Introduction

How to Be Disabled in a Pandemic

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New York City is an archipelago, a cluster of islands turned into a metropolis on a blueprint of disability and illness management. As elevated trains connected the boroughs, and the first skyscrapers and electric advertising signs began to transform the island of Manhattan in the late nineteenth century, the smaller islands in the rivers and the sound were largely delegated the infrastructures of confinement: infectious disease hospitals, sanatoria, quarantine facilities, psychiatric institutions, drug rehabilitation centers, orphanages, reformatories, migrant detention centers, prisons, and "paupers' graves." The city is significantly patterned by past and present epidemics, including yellow fever, cholera, typhus, smallpox, influenza, and HIV/AIDS. Each new epidemic activates old policies and urban spatial politics, latent and ongoing activism, and traumatic public memories.

When reports began surfacing in late 2019 about a new virus that was causing a pneumonia outbreak in Wuhan, China, most New Yorkers hardly paid attention, with little thought to its potential to spread globally or impact their own lives. In January 2020, however, the Centers for Disease Control and Prevention (CDC) announced that the virus was rapidly spreading in nursing homes in Washington State. By February 29, when the first case was officially confirmed in Manhattan, thousands of New Yorkers had already fallen sick without diagnosis.

American politicians, including then-president Donald Trump, dubbed this new coronavirus the "Wuhan" or "Chinese virus," summoning tropes of pandemic xenophobia. The *New York Times* published interactive graphics that modeled the virus spreading from Hubei Province to New York, even as researchers at Mount Sinai Hospital pointed to Europe as the source of most early infections in the city (Wu et al. 2020; Gonzalez-Reiche et al. 2020). The emerging narrative in the United States seesawed between B-movie horror—fomenting panic about an unanticipated, racialized contagion—and clinical detachment, with scientists and journalists "reassuring" audiences that "only the most vulnerable need to worry" (Martens 2020). Elderly and disabled people, especially residents of hospitals and institutions on New York's "other islands," were those expected to die.

Disability justice activists were among the first to acknowledge the impending threats of what came to be called SARS-CoV-2, or COVID-19, demanding that risks be taken seriously (see a more detailed timeline at the end of this book). They were also the first to argue that disabled people were being disproportionately impacted by city and national policies, work and housing conditions, ableist stigma, racism, and other forms of structural violence as much as by the virus itself. Calling attention to pandemic ableism (Hill 2022) and other viral inequalities, they challenged the neo-eugenicist views of public officials, media personalities, and even friends and family members who routinely dismissed them as disposable.

New York City's infection rate was initially five times higher than the rate in the rest of the country; in mid-March 2020, roughly one-third of all total confirmed US cases were in the metropolitan area (CDC 2020). Before a global pandemic had officially been declared by public health or government officials, disability activists began organizing mutual-aid networks and knowledge-sharing projects, using a range of tools including webinars and Zoom meetings, social media, podcasts, listservs, Google Docs, digital cash payments, DIY crafting, and socially distanced meet-ups. This was hardly surprising, given the extensive individual and communal "disability expertise" (Hartblay 2020) achieved through years of navigating, protesting, and reinventing the numerous political, health, media, and other social systems that exhibit neglect or open hostility toward disabled people. Many of these interventions were remote or public examples of what activist Mia Mingus (2011) calls "access intimacy," the relational process of meeting another's needs through knowledgeable improvisational care.

On March 7, 2020, a coalition of organizations in New York City hosted a webinar for nearly one thousand participants titled “COVID-19 (Coronavirus) Preparation for People Living with Chronic Illnesses in the U.S.,” with information and strategy sessions rooted in “herbal remedies, Clorox, western medicine, anarchist DIY brilliance, and poetry” (Davids 2020). Two days later, a group of disabled and chronically ill artists organized Crip Fund, a mutual-aid campaign to pool donations and distribute money, food, medicine, and other aid to disabled, ill, and immunocompromised people “in need of in-home care,” prioritizing at-risk queer and trans people of color. Nevertheless, Mayor Bill de Blasio did not declare a state of emergency until March 12. The same day, Governor Andrew Cuomo limited gatherings to fewer than five hundred people, still leaving hospitals, schools, the subway, and many businesses exempt. As disability organizations launched teach-ins and fund-raisers, mainstream news reporting remained incredulous, running headlines like, “Broadway Goes Dark.”

Throughout early March 2020, disability activists around the world compiled and distributed syllabi, crip survival guides, and other informational resources, combining practical information with political education. For example, Leah Lakshmi Piepzna-Samarasinha’s rapidly updated Google Doc “Half Assed Disabled Prepper Tips for Preparing for a Coronavirus Quarantine,” posted on March 9, offered practical suggestions on everything from food preparation to home sterilization to accessing medication (Piepzna-Samarasinha 2020). Many groups also quickly set up mitigation projects by distributing homemade sanitizer and masks to disabled, unhoused, and other uniquely at-risk communities (Kopit and Yi 2022; Green 2020). Activists also launched impactful social media campaigns such as #HighRiskCovid19, in which first-person testimony educated the public about the unique threats of infection for immunocompromised people.

New York City public schools turned to remote learning on March 23, and four days later, the exponential spread of the pandemic had already led to over twenty-three thousand confirmed cases and 365 deaths in the city. Infections continued to escalate with fierce velocity. #DisabledPeopleToldYou began circulating on Twitter, underscoring examples of disability expertise for a broad audience regarding chronic illness, quarantine, and remote work. In the words of disability activist Imani

Barbarin (2020), the pandemic would also be a "mass disabling event"—and those who were affected by COVID and post-COVID conditions had a community ready to advocate for them. Andrew Pulrang (2021) summarized these insights for the decidedly conventional readership of *Forbes* magazine: "While we were at higher risk, it sometimes felt like we were better equipped to handle the pandemic than people without disabilities." He continued, "Disabled people sometimes half-jokingly refer to ourselves as 'oracles' or 'canaries in the coal mine.' As disabled people, we often encounter new problems and threats before most people notice them or truly recognize their potential scale." Similar stories of pandemic ingenuity appear across the chapters of this volume, and we refer to this bifurcated experience as the "disability dialectic": faced with the enormous threats and terrible consequences of the pandemic, disabled people have manifested remarkable creativity and resistance.[1]

Despite this important work, many disabled people remained uniquely vulnerable, isolated, or silenced. Many held jobs as "essential workers," exposed to constant risk through food and mail delivery or working in markets, hospitals, and pharmacies. Others were incarcerated or otherwise confined, with little access to public health information, care, or the means for isolation, mitigation, and communication. Many suffered as a result of interruptions to health care, and far too many died.

The initial impact of the virus in New York was scaffolded by deeply entrenched inequalities, in particular, racial ableism—the racialization of oppression related to disability (Ben-Moshe 2016). The news platform *The City* aptly characterized the New Yorkers who were buried in the potter's field on Hart Island in the first year of the pandemic: "Most were elderly from nursing homes; Black and Hispanic frontline and essential workers from low-income neighborhoods who risked losing a paycheck if they didn't work during the pandemic's peak; and residents of The Bronx and Queens, where life expectancy has long been lower than other boroughs amid a lack of access to health care" (Stabile Center 2021).[2] Such realities serve as a stark reminder that, as much as the pandemic offers examples of disability efficacy in times of crisis and transformation, disabled New Yorkers—especially those who are multiply marginalized or institutionalized—continue to experience extreme precarity. Mass debilitation and death, moreover, are not the occasion for what Michele

Friedner calls "feel-good disability studies."[3] The *feelings* of expertise, like that of resistance, are often grief and anger.

New York City: Hierarchy, Carewashing, and Pandemic Cultural Production

How to Be Disabled in a Pandemic gathers history, ethnography, and first-person accounts of disabled life during the first four years of the COVID-19 pandemic in New York City. With our title, in one sense, we gesture to the many forces of disablement under crisis conditions: if pandemics themselves are mass disabling events, so too are pandemic protocols that create debilitating or deadly conditions of illness exposure, work and housing precarity, and lack of health resources for certain people. In another sense, our title cheekily conjures the genre of self-help, valuing disability and disabled life in and beyond pandemic times: disability sociality, protest, and epistemologies of pandemic survival. Across fifteen chapters, we move beyond the rhetoric of the pandemic's disproportionate impact on a monolithic group of disabled people.

Our focus on one city has allowed us to compare disability experiences that differ with regard to factors like neighborhood, age, race, housing, and carceral status, while situated within a similar geographic location, set of legal constraints, and public health regime.[4] Throughout the pandemic, the authors of *How to Be Disabled in a Pandemic* mostly stayed in the city, researching our own or neighboring communities and recording stories that generally failed to make it into the papers or onto the television. We write about prisons, migrant detention centers, subways, shelters, the New York Public Library, a Chinatown senior center, digital advocacy spaces, racial justice organizing, the homes of single parents, and the work of disability artists. We write about a hybrid city: online, outside, and behind closed apartment or institution doors. As a multiyear endeavor, this book sustains attention to disability experience from the early fraught and chaotic moments of the pandemic in spring 2020 to the illusory "post-pandemic" calm of 2023 and 2024. We collectively track shifts in pandemic experiences and politics from the launch of shelter-in-place orders to the introduction of vaccines, various claims of "reopening," discourses of Long COVID, and the "post-pandemic rollbacks" of access gains. Pandemic profiteering by drug companies, Big Tech, and mask hoarders has made us think critically about the rush of academic "pandemic projects" and plan a response that was longer term but still necessarily incomplete.

Each chapter offers its own distinct argument about the experience of the pandemic in a particular disability world. Yet across the different boroughs and groups of people we spoke to, several patterns also emerge.

First, there is a *hierarchy of disability "vulnerability"* in New York, as in other cities. The phrase "hierarchy of disability" has often been used in disability studies to describe privilege and inequality within the disability rights movement (e.g., early leadership by white men with physical disabilities), with "hierarchy of disablement" used in health circles to refer to "severity," stigma, or capacity for assimilation (Schalk 2020; Deal 2010). With the phrase "hierarchy of disability 'vulnerability,'" we acknowledge the differential likelihood of people to become disabled, as well as the differential likelihood of disabled people to be protected during the pandemic as a result of other elements of social status.

We take a critical approach to the term "vulnerability," which is an often-unexamined part of the jargon of health care, human rights, and many other fields. "Vulnerable" suggests increased susceptibility to harm, but it can also refer to a person in need of care and protection—usually as a result of age or disability. The use of the term "vulnerable" in public health is often patronizing and disenfranchising, signaling a population that seemingly requires management. As such, the word has been critiqued by disability ethicist Adrienne Asch, among others (Bergstresser 2014). We are interested in the ways people have structurally been made vulnerable to the effects of the pandemic. In New York City, we note that people with similar disabilities have been differently susceptible to infection, death, and social inequality on the basis of age, gender, race, class, job, neighborhood, immigration status, and other factors (Mizner 2020; Landes, Finan, and Turk 2022; Gawthrop 2022). And when certain disabled New Yorkers were deemed vulnerable to COVID-19, they were left to their own devices, even as others were granted social protections and services.

Across our chapters, we see an implicit vulnerability calculus taking place in institutions across the city, whereby some disabled people were abandoned in nursing homes and left to die and others were seen as vectors or safety threats and confined. Some nondisabled people, like health-care and essential workers, were disproportionately exposed to illness and trauma; and some neighborhoods were broadly debilitated through lack of access to resources. This hierarchy of disability "vulnerability" underscores who is unprotected during a pandemic, who is considered a threat, and who is given priority for care.

Second, and deeply related to this first pattern, we witnessed *disability and "care" deployed as population management tools* during the pandemic; this was often done in the name of public health and safety but did not serve disabled populations. That is, whether disability is positioned as a metaphor or reality, it has often served as a rationale for policy decisions, such as locking up certain people or diverting resources away from them. Disability is a key element of urban biopolitics, utilized as a justification for medical triage, restricting civil rights, or isolating groups of people in various institutions. As disability activist Marta Russell pointed out regarding the nursing home industry, disability can be a source of profit, and disabled people are sometimes treated as commodities in health-care settings (1998, 98). In allotting health care and other resources, disability is also often a proxy for race, for age, for weight, for lack of citizenship, for neighborhood—from mortality risk measures to definitions of "preexisting conditions" to critiques of individual behaviors and cultural practices. In some cases, city officials publicly described certain groups as "disabled" (e.g., unhoused people) to justify managing them "for their own protection"—a phenomenon known as "carewashing" (Chatzidakis and Littler 2022). Carewashing is often applied to corporations or government institutions that "commodify care" through branding to obfuscate their more harmful activities. Thus, while "care" is an important ethic within disability activism (Piepzna-Samarasinha 2018), it also became a co-opted keyword in many industries and fields during the pandemic. Following Michelle Murphy's call for tactics of "unsettling care" (2015), we have found countless examples of what might be called "the care con"—leveraging the language, logic, or promises of care to administer a population in unwanted or even harmful ways.

Finally, throughout this book, we also document abundant examples of *crip pandemic cultural production* (following Alexandra Juhasz and Theodore Kerr's work on "AIDS cultural production" and "pandemic media"; Juhasz and Kerr 2023; Juhasz 2023). Crip pandemic cultural production includes social practices as well as disability art, media, and aesthetics. Indeed, a primary motivation of this project has been to archive ephemeral evidence of this important cultural work, much of which circulates widely but informally through events, social media, zines, and other formats that are at risk of being lost to longer-term collective memory. Importantly, we note myriad affects expressed by disabled people across this cultural work—ranging from frustration to hope, despair to relief—including many ambiguities, ambivalences, and contradictions. We have also seen new and broad audiences taking up the already-existing insights and methods of chronically ill and disabled activists and scholars, extending their wisdom to the current pandemic. Our chapters describe disability expertise as lay expertise, as artistry, and as conventional scholarly and bioethics expertise.

The two parts of our book—"Living with 'Disproportionate Risk': Policies, Institutions, and Congregate Settings" and "Disability Communities: Expertise, Activism, and Solidarity"—also point to a gap with regard to *which* disabled people have found platforms, audiences, and the means to set or influence policy. Those in permanent "lockdown" in various congregate settings faced the greatest amount and intensity of pandemic constraints and consequences, while others who experience more physical and social freedoms were able to push the boundaries of disability activism.

Pandemic Theorizing and the Most Impacted

Our title, *How to Be Disabled in a Pandemic*, invokes two canonical texts for theorizing the cultural politics of AIDS: Douglas Crimp's article "How to Have Promiscuity in an Epidemic" (1987) and Paula Treichler's book *How to Have Theory in an Epidemic* (1999). These scholars point to the urgency of theorizing a viral pandemic in real time, in both the temporalities of its emergence and as it becomes increasingly endemic. In 1987, Crimp insisted on reframing AIDS expertise as grounded in queer life and epistemology, countering an onslaught of homophobic discourse by arguing that "the gay movement is responsible for virtually every positive achievement in the struggle against AIDS during the epidemic's early years," including not only political and medical victories but also social practices like the development of safe sex techniques

Figure 1.1. "Masks" (2020). Brothers Sick (Ezra Benus and Noah Benus). (Image courtesy of Brothers Sick)

(1987, 250). In conversation with Crimp's work, Treichler noted that "scientists, physicians, and public health authorities [have] argued repeatedly that AIDS represented 'an epidemic of infectious disease and nothing more.'" She instead theorized the crisis as also an "an epidemic of meanings" and political decision-making (1999, 1). Despite these important contributions, we note that these earlier works lacked a theoretical framework that connected AIDS to disability studies and activism. This gap has increasingly been narrowed in the intervening years by scholars and activists working at these intersections, especially in the context of COVID-19 (McRuer 2002; Hrynyk 2021; WWHIVDD Collective 2020a; Schalk 2022; Bhaman, chapter 3 in this volume). By invoking these titles, we not only center the experiences of those who have been most impacted but also underscore the many strands of history, theory, and activism that have converged in the COVID-19 pandemic and enable the analyses in this volume.

Disability is not a homogeneous category or a single "movement"; as an experience, identity, or political affiliation, it is also shaped by vectors such as race, gender, class, and citizenship. Our focus on disability further reveals the term to be in a constant state of negotiation, especially in the collective experience of a public health emergency. Borrowing from disability activist Patty Berne (2015), cofounder of the arts organization Sins Invalid, we have worked with a capacious definition of disability that includes "people with physical impairments, people who identify as 'sick' or are chronically ill, 'psych' survivors and those who identify as 'crazy,' neurodiverse people, people with cognitive impairments, people who are a sensory minority," and people with various experiences of aging, injury, and addiction. We also note the complex and at times contested nature of identifying as disabled. For many, the label offers a strong source of community and identification and may help validate experiences that are not recognized in traditional medicalized settings (such as those seeking support for Long COVID). Some discuss a slow process of coming to identify as disabled through the sequelae of illness. For others, it can still be viewed as a source of stigma or liability, particularly for those whose experiences of disability are rooted in physical and structural violence (such as police brutality, incarceration, and addiction), those whose cultural upbringings disavow or stigmatize disability, and those who have historically been excluded from mainstream US disability rights activism. Authors and interlocutors in this book use varied terminology to describe their identities, including more specific terms to describe experiences or impairments; many use "crip" as a proud reclamation of the term's origins as a slur (McRuer 2006). Among the authors in this book who identify as disabled, there has been no singular experience of the pandemic.

One of Crimp's most forceful arguments, that "anything said or done about AIDS that does not give precedence to the knowledge, the needs, and the demands of people living with AIDS must be condemned" (1987, 240), resembles a slogan of the disability rights movement: "nothing about us without us" (Charlton 2000). To the same end, we insist that there is no adequate theory of the pandemic that is not a disability theory. However, this ethos sits uneasily with the current state of "pandemic theorizing" (Patsavas and Danylevich 2022). If older people and those living in nursing homes or other congregate settings, especially in certain zip codes, have been at the greatest risk of infection and death from COVID-19 in the US, they have hardly featured at all in popular journalism, academic publishing, or even disability media, much less spoken for themselves (Mizner 2020). The editors of a 2022 special issue of *Lateral: Journal of the Cultural Studies Association*, titled "Crip Pandemic Life: A Tapestry," call attention to this gap in disability pandemic studies more generally: "The present installment of our tapestry-archive lacks—and desires—more voices from Black disabled folks; scholars, artists, and thinkers from the global south; incarcerated and/or institutionalized people; refugees; indigenous voices; those disabled by war and climate crisis; and those newly disabled from Long-COVID. The silences and gaps of those disabled and chronically ill lives lost and those too sick, too isolated, too pained, or too fatigued to actively offer their accounts, experiences, and wisdom to this collective project also demand acknowledgement" (Patsavas and Danylevich 2022).

How to Be Disabled in a Pandemic is an open-ended proposition. Too many disabled New Yorkers exist to be represented in one collection, but by convening a large, mixed-background group, we have prioritized a breadth of pandemic narratives—while acknowledging that several gaps remain. Our collection includes researchers with a wide range of disability expertise that has grown from our work *as* and *with*: autistic adults, people living with chronic illness, blind accessibility experts,

Figure 1.2. Photograph of a mural painted by artist Chella Man, depicting illustrated hands spelling out the message "Black Disabled Trans Lives Matter" in American Sign Language. The *a* letters in the words "black," "disabled," and "trans" are all connected. The hands are colored using the colors of the Progress Pride flag. (Photo by Faye Ginsburg, taken on August 21, 2020, on MacDougal Street in Greenwich Village)

Black pregnant people experiencing mental health challenges, people with mobility impairments, adults with intellectual and developmental disabilities and their supporters, antiracist activists, and incarcerated and unhoused disabled people.[5] In doing so, we attend to the particularities of individuals and communities, while also documenting cross-disability and cross-issue collectives. We also foreground the structural logics of death and survival that become apparent during pandemics, following the work of the writer/activist Steven Thrasher, who cautions about the unequal tolls of COVID, like HIV/AIDS, on a "viral underclass" (Thrasher 2022).

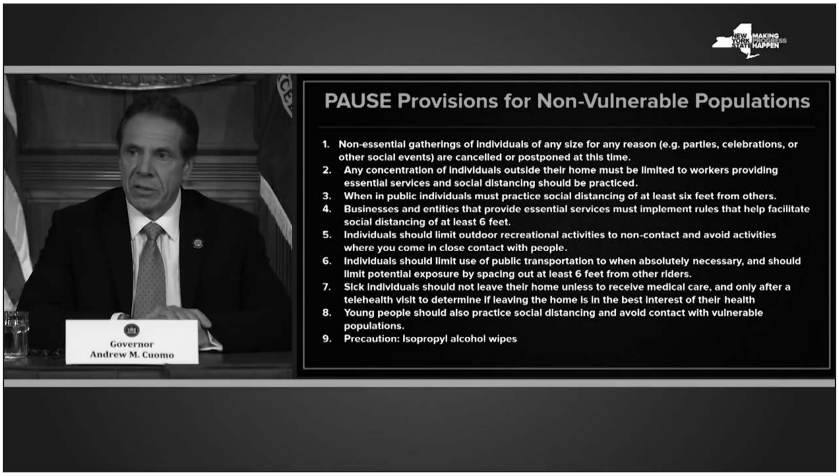
Many of us write from a place of unwellness, employing what Melissa Kapadia (2020) calls "illness methodology": "the application of ill lenses and ways of knowing to the practice of research." Throughout our collective process, we also kept in mind Mimi Khúc's "pedagogy of unwellness," which critically decenters wellness by insisting that "we are all differentially unwell. . . . We are unwell in different ways at different times, in relation to differentially disabling and enabling structures, so we need differential care at all times" (2021, 370). Moreover, the specific qualitative methods used on our team were eclectic, reflecting different disciplinary backgrounds and social positions. They range from participant observation (online and face-to-face) to interviews, legal analysis, archival research, oral histories, and art criticism. Some of our authors engage remote ethnography as a long-standing practice of disability sociality and research, publicized by the pandemic but also preceding it (Rogers 2023). We have also invited conversations among activists and practitioners.

"Lockdown" versus Lockdown: Two New Yorks

New York City was one of the major global epicenters of the pandemic, particularly in early spring 2020, when infection and death rates skyrocketed and information and mitigation strategies were barely emerging. The city has also been a test bed for national policies like ventilator and vaccine allocation protocols. As Governor Cuomo put New York State "on pause" beginning on March 22, 2020 (see figure I.3), his national broadcasts became immensely popular, providing updates on COVID cases in the state, directives to stay at home, and a bracing sense of determination to fight this unknown virus together (despite a frequent failure to translate this ethos into equitable policies).[6]

Yet disabled people experienced two starkly different New York Cities during the COVID-19 pandemic: the metropolis for the unconfined, and the outer boroughs, islands, and institutions of the confined. Disabled and nondisabled people living in jails, prisons, migrant detention centers, group homes, nursing homes, and other institutions lived and died in pandemic conditions intentionally distinct from disabled and nondisabled New Yorkers on the outside, part of the disability "vulnerability" calculus of city planning.[7] The mother of one of our early collaborators, the New York University bioethicist Arthur Caplan, died of COVID in a nursing home in spring 2020. Caplan, who like many people was only able to wave at his mother through the window as she was dying, calls nursing homes "forgotten institutions" where "we let the elderly go," along, too often, with their care workers (Mathews 2020).[8]

In addition to the checkerboard map of COVID-19 deaths by zip code (see figure I.4), the city can be divided according to those who have



PAUSE Provisions for Non-Vulnerable Populations

1. Non-essential gatherings of individuals of any size for any reason (e.g. parties, celebrations, or other social events) are cancelled or postponed at this time.
2. Any concentration of individuals outside their home must be limited to workers providing essential services and social distancing should be practiced.
3. When in public individuals must practice social distancing of at least six feet from others.
4. Businesses and entities that provide essential services must implement rules that help facilitate social distancing of at least 6 feet.
5. Individuals should limit outdoor recreational activities to non-contact and avoid activities where you come in close contact with people.
6. Individuals should limit use of public transportation to when absolutely necessary, and should limit potential exposure by spacing out at least 6 feet from other riders.
7. Sick individuals should not leave their home unless to receive medical care, and only after a telehealth visit to determine if leaving the home is in the best interest of their health
8. Young people should also practice social distancing and avoid contact with vulnerable populations.
9. Precaution: Isopropyl alcohol wipes

Figure 1.3. Governor Cuomo unveils the New York State PAUSE plan, effective March 22, 2020. (New York State Governor 2020)

freedom of movement and access to the internet, even under so-called lockdown conditions, and *disability inmates*, the rapidly growing segment of New Yorkers who are confined in various settings. The term “lockdown” as colloquially applied to the New York State “PAUSE” program for social distancing or quarantining among the general public was little more than cruel hyperbole, as incarcerated and formerly incarcerated people were quick to point out (Metcalf 2020). “Lockdown” is a North American word coined in the 1970s to refer to a confinement within a confinement, a form of punishment for people incarcerated in prisons and psychiatric hospitals: “the confinement of prisoners to their cells for an extended period of time, usually as a security measure following a disturbance” (*Oxford English Dictionary*). Illness from COVID-19 became a reason for literal lockdowns in carceral settings, and the pandemic itself became a rationale for the increased institutionalization of those who seemed to pose public health or safety risks, especially those with mental disabilities.

In New York City, the pandemic eroded many of the post-1960s gains of the global deinstitutionalization movement and civil rights for people with mental disabilities. Former police captain Eric Adams won the 2021 New York City mayoral election in year two of the pandemic with a “war on crime” campaign that has often manifested itself as a war on unhoused and disabled people. Many were forced into parks and streets as a result of subway closures for overnight disinfection, leading to public anxieties about increased homelessness (with actual numbers difficult to measure).[9] As Metropolitan Transit Authority ridership rebounded in 2021, fears regarding transit crime, including a few high-profile incidents of violence by people labeled mentally disabled, led Adams to announce large-scale police patrols of the subway system shortly after he was sworn in on January 1, 2022. On November 29, 2022, the mayor additionally announced an eleven-point “Psychiatric Crisis Care Legislative Agenda” that would allow unhoused and/or disabled people to be involuntarily hospitalized, with New York Police Department and Department of Health (DOH) teams deployed in subways to remove “those appearing to have serious mental health issues” (Office of the Mayor 2022). The language of care in this agenda signaled carewashing to many disability

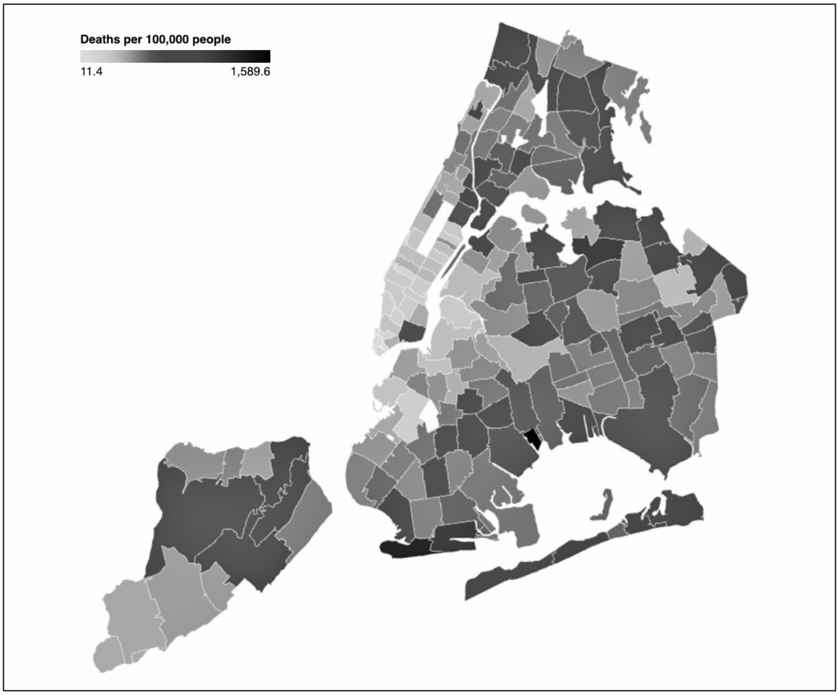


Figure 1.4. COVID-19 data by zip code: deaths per one thousand people. (New York City Department of Health and Mental Hygiene n.d.)

activists, who responded by pointing out the lack of hospital space and, more importantly, lack of economic and social supports for housing, work, and health care in the city.

If disability is often used as justification for confinement, that same confinement has also exacerbated injury, illness, and other impacts of COVID-19, with the worst congregate settings effectively functioning as kill shelters. Even city planners with the best intentions to reform nursing homes and other institutions have failed to follow through with any notable improvements. Our research confirms that most congregate settings are not "medically appropriate housing" for older and disabled people; this is an artifact as much of history and policy as of individual physiology or the nature of group living (Bhaman, chapter 3 this volume). Instead, institutionalized disabled people have been widely written off as "acceptable losses," a situation that activists have repeatedly decried as neo-eugenics (Kukla 2020). At the same time, as part 1 of our volume attests, congregate settings and their residents are not all identical, even if the category is often used in a blanket way by politicians, public health workers, and even disability activists. For noncitizens, incarcerated people, and those assigned by the courts to guardianship and conservatorship, the impacts of the pandemic have been dire in highly specific ways, with few opportunities for creative or public response (Bardelli, Thomas, and Brown, chapter 1 this volume; Salyer, chapter 2 in this volume). That is, for disabled people subject to carceral forms of control, *disability expertise* unfortunately does not always translate into *disability autonomy* or *disability authority*.[10]

The Disability Dialectic

A dialectic of risk and resistance also threads through the chapters that follow: among those who survived, among those with means, amid networks of mutual support and care, and among disabled artists who demonstrated time and again that "disability is an ingenious way to live" (Neil Marcus, in Ehrlich 2006, 58). In documenting moments of struggle, insight, and improvisation, however, we resist the impulse to romanticize precarity. As anthropologist Liliana Gil has shown, too many theories of "innovation from below"—whether linked to disability, poverty, or culture—propose that "experiences of precarity contain a valuable repertoire of techniques." These theories entail a number of pitfalls: the "bourgeois fantasy" of subaltern resourcefulness; the co-optation of precarious ingenuity "for its entrepreneurial potential"; and the forwarding of this ingenuity "as a scalable solution for global challenges. A temporary disguised as a structural solution" (Gil 2022, 30, 49). We note that the abundance of theories of design and innovation in disability studies have largely failed to engage with anthropological and decolonial critiques of innovation rhetoric or the neoliberal logic of individuals "making do" in the absence of governmental concerns for social welfare.

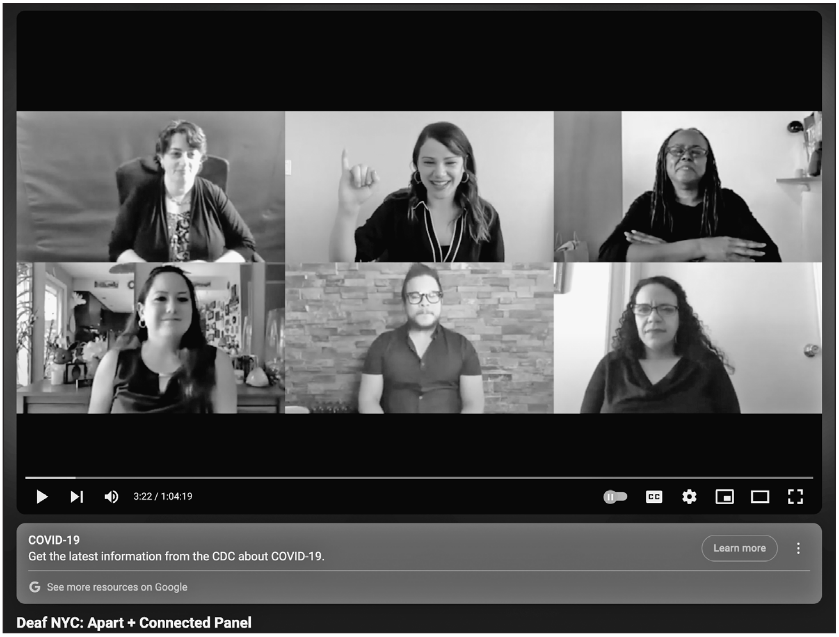
A disability dialectic—with often precarious gains or ephemeral cultural forms—has played out in many different arenas of public life and discourse during the COVID-19 pandemic, especially as disabled people contest institutions and policies that are both overtly and more insidiously ableist. When CDC director Rochelle Walensky, a top public health leader in the US, apparently claimed that it was "encouraging news" that the majority of COVID-19 deaths were among those "who were unwell to begin with," it prompted massive protest (Hubrig 2022; Ruiz-Grossman 2022). #MyDisabledLifeIsWorthy, a hashtag launched by Imani Barbarin in January 2022, directly countered Walensky's comments and reasserted the value of disabled life (Barbarin 2022). #MyDisabledLifeIsWorthy sparked wide-ranging conversations about neo-eugenics in government policies, and within a week, on January 14, Walensky met remotely with a group of disability activists to apologize for her comment, promising regular meetings going forward (CDC 2022b). Despite this seeming win, these regular meetings did not happen, and biases in public health policy effectively became self-fulfilling prophecies, requiring an ongoing, iterative series of protests.

Ableist sentiments were further translated into a range of policies that directly threatened many disabled people's health and ability to participate in public life. One major form of injustice that emerged in spring 2020 centered around medical triaging and the rationing of lifesaving treatments that deprioritized or outright denied care to people with a variety of disabilities, judging that their lives were "too expensive" or "lost causes." For example, a 2021 report by the National Council on Disability found that "people with intellectual or developmental disabilities, and medically fragile and technology dependent individuals, faced a high risk of being triaged out of COVID-19 treatment when hospital beds, supplies, and personnel were scarce" (National Council on Disability 2021, 1). In the earliest days of the pandemic, access to ventilators was notably limited, leading to state- and hospital-based rationing proposals for withholding or withdrawing lifesaving equipment from certain groups of disabled people (Mills, chapter 5 this volume). Similarly, when vaccines became available to select groups, many disabled people who were at increased risk were nonetheless not included on the initial lists for priority access in New York State, as only a limited number of "comorbidities" were considered. Unsurprisingly, people whose conditions were not listed protested their longer waits, while activists in other states contested policies that failed to recognize disabled people at all (New York State Governor 2021; Miller 2021; Sharp 2021). The pandemic underscored the endemic ableism of health-care allocation and the stark irony that those who need care the most often cannot access or afford it in the highly stratified privatized US health system. At the same time, as supply chains faltered at different moments, disabled authors shared their unsentimental expertise about how to self-ration when unable to access or afford drugs and medical supplies, offering advice about things like sharing insulin and other hormones or crowdsourcing catheters (Trowe 2022; Mills, chapter 5 in this volume).

Disabled people have organized creatively against any number of structural and legal barriers to health care, education, and information, transforming architecture, city streets, and digital media in the process. During the pandemic, activists were pleased to see expanded options for telemedicine, for which they had long been advocating (and which was temporarily expanded by Medicare and most private insurance under pandemic emergency orders). Yet they also expressed frustration at seeing "ableds accommodating themselves with the accessibility . . . disabled people fight for every day," exemplified by the hashtag #AccessibilityForAbleds (McWilliams 2020). The pandemic revealed just how easy it could be to provide certain accommodations—such as remote access to work, school, and therapy—that disabled and chronically ill people had been demanding, unsuccessfully, for years (Acton and Hamraie 2022).[11]

With the prioritization of urgent COVID-19-related care, necessary in-person appointments were frequently delayed or canceled as medical resources were reconfigured or facilities deemed too risky (Akobirshoev et al. 2022; Moore et al. 2022). Moreover, as care professionals, especially at-home care workers, became ill, refused vaccines, or left the profession, many disabled people found it increasingly difficult to receive basic services; the National Council on Disability notes that this left "some at risk of losing their independence or being institutionalized" (2021, 2). This complex situation highlights the overlapping precarities of the pandemic: the majority of nursing assistants and home-care and direct-care workers are women of color, who earn less than white men and who also experienced higher rates of death than average from COVID-19 (Campbell 2017). Under these seemingly impossible conditions, disabled people and their families demonstrated "ingenuity and creativity . . . to make home accessible" using a range of improvised hacks. Laura Mauldin (n.d.) documents these in her research on "disability at home," accompanied by a photo website where people share images and stories of how they have created access on their own.

Many blind and Deaf people also faced specific barriers to information and treatment for COVID-19 as a result of inaccessible websites, the limited availability of captioning and interpreters, or a lack of materials in Braille and other accessible formats (Coklyat and Fleet, chapter 9 in this volume). For instance, many forms of COVID testing have been inaccessible to blind people, from drive-through testing sites to home tests that rely on visual instructions and displays (Morris 2022; Smith 2022). Some apps, such as Be My Eyes, founded by the visually impaired inventor Hans Jørgen Wiberg, have allowed blind people to video-call sighted people for assistance with visual tasks such as reading rapid test results. Frustrated by the slowness and potential COVID exposure of in-person testing sites, Mark Riccobono, president of the National Federation of the Blind (NFB), wrote to President Biden on January 3, 2022, on behalf of the thousands of NFB members to demand that the free COVID tests provided by the federal government include versions accessible to blind people (Riccobono 2022). He followed up with the Food and Drug Administration (FDA) commissioner shortly after, requesting that kit instructions on the FDA site be posted as accessible PDFs. In response, in June, the US Postal Service temporarily provided what it called "more-accessible" COVID tests, although these versions still required a smartphone and navigation of the Ellume app (not created for blind people) to hear audio instructions and results.



COVID-19
Get the latest information from the CDC about COVID-19.

See more resources on Google

Deaf NYC: Apart + Connected Panel

Figure 1.5. “Deaf NYC: Apart + Connected Panel.” On May 12, 2020, Deaf residents of New York City—Roxanna Aguila, Carlos Aponte-Salcedo Jr., Patrice Creamer, Marina Fanshteyn, and Alexandria Pucciarelli-Miller—shared perspectives, challenges, and hopes during a virtual panel discussion on the pandemic, hosted by Brianna Di-Giovanni, intern at the Drs. John S. & Betty J. Schuchman Deaf Documentary Center at Gallaudet University. They discussed a range of questions emerging for Deaf New Yorkers in the early months of the pandemic: How has life changed during this pandemic for New York City’s Deaf community? When everyone wears face masks, how does that affect interactions? When is information fully accessible, and how can communication be better? Are there signs that are new or signs that have taken on new meaning? Are there ways that Deaf cultural life is uniquely helpful during this time? (Schuchman Center 2020)

As with any dialectic, experiences of disability during the pandemic were hardly defined strictly by either vulnerability or creativity; instead, disabled communities often directly wrestled with this sort of binary thinking, challenging each other to embrace complexity. The pandemic also raised numerous instances of what disability scholars describe as “access friction” (Hamraie 2017; Hamraie and Fritsch 2019), in which actions that increase access for some may limit or hinder access for others.

For example, while masking in public spaces has been a key mitigation strategy, particularly important for immunocompromised people, most masks are opaque and muffle sound, which can pose a barrier for deaf and hard-of-hearing people, especially when reading lips (Rogozen 2020; Stine 2020). Similarly, while options for remote work, schooling, and socializing provided welcome enhancements for those who had long been advocating for such access strategies, for many disabled students—among other groups—remote participation both exacerbated existing inequities and instigated new ones (Beery 2020; Scott and Aquino 2020; Freidus, Fish, and Turner, chapter 6 in this volume).

Solidarity and “Crip Doulaing”

While the disability dialectic suggests resistance and creative response by those who are immediately experiencing conditions of inequality and abandonment, many of our chapters foreground instead cross-disability aid and illness coalitions, what the late disability rights activist Stacey Park Milbern has named “crip doulaing.” In conversation with Leah Lakshmi Piepzna-Samarasinha shortly before the start of the pandemic, Milbern underscored the urgency of “disability doulaship”:

> I see a lot of disabled people of color doing a ton of work in supporting people rebirthing themselves as disabled (or more disabled). This looks like a lot of things—maybe learning how to get medicine, drive a wheelchair, hire attendants, change a diet, date, have sex, make requests, code switch, live with an intellectual disability, go off meds, etc. etc. . . . I feel like society not having language to describe this transition or the support it requires speaks to the ableism and isolation people with disabilities face in our lives. . . . Without crip intervention, we are frequently left alone to figure out how to be in our bodyminds and in this ableist world. (Piepzna-Samarasinha 2018)

In parallel, the What Would an HIV Doula Do? collective members invoked the history and importance of illness doulas in their zine *What Does a COVID-19 Doula Do?* (WWHIVDD Collective 2020b). Although they point out that “AIDS and COVID have little in common,” AIDS activism has had an enduring influence on other illness communities.

In the zine, Jih-Fei Cheng argues that AIDS activists "taught us to research and educate authorities" as well as serve as illness doulas for one another (2020b, 35), while Alexandra Juhasz describes illness doulas as "hold[ing] space for people made vulnerable due to one or many viruses. Doulas make space for fear and love, help and incapacity" (2020b, 22).

The pandemic has not only impacted those who already identified as disabled but also catalyzed new experiences of disability and countless examples of illness coalitions. Perhaps most obviously, COVID-19 has rendered millions of people newly chronically ill, with a range of symptoms affecting vascular, respiratory, immune, digestive, neurological, and reproductive systems, summed up under the term "Long COVID" (Davis et al. 2023). As the journalist and science writer Ed Yong (2021) has described it, patients with Long COVID are now living in a "hinterland of disability," a neglected liminal space between full health and hospitalization or death, "where millions of people are already stuck, and where many more may end up" (see also Yong's foreword to this volume). Like other chronically ill communities whose sicknesses are not easily treated by current biomedical knowledge, people with Long COVID are engaged in activism to gain both recognition and resources, an ongoing fight in which they have often worked in solidarity with existing disability activist movements (Kornstein and Rogers, chapter 8 in this volume).

We also call attention to depression and other mental health experiences and the self-help and mutual-aid networks that were activated in the absence of adequate therapy for most New Yorkers. According to studies by the Pew Research Center and Kaiser Family Foundation, approximately 40 percent of US adults experienced mental health challenges during the pandemic, including new symptoms of anxiety or depression, with increased rates among communities of color, women, teens and young adults, low-wage and other frontline essential workers, and disabled people (Panchal et al. 2021; Pasquini and Keeter 2022; Mbonde, chapter 12 in this volume). Such experiences will continue to have profound impacts, particularly given the disproportionate rates of mental disability (including burnout) among health-care and home-care workers (Sexton et al. 2022; Murthy 2022).

Additionally, the emergence of the pandemic coincided with increased public attention to anti-Black police violence and vigilante attacks targeting Asian American and Pacific Islander communities (spurred by xenophobic attitudes focusing on the virus's origins in China). In response to these multiple traumas, the New York–based Asian American Feminist Collective and Bluestockings Bookstore published *Asian American Feminist Antibodies: {care in the time of coronavirus}* (see figure I.6), a digital zine that encourages solidarity across diverse experiences of illness, labor, and age. The zine collects "practices of care that come out of Asian American histories and politics," in refutation of racialized stereotypes about the virus. (Two contributors to this volume, Rachel Kuo and Salonee Bhaman, are among the zine's authors.)

Networks like Sick in Quarters (SiQ), launched in 2020, hosted smaller community-building workshops online, including virtual "right to mourn" spaces and listening session "hideaways" (Sick in Quarters 2023). SiQ describes its online meet-ups as a "container for collective mourning, the kind of pain and alienation that was already familiar to disabled and immunocompromised lives."[12] These projects thus highlight the importance of grief not only as an individual affect but also as a collective and political process in responding to the pandemic and forging intersectional solidarities.

Many of these same disability networks responded forcefully and with direct action to the "double pandemic" of racism and racialized police violence in the US (Mohapatra et al., chapter 11 in this volume; Mbonde, chapter 12 in this volume). Such activism multiplied exponentially in May and June 2020, following the police murder of George Floyd, when uprisings against anti-Black violence and police brutality took over the recently empty streets of many US cities including New York. Sick in Quarters published the *Stay Safe—COVID-19 Protest Resources* brochure (figure I.7), with advice for decreasing the chance of viral spread during and after direct-action events, as well as information about protest rights and how to stay safe while interacting with police. As discussed in this volume, police and prisons contribute profoundly to experiences of disability through both inflicted injuries and the often-intentional denial of care (Bardelli, Thomas, and Brown, chapter 1 in this volume). In this context, the intersections between prison abolitionist work and disability justice have been some of the most urgent forms of activism throughout (and preceding) the pandemic. Sick of It! A Disability Inside/Outside Project—"a group of abolitionists and disabled activists working to build connections between the free world disabled community and

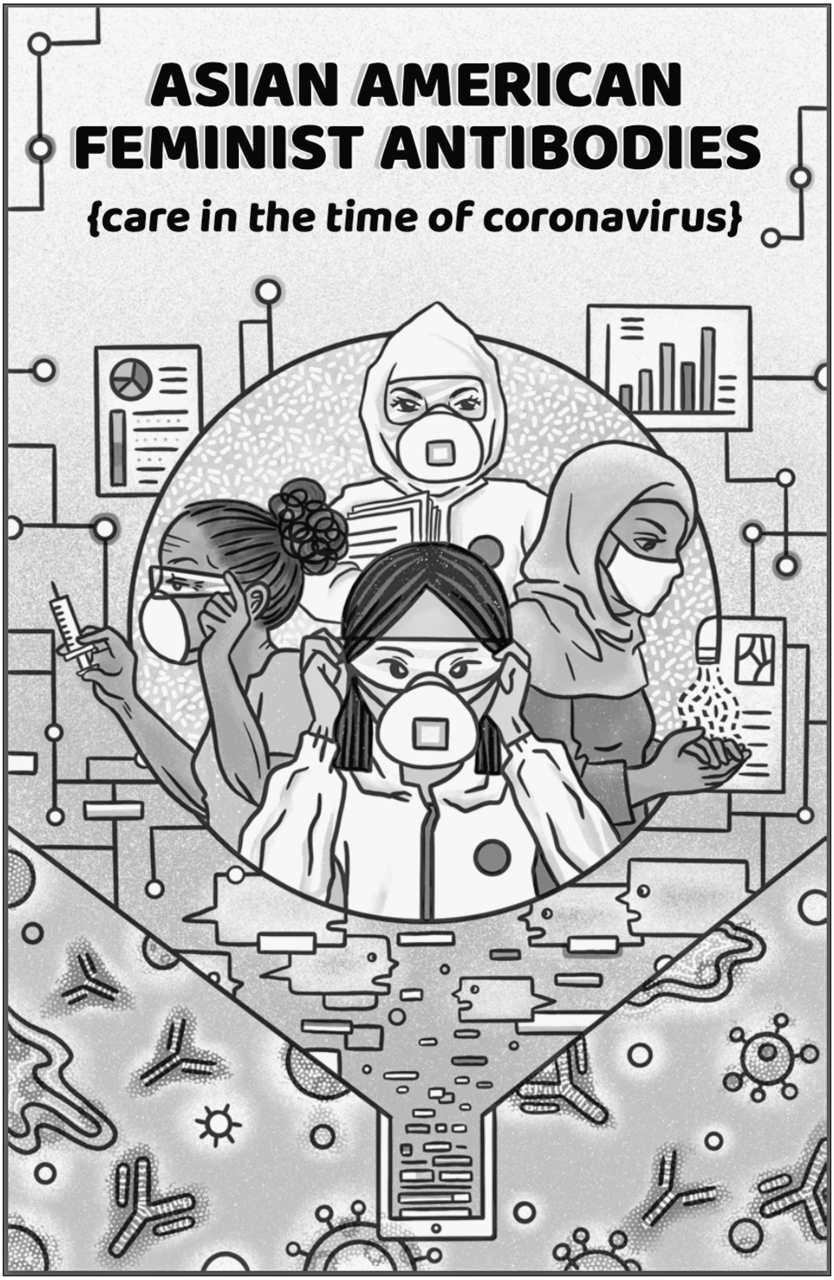


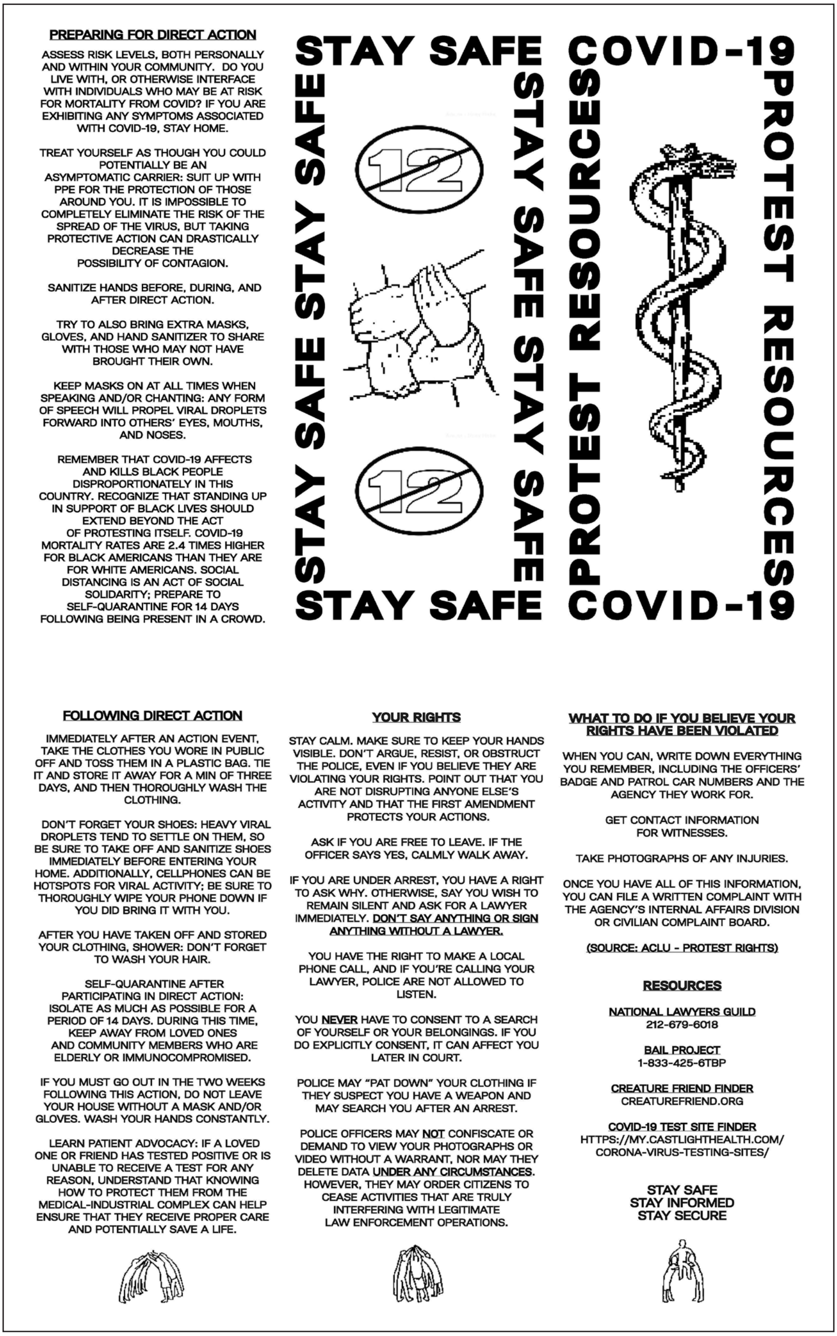
Figure 1.6. *Asian American Feminist Antibodies: {care in the time of coronavirus}*, by Salonee Bhaman, Rachel Kuo, Matilda Sabal, Vivian Shaw, and Tiffany Diane Tso. (Cover illustration by Amira Lin)

those behind bars"—released the first of several zines in October 2020. These featured "writings about disability justice, strategies of care and work submitted by our incarcerated community, . . . [and] a penpal project to connect disabled folks inside to outside disabled penpals" (Sick of It!, n.d.).

Brief Overview of the Book

How to Be Disabled in a Pandemic documents pandemic cultural production alongside pandemic disablement, cross-disability organizing alongside government hierarchies of disability "vulnerability." Part 1, "Living with 'Disproportionate Risk': Policies, Institutions, and Congregate Settings," addresses the specific experiences of disabled people who find themselves inscribed into "risk" and its discourses for diverse reasons. We open with a chapter on incarcerated disabled people and illness as reason for punishment in state prisons (Bardelli, Thomas, and Brown), followed by a chapter on disability and COVID in migrant detention centers, raising the question of who counts as a New Yorker (Salyer). Daily experiences of the coronavirus in New York City have been profoundly shaped by the prior emergence of AIDS in this city, with many policies related to homelessness, long-term care, and quarantine during epidemics having been established in response to that earlier crisis. Thus, the next chapter in our volume examines the legacy of laws governing shelter for unhoused people during the early AIDS epidemic and the ways enforced shelter often exacerbates risk (Bhaman). Other chapters trace the rapidly changing MTA policies for mobility-impaired New Yorkers (Grenier); ableism and racial bias in state and hospital ventilator-allocation protocols (Mills); the loss of services, sociality, and attention experienced by "special ed" students in the schools (Freidus, Fish, and Turner); and adults with intellectual/developmental disabilities living at home, often with aging family members who resumed caregiving as long-standing paid caregivers or personal assistants became unavailable (Ginsburg and Rapp). All chapters here chronicle experiences of living at "disproportionate risk" during the first three years of the pandemic.

Part 2, "Disability Communities: Expertise, Activism, and Solidarity," focuses on crip pandemic doulaship and cultural production. This part opens with an account of people with myalgic encephalomyelitis (ME)



PREPARING FOR DIRECT ACTION

ASSESS RISK LEVELS, BOTH PERSONALLY AND WITHIN YOUR COMMUNITY. DO YOU LIVE WITH, OR OTHERWISE INTERFACE WITH INDIVIDUALS WHO MAY BE AT RISK FOR MORTALITY FROM COVID? IF YOU ARE EXHIBITING ANY SYMPTOMS ASSOCIATED WITH COVID-19, STAY HOME.

TREAT YOURSELF AS THOUGH YOU COULD POTENTIALLY BE AN ASYMPTOMATIC CARRIER: SUIT UP WITH PPE FOR THE PROTECTION OF THOSE AROUND YOU. IT IS IMPOSSIBLE TO COMPLETELY ELIMINATE THE RISK OF THE SPREAD OF THE VIRUS, BUT TAKING PROTECTIVE ACTION CAN DRASTICALLY DECREASE THE POSSIBILITY OF CONTAGION.

SANITIZE HANDS BEFORE, DURING, AND AFTER DIRECT ACTION.

TRY TO ALSO BRING EXTRA MASKS, GLOVES, AND HAND SANITIZER TO SHARE WITH THOSE WHO MAY NOT HAVE BROUGHT THEIR OWN.

KEEP MASKS ON AT ALL TIMES WHEN SPEAKING AND/OR CHANTING: ANY FORM OF SPEECH WILL PROPEL VIRAL DROPLETS FORWARD INTO OTHERS' EYES, MOUTHS, AND NOSES.

REMEMBER THAT COVID-19 AFFECTS AND KILLS BLACK PEOPLE DISPROPORTIONATELY IN THIS COUNTRY. RECOGNIZE THAT STANDING UP IN SUPPORT OF BLACK LIVES SHOULD EXTEND BEYOND THE ACT OF PROTESTING ITSELF. COVID-19 MORTALITY RATES ARE 2.4 TIMES HIGHER FOR BLACK AMERICANS THAN THEY ARE FOR WHITE AMERICANS. SOCIAL DISTANCING IS AN ACT OF SOCIAL SOLIDARITY; PREPARE TO SELF-QUARANTINE FOR 14 DAYS FOLLOWING BEING PRESENT IN A CROWD.

FOLLOWING DIRECT ACTION

IMMEDIATELY AFTER AN ACTION EVENT, TAKE THE CLOTHES YOU WORE IN PUBLIC OFF AND TOSS THEM IN A PLASTIC BAG. TIE IT AND STORE IT AWAY FOR A MIN OF THREE DAYS, AND THEN THOROUGHLY WASH THE CLOTHING.

DON'T FORGET YOUR SHOES: HEAVY VIRAL DROPLETS TEND TO SETTLE ON THEM, SO BE SURE TO TAKE OFF AND SANITIZE SHOES IMMEDIATELY BEFORE ENTERING YOUR HOME. ADDITIONALLY, CELLPHONES CAN BE HOTSPOTS FOR VIRAL ACTIVITY; BE SURE TO THOROUGHLY WIPE YOUR PHONE DOWN IF YOU DID BRING IT WITH YOU.

AFTER YOU HAVE TAKEN OFF AND STORED YOUR CLOTHING, SHOWER: DON'T FORGET TO WASH YOUR HAIR.

SELF-QUARANTINE AFTER PARTICIPATING IN DIRECT ACTION: ISOLATE AS MUCH AS POSSIBLE FOR A PERIOD OF 14 DAYS. DURING THIS TIME, KEEP AWAY FROM LOVED ONES AND COMMUNITY MEMBERS WHO ARE ELDERLY OR IMMUNOCOMPROMISED.

IF YOU MUST GO OUT IN THE TWO WEEKS FOLLOWING THIS ACTION, DO NOT LEAVE YOUR HOUSE WITHOUT A MASK AND/OR GLOVES. WASH YOUR HANDS CONSTANTLY.

LEARN PATIENT ADVOCACY: IF A LOVED ONE OR FRIEND HAS TESTED POSITIVE OR IS UNABLE TO RECEIVE A TEST FOR ANY REASON, UNDERSTAND THAT KNOWING HOW TO PROTECT THEM FROM THE MEDICAL-INDUSTRIAL COMPLEX CAN HELP ENSURE THAT THEY RECEIVE PROPER CARE AND POTENTIALLY SAVE A LIFE.

YOUR RIGHTS

STAY CALM. MAKE SURE TO KEEP YOUR HANDS VISIBLE. DON'T ARGUE, RESIST, OR OBSTRUCT THE POLICE, EVEN IF YOU BELIEVE THEY ARE VIOLATING YOUR RIGHTS. POINT OUT THAT YOU ARE NOT DISRUPTING ANYONE ELSE'S ACTIVITY AND THAT THE FIRST AMENDMENT PROTECTS YOUR ACTIONS.

ASK IF YOU ARE FREE TO LEAVE. IF THE OFFICER SAYS YES, CALMLY WALK AWAY.

IF YOU ARE UNDER ARREST, YOU HAVE A RIGHT TO ASK WHY. OTHERWISE, SAY YOU WISH TO REMAIN SILENT AND ASK FOR A LAWYER IMMEDIATELY. **DON'T SAY ANYTHING OR SIGN ANYTHING WITHOUT A LAWYER.**

YOU HAVE THE RIGHT TO MAKE A LOCAL PHONE CALL, AND IF YOU'RE CALLING YOUR LAWYER, POLICE ARE NOT ALLOWED TO LISTEN.

YOU **NEVER** HAVE TO CONSENT TO A SEARCH OF YOURSELF OR YOUR BELONGINGS. IF YOU DO EXPLICITLY CONSENT, IT CAN AFFECT YOU LATER IN COURT.

POLICE MAY "PAT DOWN" YOUR CLOTHING IF THEY SUSPECT YOU HAVE A WEAPON AND MAY SEARCH YOU AFTER AN ARREST.

POLICE OFFICERS MAY **NOT** CONFISCATE OR DEMAND TO VIEW YOUR PHOTOGRAPHS OR VIDEO WITHOUT A WARRANT, NOR MAY THEY DELETE DATA **UNDER ANY CIRCUMSTANCES**. HOWEVER, THEY MAY ORDER CITIZENS TO CEASE ACTIVITIES THAT ARE TRULY INTERFERING WITH LEGITIMATE LAW ENFORCEMENT OPERATIONS.

WHAT TO DO IF YOU BELIEVE YOUR RIGHTS HAVE BEEN VIOLATED

WHEN YOU CAN, WRITE DOWN EVERYTHING YOU REMEMBER, INCLUDING THE OFFICERS' BADGE AND PATROL CAR NUMBERS AND THE AGENCY THEY WORK FOR.

GET CONTACT INFORMATION FOR WITNESSES.

TAKE PHOTOGRAPHS OF ANY INJURIES.

ONCE YOU HAVE ALL OF THIS INFORMATION, YOU CAN FILE A WRITTEN COMPLAINT WITH THE AGENCY'S INTERNAL AFFAIRS DIVISION OR CIVILIAN COMPLAINT BOARD.

(SOURCE: ACLU - PROTEST RIGHTS)

RESOURCES

NATIONAL LAWYERS GUILD
212-679-6018

BAIL PROJECT
1-833-425-6TBP

CREATURE FRIEND FINDER
CREATUREFRIEND.ORG

COVID-19 TEST SITE FINDER
HTTPS://MY.CASTLIGHTHEALTH.COM/
CORONA-VIRUS-TESTING-SITES/

STAY SAFE
STAY INFORMED
STAY SECURE

Figure 1.7. Sick in Quarters (SiQ), a collective of disabled and chronically ill artists and activists, published this black-and-white brochure online in 2020 with advice for decreasing the chance of viral spread during and after direct-action events. The brochure also contains information about protest rights and how to stay safe while interacting with police.

and other chronic illness activists responding to the emergent disabilities of Long COVID (Kornstein and Rogers). The following chapter, a conversation between Chancey Fleet and Bojana Coklyat, shares the complex experiences of blind New Yorkers, including the patchwork accessibility of remote access, the global organizing efforts of librarians at the New York Public Library, and the "post-pandemic" rollbacks of accessibility gains (Coklyat and Fleet). We also include chapters on immigrants in New York's Chinatown who find community and creativity in a local senior center, while facing increasing vulnerability not only

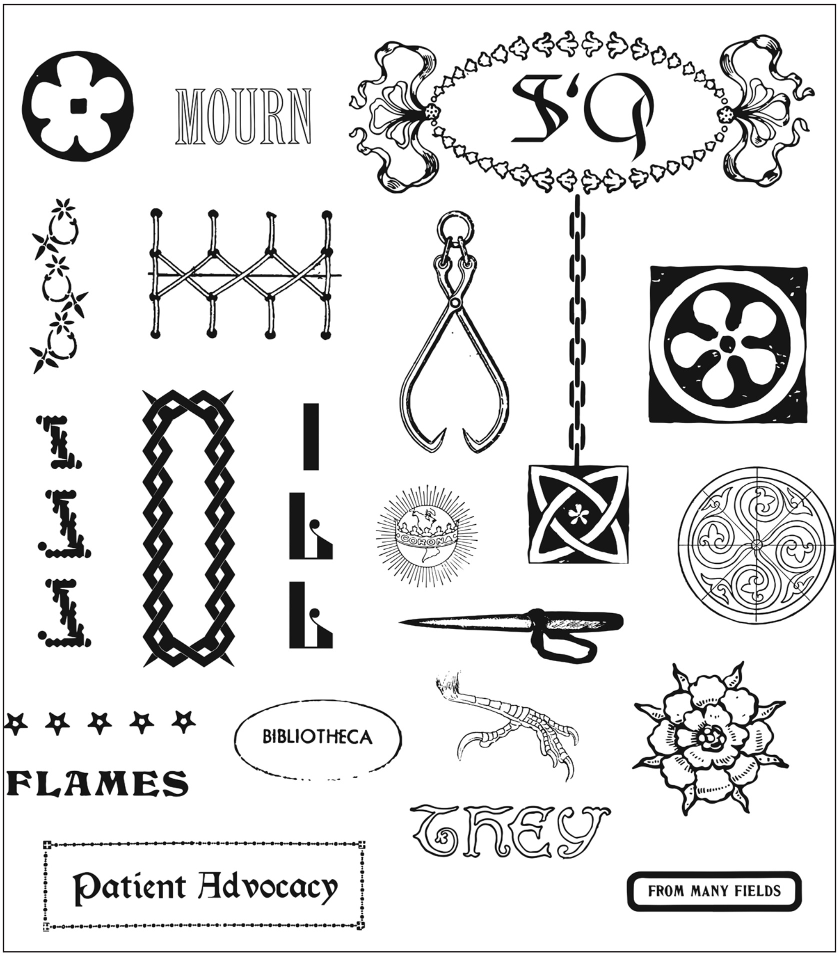


Figure 1.8. SiQ T-shirt design. (Courtesy thai lu)

from the pandemic but also from anti-Asian threats and violence (Li); a roundtable of Asian American disability activists discussing tensions as well as coalitions among groups drawn from varied regional, national, caste, and class backgrounds (Mohapatra et al.); and an analysis of the "iron cage" of medical bureaucracy and health-care disparities that challenge Black people's mental health (Mbonde) in the context of the dual pandemics of COVID and anti-Black racism. The following chapter discusses the pandemic sociality and mutual aid of autistic adults, including low-wage essential workers who were temporarily freed by the CARES Act for social and creative pursuits (Ryan). The penultimate chapter considers how New York City's disabled artists found ways to "make art in bed" while studios and other art spaces were closed, embracing the need for rest and creativity in the midst of COVID (Watlington). The second part concludes with a reflection by Amanda Morris, the first disability reporter at the *New York Times*, on what it was like to cover the pandemic in New York City, the stories she was not able to tell, and the ongoing deaths of immunocompromised New Yorkers from COVID in the present.

We are also pleased that this collection is bookended by the words of the celebrated journalist Ed Yong and the late disability activist Judith Heumann. Yong reflects in his foreword to the volume on the limits of legal definitions of disability and the need to center the voices of disabled people in research and reporting. In the coda, we reprint an excerpt from Judith Heumann's 2022 NYU commencement speech, in which she addresses both the experience of COVID that students sustained and the impact of this experience on the future of disability activism. In order to provide further resources for readers and documentation of some of the otherwise-ephemeral cultural production of the pandemic thus far, we have also included a brief timeline of key public health and disability activist events in New York City's experience of the pandemic, a glossary of terms that have been crucial to crip pandemic theorizing, and images of activist media and actions discussed throughout the book.

Ongoing Pandemics, Disabled Futures

As we complete the edits for this volume, we note the recent appearance of many other journals and books filled with academic "postmortems" of the pandemic, mostly focused on its first year alone.[13] Scholars have extrapolated "permanent changes" from 2020 data, ranging from outdoor dining in New York to wealth gains for certain Americans (and higher rents for others) to work-from-home options around the world (already increasingly rolled back). More importantly, far too many "lessons learned" have focused on the experiences of the nondisabled or gains for the well, rather than the essence of a pandemic: infection, illness, mortality, and disability. One thing remains clear: the COVID-19 pandemic and its impacts are certainly not over—for disability communities or anyone—and the curtailment of public health measures has served to exacerbate risk for disabled, elderly, and immunocompromised people once again.

Nevertheless, on September 18, 2022, President Biden declared on *60 Minutes* that "the pandemic is over," adding, "We still have a problem with COVID. We're still doing a lotta work on it, . . . but the pandemic is over" (Pelley 2022). Many other political and corporate leaders not surprisingly followed suit—if they had not already declared a return to normalcy—loosening what few public health measures remained in place. Just days before, New York Governor Kathy Hochul dropped the mask mandate on New York City's public transportation. This was despite protests from disabled activists (Nessen 2022), who quickly criticized such policy changes as a "you do you" approach to COVID-19 mitigation, rooted in individual responsibility rather than collective action. The shift to voluntary masking on public transport put immunocompromised people at risk, as demonstrated by a new set of MTA posters illustrating riders in various states of masking (Lincoln and Sosin 2022; see figure I.9). Moreover, the Biden administration ended the official US public health emergency on May 11, 2023, signaling a new approach to pandemic policy in which the government would no longer fund testing, vaccines, or treatments but would instead offload these and other responsibilities to the private sector (LaFraniere and Weiland 2023; Cubanski et al. 2023).

Still, the SARS-CoV-2 virus continues to mutate and spread globally. As of April 27, 2024, the CDC reports that 1,190,122 people have died from COVID-19 in the US since the start of the pandemic (CDC 2024). The virus itself and factors related to the pandemic (e.g., depression and addiction) have caused a notable reduction in life expectancy for Americans (Ghorayshi 2023). With each revision of our introduction, we have witnessed new variants, patterns of symptoms, and vaccine protocols.

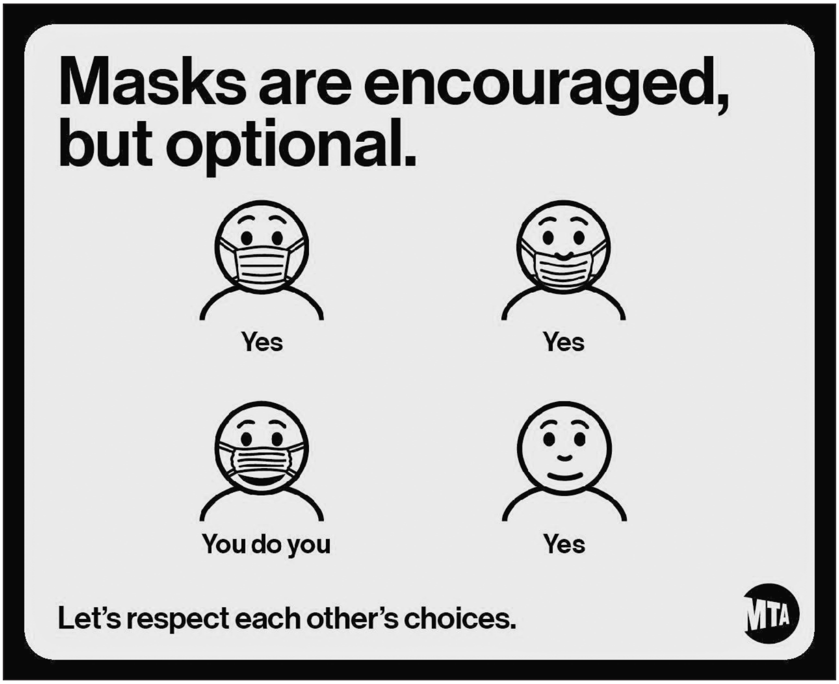


Figure 1.9. MTA "you do you" poster, September 2022. Critics were vocal: "Whoever designed your poster should be fired. It's public endangerment and mask misinformation!!" said Dr. Eric Feigl-Ding, an epidemiologist, in replying to MTA's tweet about the change (Chappell 2022).

In 2022, COVID-19 remained the fourth leading cause of death in the United States, and in the first half of 2023, the elderly accounted for more than 60 percent of all US COVID-19–associated hospitalizations and nearly 90 percent of in-hospital COVID-19 deaths (Rabin 2023; Taylor et al. 2023).

In New York, 46,365 people have died from the coronavirus as of May 9, 2024, about 1 in every 190 residents, a large fraction of those in nursing homes and other congregate settings, many without internet or computer access, and mostly overlooked in popular reporting (NYC Department of Health, n.d.). None of our chapters on congregate settings ends on an optimistic note; none gives any indication that "lessons were learned" from the pandemic to rethink these institutions. In fact, the 2020 New York State budget made it harder to achieve eligibility for home-care services and easier for people to be placed in nursing homes

(New York State Senate, n.d.). By some estimates, 38 percent of early COVID deaths occurred in long-term care and nursing homes alone, and that has been by design (Girvan and Roy 2020).

Strategies for addressing COVID-19 and its lasting impacts must continually evolve. As the microbiologist and essayist Joseph Osmundson writes, "Our work is not to get rid of viruses, or we would, by definition, fail. Our work is to live alongside viruses and to protect as many human lives as we can" (2022, 64). Not surprisingly, disability justice activists remain some of the most vocal critics of a return to so-called normalcy, highlighting preexisting inequities and ongoing threats (especially for immunocompromised people), publishing new survival guides, and reimagining a more just and interdependent future (Piepzna-Samarasinha and Zavitsanos 2023; Mingus 2022).

Activists also continue to demand recognition of Long COVID, noting that each additional infection poses a risk, even for seemingly healthy individuals. The CDC estimates that approximately one in five people

Figure 1.10. Photo of the Brooklyn Bridge at night, March 14, 2021, with projections of photographs of some of the thirty thousand New Yorkers who died of the coronavirus during the first year of the pandemic, for the city's first COVID-19 Day of Remembrance. (Photo courtesy of the New York City Mayor's Office; Chung 2021)

Figure 1.11. Naming the Lost Memorials (NTL), City Lore, and twenty other New York City community groups created “The Many Losses from Covid-19,” a public art memorial along the fence at the entrance to the Green-Wood Cemetery in Brooklyn in May 2020. Since then, volunteer artists and activists have curated NTL memorial sites in New York City, with thousands of nameplates and personalized drawings and photos, created by the families and friends of those who have lost loved ones to the virus. (Photo: Erik McGregor/Sipa USA/Alamy)

with previous infections develops at least one long-term symptom (CDC 2022a; Ledford 2022). Indeed, rates of disablement have risen since 2021 (US Bureau of Labor Statistics 2023). To that end, coalitions like Long COVID Justice have released statements arguing, "We are experiencing a mass disabling event, and disabled people and those with Long COVID must be at the forefront of addressing this unprecedented moment," demanding that political and public health leaders operate from a position of disability justice (Action Network, n.d.).

Our book centers on a lesson provided by Alice Wong (2020) and Leah Lakshmi Piepzna-Samarasinha (2022), that "the future is disabled." Piepzna-Samarasinha elaborates that we must genuinely engage the possibilities of a disabled future, "not just as a cautionary tale or scary story, but as a dream" (2022, 22). Nondisabled people and the "privileged disabled" alike cannot merely learn to live expertly and creatively with viruses to actualize the disabled future (Russell and Malhotra 2002, 218). Rather, the authors in this volume observe the many ways "disabled people are constantly creating an improbable crip future in the face of all that wants to eliminate us" (Piepzna-Samarasinha 2022, 31). At the same time, we caution that the state has gone beyond the usual politics of disposability, mobilizing discourses of disability and care to shore up structural injustice, allocate resources, and institutionalize growing numbers of disabled people who are disproportionately subject to lockdown. In this context, embracing the growing reality that the future is disabled demands that we actualize the dream of disability justice in all corners of New York City and beyond.

May 2024

NOTES

1 James Charlton, in his classic history of the disability rights movement, *Nothing about Us without Us*, writes, "Simply put, this book is about the dialectics of the disability experience: oppression and its opposites, resistance and empowerment" (2000, 5). Since then, the phrase "disability dialectic" has circulated in the work of several other disability studies authors, sometimes in registers distinct from our meaning here.

2 Hart Island is the largest mass grave in the United States, and over a million people have been buried there, from those lost to the flu of 1918 to those lost to AIDS in the 1980s. Hart Island was formerly run by the New York City Department of Correction, which employed incarcerated people at another nearby island, Rikers,

to undertake the labor of reopening or digging new mass graves during each new epidemic. In a cruel echo of history, Rikers inmates were once again brought over to Hart in spring 2020 and paid six dollars an hour to bury the unclaimed bodies of thousands of people who had died in the first months of COVID-19 (Grim 2020). One-third of the burials were Bronx residents (Stabile Center 2021).

3 Michele Friedner to Mara Mills, personal communication, November 12, 2023. See also Friedner (2017) on "disability as 'feel good' diversity."

4 With a similar impulse, in November 2020, the epidemiologists Deborah Wallace and Rodrick Wallace published the brief *COVID-19 in New York City: An Ecology of Race and Class Oppression*. Other collections have looked at racial disparities in infection across the US as a whole or have investigated global inequalities (Thomas, Henderson, and Horton 2022; Wright, Hubbard, and Darity 2022; Manderson, Burke, and Wahlberg 2021).

5 We also connected with other pandemic researchers whose work overlapped with our own—see this book's acknowledgments section—through having remote exchanges focused on ethics, methods, and unexpected findings. (For a more complete list of related projects, please see our website: https://disabilitycovidchronicles.nyu.edu/resources.)

6 For the full ten-point PAUSE plan, as well as "Matilda's Law" for "vulnerable populations," see New York State Governor 2020. Initially admired, Cuomo's leadership collapsed when his political career was torpedoed by a confluence of scandals, including a damning May 2020 report that revealed his strategic undercounting of COVID deaths occurring in nursing homes: long-term care residents who contracted the virus and then were moved to hospitals to die were intentionally left out of tallies.

7 For a powerful chronicle of what transpired in the Coler Nursing Home on Roosevelt Island, see the documentary *Fire through Dry Grass* (Molina and Neophytides 2023).

8 The "lockdown" of nursing homes also had "devastating effects" on residents' physical abilities and mental health, as a result of isolation and short-staffing (National Consumer Voice for Quality Long-Term Care 2021).

9 More recently, homelessness has increased across the United States for reasons that seem to be linked to migration and the government's response to it. See DeParle 2023.

10 We thank Michele Friedner for raising the question of "disability authority" in the Q&A for a "COVID and Cripistemology" panel at the Society for the Social Studies of Science (4S) conference in November 2022, at which several of our contributors presented.

11 For some, the shifts to remote work, education, and other services created new barriers due to limited access to technology, interpretation, or other supports (Weber 2022). Cherokee activist and journalist Jen Deerinwater has detailed the stakes of digital inequality for Indigenous New Yorkers during the pandemic, as well as their technical and economic barriers to "remote access." In New York State, for instance, the Shinnecock lands on Long Island have had only one internet provider, which charges higher fees than most of the tribal members can afford—60 percent of whom live in poverty. With libraries closed and home internet far from universal, telehealth, remote work, and education became challenges rather than solutions for social distancing. Deerinwater importantly points out that Indigenous people "have the highest rates of disability per capita in the U.S. . . . due in large part to the longstanding impacts of colonialism" (2023, 350).

12 thai lu to Mara Mills, personal communication, November 7, 2023.

13 Works focusing solely on New York City include the self-published memoir *Pandemic NYC: An Insider's Account of a COVID-19 ICU*, by traveling ICU nurse E. G. Whitney (2020); *COVID-19 in NYC: An Ecology of Race and Class Oppression* by epidemiologists Wallace and Wallace (2020); *Covid-19 Response in NYC: Crisis Management in the Epicenter of the Epicenter* (Iavicoli, Madad, and Wei 2023); and *2020: One City, Seven People, and the Year Everything Changed* by NYU sociologist Eric Klinenberg (2024), profiling seven New Yorkers during the first year of the pandemic.

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