks she is crazy, cocreating a resistance community and rebuilding it when it's destroyed.

For years awaiting this apocalypse, I have worried that as sick and disabled people, we will be the ones abandoned when our cities flood. But I am dreaming the biggest disabled dream of my life—dreaming not just of a revolutionary movement in which we are not abandoned but of a movement in which we lead the way. With all of our crazy, adaptive-devised, loving kinship and commitment to each other, we will leave no one behind as we roll, limp, stim, sign, and move in a million ways towards cocreating the decolonial living future.

I am dreaming like my life depends on it. Because it does.

³⁸ Patty Berne, "Disability Justice: A Working Draft," *Sins Invalid*, June 10, 2015, <http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne>, accessed June 18, 2018.

³⁹ Cyree Jarelle Johnson, personal communication with the author, May 15, 2018.

⁴⁰ <https://www.lightningbolt.vision>