

One

DESIRING DIAGNOSIS

• • • You are concerned about fatigue. You sleep, and you sleep, and you do not feel rested. Days bleed into one another. Secretly, you wonder if you have an alter ego that runs marathons in the milliseconds between blinks. Your eyelids are leaden, so durably reinforced that they could shatter anything you might attempt to wedge between them. Words blur, thoughts vaporize, and bones burn from the weight of your insomnia. Everything you touch turns to iron, even your curtains. Sleepily, you resort to Google, then Reddit, and then TikTok. You have found fellow long-haulers, others whose bodyminds¹ clump like undissolved sugar at the bottom of a cup. Exhaustion, mind fog, unrequited sleep: you have company.

We begin with a question and then a provocation:

First: What condition do you think you have?

Second: What if you claimed this condition without seeking confirmation from a doctor?

Do you think you might have long COVID? Having heard about the link between autism and sleep disorders, do you think you might be autistic? Maybe you might be depressed? Maybe you worry about all the possible illnesses you could contract while breathing in public and have narrowed in on OCD? Maybe you're noting some facial puffiness and suspect a thyroid condition?

We realize that you might think any, all, or none of these things about your bodymind. However, we begin here in recognition that our bodies, along with the ways we experience and narrate them to others, are infinitely complex. Our bodyminds are differentially etched by the impacts of racism, sexism, trans antagonism, and ableism. Our pain can run deep, and bearing it can be hard. We have all felt the desire to narrate the things we feel deep in our bodyminds, the groans and aches and insights that often linger at the edges of perceptibility. What might it mean to proclaim these bodily groans and aches and insights on social media? What might it mean to embrace the transitory, impermanent nature of self-diagnosis?

Here we introduce (and eventually will end with) the question of the impermanence of diagnosis and the potential of reclaiming self-diagnosis. We do so because self-diagnosis is both complicated and provocative. Reading this, you might be concerned that we're promoting disinformation, encouraging social media users to appropriate embodied experiences that aren't theirs. And in some ways, you're probably right: encouraging brazen and prolific self-identification opens the floodgates to all means and modes of claiming disability experience. But this is precisely the point. In writing this, we find it important to note that each of the conditions we've named so far brings with it problems of diagnostic access (as does each of those conditions we have not named). Diagnostic inaccessibility stems from various systemic barriers, not the least of which are persistent clinical disbelief, disproportionate access to care, and the illegibility of one's own symptoms. One's very body becomes a set of symptoms and behaviors to decode within existing clinical narratives and diagnostic criteria for what counts as a given condition. In response to this diagnostic minefield, we want to draw the "dis" in disinformation toward disability, jamming the clinical categories that contort our bodyminds into untenable positions.

In the following sections, we'll take you on a winding crip journey. If you get frustrated by how quickly we segue to another diagnostic topic, we hope you'll persist with us, knowing that we're getting there on crip time, on ADHD time, on depressive time, on always-perpetually morphing self-diagnosis time.

BROKEN PROMISES

Diagnosis implies a promise that is rarely, if ever, met. As we reflect on this statement, we bring to mind the many promises that diagnosis (and its attendant technologies of assessment and classification) have failed to deliver. College students are being diagnosed with mental health conditions such as anxiety and depression at unprecedented rates; what promises do these assessments bring? Like many others in the United States, our respective college campuses respond to psychiatric diagnoses with lackluster wellness initiatives and mass subscriptions to cognitive-behavioral modules online. This impersonal mode of treatment, aimed at curing what supposedly ails college students (along with those of us writing this book), is proffered as the culmination of many a university promise. Such promises include valuing college students' holistic well-being; supporting those who experience trauma or crisis; valuing diversity, equity, and inclusion on campus; and providing an educational experience that will not cause or exacerbate students' mental distress. A guiding assumption in these wellness initiatives is that taking a university-funded online quiz about one's individual cognitive distortions will fulfill these promises, which are nevertheless repeatedly broken.

In this chapter, we make clear the stakes of being diagnostically denied. Diagnoses bring with them implied guarantees of community and care; diagnoses provide validation for the painful and gurgly and lurching things we feel deep within us. Diagnosis can mean life or death, community or isolation, movement or incarceration, joy or despair. In trying to illuminate these stakes, we draw attention to dual strands of digital diagnosis:

1. The clinical fixation with not only fixing errant bodyminds but also *fixing how we fix* errant bodyminds through the use of high-capacity digital tools.
2. The counter-diagnostic² impulse on social media, wherein mad, crip, BIPOC, and trans users refashion what it means to have a wayward body, through self-diagnostic narratives and crowd-diagnostic care.

As we go, we provide a series of case studies that we hope showcase the competing and, at times mutually sustaining, facets of the clinical and the counter. We analyze digital diagnostic forms and earlier sociotechnical experiments in diagnosis to consider what it means to *desire* diagnosis. This desire, which could be on the part of a patient or a platform, has historically been accompanied by a set of harms, thus animating new discourses about machine-driven misdiagnosis and overdiagnosis. Because digital diagnosis is threaded between desire and harm, care and control, it is a key site for the ambivalence we name *technoskepticism*.

We begin by describing how digital diagnostics are presented as “fixes” to existing but insufficient diagnostic criteria; they assume that increasing the digitization process will correct the problem of inaccurate solutions to disabled people’s supposed problems. We then continue by analyzing how digital diagnostics are positioned as arbiters of diagnostic truth that remedy the problem of self-reporting by creating a new eugenic practice: digital phenotyping. The outsourcing of diagnosis to machines indexes the ongoing mistrust and contempt for certain human bodies belonging to BIPOC, disabled people, and especially those underdiagnosed because of medical racism. Similarly, when teen girls who use TikTok claim they have Tourette’s, ADHD, and autism, their self-diagnoses are derided as “Munchausen’s by TikTok.” At the same time, the rhetorical and epistemological power of diagnosis often serves as a means to control, understand, and make meaning out of disabled bodies. This is especially true when those diagnoses are wielded by clinicians and parents, and not by disabled people themselves, as we show through a close reading of the case of Ashley X, a child diagnosed with static encephalopathy, which raised debates about medical ethics in the aughts. We conclude by describing how disability activists like Alice Wong have leveraged mutual aid networks, why we love these networks, and why unabashed self-diagnosis may be the most desirable adjunct to treatment for those who are so rarely believed in our age of automated abandonment and misdiagnosis at scale.

FIXING NEEDS FIXING

What of these promises, then? Diagnosis suggests that we now possess more knowledge about our bodyminds than we did previously. To be diagnosed is to be *known* in some way. We might now find ourselves known—or recognized—by doctors and other health-care providers. We might be known or better understood by our loved ones. This knowing might also provide community and respite among those who share our diagnoses. In this way, diagnosis promises a narrative template through which individuals can re/story themselves: bodily changes and sensations are re-understood as clinical symptoms, and diagnosed bodyminds are, in turn, made legible through established clinical terminology. Facial swelling becomes a *butterfly rash*. A penchant for repeating the words “donut time” becomes an *echolalic tic*. Disinterest in typical pleasurable interests becomes *anhedonia*, a checklist item for *major depressive disorder*. The promise, then, is that in identifying what is happening with our bodies, we not only know something more about ourselves but we (and/or our care providers) are also more equipped to *do something* with this knowledge.

What, we wonder, does this fixation on *doing something* look like as diagnosis, treatment, and care become increasingly digitized?

As scholars of race and disability, many of us have written at length about the fraught logics that animate the cultural push toward solutions. Illness and disability are typically positioned as problems to be solved—or, put alternatively, *ill and disabled folks* are typically positioned as problems to be solved. This solutionist desire undergirds a landscape of digital health provision where diagnosis itself has been reframed as an imminent problem in need of fixing. In other words, digitizing the clinical practices of diagnosis and detection promotes the colonial promise of charting and ultimately conquering the unknowns (as well as the knowns and the semi-knowns) of human bodyminds.

Digital diagnostics operate from the premise that existing diagnostic criteria are insufficient or in need of ever-further digitization. Digitizing diagnosis is framed as a pursuit of knowledge, thereby a way of *doing something* about variations that cause disease. Whether these variations are genetic or phenotypic, inherited or behavioral, the

promises of digital identification remain steadfast. It appeals to speed and automation, the crunching of unimaginably vast troves of data, pattern-seeking and monitoring, and individualized care. Anyone with a body (which, we presume, is anyone reading right now) has encountered these promises in some form or another.

Take, for example, autism. Autism is a highly raced and gendered condition in the cultural imaginary; the figuration of the little white boy as its patron poster child filters into all aspects of clinical research, care provision, media representation, and diagnostic re/formation. The *DSM* criteria for autism flow from decades of research whose subjects have overwhelmingly been white and male.³ When applied to children who are neither white nor male, these criteria are somehow still expected to reliably identify autism, despite their complete inability to imagine (let alone represent) the existence of, for example, autistic Black girls.⁴ One notorious blog post, written by well-known autistic author John Elder Robison, was erroneously and horrifyingly titled “The Myth of the Black Aspergian.” Drawing from clinical biases, the author suggested that there are no autistic Black people.⁵ Numerous autistic people of color, autistic queer and trans people, and autistic ciswomen have identified autism’s conceptual elisions and built-in oppressive diagnostic constructions.

In many respects, the drive to self-diagnose as autistic on social media might be best understood as a *crip-led retrofit*,⁶ one that works to communally refashion the white masculinity of a previously uncommon condition into something that leaves space for racial and bodily difference. Black autistics narrate executive dysfunctioning while Black via #autizzy on Twitter and TikTok; queer and trans autistics relate what it means to be #gendervague on Tumblr; and autistic women and BIPOC folks describe the intricacies of #masking and how individuals might re-see their personality traits against and through rigid diagnostic criteria. These self-diagnostic moves counter the clinical.

The clinical drive toward knowing bodyminds through the conquest of their biological materials and machinations feeds familiar neoliberal promises of individuality and productivity. It is a Western, white logic that forwards an epistemology of avoidance in its pursuit of eugenically detecting and perfecting bodyminds. By “epistemology of avoidance,”

we suggest that the “knowing” of digital diagnosis is premised on the hope of avoiding aberration and abnormality. These hopes hinge on the vague notion that there is a mythic ideal bodymind from which the disordered, diseased, and disabled depart. Such hopes also spring from an impulse to sequester and contain, one that sees contagion wherever it looks. For example, the turn in genetic counseling to reframe genetic *mutations* as genetic *variations* still hinges on this sense of plausible perfectibility, however unreachable it may be. As a departure from the norm, *variation* recycles the presumption that a problem body needs to be contained and cured.

In her work on biopolitics and contagion, scholar of rhetoric Lisa Keränen refers to our present moment as one of the “genomic gaze.” “What happens,” she asks, “when humans increasingly think of themselves in biological and genetic terms?”⁷ In the case of genetically confirmed disabilities in particular, clinicians operate under the assumption that one’s genome has encoded both the future possibilities and limitations of the body. This is *entelechy* at work—the idea that the possibilities for our very being are encoded and delimited within our biology. Within this framework, a pathogenic genetic variation represents a known future one would rather avoid.

In many ways, the avoidance of genetic variation is also a promise wrought by discourses of precision medicine, which works to tailor treatments with high specificity at the individual level. In its pitch for Next Generation Sequencing (NGS) in 2018, the U.S. Food and Drug Administration (FDA) claims, “Precision care will only be as good as the tests that guide diagnosis and treatment.” Elsewhere, the FDA highlights its understanding of precision medicine as being the “right treatments to the right patients at the right time.”⁸

NGS has promised all sorts of things, largely through an implicit promise to avoid the wrong fixes and the wrong people, as well as to avoid intervening at the wrong moment in a condition’s progression. Noted for its ability to speedily analyze and parse large segments of a person’s genome, NGS promotes the hope that pinpointing one’s genetic variations will provide not only an explanation and the potential for cure, but that it will do so with a high degree of accuracy and immutability. This explanatory potential doesn’t necessarily begin or end

at disability. Instead, it ranges across any imaginable biological trait or need, especially those that are connected to perceived social problems like poverty, dispossession, or hunger.

Ruha Benjamin notes that these drives toward digital identification and bodily tinkering are “[t]echnological fixes for social problems, where ‘fixing’ is not only about solving, but also holding some things in place.”⁹ In other words: precision medicine’s concern with the individual is an avoidance of our social commitments to one another. Instead of representing interdependent networks of care and kin, precision care presents a version of responsibility that rehashes the same-old of neoliberal mandates: recouping the productive citizen, making health the never-ending and elusive mandate of the individual. And, as Benjamin so keenly imagines, the futures that genomic research promises are those that conceive broad-scale social problems as problems of individual bodyminds. Hunger, in these constructions, becomes something to solve genetically instead of something to solve socioculturally; Benjamin forewarns a future in which clinical actors work to genetically eliminate what makes us feel hungry rather than to do the work of systematically reimagining distribution of resources, tending to the earth and our climate, and prioritizing those most vulnerable to ecological catastrophe and state-sanctioned violence.

SCROLLING SANE: DIGITAL DIAGNOSTICS AND DISTRESS DETECTION

How does the turn to data-driven, automated diagnostics continue to abdicate responsibility, and what dominant structures does it reinforce? Like most identity categories, disability has become increasingly algorithmic, entangled with and emerging from data collected on digital devices and social media platforms.¹⁰ But big data and psychiatry have long been entangled. Materially, much of modern psychiatry was born from big data. Psychiatric institutions like the Rockland State Hospital were early adopters of computing, pioneering its use for automated diagnosis, record-keeping, and data analysis from drug trials—a marriage that helped drive a contemporary conception of mental illness as biological and treatable by targeted regimes of drugs.

But even more deeply, psychiatric diagnosis and big data mining share an epistemological orientation that long precedes the emergence of digital tools: both abandon a search for ground truth in favor of reliable correlations. With the arrival of the *DSM-III* in 1980, symptoms became more important than underlying causes.¹¹ Validity—the idea that a diagnosis, however vaguely, captured *something happening somewhere*—was replaced by reliability, the idea that diagnoses would be deployed consistently across populations. That is, reliability, in some essential sense, gestures toward the notion that diagnosis is reproducible. This reproducibility is bolstered by the logic of big data, wherein big data mining sifts through enormous datasets searching for hidden but reliable correlations and patterns that can be operationalized without modeling an underlying cause: an epistemological shift from the traditional scientific method, one often called “the end of theory.”¹²

Health, in terms of machine learning, is sorely lacking in diverse data for disease prediction and prevention. My research during my undergraduate tenure revolved around machine bias in health care, specifically chronic kidney disease (CKD). At the time, there was only one predictive model that hospitals would employ to predict a patient’s likelihood of developing CKD. The problem was that it only worked for old, white men. Granted, CKD in older people was better documented and more common so it created an unbalanced dataset against younger people. However, when it came to gender, race, and ethnicity, it didn’t make sense to me why the accuracy score was so low. It seemed unacceptable to me that this would be used as a basis of wellness and of expectation of future wellness for anyone who wasn’t a white man. I designed a linear regression model based on a more diverse dataset, and unsurprisingly it dramatically improved the accuracy of CKD prediction. The alarming part was the fact that this simple shift was ignored and that the model was considered to be good enough for whatever the desired and valued population was.

—Josie Williams

As the *DSM* posits, there is no need to know what “mental illness” *is*, just how to reliably identify it from its signs. There is no need to know *why* Facebook users click this or that ad when it rains in Poughkeepsie, only that they *do*. The development of AI-based psychodiagnostics

takes one black box—a diagnosis is whatever psychiatrists reliably label as such—and embeds it in another. An AI diagnosis is thus whatever conjunction of correlations machine learning uncovers.

Since the 1970s, psychiatry has been largely uninterested in social problems and conditions as the cause of mental distress: mental illness has been made individual, something that originates in the head and not in the world around us. The past decades have seen an accelerating if troubled turn to re-envision diagnosis and treatment as being based on biomarkers such as brain structure and chemistry.¹³ Unsurprisingly, “objective,” biomarker-based diagnosis entrenches diagnosed individuals even more firmly within expanding digital structures based on racialized, gendered, and classed surveillance and control of disabled populations. For instance, police departments nationwide have established digital registries where diagnosed individuals (or, often, their parents) can register their diagnosis: *tell us what you are, so we’ll be less likely to murder you*.¹⁴

But this push toward biomarkers that began with modern psychiatry also takes on new, extractive forms as it scales toward big data, where disability becomes desirable as a resource for bioprospecting. A concrete example: researchers searching for the genetic drivers of autism or Alzheimer’s frequently bombard diagnosed individuals with requests for their saliva, blood, or brains (or those of their relatives).¹⁵ Digital phenotyping dementizes us, reducing us from psychic persons to collections of buggy behavior, bad genetics, and broken brain chemistry. But those tics and mutations, in the eyes of big data, speak more truly for us than we could. For instance, projects like MIT’s Senscode promise “objective,” “data-driven biomarkers” for major depressive disorder, trustworthy signals derived from wearable sensors tracking everything from skin conductance to sleep quality. And ubiquitous university-run “Grand Challenges” aim to leverage AI to reduce “the burden” of everything from depression to autism to Alzheimer’s.¹⁶

Digital diagnostics come packaged in a rhetoric of accuracy, the guarantors of a diagnostic truth that cannot be gleaned from standard checklists and self-reports. They forgo the life story, patient history, and personal engagement required when asking someone how they feel and taking the response seriously. Instead, they prefer to read diagno-

ses directly from the body or data exhaust of lives lived on platforms. Dramatic swings in how often you tweet? Bipolar disorder. Does your Alexa capture slowed speech and a higher proportion of first-person pronouns? Unipolar depression.

In some respects, these digital tools—from academic pilot projects like Senscode to systems rolled out by corporate wellness behemoths like Headspace—are positioned as reading and understanding our diagnoses from our bodies, voices, faces, or words more accurately than we, or anyone else, possibly could. Operating with a degree of scrutiny and at a scale unmatched by a human clinician, they often translate diagnostic criteria from the *DSM* or the International Classification of Diseases (ICD) of the World Health Organization into machine learning features, with those features designed to capture data corresponding to those criteria. Since many of these tools leverage data from smartphones and social media platforms, they recast *wellness*—the subject of our next chapter—as knowing how to scroll, like, filter, and post in the way that giant tech companies prefer and consider normal. They also presume that you own a smartphone, use social media, and have the kind of body those tools and their developers imagine as belonging to a “normal” user.

Beyond watching you scroll or click, or listening to you speak, some tools cast a wider net, leveraging dozens of digital and bodily traces to arrive at a final diagnosis. However, each additional feature comes with a loss of interpretability: visual acuity in your left eye might be “predictive” of borderline personality disorder, but only if conditioned on annual income, access to insurance, and right-handedness.¹⁷ *Why* your inability to read subtitles or street signs with one eye covered has anything to do with a psychiatric diagnosis is buried in this proliferation of signals. But researchers have pointed out that even this is a conservative approach: if diagnostic criteria don’t capture a ground truth in the first place, why design the features at all? Why not let AI systems derive their own diagnostic criteria directly from the data? And it turns out that deep learning psychodiagnostics are supposedly significantly more “accurate” than those carefully tailored to the manuals.¹⁸ Of course, as algorithmic opacity researchers like Jenna Burrell have pointed out, the way that deep learning systems identify anything, from photos of ce-

lebrities to supposed psychopathologies, is completely alien to human ways of knowing.¹⁹ These deep learning diagnosticians create features that might bear no interpretable relationship to any common understandings of what a disability is or involves. Even if such systems are branded as more accurate, what they dream of as symptoms, we'll likely never know.

Dementializing diagnosis and replacing self-reports with biomarkers and behavioral data destabilizes diagnostic identities. Diagnostic subtypes in this regime are impermanent, they blur and merge or disappear; individuals who are legible as autistic or schizophrenic or depressed at one moment might not be read that way at another based on heart rate or vocal frequency. It's true, of course, that revisions of diagnostic manuals like the *DSM* and *ICD* create and collapse disability identities, a process that, historically, has been little open to contestation on the part of those affected by it—a process, however, that plays itself out over years or decades. If part of the promise of diagnosis is a sense of fixity, of lasting self-insight and access to care, “objective” digital phenotypes might be evanescent cloud-castles, identities that shift, appear, and disappear in the blink of an eye.

At the same time, the belief that self-reports and self-diagnosis are not to be trusted is part of the “problem” these tools are trying to “solve.” Biomarkers supply “objective” insight into individuals who are presumed unable to speak for themselves, who are always already untrustworthy, too sick to know what they feel, or guilty of malingering to shirk work or court attention. But self-reports and self-diagnosis are often baked into these “objective” tools from the beginning. For instance, researchers who work to build them rely on standard reference datasets like the RSDD (Reddit Self-reported Depression Diagnosis dataset). The RSDD contains the posts of 9,000 Reddit users who, at some point in their posting history, disclosed a depression. It is often used to train and test models that diagnose based on word choice and posting behavior. Another dataset is the DAIC (Distress Analysis Interview Corpus), a set of 189 clinical interviews with U.S. veterans who are also Los Angeles residents, that is a common choice for modeling subtle verbal and physical signals of depression, anxiety, and PTSD.²⁰ In the effort to redefine oblique signals as diagnostic symptoms, researchers

turn to these datasets as a source of ground truth for training machine learning models. Trapped in amber, these reports of pain, anxiety, sadness, and trauma remain vital evidence for the development of diagnostic systems years later, whereas elsewhere online, TikTok or Twitter users who bypass the medical establishment to assign themselves Tourette's or chronic fatigue are subject to suspicion and social policing. So, it's not that self-reporting and self-diagnosis are suspect, but rather that some of these reports and diagnoses—transformed into training data and operationalized at the heart of AI diagnostics—are more trustworthy than others.

MUNCHAUSEN'S BY TIKTOK

When it comes to diagnosis, then, whom do we trust? Trust is a messy thing. As we've seen through the digital advocacy of folks with contested conditions—such as chronic fatigue, fibromyalgia, long COVID, chronic Lyme disease, and more—the question of observable, reliable evidence often rings higher in the trust hierarchy than patient self-report. To the extent that self-report is deemed worthy, it's often because these reports culminate in the aggregate, are made known through replicated patterns, and cross a clinically determined threshold of pathogenicity. How many people are self-reporting? Do your self-reports match the self-reports of others in a sufficiently similar way? Do your self-reports suggest you've got enough of a disease mechanism to push you over the threshold of “disorder” (as opposed to being slightly weird or not quite ill enough to be diagnosably ill yet?) In other words, clinical diagnosis rarely values self-report alone. Without evidence, aggregation, patterns, or confirmed biomarkers of sufficient severity, self-report is not enough—and may be used as evidence *against* the person self-reporting.

Enter self-diagnosis, a counter-diagnostic mode of coming to self-knowledge that has supposedly reached epidemic status in the wake of the COVID-19 pandemic. Reports from *Wired*, the *New York Times*, the *Wall Street Journal*, and *Vox*, among other venues, have chronicled stories of teens who've adopted neurodivergent mannerisms and identities en masse since 2020.²¹ These reports recycle common tropes about

hypochondria, gender, race, and disability, none-too-subtly suggesting that diagnostic hysteria is running rampant on social media. Yet, few of these articles leave room for the possibility that historically underdiagnosed people are using self-diagnosis to make themselves known. Pathos operates as the common formula in these reports, rendering the self-diagnosed as a sad or horrifying spectacle: Teens are developing “explosive” tics! Teens are describing supposedly everyday brain blips, such as staring or losing focus, with terms like *dissociation* or *masking*! Teens are flocking to Instagram and TikTok to claim newfound Tourette’s, ADHD, and autism!

Researchers echo these pathos-laden sentiments, frequently describing digital self-diagnoses as the effects of social contagion. Given that the COVID-era focus on self-diagnosis has revolved around children, researchers frequently suggest that adolescent minds are more susceptible to crip content, absorbing mad and ticcy mannerisms like sponges. But also notable in the recent spate of contagion discourse is that the increase in self-identifications has largely been in cisgender girls and transgender and nonbinary teens. The gender of self-diagnosers contrasts with the historical and contemporary gender gaps present in many of the conditions being chronicled: Tourette’s and autism both hold a 4:1 cismale-to-cisfemale diagnosis ratio; ADHD’s gender ratio currently hovers a little over 2:1 cismale-to-cisfemale.²² Time and again, scholarly and popular commentary obsesses over this disconnect as a rationale for self-diagnoses being wrong, worrisome, or terrifying. If it’s supposedly “rare” for cisgender girls and trans kids to be neurodivergent, then surely they cannot be experiencing the symptoms or identities they claim.

Yet still, the gaps in diagnosis for children of color provide even more material to claim that self-diagnosis is mere teenage malingering. The CDC, for example, in 2009 reported that white children were diagnosed with Tourette’s twice as frequently as Black children. While the CDC presently claims that equivalent diagnostic rates now hold across racial and ethnic groups based on a 2016–17 study,²³ this claim is drawn from parental survey responses about their six- to seventeen-year-old children.²⁴ This claim about diagnosis fails to account for the misdiagnosed and undiagnosed children who came before that study’s cohort. In like kind, such claims about supposed diagnostic equity do not track

with the narrated experiences of BIPOC neurodivergent folks who express their frustrations with clinical assessment on social media. As they routinely note, there is a paucity of research on the qualitative lived experience of Blackness, tic disorders, and other forms of neurodivergence. Black neurodivergent folks on social media, across diagnostic identity, frequently narrate misdiagnosis (often with highly stigmatized conditions such as conduct disorders) and delayed time to diagnosis (often failing to be diagnosed until adolescence or adulthood). More than this, disbelief persists in all corners of the clinical encounter, resulting in uneven access to care and racist encounters with providers.

Turning to social media as a Black neurodivergent person often feels like the only option when the metrics involved in official diagnosis are predicated on a white experience of neurodivergence. Symptoms of ADHD in Black children are ignored altogether at best, or read as behavioral problems at worst. In addition, many of the questions relating to childhood behavior rating rely (1) on behaviors that are culturally restricted within Black families (you won't embarrass us like that in school!) and (2) would be unlikely for a Black parent to admit to their child displaying, much less seek diagnosis for.

When seeking an ADHD diagnosis as an adult, I was frustrated by the questions that focused on childhood experience—which I hardly remembered—which didn't seem to translate to the experiences I identified so strongly with in my community online, that focused more on the day-to-day idiosyncrasies of ADHD.

I found myself arguing with the service provider, leaning on my credentials as a Black person with a long history of advocating for racially-inclusive mental health services in the UK, railing against the diagnostic tools themselves with their lack of culturally-specific or gender-specific questions that would speak to how I could have been overlooked for so long. Speaking to other Black people diagnosed with ADHD about their experiences with these tests came with a unanimous instruction to “say what you need to say to get the diagnosis.” As ever, Black people prioritize grassroots community and mutual aid to meet our own needs.

—Rianna Walcott

In this broader milieu of racist diagnostic withholding, TikTok provides a vital community for folks teetering in diagnostic liminality. And yet, the cultural logic that self-diagnosis online represents fraud

persists, relying on the logics of racial disparity to claim that BIPOC folks can't have autism, ADHD, or Tourette's.

In unfurling social contagion as an animating logic of self-diagnosis, scholars highlight that social media provide gratification, attention, in-built community, and amplification at speeds and scales unprecedented in clinical meatspace. This, in turn, enables clinicians to suggest that TikTok provides fertile virtual ground for conversion disorder en masse. But so too does this discourse suggest that self-diagnosis is merely attention-seeking behavior for content creation and garnering large followings. Conditions such as Tourette's, autism, ADHD, and dissociative identity disorder (DID) typically involve locomotive differences and embodied displays of disability such as ticcing, stimming, fidgeting, catatonia, and/or stark changes in facial expression and persona.

Those who claim self-diagnosis as social contagion often pinpoint the embodied performance of neurodivergence as a key site of fakery, even if that fakery is unintentional on the part of the supposedly contaminated teen. Mental health providers are quick to describe teen girls' tics as atypical or as lacking in premonitory urges (i.e., tics are often described as relieving an uncomfortable or urgent sensation). "Explosive" frequently rears its head as a descriptor for tics in these accounts as well, meant to contrast with the societal expectations of demureness demanded of teen girls. Providers are likewise quick to identify the narrations of self-diagnosed girls and BIPOC folks as not reaching a necessary threshold of pathology. TikTok depictions of autistic masking—the survival tactic of suppressing autistic mannerisms in public space—are dissected by providers as merely representing an adult experiencing everyday neurotypical life or everyday Black life rather than everyday autistic (Black) life.

Of course, the implication that self-diagnosis on TikTok represents a kind of digital Munchausen's is not new. In 2000, Marc D. Feldman referred to supposedly fraudulent disability identifications as "Munchausen by Internet."²⁵ At the time, Feldman's focus revolved around case studies of trolls posting on self-help and disability support forums and inventing whole new lives, conjuring fake children, and stringing together increasingly complex narratives meant to outdo others' stories

on these forums. Of note to the present TikTok conversation, Feldman emphasized that virtual spaces represented prime new territory for people with factitious disorders: the internet provides ready access to vast audiences of sympathizers. People with Munchausen's, Feldman claimed, can create multiple personas on multiple forums, allowing more potential for gratification with a lesser chance of getting caught than, say, faking a diagnosis and seeking attention at a clinic.

The rhetoric of massive social networking bleeds into diagnostic language. Transmission occurs via repeated social contact, which digital spaces amply afford. When psychiatry was refashioned along biological lines, mental illness became contagious. As David Healy writes, starting with the *DSM -III*, "the exemplar of a categorical disease state was the bacterial infection."²⁶ One reason why we have "epidemics" of depression is that minds were no longer vulnerable to Freudian psychic conflict; instead, they succumbed to something that resembled TB. If the biologization of psychiatry both individualized mental illness (something that results not from social conditions but from misproportioned brain chemistry), social media doubled down on a contagion model of everything: viral memes, memetic behavior, mis/information. Platforms view their users as a connected social graph through which information, affects, and identities flow—a vision they posit and continuously experiment on, as in Facebook's emotional contagion experiments from 2014, in which users' news feeds were invisibly manipulated to make the users slightly more, or slightly less, depressed.²⁷ What we want to emphasize here is less the ways that platforms play with users' feelings, dosing them with tiny hits of depression, but the way that they reframe (and then instrumentalize) depression itself as contagion across a network. This vision of massive contagion grounds moral panics around Munchausen's by TikTok.

There is much that is broken here. Absent from the discourse on factitious TikTok is the recognition that digital diagnosis is racist, sexist, transphobic, ableist, and just all-around violent. More than this, once people identify as or are identified as mentally ill, they are often told that any and all other symptoms are just all in their heads. As we wrote this chapter, we routinely meditated on the story of April Burrell, a Black woman who was institutionalized for twenty years due to presumed

schizophrenia.²⁸ In actuality, Burrell had lupus, which manifested as cognitive symptoms by affecting her brain. We found ourselves thrown by the commentary concerning Burrell's story on our social media feeds, which seemed entirely focused on congratulating psychiatry for suddenly realizing that mental illness might actually be caused by conditions that impact the body. Why, we wondered, had Burrell not received an ANA blood test far earlier as part of routine care? Where was the social media commentary on the violence of institutionalization and mad Black containment? Discourse on self-diagnosis and Munchausen's by TikTok ignores these harsh truths: doctors have the power to steal lives.

It's been more than twenty years since rhetorician Catherine Prendergast's observation that people don't listen to you when they think you're crazy.²⁹ Munchausen's is one such signifier that compels clinicians and parents to stop listening; when self-diagnosis is presumed factitious, we are primed to see such narrations as manipulation and attention-seeking. Given the stakes, we must rethink digital self-diagnosis as a *bodily necessity*. Precarious people self-diagnose in the face of rampant misdiagnosis and non-diagnosis. We *need* self-diagnosis. What might it mean to rethink self-diagnosis as a nourishing refusal of the digital clinic?

As we reflect on TikTok and the "For You" algorithm's propensity to direct us to disability content (as though it knows more about our bodyminds than we do), we are time and again drawn to the question of im/permanence. In this, we are thinking about Kai Cheng Thom's work on reapproaching gender identity as a question for right now rather than as a permanent, fixed identity.³⁰ In like kind, how might we move away from an understanding of diagnosis as linear and (absent cure) permanent? Self-diagnosis provides a means for becoming: it can offer a transitory, just-for-now space that enables people to grapple with the complexities of their bodyminds.

Did I ever desire my diagnosis? And if so, what did I feel when I "lost" it? Did I feel relief, ambivalence, or perhaps even a muddled sense of self when the diagnosis had defined my life for so long? Was I no longer "unique" by virtue of not being the sickest person in the room (however such a thing is

measured) anymore? Or conversely, could I finally achieve some kind of self-actualization once I no longer fit a rubric designed to be one-size-fits-all? Mainstream medical discourse sets the expectations of a relatively linear temporality that can be separated into pre- and post-diagnosis. These two prefixes, in turn, sandwich the treacherous and often interminable interval that is treatment. And at the tail end of this timeline is something even more nebulous and certainly not guaranteed: recovery. Or is it having recovered? The difference between the two may seem merely syntactical, but each represents a distinct temporal orientation as well as a different outlook on the relationship between illness, selfhood, and mind and body. To be in recovery is to suggest that recovery is an ongoing process—that one is never truly recovered and is always in danger of slipping. To be recovered, by contrast, is to posit a before and after. But how, then, do we measure this before and after?

Today, I say that I've been recovered from anorexia for exactly ten years. Sometimes I second-guess myself and swap "recovered" for "in recovery" because I'm aware recovery is a nebulous concept. The reality is that the exact date is somewhat arbitrary. Since I was diagnosed, the criteria for anorexia have changed—many eating disorder sufferers and survivors have celebrated that the *DSM* no longer lists a particular BMI. They rightly point to the racially biased history of the BMI and its unreliability, which has caused so many to go undiagnosed and their insurance to not cover the cost of treatment.

Eating disorders are a particularly thorny set of illnesses because they are arguably physical as much as they are mental. Just because your body is now considered "healthy," that doesn't necessarily mean that you've recovered (there are even accounts of eating disorder clinics deliberately keeping patients' weight below a certain threshold so their insurance won't leave them in the lurch).

Still, what I consider the "before" and "after" of my life-threatening diagnosis isn't something that I can concretely name—it was a singular, fleeting moment when I realized that none of the *DSM* criteria seemed to apply. Do I think the *DSM* is a flawless document? Absolutely not. Even as these metrics are flawed and the system is designed to skimp on or deny care altogether, the *DSM* functions as a kind of mirror that makes you wonder: am I seen? How do I orient myself even if the answer is no? Today I

embrace the *during* alongside the *after*, knowing that this stretch of time is elastic and stretches on—into the *that-has-been*,³¹ into the *hereafter*.

—unsigned

HELP 'EM WHERE IT HURTS

Diagnosis, whether self-directed or delivered by a medical professional, often passes through pain. But who gets to narrate pain, their own or others'? And whose narrations of pain are believed, taken seriously enough to be worthy of intervention? Pain is paradoxical. On the one hand, acute pain—passing, transitory sensations that dissipate within minutes, hours, or days—is often declared to be a universal human experience.³² On the other hand, chronic pain—pain that remains over a longer scale of time—and disabling pain are much more contested experiences. We accept claims about pain differently depending on who reports them. For instance, heart attack pain is more accurately and quickly diagnosed in men than it is in women because it has a more classic presentation. Our understanding of pain is also imbricated in our racial biases. White patients are more likely to be believed when they report pain.³³

Chronic pain is also closely associated with techno-bureaucracies of disability. In short, it is a debilitating condition that often reduces an individual's capacity to work a "traditional" nine-to-five, labor-intensive job. Thus, within a neoliberal landscape designed to extract as much labor from workers as possible (including emotional labor), it makes sense that the larger medical-industrial complex would be distrustful of pain as experience. There is an economic imperative to withhold care, as care might reduce profit. Thus, the systems of care we participate in are often inextricably tied to the drive to diagnose the "problem body" so it can be rehabilitated and made normal. It is perhaps unsurprising that in order to access care, pain must be transformed into a legible spectacle. The iconographic and numerical pain scale is one example of this attempt to transform the inner, subjective experience of pain into a supposedly "objective," exterior self-report of pain. The scale ranges from zero, meaning no pain—signified by a green smiling face—to a ten at the other end of the spectrum, signifying extreme pain—a red,

frowning face. At its root, the desire for diagnosis is the desire to have one's pain believed, as well as to have options for relief.

Yet, even the iconography of pain scales depends on a presumption of particular communication styles, that is, the capacity to verbally communicate a number or to point at a sign. Pain scale styles also do not account for patients with flat affect. All of this is to say that provision of care is often dependent on self-reporting, even and especially as care is often mediated through the medical expert. We return to the notion that pain is paradoxical. On the one hand, patients self-report their pain to the medical expert, and they are believed (or not). On the other hand, patients who self-diagnose through self-reporting face additional barriers to belief. This is essentially an analogous process, albeit without the mediating force of the medical expert who is empowered to make determinations of productivity, normality, or abnormality.

Digital platforms—from blogs, to Kickstarter, to TikTok—increasingly provide the theater where we transform our pain into a legible spectacle, an appeal for validation and care. Pain's paradoxes find new homes in these digital environments, which enable the new networks of self-diagnosis we discussed above. But these new digital spaces retie the knot between pain, belief, agency, and care in ambivalent ways—ways that warrant a thoroughgoing skepticism. As we show here through a comparison of the cases of Ashley X and Alice Wong, these spaces can be leveraged to build consensus around the control of a “problem body” depicted as devoid of agency, but they can also host far-reaching mutual aid networks that might point us toward futures where care is always there for the asking.

Even “accurate” diagnoses can be used as to justify inaccurate, unjust, and inhumane therapeutic intervention. At age six, Ashley X was medically diagnosed with static encephalopathy and described on her parents' blog as “permanently unable.” In Ashley's case, her parents exploited her diagnosis to justify invasive regimes of extraction, violence, and erasure, using digital platforms to evoke both the potential pain and trauma they thought threatened their daughter, and their self-imposed parental duties to avoid it at all costs. Ashley's parents, online and offline, presented care from strangers as an outcome that would lead inevitably to Ashley's mistreatment and sexual abuse. Spurred on by the severity of her diagnosis, as well as the looming anxiety of pre-

cocious puberty, they, along with their medical team, opted for a series of pharmacological and surgical interventions to keep her as small (and childlike) as possible.³⁴ These included a high-dose estrogen treatment to permanently stunt her growth and a hysterectomy alongside removing her breast buds to “reduce the complications” of puberty.³⁵

Here, Ashley’s parents wielded diagnosis as a cudgel to disqualify critique. The severity of these operations became a symbol of the lengths to which her parents would go to care for her. These treatments were and are framed as a concrete material strategy to reduce possible future mental anguish from the perceived danger latent in care from strangers, based on the fanciful notion that a child-like body provides protection from the specter of sexual abuse. Parental blogs, like those that Ashley’s parents maintain, can bolster convictions that parents, not their children or wards, know what is best, even when this conflicts with disabled self-advocates who argue that disabled people should be allowed to advocate for themselves. Such frictions persist, however, because parental advocates often emphasize the unique particularities of their care of/for their significantly disabled children³⁶ and are able to capitalize on the insularity of discourse in the blogosphere. Here, Ashley’s parents’ choice of words to describe her to their digital audiences—“permanently unable”—is telling. The term implies that she is somehow beneath disability, that she represents some theoretical limit of disability at which it becomes, simply, inability, a state approaching the inertness of a mineral. And “permanent” implies, rightly or wrongly, that she will never develop even the most minimal agency. This is as much a crucial diagnosis as “static encephalopathy,” in that it aims to ensure that Ashley X is never even mistaken for a person *who has agency and who could self-advocate*—an aim that the medical interventions inscribe on her body.

Asian American disability access activist Alice Wong, who was diagnosed with spinal muscular atrophy, serves as a contrast to Ashley X. We draw Wong in here because, like Ashley, her narrative is easily accessible online. Likewise, that narrative illustrates a diagnostic process and the invasive surgical procedures that can ameliorate pain and forestall death. Wong’s activism also works to persuade audiences, and to reinscribe the material realities of disabled life for virtual communities. Unlike Ashley however, Wong’s care is not mediated through paren-

tal activism, even though her parents can and do support her. Instead, Wong engages in self-directed care. For example, when she experienced a medical crisis in June of 2022 that required an emergency tracheostomy, her surgery was presented as a way to preserve the ideal of continuous home care administered by family and friends.³⁷ One difference, however, is Wong's surfacing of the constant need for direct care from a chosen set of workers who come into the home to perform ADLs—activities of daily living (bathing, eating, toileting, dressing, etc.). She hires (and fires) her own workers. Alongside family and friends, she trains them in her specific care needs. But what we want to highlight in comparing these cases is the digital nature of activism and community-building across different platforms and/or ecologies, and the pliable nature of diagnosis itself as a rationale for a range of outcomes. Wong leverages digital networks to self-advocate, while Ashely X's parents leverage those same networks to act as their daughter's voice. Across these cases, diagnosis becomes a field of communicative possibility, freighted with meaning that impacts communities differently, and in doing so, operationalizes care and aid differently.

Returning once more to Alice Wong, her family and friends also engaged in mutual aid to address Wong's vastly changed care needs. Yet mutual aid depends on systems of support already being in place, which, in turn, perpetuates further systems of support. It is deeply relational and cannot be practiced as a solitary experience. Marginalized communities and individuals often use technological infrastructures such as GoFundMe—as Wong did—to invite networks of individuals to support a goal. This is a distinctly neoliberal phenomenon wherein the state offloads its duty of care to private individuals. However, platforms that incentivize collective support are also themselves an outgrowth of participatory crip culture online, as Elizabeth Ellcessor writes.³⁸

Importantly, however, even if GoFundMe's very existence suggests the ubiquity of crisis in our present moment, mutual aid remains a valuable alternative to diagnosis as a form of parental fiat. As Dean Spade writes, "Mutual aid is collective coordination to meet each other's needs, usually from an awareness that the systems we have in place are not going to meet them. The systems in fact have often created the crisis, or are making things worse."³⁹

In other words, mutual aid is a community-facing solution, not one

shrouded in discourses of medical (or parental) authority. But mutual aid is precarious, even as it attempts to address precarity. Alice Wong was able to successfully fund her medical care needs because she is a recognized content creator and disability access activist. Wong runs the Disability Visibility podcast/platform and in that role was able to amplify her own narrative. To be clear, we do not criticize Wong for doing so. In fact, this activist tactic is built on the notion that the personal quest to survive in a care desert is an inextricable part of a collective goal. Still, Wong does not exist in a care desert. She is a relatively well-connected cultural worker and advocate. In this sense, advocacy is a kind of care—and it is. This recalls recent work in the ethics of care that stipulates care as a relational matrix. After all, one can be both a caregiver and care receiver.⁴⁰

As Spade and others have pointed out, mutual aid is also part of an older tactic of community organizing and activism, influenced by queer BIPOC activism. However, these strategies constitute a tactical practice across networked platforms as they proliferate in digital space.⁴¹ Imperfect alternatives to extractive care already exist—for instance, policy collectives like Health Justice Commons or the Disability Justice collectives in California and Seattle and Atlanta. Each of these groups, collectives, and formations works to empower the individual in the face of seemingly insurmountable violence and injustice. In noting the many broken promises that diagnosis makes (and exponentially so when done at a digital scale), we build on these alternatives to imagine a counter-diagnostic digital future where disabled and BIPOC individuals—like Alice Wong—or trans folks, or autistic queers, or any combination therein, are sustained through loving networks of criptastic care.

IMAGINING COUNTER-DIAGNOSIS

In the early 1970s, three men and six women presented themselves at a dozen psychiatric hospitals across the United States. In their clinical interviews, they all reported that they were experiencing auditory hallucinations in the form of voices that said “hollow,” “empty,” and “thud.” All were promptly diagnosed—seven with schizophrenia and one with

manic-depressive psychosis—and admitted. Once in the wards, these patients presented no further symptoms and told attendants and doctors that their hallucinations had ceased and that they felt, in fact, perfectly fine. From their perspective, all of this was true: these patients had no history of mental illness and did not identify as having a psychiatric diagnosis. They were malingering as part of an experiment orchestrated by a Stanford psychiatrist, David Rosenhan. The hospital staff, however, disagreed, reinterpreting much of their behavior—the prolific note-taking typical of graduate students in the field, for instance—as pathological symptoms. They were released only when they capitulated to the diagnosis assigned to them at their admission. Now satisfied, the psychiatrists prescribed them antipsychotics, pronounced them “in remission,” and showed them the door.

Published in 1973, “On Being Sane in Insane Places” was received as a damning critique of the validity of diagnosis.⁴² The experiment fed fuel to the antipsychiatric fire, providing ballast to the deinstitutionalization movement as well as motivating the American psychiatry establishment to double down on diagnostic reliability in the creation of the *DSM-III*.

Decades later, Rosenhan’s methods and data were repeatedly called into question, and much of the latter may have been a fabrication. But we want to take “On Being Sane in Insane Places” in a different direction. Rosenhan and his confederates thought they were debunking diagnosis. However, we might take their fleeting simulations of schizophrenia as instructive, as foreshadowing a different relationship to disability identity, one that spoofs and spams the systems that try to fix us into a diagnostic category and then fix us, treating us as problems to solve.

The skepticism shown by hospital officials to Rosenhan’s “pseudopatients” echoes in the moralizing suspicion of contemporary self-diagnosis, treated not as a revindication of diagnostic agency from broken systems but as the last word in self-delusion or pathological malingering. We’re told when we try to say what we think we have, that what we actually have is Munchausen’s by TikTok. But, at the same moment, algorithmic tools elide self-reports in order to continuously reshuffle us into diagnoses via “objective” biomarkers. As we’ve shown, though, these categories are constantly flickering, opaque when we can

see them, detached from any model of ground truth, and shifting when we're not looking: they threaten to put us in the position of Munchausen's by neural network proxy.

Both the antipsychiatry advocates and the *DSM* defenders on either side of "On Being Sane in Insane Places" assumed that there was *some* stability to diagnostic identity. That the confederates were labeled as "in remission" when released was a way of keeping the label of schizophrenia glued to them in the absence of symptoms and outside direct institutional control. But fifty years later, we might reread their simulations, their desire for diagnoses that would expose the system for what it was, through a different lens.

Robert McRuer's *Crip Theory* argues that we might reject stable disability identities in favor of fleeting moments of crip embodiment, necessarily transitory performances or enactments of disability.⁴³ Early in this section, we called for brazen and prolific self-identification, opening the floodgates to claiming disability experience in the face of systems that deny the validity of self-insight and erect persistent barriers to diagnoses and care. Through McRuer, we might reread "On Being Sane in Insane Places" against its time as an early model for precisely this kind of promiscuous claim, unfolding on TikTok and Twitter instead of in the consulting room or psychiatric ER.

There is, of course, a risk, particularly when the institutional care that does exist is precarious and finite. Transphobic groups such as TERFs and Proud Boys seem to have read Rosenhan, too, as when they dispatch their confederates to simulate gender dysphoria in an attempt to discredit and abolish the already shaky infrastructures for trans care.⁴⁴ But this malingering, instead of demonstrating that gender-affirming care is being doled out inappropriately, reveals just how many barriers must still be overcome on the way to receiving it. We say, let the TERFs get their hormones and the Proud Boys their orchiectomies, along with everyone else who wants or needs them—and the sooner, the better.

We've already discussed mutual aid as a form of care that embodies the ways that care can be horizontal and relational instead of carceral and unidirectional: a *noblesse oblige* reluctantly doled out via byzantine bureaucracies and paid for by submitting to state surveillance and control. Rosenhan, via McRuer, might model another kind of sideways

social relation, one that might help us imagine another kind of counter-diagnosis.⁴⁵ There are ways to persist inside systems that treat you as a burst of noise disrupting the signal, as malaria in the social bloodstream. Michel Serres theorized this way of inhabiting a system without being of it, floating in the channel and diverting its flow, as a “relation to a relation” that he called *the parasite*.⁴⁶ If diagnosis is the top-down channel that connects us to psychiatric governmentality, we might think of brazen, transitory self-diagnosis as a way of establishing a horizontal and parasitical relation to that relation. One tactic for survival in a system designed to eviscerate your claims to self-insight, slot you into an atomized digital identity, and deny you care? From the 1970s asylum to the TikTok-driven viral diagnosis *du jour*: just say “thud.”

CONCLUSION

As you read (or listened, or felt, or stimmed), we hope that you’ve lingered on what we think are some of our key takeaways about diagnosis:

1. Diagnosis isn’t permanent: Our bodyminds, as well as clinical understandings of our bodyminds, shift and morph over time and space, as do the technologies used at various times to map and diagnose them. How might contemporary warnings and lamentations about rampant teen self-diagnosis on social media be forestalled if we were to reimagine diagnosis (whether clinical, self-, over-, or mis-) as transitory, temporary, unfixed, or always already moving?
2. Digital diagnosis skews the already tense relations between patient self-report and data-driven phenotypes or biomarkers in overwhelming favor of (and deference to) the latter. It reinforces and naturalizes the many ways in which clinicians rely on so-called “objective” markers of disorder, whether via blood tests, X-rays and MRI scans, observable behavioral patterns, or any of the many other ways that clinicians work to reliably read and interpret illness on the body. As both Simone Browne and Ellen Samuels have revealed, this surveillant drive to read truth directly from bodies, behaviors, tissues, and genetic material plays a central role

in sustaining the violences of the state.⁴⁷ In other words, the drive for verification provides a rationale for elision, violence, and denial of all kinds.

3. Self-diagnosing—what we also refer to as counter-diagnosis—can provide additional and more affirming avenues for giving and receiving care. It reorients us from deference to the clinical gaze and instead points us toward the possibilities and paradoxes of community-based retrofitting online.

We hope that this exploration of counter-diagnosis can open up a broader, wilder conversation about how to protect our humanness in the face of data-driven diagnostic regimes. Too often, the overwhelming persuasive power of diagnosis establishes stubbornly immutable and essentializing ideas of who we are and what causes pain and suffering. By contrast, counter-diagnoses assert what our bodyminds tell us when we can hear them speak, and allow us to retrofit or remediate broken systems when we can articulate them within communities of care.