

# Disappearing Act

## *Disabled Embodiment and the Haunting of the Biopsychosocial Model of Chronic Pain*

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### ABSTRACT

Chronic pain, illness and disability are widespread phenomena. The biopsychosocial model of pain has been broadly adopted as the dominant paradigm for understanding chronic pain in psychological and medical fields. However, neoliberal capitalist forces have steered the implementation of this model in ways that reduce the complex etiology of chronic pain to individual psychological and behavioral factors. This effectively disappears the somatic experience of sick/disabled people, and occludes the biological, psychological, social, and systemic harm of ableism. This paper offers a perspective on chronic pain from a disability justice lens, laying out the life and death stakes of accessibility (especially during the pandemic age) It explores both the limitations and potential of somatics to support a client's sense of agency within their experience of chronic pain. It is at once a memorial, a call to reflection and action on the part of clinicians, and an inquiry into the liberatory potential of sick/disabled embodiment in the therapeutic container and beyond.

**Keywords:** Somatic psychology, chronic pain, biopsychosocial, ableism, disability justice, accessibility

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Dedicated to Teighlor Countessa McGee  
beloved friend, poet, prophet

There is nothing I say, write or do about  
disability that does not have you in it

יהי זכרה מהפכה

*May your memory be for a revolution*

*This loop once again  
implies that being disabled  
from chronic pain is our own fault.*

**Crip New Year Mantras**

1. A broken body is still able to climb out of God's palm and see the world
2. I do not live in the hands of those who do not see my worth
3. It is not my time to return to ash and dust
4. I will not be half consumed and left as table scraps

—Teighlor McGee  
*Black Disability Collective*

Chronic pain and illness are clinically prevalent phenomena, with chronic pain affecting an estimated 20% of people worldwide (Meehan et al, 2021). 1 in 4 people in the US have a disability of some kind (CDC, 2019).<sup>1</sup> I personally have had 17 years of ongoing (and ever-evolving) experience due to Hypermobile Ehlers-Danlos Syndrome and associated comorbidities. With the Covid-19 pandemic unfettered by global vaccine inequity and eugenicist US public health policies, millions more are having their lives transformed by chronic pain and sickness due to Long Covid. The paradox is that within this ubiquity, peoples' lived experiences with chronic pain are unseen – amounting to that of an “invisible disability” (Meehan et al., 2021). This is due not only to the apparent appearance of (and ensuing assumptions around) “health;” this *invisibility* extends to how society treats disabled people at large. We are a population that is exiled, ignored, and deemed expendable. Our needs for access to participation in the public domain are routinely forgotten, or we are exhorted to “overcome” (meaning, hide) our pain in order to comply with the white supremacist, capitalist, homogeneous ideal of the “abled body:” one that is able to be exploited for labor. Most of the articles I reviewed introduced their research into chronic pain by simultaneously bemoaning the millions of dollars of lost economic productivity, and the burden of millions sunk into healthcare costs. Whose pain are we actually concerned with as healing practitioners – that of the person, or that of capitalism?

How do we define pain? From whence does it arise? In 2020, “for the first time in 40 years, the most widely accepted definition of pain” from the International Association for the Study of Pain “was updated to reflect advances in understanding.” The IASP defines pain as “*an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage*” (Raja et al., 2020) (Meehan et al, 2021). They elaborate that “pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.” There is further clarification that “pain cannot be inferred solely

from activity in sensory neurons”, which confirms that pain is capable of arising without actual tissue damage or dysfunction (Meehan et al, 2021). This updated IASP definition reflects the deep impact of the biopsychosocial (BPS) model of pain, which was originally developed by Dr. George Engel in the 70s in an effort to shift care to be more “holistic and patient centered” (Hunt, 2022). This was a “radical break” from the traditional biomedical model that always “considered pain as a direct consequence of an underlying pathology” such as disease or injury (Vlaeyn, 2007). The biomedical (BM) paradigm, epistemologically born from the Cartesian mind/body split, has been widely critiqued for being “reductionist and dualistic.” On the other hand, the BPS model “ostensibly acknowledges” the impact of social and psychological variables of a person’s “interpersonal patterns, relationships, social support, and thoughts, feelings and behavior” (Hunt, 2022) on their experience of pain. The BPS model has now become a mainstream approach to pain management for those lucky few who have access to specialized treatment (Meehan et al, 2021) – although anyone who scrolls through the content of social media “wellness” coaches will be familiar enough with the discourse. It has been “argued to add value particularly in the field of mental health (Gask 2018)” (Hunt, 2022). As I consider joining this growing field of pain psychology, I face a landscape where cognitive behavioral therapy (CBT) has thusly become a frontline treatment (often within a multidisciplinary medical program) for such wide ranging conditions as chronic back pain, chronic fatigue, fibromyalgia and arthritis (Vlaeyn, 2007).

How has this widespread shift from a biomedical to a biopsychosocial (BPS) model borne out for those most directly impacted? Has chronic pain care actually become more “patient-centered” in its approach? While a veneer of BPS rhetoric has been popularized, “the BM model remains deeply entrenched within the culture of medicine and the general public”; for example, the clinical implementation of “psychosocial therapies are often prescribed and delivered within a framework

1. It is important to note that not all disabled people have chronic pain and not all people with chronic pain identify as disabled, although there is extensive crossover. The scope of this paper is on the intersection of these phenomena. However, disability experience is vast, and can include physical impairments, neurodivergencies, developmental disabilities, sensory disabilities, mental health conditions, autoimmune disorders, terminal illness, environmental injuries, and more. As always, follow the lead of the client in how they refer to themselves.

similar to an injection or medication” (Maridan et al, 2020). As a result, this therapy still operates through an ideology of medical authority, pathology, and cure that objectifies the client instead of centering around their humanity and the expertise of their own bodymind.<sup>2</sup> Meehan and Carter further question mainstream BPS services by establishing that “the evidence base for effectiveness” is not as robust as one might assume, “mostly due to limitations in study design which is reflected in many reviews reporting low quality” (Meehan et al., 2021). While I appreciate that they call for further research with “the participation of people with lived experience to guide” the work in order to delineate barriers to care (Meehan et al., 2021), Hunt cuts to the core of the matter: barriers to care are indeed the point. Hunt reveals how the BPS model “has been manipulated to serve a neoliberal agenda to reduce state health and social expenditure, increase corporate profits, and protect the market and interests of the privileged (Jolly 2012; Berger 2014; Stewart 2019).” The resultant “undue psychologization of chronic illness through BPS theorizing...and associated agendas” has caused “enormous harm to chronically ill and disabled people” (Hunt 2022).

This harm spans the entire breadth of bio, psycho and social experience, as well as structural and systemic experience. However, throughout my initial research pertaining to the BPS model of chronic pain, it was enraging to see the violence of ableism across these realms rendered invisible over and over again. While Meehan and Carter gesture toward access issues, they are unable to articulate the cause. Only Hunt named ableism directly. As developed by Talila A. Lewis “in community with other Black and negatively racialized disabled people”, the definition of ableism is:

“a system that places value on people’s bodies and minds based on societally constructed ideas of normality, intelligence, excellence, desirability, and productivity... [and deeply rooted in anti-Blackness, eugenics, misogyny, colonialism, imperialism and capitalism. This form of

systemic oppression leads to people and society determining who is valuable and worthy based on a person’s language, appearance and/or their ability to satisfactorily [re]produce, excel and ‘behave’” (Lewis, 2022).

Even within a graduate program literally based in *somatics*, where we are constantly reminded of the downstream physical impacts of trauma, one would think topics of disability, pain, or ableism would be especially relevant; instead, materials remain scant – and where they appear, optional. Indeed, the influence of the BPS model actually “downplays biological considerations whilst the ‘psychosocial’ dons a mantle of victim-blaming: chronic illness and disability are considered to be perpetuated by maladaptive thoughts and behaviors” (Hunt, 2022). Once again, we are haunted by the conveniently disappearing sick/disabled body. By de-emphasizing the body’s material somatic reality in the etiology of chronic pain, systemic issues such as the inaccessibility of health care services, benefits, social supports, public spaces, housing, etc. are excused; instead, the onus of responsibility is cast upon the individual and their (un)willingness to “heal,” in an ableist neoliberal idealization of “self-sufficiency, autonomy, personal responsibility, free will, and self-determination (Adams et al., 2019)” (Hunt, 2022). Also erased is the tangible harm the bodyminds of sick/disabled people go through at the hands of the structures we live within. The physical harm caused by the denial of care justified by the medical gaslighting operationalized within the BPS model is apparent. However, inaccessibility, “stigma and epistemic injustice” also have “biological impacts:” they act as “chronic and uncontrollable stressors...[leading to] allostatic(over)load”<sup>3</sup> which in turn “increases susceptibility to further ill-health (Heise et al., 2019; Metzl and Hansen, 2014)” (Hunt, 2022). Put more simply, the stress of ableism itself flares our pain; being in more pain (i.e., having a bodymind that more greatly deviates from the norm) typically means facing more ableism, both internally and externally. It is a vicious loop, one the BPS model

2. “Bodymind” refers to “the relationship between the human body and mind as a single integrated entity... to affirm our minds and bodies cannot be separated” (Sins Invalid, 2019).

3. “Allostatic load refers to the cumulative burden of chronic stress and life events [involving] the interaction of different physiological systems...when environmental challenges exceed the individual ability to cope, then allostatic overload ensues” (Guidi et al, 2020).

obscures in favor of promoting the idea that it is our personal *fear* of pain that limits our movement, thereby increasing pain and impairment. This loop once again implies that being disabled from chronic pain is our own fault.

I do not deny that there are many, many people who have found chronic pain relief with treatment approaches that utilize the BPS model, such as with pain coaches, CBT workbooks, or the app Curable. For some people, reprocessing past trauma through a few sessions of Somatic Experiencing® sessions may indeed cure their chronic back pain. But there are myriad more of us whose very *lives* are not something to *cure*. As the viral Twitter campaign (started by writer Imani Barbarin after the CDC commented it was “encouraging” that most people dying of Covid were “unwell to begin with”) declared: *our disabled lives are worthy* (Barbarin, 2022). Even if it were our trauma that predisposed disabled people to our chronic pain/illness, no amount of therapy would be able to make our chronic pain – that is, our *bodies* themselves – completely disappear from whence they came. Can somatic psychotherapy – with its “focus on valuing the sensed experience of the individual as a whole person (Dowler 2013) and not just as a set of painful body parts” – actually resist this habitual erasure? Can the “common themes of somatics” such as “pleasurable movement, validation of subjective experience, sensory exploration, play and contemplation” conjure our embodiment back from the other side (Meehan et al, 2021)? No longer willing to view it as an apparition flitting at the corners of our clinical eyesight, I seek to resurrect the sick, tired, painful body within the therapeutic space by centralizing an exploration of (especially queer) disabled embodiment in my approach towards chronic pain treatment. (*Queer*, not as the umbrella term it has become for non cis-heterosexual identities – *queer*, as in embodiments of non-cisheteronormative identities that actively agitate against and create alternatives to systems of oppression.) Toward this end, I have greatly appreciated the proposals Meehan and Carter offer as an initial road map to how so-

matic practices can play a supportive role for people in pain. While several of the perspectives they explore remain entrenched within the neoliberal rhetoric of “self-management” and “self-authority” (with all their attendant implications of control and dominion over the flesh), there is a vital somatic principle at the core of these semantics: there is powerful and liberatory healing available to us in having an expanded capacity for and sense of *agency* in our relationships with both our body-minds and the world.

In fact, it was my claiming of disabled embodiment and identity – not a refusal of it, as suggested by the BPS model – that restored my agency within a life of incurable and constant physical pain. Through a (never-ending) process of releasing my internalized ableism by engaging with the disability justice movement,<sup>4</sup> I build supportive relationships with sick/disabled communities, cultures, and histories. I grant myself permission to use the mobility aids I was told would only enfeeble me further, which in fact enable me to do more. Empowered within this collective embodiment, I restore my sense of self-worth into alignment with my deepest values, instead of letting it be dictated to me by my value to capitalism. As an anarchist, I am deeply inspired by the idea of “agency *without mastery* (Gilmore 2012, p. 95)” (Meehan et al, 2021) as a model for relating with chronic pain phenomena. This languaging highlights how agency within sick/disabled embodiment necessitates a dialectic with *surrender*. I’m not suggesting passivity in the face of chronic conditions; I still navigate my pain through physical therapy, psychotherapy, acupuncture, meditation, community care, and more. Rather, by learning to surrender to painful sensations, pain transforms from an enemy that needs conquering on the battlefield of my bodymind to a well of wisdom within myself that deserves listening to. Pain invites care, uplifting the needs we’ve been taught to ignore by systemic oppression. Somatics for chronic pain could offer a potent “means of...becoming an expert in one’s own needs and capacities” (Meehan et al, 2021). Indeed, the liberatory potential of sick/disabled embodiment goes

4. Disability justice (DJ) is an alternative framework to the disability rights movement, which has “historically centered white experiences” and “focuses exclusively on disability at the expense of other intersections of race, gender, sexuality, age, immigration status, etc.” DJ “centers the leadership of disabled people of color and of queer and gender nonconforming disabled people” (Sins Invalid, 2019).

far beyond any one individual bodymind. As Aurora Levins Morales writes, “what our bodies require in order to thrive, is what the world requires. If there is a map to get there, it can be found in the atlas of our skin and bone and blood” (Morales, 2013). Why assume the most therapeutic goal would be to eliminate pain and illness entirely, as if we even could? These experiences can be a pathway to wisdom, liberation, and transformation at the level of both the individual and collective bodies.

That being said, the experience of chronic pain is still fundamentally a deeply uncomfortable one, which elicits suffering from challenging physical sensations as well as ableism. While I utterly reject the eugenicist stream within somatic psychology, it is still very much worthwhile to consider how we can support clients living with chronic pain to suffer less. Meehan and Carter outline the potential benefits of somatic practices in chronic pain treatment by first considering *interoception*, our felt sense of “our physiological condition of the whole body” and “the basis for the subjective image of the material self as a feeling (sentient) entity” (Meehan et al, 2021). Interoception plays a key role in fundamental “coping strategies such as becoming aware of body cues for rest, pacing or decreasing hyper-alertness to pain signals,” as well as in “relaxing the nervous system, and therefore tensions or emotions that increase pain.” For example, I can invite a client’s interoception to take an oscillating quality by “modulating our attention, sometimes attuning to pain experience, and other times bringing attention to pleasurable” (Meehan et al, 2021) or neutral sensations, or even numb spaces in the body. While these approaches have the potential to powerfully augment a client’s sense of agency within their experience of pain, I am grateful Meehan and Carter recognize upfront that “the focus on sensory stimuli can be overwhelming” for many people (and can be for many reasons beyond pain – trauma histories, neurodivergencies, etc.). It is vital to never assume that somatic interventions will be grounding or resourcing for a client. Therefore, “(Farb et al., 2015) suggests that the central question actually is “understanding how to skillfully relate to interoceptive sensations, and under what circumstances they should be attended to” (Meehan et al, 2021). Also considered are explorations of *exteroception* (the sense of “outer environment through ‘touch’, including sensations such as pressure, heat, cold, pain, and vibra-

tion”) and *proprioception* (“awareness of balance, movement and body position in space”). They focus on these as interventions in (purported) pain catastrophizing, encouraging “appropriate levels of movement” by “sensing the environment, exploring triggers for fear, and developing strategies for moving with confidence” (Meehan et al, 2021). However, in my experience the most common challenge for disabled people with chronic pain is not that we catastrophize our fear of pain to the point that we pathologically limit our movement. I observe (and myself experience) people routinely pushing through our pain to *over-exert* ourselves, again and again, due to lack of support and the inaccessibility of the systems we live within. The pathology here is societal, and therefore can be healed only by way of collective liberation. However, proprioception and exteroception are still beneficial tools to explore increasing the range of agency-expanding strategies available to sick/disabled clients, especially as many of us are surviving this forced overexertion by way of bodily dissociation. For example, we can experiment with moving through our environments with more ease and less bracing in order to conserve energy and reduce the risk for flares.

These initial proposals around interoception, exteroception, and proprioception are all very useful on a pragmatic clinical level. It is enough to resurrect the embodiment of chronic pain; however, it falls short of a true *revival*. Despite holding the whole self in an avowed sanctity, I fear somatics for disabled people will take on a zombified approach, in which we (symbolically) stagger about in an endless search, tracking not for “braaaains!” – but for “sensaations!” to consume in order to help us manage dragging out our miserable, marginalized existences a little longer. The ableist necrosis of shame and isolation remains untouched. Indeed, as “physical pain and social pain (from rejection, exclusion, or loss) appear to share neurobiological mechanisms” (Maridan et al, 2020), we find our chronic pain amplified not just by our central nervous systems, but by the constant onslaught of unrestrained ableism during the pandemic age. Being seen as disposable by neo-fascist anti-vaxxers is one thing; it cuts to the very quick to be abandoned by spaces that we called home, by movements that avowed community care. I hold close to my heart how these “challenges to ontological security (isolation, stigma, inaccessibility and disconfirming



experiences with people/systems)” – as well as the exhausting somatic reality of chronic pain – “often leads to increased suicidality” (Hunt 2022). Indeed, my heart has already been rent by the people in my sick, disabled, queer, trans communities who have died by suicide during the pandemic. It aches for the many more alive and struggling with suicidal ideation. How can somatic psychology reaffirm *our right to life* with pain, while also honoring just how much it can hurt? How might we exorcise the rampant ableism of the field, in order to increase accessibility to the life-nourishing potential of somatics?

Just as the real work of spiritual cleansing cannot be bypassed through a quick trip to buy herbs at the crystal shop, accessibility is not merely a matter of accessories – of adding a ramp to your building or a Diversity Equity Inclusion training to your resumé. If it weren’t already clear, let me be perfectly plain: my choice of words is not a metaphor. The ghosts behind the haunting of the BPS model and other ableist paradigms are of real people. Access is a matter of life or death. Access is a matter of dismantling colonialism, capitalism, and white supremacy. My beloved friend Teighlor McGee (writer, activist, and founder of the Black Disability Collective) was literally killed by medical gaslighting and over-psychologization of their symptoms, fueled by the toxic racism, misogyny, and homophobia of the professionals they were forced to entrust with their “care.” Their story, and others like it, are not rare. With Black and brown people bearing the brunt, the pandemic is causing mass disablement and mass death. In the U.S., over a million people have died from Covid, with at least 3,756 people dying the week I submitted this paper alone (CDC, 2023). Studies estimate up to 23 million people are impacted by Long Covid so far (GAO, 2022). Black people die from Covid at twice the rate, and are hospitalized at two and a half times the rate of white people (CDC, 2020). I am curious; in light of the failure of our public health systems, are you doing what you can as an individual to reduce Covid community transmission – namely, getting the bivalent booster and masking in public settings? Do you have layers of Covid harm reduction built into your delivery of in-person services?<sup>5</sup> If not, I invite

you to sit with this question: Are you comfortable with your complicity in their maiming? In their deaths? The likely answer is, no. Thankfully, as far as the bare minimum goes for the pandemic, these are simple behavioral changes the vast majority of people can make. It is a more challenging shift to transform one’s personal internalized ableism (never mind that of society as a whole!). Remember, ableism affects us *all*, regardless of if we are disabled or have chronic pain – it is the root of the shame you feel when you take a day off, the whisperer of the lie that the only reason you should rest is so you can go back to work harder, faster, longer. Likewise, accessibility pertains to every human alive. We “all function differently depending on context, environment” or somatic state; “all body-minds have strengths and needs that must be met” in order for our presence – our very lifeforce – to be in the room (Sins Invalid, 2019).

I am still dreaming beyond the BPS model of chronic pain, envisioning an approach that sees sick/disabled embodiment as “unique, whole and essential”, just as “all bodies are” (Sins Invalid, 2019). “In the face of systems that want us dead,” that want to disappear our bodyminds outside of clinical purview, “sick and disabled people have been finding ways to care for ourselves and each other for a long time” – a life-sustaining practice often known as “care webs” (something that is and has been embodied for millennia in the “Black, Indigenous, and brown communities [that] have complex webs of exchanges of care”) (Piepzna-Samarasinha, 2018). I want to develop somatic approaches to mapping both internal and external care webs, integrating moments of nourishing intimacy, support, and solidarity from relationships with human and beyond-human kin, allies, and ancestors alike. I wonder how we can engage practices of interoception, proprioception, and exteroception to support a client’s felt sense of self-compassion and of interdependence. How can we explore pain as a vital and urgent bellwether of the wellness of the collective body – humanity’s and the earth’s? What does trauma treatment look like when recovering one’s sense of “safety” out in the world is not an option, given the vast scale at which sick/disabled bodies are endangered by mass pandemic

5. Please refer to the Appendix for more information on The People’s CDC, which has abundant free resources on how to implement Covid harm reduction protocols and practices.

apathy? How might we hold space to grieve lost capacities and lost relationships, while honoring the rage, creativity and perseverance it takes to thrive as a disabled bodymind? Tools stemming from the BPS approach to chronic pain (such as a cognitive reframes, behavioral change and sensorial mindfulness, as well as the broader practice of somatics) can all potentially bring what attenuated relief is possible while we are still surviving within unjust systems by modulating our experience of chronic pain. However, first clinicians must relocate their orientation to these practices within an ethic of disability justice, in order that they might *see us* amid the forces that seek to occlude the full bio, psycho, social, and structural breadth of our suf-

fering. Don't keep the living exiled in the realm of ghosts. Don't ignore the dead. Don't let us haunt you. In this Internet age of widely available information, ignorance of the stakes at hand is a choice. Clinicians have the agency to choose differently. I offer an initial list of disability justice resources, centering the leadership of those most impacted, below. I invite you to start the journey, with humility and with accountability, to see us here with you in the land of the living. There, we might all "move together," as "people with mixed abilities, multi-racial, multi-gendered, across the sexual spectrum" with "a vision of collective liberation that leaves no bodymind behind" (Sins Invalid, 2019).



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## Appendix 1: Disability Justice Resources (a very incomplete list)

### Essential Articles

- “10 Principles of Disability Justice” by Sins Invalid  
<https://www.sinsinvalid.org/blog/10-principles-of-disability-justice> or in their book  
“Skin, Tooth, and Bone: The Basis of Movement is Our People – A Disability Justice Primer” (Berkeley, CA, 2019)
- “Care Webs: Experiments in Collective Access” by Leah Lakshmi Piepzna-Samarasinha  
<https://static1.squarespace.com/static/5a354481a9db0961249f52ec/t/5f5c2593ce23ec19f7cae9f8/1599874451239/Care+Webs.pdf> or in her book  
“Care Work: Dreaming Disability Justice” (Vancouver, BC: Arsenal Pulp Press, 2018)
- “You are Not Entitled to Our Deaths: Covid, Able Supremacy and Interdependence” by Mia Mingus  
<https://leavingevidence.wordpress.com/2022/01/16/you-are-not-entitled-to-our-deaths-covid-abled-supremacy-interdependence/>

### Additional Books

- *Brilliant Imperfection: Grappling with Cure* by Eli Clare (Durham, NC: Duke University Press, 2017)
- *Kindling: Writings on the Body* by Aurora Levins Morales (Palabrera Press, 2013)
- *Black Disability Politics* by Sami Schalk (Durham, NC: Duke University Press, 2022)

### Podcasts

- Disability Visibility by Alice Wong, <https://disabilityvisibilityproject.com/podcast-2/>
- Disability After Dark by Andrew Gurza, <http://www.andrewgurza.com/podcast>

### Additional DJ Visionaries and Content Creators

- Walela Nehanda, <https://itswalela.medium.com/>
- Leroy Moore, <https://kriphopnation.com>
- Imani Barbarin, <https://crutchesandspice.com>
- Talila “TL” Lewis, <https://www.talilalewis.com/>
- Lydia X. Z. Brown, <https://autistichoya.net>
- Rabbi Elliot Kulka, <https://elliotkukla.com/>
- Dr. Caleb Luna, <https://www.caleb-luna.com/>
- Teighlor McGee, <https://instagram.com/blackdisabilitycollective>

### Disability Justice + the Pandemic

- **The People’s CDC** – <https://peoplescdc.org/category/resources/>  
The People’s CDC is a coalition of public health practitioners, scientists, healthcare workers, educators, advocates and people from all walks of life working to reduce the harmful impacts of COVID-19. We provide guidance and policy recommendations to governments and the public on COVID-19, disseminating evidence-based updates that are grounded in equity, public health principles, and the latest scientific literature.
- **Long Covid Justice** – <https://longcovidjustice.org/>  
Long COVID Justice is building and strengthening networks of people with Long COVID and associated conditions (LCAC). Together, we are building collective efforts and campaigns for research, healthcare, the caring economy, and racial, social, economic and disability justice. Our work is done by and for chronically ill and disabled people, our families and communities.