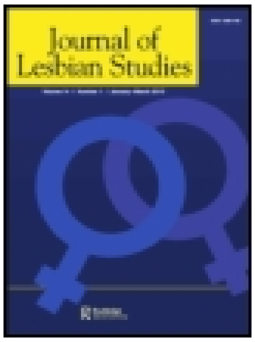

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Care haunts, hurts, heals: The promiscuous poetics of queer crip Mad care

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ABSTRACT
Care is a dirty word for many in our communities. "Caregiving" has become a euphemism for often-indifferent, under-funded labor that is done to our bodies to (barely) enable our continued survival. Care is a dirty word in many of our leftist-feminist communities. Care work is a classification of highly gendered and racialized labor that remains largely unpaid, underpaid, and deeply devalued. Care is a dirty word in our Mad, disability, queer activist communities. "Taken into care" often refers to indefinite confinement, forced extraction from communities and families, and the removal of one's right to self-determination. Is care even worth reclaiming? In this creative duo-ethnography, a Mad fat femme and a crip ill non-binary queerdo wander through various moments when care has most impacted our lives, our relationships, and our communities. We have each held one another with care on the precipice of dying. Our bodies have shouldered the love-labor of care in the most intimate, exigent, and banal of moments: consensual and playful medication reminders, post-surgery tampon changing, literally squeezing out another's breath to stay alive—and then repeating—hundreds of times an evening. We have also experienced care that was much too careful, and anything but full of care. We have shared care promiscuously with our crip and Mad (arts) communities in ways that have been life affirming, life changing, sometimes life making, other times life threatening. Through this wandering with ideas, moments, and communities, we reflect upon multiple dimensions of Mad, queer, crip care. Whom is the caring for? What is our care about? And how can our care be given or giving, taken or shared, offered, enabled, and co-created with flourish?

KEYWORDS
Disability justice; Mad studies; eugenics; caregiving

Why should we care?

We are two Mad and crip queers who care. We care with each other and with a handful of others, and their others. We care-share in long- and short-term dyads, morphing triads, and intricately woven webs of support (Piepzna-Samarasinha, 2018). We care with folks of a broad range of

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identifications, but the formations at the heart of our practice are distinctly crip, Mad, and queer. We play and work care-fully—but rarely carefully—together. We care with flourish, we care to flourish, we flourish because of this care. Although we often refuse specific kinds of "care" when we can afford to, we refuse to reject care, as a concept and a praxis. We reaffirm the importance of care—resonating and building from the ideas and practices of a host of queer disabled, Mad, neurodivergent and sick activists, artists, and scholars whose words, friendship, and engagements with the embodied and material practices of care have literally kept us alive. This, like much of our recent work that they have enabled, is a love letter (Eales, 2018), with all of the lust and dizziness and pain that love invites.

In this article, we work to honor Neil Marcus' famous statement that "disability is an art, it is an ingenious way to live" (as quoted in Price & Kerschbaum, 2016, p. 51). More specifically, Price and Kerschbaum (2016) propose that disability, and critical disability studies, are a methodological intervention, in that "disability crips methodology" (p. 20). Crip ways of being "open up desire for what disability disrupts" (Fritsch, 2013, para 2). It's precisely the ways that disability disrupts normative schedules, relationships, and ways of doing things that make care feel so deeply queer. Prioritizing the presence of crip existences invites us to imagine and enact methodology otherwise, precisely because disability is generative of new ways of being, knowing, relating, writing, and acting in the world. By extension, Madness maddens methodology. This article is thus shaped by relating criply and madly to ourselves, each other, the world, and our writing because interdependent queer crip Mad co-existence and co-creation are a vital situated means of learning about our social, cultural, and political circumstances and possibilities. Taking seriously that disability crips, and Madness maddens, methodology, the methods, processes, and practices of crafting this queer crip Mad research-creation article revolve around "a [serious] form of play" that is iterative, emergent, and inseparably weaves analysis, critique, theory, methods and ways of being (Chapman & Sawchuk, 2012, p. 12).

A note about content: We care that you, who is reading this, get to consent to witnessing the harms and pleasures we will be recounting, and get to access whatever care supports (human and nonhuman) that you desire to be fully held within this engagement (see Carter, 2015; Kafer, 2016). Clare (2017) argues that these kinds of content notes "are in essence tools for self-care and collective space care" (p. xx). In this short piece, we will engage with some of the violent discourses and practices that have constituted contemporary engagements with care. This includes eugenic discourse, deficit-based language, and charitable reliance on fear, pity, and disdain. We will discuss systemic marginalization of our racist, ableist, and sanist political, economic, and "social security" systems. We will recount our own experiences of micro- and not-so-microaggressions, as well as our experiences of disability, illness, Madness, suicidal ideation, and death. In short, we will seek to acknowledge and resist some of the many violences that have been done in care's name, while also honoring our experiences of care as embodied enactments of queer desire, and crip politics, and survival, and love, and sometimes fear and desperation. We tell these hard, complicated, beautiful stories because they matter. Care matters. Like bones, and skin, and lungs, and blood, and spirit, and meaning, and dreams, it matters.

One of us is a Mad fat White femme settler dogmom attempting, with difficulty, to conceive a "gayby" into a queer crip Mad community of care. I am in the midst of a tender separation with a former care community, while growing more non-monogamous ties to other queer crip Mad creators. I am precariously underemployed, having been raised in relative (Western) poverty, and I am in the midst of struggling with how to enact complex relationships to productivity, meaning, capacity, stability, and politics. I'm tired and hurting and burned out. I almost just don't care anymore. Almost.

One of us lives as White, crip, non-binary, queer, sick settler. A recovering Paralympic athlete (Peers, 2012): bones, lungs, muscle, spirit—mostly spirit—recovering still. Mobility and breath are often no longer solo sports. Fingers weave into the pockets of my ribs, become my intercostals, entrained to the erratic peculiarities of my breath and the shifting limits of my consent, they have, on many an occasion, cleared death from my throat. I prefer to top my care from the bottom. Generous, firm, politicized, and consensual care equates to survival.

As queers, it still feels itchy to name ourselves through our embodiminds, and through that which we need to survive. As though admitting to any embodied needs or knowledge is the most anti-queer of moves. Needs and desires (other than sex) and bodies and flesh (other than anuses and penises) have been too often written off as essentialist, and thus anti-queer (see, for example, Garber et al., 2001, on the false dichotomies of queer theory and the work of Black feminist poet-activists like Audre Lorde). But as Butler (2016) argues, "one can have a sense of what is essential for one's life without exactly being an essentialist" (p. 17). We affirm that there is no more important queer project than for neuroqueers, crips, and non-normates more generally to survive *with an essential flourish* (Peers, 2018) in the face of that which would render our most basic needs undesirable, untenable, unreasonable, or "special." There ought to be nothing special about survival. We have learned this much: the care work and play of other Mad, crip, (neuro)queers are essential for both of our existences. We survive only with and through each other. “Survival can thus be what we do for others, with others. We need each other to survive; we need to be part of each other’s survival” (Ahmed, 2017, p. 235). Survival is collective work. It is political work. And some of this vital, collective, political work takes the form of care (Piepzna-Samarasinha, 2018). As Ahmed (2017) writes, “in queer, feminist, and antiracist work, self-care is about the creation of community, fragile communities … assembled out of the experiences of being shattered” (p. 240). Broken. Crip. Mad. Disabled. Oppressed. Sick and tired. It is from the experience of being socially, politically, and materially shattered that we have come to know and learn a praxis of collective care: “We reassemble ourselves through the ordinary, everyday, and often painstaking work of looking after ourselves; looking after each other” (Ahmed, 2017, p. 240).

We have both held one another, and many others, with care on the precipice of dying. Our bodies have shouldered the love-labor of care in the most intimate, exigent, and banal of moments: consensual and playful medication reminders, postsurgery tampon changing, literally squeezing out another’s breath to stay alive—and then repeating—hundreds of times an evening. We have both experienced care that was much too careful, and anything but full of care: awkward, disconnected, “professional.” We have shared care promiscuously with crip and Mad care partners and communities in ways that have been life affirming, life changing, sometimes life making, and sometimes life undermining or even life threatening. Through the wandering with ideas, moments, and communities that follows, we reflect upon multiple dimensions of our lived experiences of Mad, queer, crip care. Whom is the caring for? What is our care about? And how can our care be given or giving, taken or shared, offered, enabled, and co-created with flourish?

Care is a dirty word

Care is a dirty word for many in our disability communities. We are taught to *care about* disability as an individual tragedy faced by the innocent, which renders life impossible or undesirable.

> A dark black and white poster of young White boy drowning with pleading eyes
>
> “Cystic Fibrosis is like drowning on the inside” (Dow, 2010).
>
> A dark black and white poster of a young White boy sitting in a wheelchair on a dirt path
>
> “He’d like to walk away from this poster too” (Mills, 2010).

The subjects of these charitable North American disability ad campaigns, as Withers (2012) argues, are almost always White children, even when children rarely get the condition being fundraised for (e.g., breast cancer).

These literal poster children are constructed very much in line with what Muñoz calls "sovereign princes of futurity" (p. 95): cisgendered males who are "always already White," and who represent the seemingly natural and rightful development of all White children toward a future filled with their economic prosperity and personal and national sovereignty (). The stakes of a poster-prince-of-futurity who is threatened by disability is thus more than the tragedy faced by *this* White child. Rather, it is the tragedy threatening the future of White children, the entire White future: that is, the future of White European/Canadian/American "civilization," and the White settler-colonial sovereignty and exploitation-and slavery-dependent prosperity at its core. It is the image of the threatened White child, therefore, that links the individual tragedy narratives of contemporary disability charity to centuries-old, barely obfuscated and deeply interrelated discourses of White supremacy, settler-colonialism, and eugenics.[1]

It is within this matrix that eugenics offers culturally familiar discourses of social contagion to produce epidemic-style fears (where no literal infection is present) around the "spread" of undesirable and pathologized embodiminds-ments within the desirable bodies of the nation's "sovereign princes of futurity," and the proliferation of "undesirables" and "degenerates" throughout the social body of the nation. "The greatest present menace to civilization," argues prominent American White feminist and eugenicist Margaret Sanger (1921, p. 5), are "those human weeds which threaten the blooming of the finest flowers of American civilization" (Sanger, 1923, p. 60). Echoes of "the homosexual threat to civilization," "the lavender menace," "the yellow peril." Infecting "our" (White) girls, infecting our White feminism. North American eugenics has always been constructed as, at its heart, about care: caring for the nation, the future, the "finest flowers" and "sovereign princes" of American civilization, and even caring for those "human weeds." In the words of famous eugenicist Goddard, we must "hunt them out in every possible place and take care of them" (as quoted in Snyder & Mitchell, 2006, p. 117). Just as Foucault (1997) suggested, "This is the internal racism of permanent purification, and it will become one of the basic dimensions of social normalization" (p. 62) through, among other technologies, population health, national and charitable campaigns, and the resulting intervention and governance of "healthcare epidemics."

New York Times Bestseller

Under pressure: Confronting the epidemic of stress and anxiety in girls (Damour, 2019).

Black and white close-up photos of children (two female-coded, at least one racialized) from Stopchildhoodobesity.com

"Warning: Chubby kids may not outlive their parents."

"Warning: Fat kids become fat adults" (Kinzel, 2013).

> If you *really cared* about them, you would annihilate it, destroy the scourge. Declare war. A permanent, vigilant war (Foucault, 1997).

Fatphobic public health campaigns are just one of the many ways that epidemic-style fear, and even hatred, are mobilized in the name of "caring" for "our" children and overall population. According to Abigail Saguy (2013), fatness has come to be framed as "pathological … a looming public health disaster," an epidemic, as well as a "moral panic" (p. 3). As both Black and Indigenous scholars have demonstrated, however, this moral and health "epidemic" is in no way separate from the colonial and White supremacist logics discussed earlier. Sabrina Strings (2019), for example, argues that U.S. fatphobia can be traced specifically back to fear-and-hate-filled White-supremacist constructions of Black women as lacking control over their sexual and alimentary appetites. Fatphobia, in other words, is largely constructed and proliferated through misogynistic anti-Black sentiment. Mi'kmaq scholar Margaret Robinson (2020) offers additional insight into how:

> Campaigns designed to colonize Indigenous body values and eating practices, and to assimilate them into a white Christian middle class, is a form of biopolitics rooted in a long-standing and pernicious colonial symbologies and ideologies. (p. 25)

Such campaigns include "the deliberate destruction of traditional food sources…, residential school nutritional experiments in which Indigenous children were intentionally malnourished" (Robinson, 2020, p. 25). They also include contemporary Canadian diabetes and "obesity"-based health research and promotion programs that problematize and target Indigenous (primarily) women as being inherently at risk, in deficit, and in need of (White) interventions, in relation to controlling their bodies, eating, exercise, and appetite(s). In short, "The message implicit in such practices is that the Indigenous body is too big, out of control, and getting larger" (p. 25). When we talk about disability or fatness as epidemics needing to be "wiped out," we are never far from eugenic and genocidal histories or presents.

> A giant bus decal of a racialized child wearing oversized glasses reads:
>
> "Let's wipe out cancer, diabetes and autism in his lifetime" (HuffPost Parenting, 2017).
>
> The Canadian war on queers (Kinsman & Gentile, 2010).
>
> The Bush Administration's War on Autism (Elder Robison, 2013).
>
> Conversion "therapy," Applied Behavior Analysis, electro-shock "therapy."
>
> The hope for a cure. The genetic sequencing.

But what if the scourge, the enemy, is actually (a part of your) child? Ruthlessly holding back our *real kids*, and leaving us only with "proof of (a more desirable) life." The epidemic, and the people it "infects," remain uncontrolled and uncontrollable, yet also under the maleficent unfaltering control of the scourge.

> A black and white billboard with cut-out letters (as if from a ransom note):
>
> "12 million kids are held hostage by a psychiatric disorder."
>
> One in a series of advertisements, including on the back page of *New York Magazine*, from New York University's Child Study Center:
>
> "We have your son. We will make sure he will no longer be able to care for himself or interact socially as long as he lives. This is only the beginning … [signed] Autism."
>
> "We are in possession of your son. We are making him squirm and fidget until he is a detriment to himself and those around him. Ignore this and your kid will pay … [signed] ADHD."
>
> "We have taken your son. We have imprisoned him in a maze of darkness with no hope of ever getting out. Do nothing and see what happens … [signed] Depression."
>
> "We have your daughter. We are forcing her to throw up after every meal she eats. It's only going to get worse … [signed] Bulimia."
>
> "We have your daughter. We are making her wash her hands until they are raw, every day. This is only the beginning … [signed] OCD."
>
> (Cision PR Web, 2007)
>
> Sons, we care about your self-sufficiency, productivity, self-governance, sovereignty.
>
> Daughters, we care about bodily control, your relationship to food and cleanliness. Only beauty and purity for those fine white flowers of civilization.

Despite the widespread eugenic discourse of innocent, White sons and daughters being stolen—physically or genetically—by the Other, it is, of course, the White settler-colonial nation that does the vast majority of the stealing. Stealing generation after generation of Black, Indigenous, undocumented, and disabled children: for forced labor, for residential "schools" and foster "care," for deportation, for institutional incarceration and sterilization (Hunter, 2018; Robinson, 2020; Withers, 2012). Stealing land and children has been a widespread technique of White North American sovereignty. This is perhaps why we suspect it so readily from others, why stealing children remains such a prevalent and compelling cultural metaphor that makes us *care* enough to pay the charitable ransom … that and the tax receipt (Withers, 2012). But wait! If you are among the first 100 callers, you will also receive this bonus t-shirt:

> A grey and pink child's t-shirt in a Kmart online store.
>
> The bright green ribbon houses the familiar Muscular Dystrophy slogan:
>
> "Someone I love needs a cure" (Kmart, 2018; United We Volunteer, 2019).

Someone I love believes that I need to be cured. I sometimes I believe I need to be cured to be loved.

> If collective access is revolutionary love without charity, how do we learn to love each other? How do we learn to do this work of collective care that lifts us instead of abandons us, that grapples with all the deep ways in which care is complicated? (Piepzna-Samarasinha, 2018, p. 33)

My mom tells me she feels guilty for "how I ended up" queer. Genderqueer. Disabled. Diseased. Was it her genes? Was it her parenting? Was it her pregnancy? Tired of her questioning, I ask her if she would have aborted me if she knew. "Of course not," she responds, "I'm Catholic." When I leave my marriage and start dating a queerdo, under the guise of caring for me, I am asked if I am off my meds and need to be *taken into care*. A blood relative calls to check in on me when I have a life-threatening lung infection. A care-kin takes the call, telling them that I am too sick to talk. They get enraged: Who the hell does "she" think "she" is? "Disability justice asserts that ableism helps make racism, Christian supremacy, sexism, and queer and transphobia possible, and that all those systems of oppression are locked up tight" (Piepzna-Samarasinha, 2018, p. 22). My friends tag me in a Facebook advertisement about mental illness awareness and pharmaceutical breakthroughs for ending bipolar. They add a comment: "new hope for this devastating disease! Praying for a cure." Buy this thing, text this much, support our profits to support this cause. Praying for a cure. Paying for a cure. Like and share our advertisement that we care. Bell, let's talk… (see Johnson, 2017).

Capitalism doesn't care

Care is a dirty word in our Mad, disability, queer activist communities. It is used euphemistically to refer to precisely those unpleasant, embarrassing, or violent arrangements where (the best versions of) care rarely flourishes.

Caring for disabled people has often taken the shape of a unidirectional relationship wherein the caregiver (e.g., guardian or health professional) or care provider (e.g., agency or corporation selling care) controls the how, when, who, and what of delivering life-sustaining services, often without or despite the expressed desires of disabled and ill people (Titchkosky, 2007; Withers, 2012). My schooling as an occupational therapist tried to train me into a benevolent, objective, giver of care, keeping professional distance. Not caring "too much," requiring no care, myself. I nearly failed the "professionalism" component of my certification exam. But it wasn't until I was suicidal (again—a reminder that I couldn't continue existing this way) and began co-creating crip and Mad artistic community that I sought to fail professionalism with a vengeance.

One shower a week. One “single-use” catheter for peeing per day (Huncar, 2015). Move your bowels only on command (Sullivan, 2005). Be grateful on command. We are doing this *for* you. We are caring *for* you: a drain on the (family/economy/health care/welfare) system. You better be grateful for whatever you get. We submit as a compromise for survival when we have no other choice, or the other choices are far, far worse.

If you want a say in your care, you must prove you can take care of yourself. And so I have struggled to become inspirationally independent, spending all of my spoons on the steep road, and cruel mirage—at great cost to well-being—“because down at the base of the mountain waits for a nursing home” (Clare, 1999, p. 12). You take care of yourself, or you buy the care you can afford, or you get what you “deserve.” Capitalism doesn’t care.

Caregiving has become a euphemism for under-funded, undervalued labor that is done to our bodies to (sometimes barely) enable our continued survival. It is often the compromise for survival when there are no other choices, or the other choices are far, far worse. It is feminized labor, racialized labor (Piepzna-Samarasinha, 2018). It is sometimes a labor of love, sometimes forced labor, sometimes indentured labor. It is nearly always un(der)paid labor and deeply undervalued labor.

> “I love how working-class, femme, and disabled this care labor is.
>
> I just want it to also not be seen as an automatic expectation of any femme at any time!
>
> I want some rules so we don’t feel drained, exhausted, and fucked over.
>
> I want it to be a choice.
>
> And I want its next-level genius of skill to be recognized.
>
> This is skilled labor!”
>
> (Piepzna-Samarasinha, 2018, pp.140–141)

It is the labor of often the third and fourth job that does not even add up to a living wage; that disables its workers; that refuses those workers the same supports they offered. And we accept this exploited “care,” even when everyone is harmed by it, because what other choice do we have? Capitalism really doesn’t care.

Being *taken into care* is a euphemism for indefinite confinement with minimal legal rights or recourse. Being taken. Forced extraction from communities and families. Institutionalization. “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” (Piepzna-Samarasinha, 2018, p. 39). Taking into care equates to the removal of someone from their actual networks and relationships of communal care. Refusing one's right to self-determination. From the *Report upon the care of the feeble-minded in Ontario 1907*:

> It is necessary… not to refuse to the Feeble-Minded that protection and care which alone can prevent them from wrecking their own lives and bringing into the world native-born Canadian citizens more Feeble-Minded and unfit in mind and body than they are themselves. (MacMurchy, 1907, p. 22)

All this in the name of taking (fiscal) responsibility for the care of "our most vulnerable." Indigenous, racialized, queer, disabled, and Mad folks have long known the violence and prevalence of such euphemisms; the personal, cultural, inter-relational, and intergenerational trauma of being *taken care of* so absolutely and indefinitely (see Talaga, 2018). Capitalism's (lack of) care is life-threatening.

Keep quiet

the reality slips

the frenemies they can't see

the gorging

The gain

the dysmorphia

the desires

the traitorous Mad allegiances

the pleasures

in pain

bodymindbeing under threat

care is most dangerous when (others deem) it is most needed

The violences experienced under the guise of people being *cared about* and *cared for* and *taken into care* are just a few of the reasons that many disabled and Mad activists have, since the 1960s, sought to renegotiate, if not reject, the term(s of) care (Charlton, 1998). Some also sought to reject capitalism, naming it as (one of) the engine(s) of mistreatment (Piepzna-Samarasinha, 2018). But more popular was the attempt to use capitalism for disability liberation. Some fought to replace the euphemistic words *care, caregiver*, and *patient* with *services* and *service providers* and *consumers* (Burstow, 2013; Charlton, 1998). After all, consumers have rights and status in capitalism. They are not a drain on the economy, but an economic engine that produces jobs. The consumer is always right (as long as they have access to money). "Nothing about us without us," we chanted (Charlton, 1998), meaning, of course, those of us receiving services—not those racialized and feminized folks un(der)paid to provide services. Is capitalism less careless than "care"?

Such movements fought for some important changes, fended off some specific violences for some people, and offered some new forms of access. But these movements have not worked out well for everybody, and didn't work out well for long. The freedoms and choice were by no means equally distributed, and virtually as soon as rights were won, austerity cuts were made to these very programs of support, reducing infrastructural supports, "staffing costs," and the funds and services available to disabled consumers (McRuer, 2018). A consumer is only right if they can afford to pay the price. The worker only has rights if they can afford to fight for them. Butler (2016) explains:

> The dependency of human and other creatures on infrastructural support exposes a specific vulnerability that we have when we are unsupported, when those infrastructural conditions characterizing our social, political, and economic lives start to decompose, or when we find ourselves radically unsupported under conditions of precarity or under explicit conditions of threat. (p. 19)

Precarity is the socially sanctioned removal or refusal of the basic life needs of certain *kinds* of people: the people we've learned not to care about, or perhaps more aggressively, those that we don't particularly care for (Butler, 2016). In Foucauldian (Foucault, 1997) terms, it is those that the biopolitical and eugenic state has decided to "let die," given that they cannot or will not be made to live in normatively prescribed and productive ways (p. 241). Precarity is letting people we've decided not to care about die or barely stay alive through minimal "care" that we then resent them for. Precarity makes sure that our hands don't get dirty and our budgets stay tidy. Each community's precarity is leveraged against the other (Clare, 2017). Divide and conquer. Capitalism really could not care less. It is for this reason that one of the core principles of disability justice, articulated by the Disability Justice Collective,[2] is an "anti-capitalism politic," which works to undermine able-bodied notions of productivity, as well as to "critique a concept of 'labor' as defined by able-bodied supremacy, White supremacy, and gender normativity" (Piepzna-Samarasinha, 2018, p. 27).

So, if "systems of care" are a means to justify and reproduce precarity, blaming its violences on the individual vulnerability of those it targets but purports to serve, is there any point in reclaiming care? Could care be used to critique and resist capitalism? Could care resist precarity, or at the very least keep us alive so we can resist it together? Could care be a form of praxis, an enacted vulnerability as resistance? Could the labor of care be celebrated and recognized and valued as survival making and revolution making and love making?

Care haunts, hurts, heals

Take that break.
Yes, the one that feels like an interruption. It is.
Cry shuddering tears
make jokes in the waiting room while sitting in a tiny yellow kid's chair
fluff the perfect pillow mountain
build traditions around post-emergency room ice cream
sit me in your wheelchair and roll me to the bathroom
mop up spilled coffee and pee for the 4th and 5th time
thaw this panic
stoke this anger
hold this hand
give me the full weight of your body.
"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."
(Piepzna-Samarasinha, 2018, p. 35)
My hands come to rest on tired muscles,
fingers interlacing ribs
as I squeeze.
They let out small puffs.
Meditatively, my breath trains with theirs
as I press their ribs together
gently on the exhale
and invite them open
on the inhale
I watch you slipping further and further away,
no matter how hard my fingers grip your ribs.
Try to call one more breath from your lungs.
One more,
and another.
Not yet
I still need another,
and another … .
We watch our beloved slipping further and further away.
Witness death on Skype
in the care of another.
Such deep care.
Our arms never so empty while our hearts are so full
I watch you slipping further and further away,
the cold steel bridge too close.
Negotiating consent:
engage the help that has hurt so often?
Stay or let go?
There is stillness in a lover's depression
if I let go of it needing to be otherwise.
A slowing of the day's stresses
into an intimate, connected moment.
Just her and I in an email-impenetrable bubble,

sharing with each other our darkest corners,
while wrapped in our fuzziest bathrobes
Sometimes
we can't shower and shit and show up and smile
we can't ask for what we need
we're too much and too little.
Feeling the weight of feeling a burden
Realizing what I built to hold me
in all of my brilliant Mad queer mess
no longer does[3]
Affirm and assert:
my crip kin circle
has no place
for queerphobic white disability tears
has no place
for sanist femme-phobia
Stairs and strobe lights
and no ASL.
text "apologizes":
"oversight" or "over booked" or "over budget."
Again, and again.
There's always a budget for glitter and booze,
drag queens and DJs,
stages, stairs and strobe lights.
Affirm and assert:
my queer desire has no place
for queers who have no space
for crip embodimindment
Our (neuro)queer crip Mad family
cares across continents.
Curious, promiscuous,
often messy, sometimes dirty.
Needy, flaky
["I love flaky, pie is flaky, I LOVE PIE! Flaky like pie!" (dales lange, in Eales, 2018, p. 129)]
tired, sickly and daring.
(Con)sensual.
Glasses of wine in bed on FaceTime
GIFs and gallows humor

Desiring care

Crip and Mad existence are hot. Long before I read the following words, I have felt them deep in my bones, and other places as well. "[Laughing] I don't want to ever have sex with anyone but another chronically ill or disabled person again. I'm just like, oh god, it's such a relief" (Piepzna-Samarasinha, in conversation with E. T. Russian, 2018, p. 115).

A partner borrows crutches for a recently turned ankle

crutches that are of my body much of the time.

A partner borrows a few choice limbs.

Immediately their movement pulls from my specific, genderqueer affectations

like a gendercreative kid trying on their parents' pumps for the first time

just enough swing to make a swagger

We love caring when it is playful. When it comes in a moment of open curiosity about the other, and about the others' others. Working to Madden queer theory, Huffer (2010) invites:

> … not the objectifying curiosity of the scientist, but a habit of thinking Foucault described as "the care one takes of what exists and what might exist." As an ethical approach to alterity, this curiosity as care signals a willingness to be undone by another. (p. 118)

We love care as a deeply co-creative moment—an intimate improvization—always open to the other(s) surprising you.

Pill taking has been chosen, for now,

pill remembering is harder.

Each morning

my pillbox and water bottle are lovingly placed,

a treasure hunt of reminders:

on top of the toilet seat,

amidst the kettle and coffee cups,

on the floor of the shower,

inside a box of Cheerios,

in my purse or my pumps,

zipped into my onesie.

Caring as ritual, not habit.

There is risk, intention, attentiveness, attunement. Where we continually remake that caring moment together, re-imagining what it could be. Where there is enough access to intimacy to predict a potential need, but enough humility to be open to shifting desire.

You hand me my asthma inhaler out of nowhere:

foreplay.

You anticipate gasping.

I turn it down:

breathplay.

I anticipate gasping.

The disability justice activist and blogger Mia Mingus (2017) defines access intimacy as:

> … that elusive, hard to describe feeling when someone else "gets" your access needs … . the intimacy I feel with many other disabled and sick people who have an automatic understanding of access needs out of our shared similar lived experience of the many different ways ableism manifests in our lives … . Instantly, we can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety and pain of access. I don't have to justify and we are able to start from a place of steel vulnerability. (n.p.)

Our care peculiarities need never be justified. Our vulnerabilities need no apologies. Intimate shared journeys of access to tap dancing, Seroquel, raised toilet seats, and staying on this planet.

You,

in our friendship,

and in this process,

have helped me find within myself

a decoder ring

that connects me to my will to live.

And by live, I mean: create.

And by create, I mean: love.

And by love, I mean: everything.

(Nathan Fawaz, in Eales, 2018, pp. 290–291)

We have learned from our dear partner Nathan Fawaz that acting with care is about never assuming we know there is a problem, or what that problem might be. It is about asking if and how something is a problem for me. What do I care about? What kind of care, if any, might I desire? Disrupting normative and normalizing desires; "opening up desire for what disability disrupts" (Fritsch, 2013, para 2). This resonates with Mingus' (2017) articulation that access intimacy does not always overlap with our other intimacies. Strangers, parents, lovers, and professional care workers may or may not be more willing to do the necessary work and play: to read the disability justice literatures, to read the room, to approach with deep curiosity and consent about what the other does and does not desire, or does and does not care about and, importantly, how. Thinking we know how to care best is an entirely different approach than acknowledging how our knowledge and the unknowable might support the mutual negotiations of a caring moment, a care shift, or being in long-term, intimate, care relations.

Although such disruptions of care-full normate intimacy are deeply desirable, if not necessary, so too are disruptions in the political precarities that structure the violences of care. Cripping care means fighting for washrooms all of us queerdos and crips can access. It means fighting for more care hours, and also better paid and valued care. It means fighting for broader change, sometimes, just by collectively fighting for our next breath, for the will to keep fighting. Mingus (2017) acknowledges that access intimacy does not always lead to access; sometimes it is about working together, "trying to create access as hard as you can with no avail in an ableist world. Sometimes it is someone just sitting and holding your hand while you both stare back at an inaccessible world" (n.p.).

We three spend weeks together of sweltering post-surgical summers

first mine, then yours.

Old windows barely hold out heat and wildfires,

old wiring short-circuits all attempts at cool air,

post-surgical care protocols omitted from the forecast.

Holding each of your hands before going under.

Submitting for survival not normalcy.

Poorly singing so many 80s ballads about my (literal) broken heart, twice broken.

Take another little piece.

This (w)hole in my heart that can only be filled by you, and you, and also you,

and also, two surgeons.

"Euphoria" you say, as you awake "is the opposite of dysphoria" (you are right,
dearest Nathan).

Delicious, non-monogamous care.

Care that can be held, because there are enough limbs and laughs to go around.

Notes

1. The eugenics movement refers to a set of ideologies, policies, and technologies that were widely circulating and explicitly celebrated during the late nineteenth to mid-twentieth centuries, and continue to circulate and influence policies and practices in somewhat less explicit forms to the present day (Withers, 2012). The overarching White supremacist premise is that: White non-disabled strait cismen of northern European descent are the apex of human evolution and civilization; that racialized folks have slowed or stopped their evolutionary progress and are thus less evolved; and that White folks deemed to have congenital disabilities or "unnatural" gender or sexual expressions are "degenerates," and "defectives" having devolved back to earlier, lesser, evolutionary levels, and threatening to bring the rest of the White race with them. Proponents of eugenics tend to mobilize evolutionary, genetic, anthropological,

psychological, and biomedical pseudo-science within overarching White supremacist logics and projects in order to justify, reproduce, and intensify significant social injustices and violence, including: genocides; slavery; settler colonialism; mass medical, psychiatric, and criminal incarceration; forced sterilizations; and ongoing socio-economic disparities (see Peers, 2016, Snyder & Mitchell, 2006).

2. "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" (Piepzna-Samarasinha, 2018, p. 122).
3. "We start community projects not necessarily to get fame and fortune but to try to save lives or fulfill a crucial need. Often, we make ourselves vulnerable as part of that work. We have been raised to stay humble and accessible, or value that as a principle of accountable community leadership. And when we do something, the assumption is often *Who does ze think ze is?* Our humility, accessibility, and openness make us vulnerable to attack. So often, we have not been taught that it's okay to have boundaries, say no, that we can be accountable without being 1,000% perfect all the time, that we can be leaders who get to make mistakes. Worse, our work isn't seen as real anyway" (Piepzna-Samarasinha, 2018, pp. 198–199).

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References

Ahmed, S. (2017). *Living a feminist life*. Duke University Press.

Burstow, B. (2013). A rose by any other name: Naming and the battle against psychiatry. In B. A. LeFranc¸ois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian mad studies* (pp. 79–90). Canadian Scholars' Press.

Butler, J. (2016). Rethinking vulnerability and resistance. In J. Butler, Z. Gambetti & L. Sabsay (Eds.), *Vulnerability in resistance* (pp. 12–27). Duke University Press.

Carter, A. M. (2015). Teaching with trauma: Trigger warnings, feminism, and disability pedagogy. *Disability Studies Quarterly*, *35*(2). 4652. https://doi.org/10.18061/dsq.v35i2.4652

Chapman, O., & Sawchuk, K. (2012). Research-creation: Intervention, analysis and “family resemblances”. *Canadian Journal of Communication Studies*, *37*, 5–26.

Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.

Cision PR Web. (2007, December 3). *Millions of children held hostage by psychiatric disorders: New NYU Child Study Center ad campaign debuts in NYC with website relaunch*. https://www.prweb.com/releases/child/study/prweb573881.htm

Clare, E. (1999). *Exile & pride: Disability, queerness, and liberation* (2nd ed.). South End Press.

Clare, E. (2017). *Brilliant imperfection: Grappling with cure*. Duke University Press.

Damour, L. (2019). *Under pressure: Confronting the epidemic of stress and anxiety in girls*. Ballantine Books.

Dow, T. (2010, September 22). *CF in the news: “The fear factor in health fundraising” in CMAJ*. [Blog post]. https://breathingasafamily.org/2010/09/22/cf-in-the-news-the-fear-factor-in-health-fundraising-in-cmaj-aug-2010/

Eales, L. (2018). *Making Mad Home and other love stories: Mad performative autoethnography, collaborative research-creation, and mad-accessible trauma-informed practice* [Unpublished doctoral thesis]. University of Alberta.

Elder Robison, J. (2013, April 19). *Where do we stand in the “War on Autism?”: Are we combating autism or embracing it; doing both, or accomplishing neither?* https://www.psychologytoday.com/us/blog/my-life-aspergers/201304/where-do-we-stand-in-the-war-autism

Foucault, M. (1997). *Society must be defended*. Picador.

Fritsch, K. (2013). On the negative possibility of suffering: Adorno, feminist philosophy, and the transfigured crip to come. Disability Studies Quarterly, 33(4), 3869. http://dsq-sds.org/article/view/3869/3408

Garber, L., Faderman, L., & Gross, L. (2001). *Identity poetics: Race, class, and the lesbian-feminist roots of queer theory*. Columbia University Press.

Huffer, L. (2010). *Mad for Foucault: Rethinking the foundations of queer theory*. Columbia University Press.

HuffPost Parenting. (2017, December 7). *Seattle Children’s Hospital pulls ads from buses after offending Autistic community*. https://www.huffpost.com/entry/seattle-childrens-hospital-autism-ad_n_3582030

Huncar, A. (2015, October 28). Catheter rationing degrading, spinal-injury patient argues. *CBC News*. https://www.cbc.ca/news/canada/edmonton/catheter-rationing-degrading-spinal-injury-patient-argues-1.3292045

Hunter, T. W. (2018, June 3). The long history of child-snatching. *The New York Times*. https://www.nytimes.com/2018/06/03/opinion/children-border.html

Johnson, E. (2017, November 25). Bell’s ‘Let’s Talk’ campaign rings hollow for employees suffering panic attacks, vomiting, anxiety. *CBC News*. https://www.cbc.ca/news/health/bell-employees-stressed-by-sales-targets-1.4418876

Kafer, A. (2016). Un/safe disclosures: Scenes of disability and trauma. *Journal of Literary & Cultural Disability Studies*, *10*, 1–20.

Kinsman, G., & Gentile, P. (2010). *The Canadian war on queers: National security as sexual regulation*. UBC Press.

Kinzel, L. (2013, February 27). What’s wrong with fat shaming? *Everyday Feminism*. Retrieved August 30, 2019 from https://everydayfeminism.com/2013/02/whats-wrong-with-fat-shaming/

Kmart (2018, September 1). *Inktastic muscular dystrophy needs a cure 2D FL toddler t-shirt someone I love*. https://www.kmart.com/inktastic-muscular-dystrophy-needs-a-cure-2d/p-

A027680944?selectedFilters=Sleeve%7CShort&plpSellerId=Inktastic&prdNo=37&blockNo=37&blockType=G37#

MacMurchy, H. (1907). *Feeble-minded in Ontario*. Office of the Feeble-Minded. https://archive.org/details/feeblemindedinon1907onta

McRuer, R. (2018). *Crip times: Disability, globalization, and resistance*. NYU Press.

Mills, D. (2010, February 14). *Advertising man helps spread disabled boy's message for Muscular Dystrophy campaign*. https://www.newsshopper.co.uk/news/5005803.advertising-man-helps-spread-disabled-boys-message-for-muscular-dystrophy-campaign/

Mingus, M. (2017, April 12). *Access intimacy, interdependence and disability justice. Leaving evidence*. Retrieved August 30, 2019 from https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/

Peers, D. (2012). Interrogating disability: The (de)composition of a recovering Paralympian. *Qualitative Research in Sport, Exercise and Health*, *4*(2), 175–188. Reprinted in B. Smith (Ed.) *Paralympics and disability sport* (2013). London, England: Routledge. https://doi.org/10.1080/2159676X.2012.685101

Peers, D. (2018). Engaging axiology: Enabling meaningful transdisciplinary collaboration in adapted physical activity. *Adapted Physical Activity Quarterly: APAQ*, *35*(3), 267–285. https://doi.org/10.1123/apaq.2017-0095

Peers, D. (2016). *From eugenics to Paralympics: Inspirational disability, physical fitness, and the white Canadian nation* [Unpublished doctoral thesis]. University of Alberta.

Piepzna-Samarasinha, L. L. (2018). *Care work: Dreaming disability justice*. Arsenal Pulp Press.

Price, M., & Kerschbaum, S. L. (2016). Stories of methodology: Interviewing sideways, crooked and crip. *Canadian Journal of Disability Studies*, *5*(3), 18–56. https://doi.org/10.15353/cjds.v5i3.295

Robinson, M. (2020). The big colonial bones of Indigenous North America's "obesity epidemic". In M. Friedman, C. Rice, & J. Rinaldi (Eds.), *Thickening fat: Fat bodies, intersectionality, and social justice* (pp. 15–28). Routledge.

Saguy, A. (2013). *What's wrong with fat?: The war on obesity and its collateral damage*. Oxford University Press.

Sanger, M. (1921). The eugenic value of birth control propaganda. *Birth Control Review*, October. Margaret Sanger Microfilm S70:913. Retrieved August 31, 2019 from https://www.nyu.edu/projects/sanger/webedition/app/documents/show.php?sangerDoc=238946.xml

Sanger, M. (1923). High lights in the history of birth control. *The Thinker*, October. Retrieved August 31, 2019 from https://www.nyu.edu/projects/sanger/webedition/app/documents/show.php?sangerDoc=306641.xml

Snyder, S. L., & Mitchell, D. T. (2006). *Cultural locations of disability*. University of Chicago Press.

Strings, S. (2019). *Fearing the black body: The racial origins of fat phobia*. New York University Press.

Sullivan, M. (2005). Subjected bodies: Paraplegia, rehabilitation, and the politics of movement. In S. Tremain (Ed.), *Foucault and the government of disability* (pp. 27–44). University of Michigan Press.

Talaga, T. (2018). *All our relations: Finding a path forward*. House of Anansi Press.

Titchkosky, T. (2007). *Reading and writing disability differently: The textured life of embodiment*. University of Toronto Press.

United We Volunteer. (2019). *Halos for muscular dystrophy*. https://www.unitedwevolunteer.org/agency/detail/?agency_id=10891

Withers, A. J. (2012). *Disability theory and politics*. Fernwood Publishing.