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Making and Debating the New York State Ventilator Allocation Guidelines

MARA MILLS

At a press conference on May 6, 2020, disability activist Stacey Park Milbern spoke about her fears as a ventilator user facing the COVID-19 pandemic. Lying on her side in bed, with a handwritten sign reading "Equitable Healthcare for All" propped among the sheets in the foreground, she responded to popular reports about ventilator rationing and reallocation:

> It's been pretty scary to navigate COVID-19 as a ventilator user. I was quite frightened early on when my doctor shared that I would likely not survive an exposure. My caregivers, who were not able to fully shelter in place, have had to step back from working with me. As a disabled person, it felt really critical not to get sick. I saw a Public Safety Alert from Santa Clara County, asking people to identify if they use a ventilator for county inventory. I need my ventilator to breathe. My friends and I made emergency plans about what to do if someone shows up at my door asking for my backup ventilator. I was getting advice from friends in medical fields: if disabled people get sick, we may not get care, we may be turned away, we may be discriminated against. (Fat Rose 2020)

In the first months of the pandemic, as hospitals and politicians around the United States began making plans to ration various aspects of health care—from beds in intensive care units (ICUs) to medicines and equipment—activists and advocacy groups for disabled people and seniors demanded that those who were impacted play a role in shaping these policies (Wong 2020). Milbern was cofounder of the Disability Justice Culture Club, a crip of color organizing hub in Oakland, and she also

Figure 5.1. Stacey Park Milbern at the California Care Rationing Coalition May 6 press conference. (Fat Rose 2020)

served as a disability adviser to President Barack Obama's administration. Less than two weeks after the press conference, on her thirty-third birthday, she died as a result of complications from a cancer surgery that had been postponed during the first wave of pandemic "lockdowns."

Stories and predictions about the rationing of ventilators flooded the news and social media in 2020. COVID-19 is a respiratory virus, and when patients began overwhelming hospitals in northern Italy in February and March, the world watched in shock as Italian medical societies issued protocols for rationing ventilators by age and disability. Part of a triage process, typically associated with wartime medicine, these protocols recommended assessing patients for the number of remaining "life years" and "presence of comorbidities," with ventilators and other scarce resources allocated to those who were likely to live longer and require shorter treatment times (Mounk 2020; Han and Koch 2020).

The pandemic crested across the US shortly thereafter. Some states already had "crisis standards of care" guidelines (CSCs) incorporated into their emergency plans; others began drafting them (Ne'eman 2020b; Bagenstos 2020; Manchanda, Sanky, and Appel 2021; Ne'eman et al. 2021). The New York State Department of Health (DOH) had circulated a draft ventilator allocation proposal for public comment in 2007, after which

other states began to include similar protocols in their CSCs. At the outset of COVID-19, in states where guidelines were nonexistent or not activated by a declaration of emergency, hospitals and sometimes individual physicians created their own ad hoc policies for ventilator triage (Antommaria et al. 2020).

Examples quickly circulated of disabled people being denied treatment for COVID in the US as a result of rationing, sparking massive protest among disability activists. In Austin, Texas, Michael Hickson, a Black man who had sustained a brain injury a few years before, died in hospice in June 2020 after being refused care by a hospital, on "quality of life" premises (Shapiro 2020a). In towns across Oregon—even before any shortages of ICU beds or equipment—several cases surfaced of group homes being pressured to complete "do not resuscitate" (DNR) orders for their residents at the start of the pandemic and of doctors requesting the same from patients with intellectual disabilities. Advocates were quick to note that similar practices long preceded COVID: "There has always been a bias against people with disabilities in the health care system. . . . It was largely hidden" (Shapiro 2020b).

Samuel Bagenstos, now general counsel for the US Department of Health and Human Services, argued in a May 2020 *Yale Law Review* forum that "the crisis standards of care adopted by hospitals and state agencies often employ explicit disability-based distinctions" (1). Building on a March 2020 opinion essay in the *New York Times* by disability activist Ari Ne'eman, Bagenstos pointed to the 2016 Tennessee government's *Guidance for the Ethical Allocation of Scarce Resources*, which excluded people with "spinal muscular atrophy," among others "requiring assistance with activities of daily living," from hospital admission during state health emergencies (Tennessee Altered Standards of Care Workgroup 2016). In Alabama, the 2010 state triage guidelines—*Criteria for Mechanical Ventilator Triage Following Proclamation of Mass-Casualty Respiratory Emergency*—deprioritized people with intellectual disabilities as well as older people (US Department of Health and Human Services 2020). Even newer ventilator allocation guidelines, such as those published by the University of Washington Medical Center at the start of the pandemic, emphasized "healthy, long-term survival, recognizing that this represents weighting the survival of young otherwise healthy patients more heavily than that of older, chronically debilitated patients"

(Bagenstos 2020, 3). Disability bioethicist Joseph Stramondo also examined these state triage protocols and concluded that many were based on explicit or implicit "quality of life" (QoL) metrics, which have long been the subject of forceful critique in disability studies. Stramondo has contested what is known as "the disability paradox" in mainstream bioethics, insisting that it is not paradoxical for disabled people to rate the "quality" of their own lives highly (2021, 202).

Ventilators are powerful symbols in triage situations, invoked by the "pulling the plug" metaphor and often caught up in hospital management debates about medical futility and health-care costs. Yet, after a state-by-state survey of crisis standards of care for rationing and other aspects of disaster medicine, a team of scholars led by Ne'eman found that disability activists had largely ignored CSCs before the pandemic (Ne'eman et al. 2021). Moreover, prior to COVID-19, only twenty-six states had published guidelines for allocating ventilators during emergencies (Piscitello, Kapania, and Miller 2020). In an example of what the editors of this volume call "the disability dialectic," COVID-19 brought CSCs to mainstream attention, prompting an outcry by disability activists, lawyers, and bioethicists in the press and on social media—as well several complaints filed with the US Department of Health and Human Services by disability advocacy organizations. As a result, many state ventilator triage plans were revised, and additional states created their own guidelines. Ne'eman's team concluded that those CSCs updated "later in the pandemic were more aligned with advocate priorities"—even if ableist and racial biases remained—suggesting that the "disability rights movement's successes in influencing state triage policy should inform future CSCs and set the stage for further work on how stakeholders influence bioethics policy debates" (Ne'eman et al. 2021, 831; see also Tsaplina and Stramondo 2020).

New York was one of the first states to come up with a plan for allotting ventilators during pandemics, and its guidelines have been broadly influential—however, they were never formally activated during COVID-19. When the New York State Task Force on Life and the Law, a bioethics advisory group established by Mario Cuomo when he was governor in 1985, completed an initial draft of the guidelines for the state DOH in 2007, it recommended the outright exclusion of certain patients from ventilator rationing—such as those with severe burns, those with

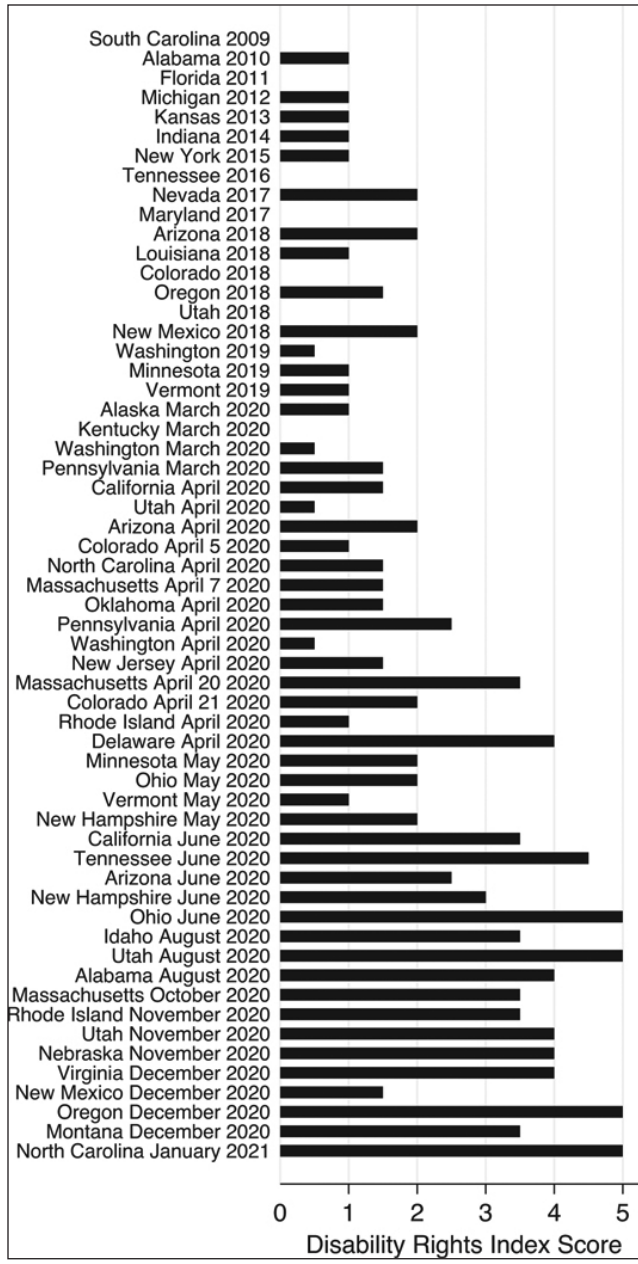

Figure 5.2. Disability rights scores for state CSCs. Multiple versions are shown by date for some states; other states have not produced CSCs and are not represented. "The absence of exclusion criteria, the prohibition of long-term survival, the prohibition of resource intensity, the inclusion of reasonable modifications to clinical instruments, and the inclusion of chronic ventilator protections each constitute one point of five." (Ne'eman et al. 2021, 844)

metastatic cancer, and dialysis users—as well as the use of SOFA scoring (Sequential Organ Failure Assessment) to deprioritize those with a higher likelihood of short-term mortality (NYS Workgroup 2007; NYS DOH 2009). (Short-term mortality was seen as a less ageist or ableist measure than overall "life years.") A group of roughly two dozen volunteers with expertise in medicine, law, and ethics, joined by religious leaders and a small paid staff, the Task Force makes recommendations to the governor and state agencies on health-care policies ranging from surrogacy to genetic testing, often in collaboration with expert workgroups it convenes on those topics. After a long period of public engagement and internal debate about the 2007 draft, the Task Force released the updated Ventilator Allocation Guidelines in 2015, removing dialysis and cancer from the exclusion criteria and including new pediatric protocols (among other changes; see Han and Koch 2020; NYS Task Force 2015). At the time that this chapter was drafted, these guidelines were still published on the New York Department of Health website. Not revised after the advent of COVID-19, they were given a low score of 1 on the Disability Rights Index.

Even if the New York guidelines were never officially "triggered," they have had far-reaching impact: they shaped ventilator protocols at hundreds of hospitals and Veterans Administration health-care centers within New York State, as well as the subsequent development of CSCs in a number of other states (Fink 2009a). During the COVID-19 pandemic, the 2015 guidelines received enormous attention from the press, bioethicists, and disability activist groups like Not Dead Yet (Ne'eman 2020a; Fins 2020a; Pierson 2022; Walsh et al. 2023). Despite the national discussion now surrounding these guidelines—and the enormous amount of state-sponsored labor that went into finalizing them—not only were they never implemented, but Governor Andrew Cuomo went so far as to remark in a 2020 press conference that the state had "no protocol" for ventilator allocation (Kaste and Hersher 2020). Susie A. Han, who directed the review and revisions for the 2015 version, recalls how resource-intensive the process was: "New York's Ventilator Allocation Guidelines represent the culmination of more than nine years of analysis, research, and consensus-building. In total (and not including staff), 69 task force members and adult clinical workgroup members effectively reached consensus on the clinical protocol and the ethical principles upon which the guidelines are based" (Koch and Han 2020, 153). Regarding Cuomo's

disavowal, she suspects that he was concerned about "political and public blowback" along the lines of earlier "death panel" controversies (Koch and Han 2020, 154).

Some physicians and hospital directors claimed that the need to ration ventilators was never reached in New York State during COVID-19 and, hence, that the guidelines were irrelevant. In fall 2020, an announcement was posted to the website for NYU's Langone Health, declaring that "prudent planning" and the transfer of fifty-five new ventilators from a state stockpile had allowed the hospital system to avoid rationing (NYU Langone News Hub 2020). Yet, in March, at the outset of the crisis, the *Wall Street Journal* published excerpts of an email written by Robert Fermia, the chair of Langone's Emergency Medicine Department, telling emergency-room (ER) doctors to "think more critically about who we intubate." As the *Wall Street Journal* explained, ER doctors were told that "they had 'sole discretion' to place patients on ventilators and institutional backing to 'withhold futile intubations'" (Ramachandran and Palazzolo 2020).[1] Immediately after this news broke, several outlets reported that NYU had "threatened to fire faculty doctors if they talked to the press without preapproval from the medical center's Office of Communications and Marketing" (Piper 2020). Han argues that Cuomo's abandonment of the state guidelines led to widespread misinformation, mistrust, and disarray in New York hospitals that first spring (Koch and Han 2020). Some hospitals attempted to implement the New York State guidelines on their own, while others worked out ad hoc or institution-based protocols.

To probe the broader questions such guidelines raise for disability ethics and activism, the remainder of this chapter examines the making of the guidelines themselves—namely, the intensive debates among clinicians, lawyers, and ethicists that yielded a fragile consensus on the 2007 draft (and, in turn, the final 2015 recommendation). As it turns out, this consensus was never unanimous, and much of the skepticism of Task Force members and expert consultants regarding the fairness and enforceability of the ventilator allocation protocols presaged the state of affairs at New York hospitals at the outset of COVID-19. In reviewing Task Force minutes, correspondence, tabletop exercises, and other records formerly held in the New York State Department of Health records, it becomes clear that "ventilator allocation" is commonly

misunderstood to refer to discrete devices and the rights of individual users. Ventilator allocation is, in fact, an elaborate sociotechnical system (a foundational concept in science and technology studies) involving the distribution of supplies and labor among states, towns, health-care providers, and patients. Wealth disparities, often linked to zip code and race, mean that individual hospitals have unequal resources in the absence of state or national protocols for distributing equipment, oxygen, and workers at the institutional level. Only an expanded definition of both "ventilator" and "allocation" could meet the stated goal of this distributive justice project—which was to "save the most lives" (Han and Koch 2020, e35).

Most disability activists do not contest the need for state CSCs—without them, hospitals and individual doctors will (and did) enact their own, often biased, protocols. Rather, as Ne'eman and colleagues have insisted, disabled people need to be included on CSC decision-making teams. The DOH records show that there was very little input from disabled members of the public in the making of the New York guidelines, perhaps as much from lack of concern among disability activists at the time, or other priorities, as from unsuccessful outreach. Adrienne Asch, a blind bioethicist, became a member of the Task Force in 2007, but her dissent from the consensus on the SOFA protocol was only registered in a footnote to the 2015 edition, noting that she preferred a random lottery for ventilators "for its objectivity" (or circumvention of obvious ableism and other forms of bias), even if it did not maximize the number of lives saved (NYS Task Force 2015, 43).

This chapter concludes with further discussion of activist responses to ventilator allocation during COVID-19 and argues the need for new disability imaginaries of what allocation might mean, especially as more disabled people—hopefully—engage in crisis standards of care planning. Other chapters in this volume detail the many different forms that disability activism has taken during the pandemic: protest, social media campaigns, mutual aid, solidarity, "crip doulaing." What is missing is a disability theory of distributive justice, one that takes into consideration not only eliminating ableism at the level of individual diagnosis in the ICU setting but ensuring access to ventilators and other health resources for broad and diverse groups of people in a given city and beyond. Countless theories of distributive justice have been proposed by philosophers

concerned with the sharing of risks, resources, and opportunities across the members of a society (Lamont and Favor 2017). Just as the disability justice movement aims beyond the model of individual disability rights, crip distributive justice would require an expansive definition of disability, including illness and injury; attention to class, race, and region; and a commitment to foundational social change rather than inclusion in an inequitable system (Sins Invalid 2019).

Methods

"Transparency" and "public engagement" were two of the core ethical principles guiding the creation of the New York Ventilator Allocation Guidelines (NYS Workgroup 2007; Antommaria et al. 2020). After publishing the 2007 draft, the Task Force solicited feedback through a variety of channels: thirteen focus groups convened in Albany, Westchester, Buffalo, and New York City; audio- and videoconferences; an email address advertised on the DOH website and in various periodicals; tabletop exercises with New York City hospital staff; and meetings with a group of clinical experts. The focus groups were organized to engage a variety of New Yorkers from diverse education, employment, and income backgrounds: "the elderly (defined as people aged 60+), parents of children under 18, individuals with serious or chronic illnesses, rural residents (defined as people residing in towns with less than 5,000 people), minorities, and young adults aged 22–29" (Han 2023a). Criticisms and comments from these groups led to further rounds of discussion at Task Force meetings (with some changeover of members and directors), eventually culminating in the "final" 2015 guidelines.

Less than a decade later, however, very little is archived or publicly available regarding the committee's internal research and debates, the comments submitted by the public, or the revision and consensus process. I submitted a FOIL (Freedom of Information Law) request with the DOH to obtain copies of the Task Force archives related to the ventilator guidelines—hoping to see what kinds of disability participation and commentary took place—only to learn that the records office apparently never received any materials from the 2015 revision group (directed by Han as well as attorneys Stuart Sherman and Valerie Koch). Moreover the DOH had already purged the materials related to the 2007 draft,

when the Task Force was directed by Powell. Fortunately, journalist Sheri Fink had previously FOILed the ventilator records in 2009, obtaining a ninety-five-page transcript of a 2006 meeting between Task Force members and an expert workgroup, ninety pages of emailed public commentary, the situation manual and tabletop exercises presented to staff at New York Presbyterian Hospital, slides and text from public presentations, and the 2009 summary of focus-group discussions created by The Research Associates. Fink published two articles about the 2007 draft guidelines for ProPublica and had saved the records, generously passing them along to me (Fink 2009a, 2009b).

I also wrote to several of the Task Force members involved in the 2007 and 2015 proceedings. Among those who replied, few had detailed memories or extensive involvement with the write-up or any connection at all to the public engagement process. As a volunteer organization, the Task Force meets occasionally throughout the year to discuss a number of different bioethical issues. The clinical working group on ventilator allocation met more intensively to generate ideas to be passed to the full Task Force, with the write-up itself handled by directors or staff—who, like Han, were themselves not present throughout the entire nine-year process. I spoke to Han and Sherman, who did not know what happened to their hard drives or email archives after they left their positions, and to Powell, who was not aware that the 2007 records had been archived at all. In fact, Powell (2022) commented to me that Task Force meetings were designed "to create a safe and private space in which people with sometimes strongly different views could speak freely and in confidence to see if they could arrive at common ground. Having those conversations made public was viewed as a way to kill any opportunity for creative solutions." The DOH policies around archiving clearly need to be articulated to the Task Force as well as the public, and this archiving and transparency gap needs to be addressed at the records level for DOH initiatives with dramatic public impacts—not only as a matter of public trust but as a way to educate citizens about the different scales and perspectives (scientific, government, religious, community) through which complex bioethical policies are considered.

The packet of comments on the 2007 ventilator allocation proposal shows that many health professionals weighed in during the public feedback period, but few other New Yorkers did. The minutes of the March

2006 meeting of Task Force members with outside experts are unusual in that the meeting itself was tape-recorded and thus fully transcribed. Other Task Force meetings on the same topic are not documented. (Han told me that later meetings, leading to the 2015 revised guidelines, were not recorded, nor were minutes or notes archived.) Powell, who introduced and moderated the 2006 meeting, explained to the group the purpose of the recording: to "keep us honest about where we did find consensus, and where we did not" and to "singl[e] out comments that actually might have been extremely useful but didn't find their full range of play during the day's conversations" (NYS Workgroup 2006, 1). Because participants were told the recording was for "internal purposes only" and because the separate records of public commentary consist of individual emails sent to Task Force members or the DOH, I maintain participants' anonymity by summarizing the themes that emerged as points of debate relevant to disability and the subsequent COVID-19 pandemic. Some of these materials were formerly posted on the ProPublica website, linked to one of Fink's articles, but now they are held privately on my and Fink's computers (Fink 2009b). When I offered to return the materials to the DOH, the records officer declined.

Contestation Surrounds Consensus

At the request of the New York DOH, the Task Force on Life and the Law convened a workgroup on "Ethical Issues in Ventilator Allocation in an Influenza Pandemic" in March 2006, cochaired by Gus Birkhead of the New York State Department of Health and Tia Powell, a psychiatrist and bioethicist who directed the Task Force at the time. Concerned about avian flu and responding to the US Department of Homeland Security's claim that "pandemic influenza [was] both the most likely and most lethal of all threats facing the United States," the DOH had drafted a pandemic preparedness plan in 2004 and circulated a revised three-hundred-page draft the week before the workgroup meeting (NYS Workgroup 2007). Based on the federal pandemic plan of 2004, the state plan laid out a range of responses such as social distancing and school closures. The goal of the workgroup was to clarify the ventilator component, thought to be critical for a future pandemic event in the period before a vaccine became available.

The workgroup consisted of roughly three dozen people with clinical and ethics expertise, including several representatives of the New York State DOH; health commissioners from across the state; bioethicists, physicians, and medical directors at Bellevue, Cornell, Columbia, NYU Langone, and Montefiore hospital systems; respiratory therapists and law professors; and representatives of the New York Academy of Medicine and Hastings Center. Several Task Force members also participated.[2] The conversation at the March 2006 workgroup meeting, like the draft guidelines issued the following year, ranged from pre-triage planning for hospitals to palliative care for dying patients and legal aid for doctors who complied with the rationing guidelines. Powell commented at this planning session, "To my knowledge, I'm not sure anyone else is . . . as brave or as foolhardy in actually trying to map out a strategy for this specific problem" (NYS Workgroup 2006).

The state pandemic plan already contained various examples of rationing, for instance, prioritizing health workers and at-risk New Yorkers for vaccines. As part of the ventilator workgroup's more focused rationing topic, it reviewed an article published in February 2006 by John Hick and Daniel O'Laughlin, physicians working with the Minnesota Department of Health and Terrorism Task Force, who recommended Sequential Organ Failure Assessment (SOFA scoring) as "the most useful" tool for predicting mortality in an ICU environment (Hick and O'Laughlin 2006). Later, Powell and the other authors of the 2007 draft guidelines would additionally cite the Ontario Health Plan for an Influenza Pandemic, published in April 2006, which also recommended SOFA scoring. Patients with high scores (high mortality probability) either would not be allocated ventilators or would have ventilators removed and reallocated if their scores worsened over time in the ICU. Prior to SOFA scoring, some patients would be denied ventilators on the basis of a set of exclusion criteria, such as "severe chronic lung disease" or "severe burn." The New York ventilator workgroup essentially adapted these rationing plans, with a particular concern to eliminate any subjective quality-of-life biases by using only "objective" mortality metrics. It termed the New York protocols "guidelines" because they were meant to be "flexible": the 2007 draft explains that the DOH could activate the guidelines for state hospitals in either a "binding" or "nonbinding" manner.

Criticisms of US ventilator allocation protocols during the COVID-19 pandemic have focused heavily on the exclusion criteria and SOFA scoring, finding them to encode a range of ableist and racist biases, as well as subjective presumptions about mortality and even implicit quality-of-life assumptions. But the New York State Ventilator Allocation Guidelines of 2007 and 2015 reached far beyond the emergency-room and intensive-care settings. The "distributive justice" statement in the 2007 draft also discussed the need for fair allocation, or reallocation, of ventilators among different hospitals throughout the state: "A just or equitable healthcare system cannot allow for more expansive access at a prestigious private facility and more restrictive access at a community or public hospital" (NYS Workgroup 2007, 16). Because SOFA scoring seems to be concrete, impacting individuals in a way that is easy to envision, it has dominated the disability activist and ethics understanding of what ventilator allocation means—even though allocation occurs at numerous distinct scales.

Triage plans also take many forms, underpinned by distinct philosophies. A 2020 survey of policies at US hospitals found that more than half did not have a ventilator allocation plan in place at all. Among those hospitals that responded and did have plans (and were not among the 10.4 percent prohibited from sharing their policies), the authors found that "the most frequently cited triage criteria were benefit (25 policies [96.2%]), need (14 [53.8%]), age (13 [50.0%]), conservation of resources (10 [38.5%]), and lottery (9 [34.6%]). Twenty-one (80.8%) policies use scoring systems, and 20 of these (95.2%) use a version of the Sequential Organ Failure Assessment score" (Antommaria et al. 2020, 188). The New York State guidelines of 2007 and 2015, an early adopter of SOFA scoring, were based on the principle of "saving the most lives," rather than the typical hospital procedure of "first come, first served" for providing ventilators to patients. During the workgroup meeting in 2006, this founding principle was debated along with several subthemes related to "ventilators" and "allocation." Much but not all of the deliberation addressed disability explicitly or implicitly, although none of the participants openly identified as disabled. The members of the working group did discuss other potential sources of bias resulting from the makeup of the group, such as the fact that only one person of color was present.

During the COVID-19 pandemic, the presence of Adrienne Asch on the Task Force has occasionally been invoked—in a version of tokenization or even cripwashing (the use of disabled people or disability rhetoric to justify problematic policies)—to demonstrate the inclusion of disability perspectives in the making of the New York ventilator guidelines (Fins 2020a, 2020b). It is rarely, if ever, pointed out that she only joined the Task Force in 2007, and she preferred the random lottery approach, which would give everyone in a particular emergency setting an equal chance, even if it did not optimize the number of lives saved. But even patient lotteries do not solve the problem of allocation between hospital departments, hospitals, cities, and states—that is, between populations rather than individuals—a task for future disability theory.

What Is a Ventilator?

At the start of the 2006 workgroup meeting, Birkhead noted that New York State was already planning to increase the state stockpile of ventilators in preparation for a pandemic. In the open discussion period, it quickly became clear that ventilator use requires much more than devices alone. One participant mentioned oxygen supplies as a limiting factor, as well as federal patterns of oxygen distribution. Others brought up the issue of disposable materials like oxygen meters, cannulas, and other tubing, some of which could not be stockpiled without compromising their integrity over time. Far and away, there was consensus that labor, and not technology, would be the limiting factor in a crisis. Health-care workers would become sick themselves, and some would quit their jobs or flee cities. And already, far too few people were trained in intubating patients, monitoring them while on ventilators, and maintaining the equipment to meet the needs of a pandemic. Even if the state stockpiled an enormous number of ventilators, rationing would be required to address labor, oxygen, and disposables.

At the start of any pandemic, as part of the state emergency plan, hospitals trigger "surge capacity" protocols to convert as many spaces as possible into ICUs. Joseph Fins, a bioethicist, internal medicine physician at New York Presbyterian, and Task Force member, described what this looked like in practice during the onset of COVID-19 in New York City:

> An inadequate number of ventilators was met with remarkable innovation. Anesthesia machines were repurposed to ventilate patients, and ventilators were modified to accommodate two patients at a time. Pop-up ICUs were built in converted operating rooms, hospital lobbies, and on regular medical floors never designed for such a purpose. Field hospitals were built on Baker Field in Central Park and the U.S. Navy ship Comfort came to our assistance, docked on the Hudson. . . . Physicians who were not intensivists and hadn't been in an ICU since medical school or residency were given charge of patients who were critically ill, often working beyond the limits of their training. In his Executive Order of March 23, 2020 Governor Andrew Cuomo . . . allow[ed] practitioners to practice outside their usual scope of practice and permitt[ed] practitioners licensed in other states to come to New York in mutual aid during the public health emergency. This also allowed medical students to graduate early (as they did during World Wars I and II) to add to the workforce. (2020c, 142)[3]

Different types of ventilator were called into ICU service, but without activation of the allocation guidelines by the state, hospital systems made their own plans for distributing ventilators as well as ECMO (extracorporeal membrane oxygenation) machines.[4]

Tia Powell and Elizabeth Chuang have similarly described the surge capacity preparations at Montefiore Health System in the Bronx, with the conversion of administrative spaces and gyms into hospital rooms and the onboarding of many trainees. Despite this expansion of capacity, they surmise that "ad hoc rationing" probably took place at the hospitals "hit earliest and hardest" (Powell and Chuang 2020, 63). One Manhattan surgeon I spoke to told me their "hospital looked like a war zone," with operating rooms used as overflow ICUs, plastic shields cordoning larger areas into smaller ones, a rush to install new heating, ventilation, and air-conditioning (HVAC) systems and high-efficiency particulate air (HEPA) filters, and the creation of temporary morgues using refrigerated trucks parked outside hospital buildings. Shortages of oxygen concentrators and oxygen itself also began to be reported, in New York and around the world, not only in hospital settings but for home use by those who were newly disabled by Long COVID and post-COVID symptoms (Sampson 2020; Devereaux et al. 2021; Rivera 2021; Ross and Wendell 2023).

A related aspect of the state emergency plan, enacted during the early months of COVID-19, was the cancellation or postponement of elective surgeries to prioritize the treatment of those who fell ill from the virus. In regular times, the workgroup underscored that 85 percent of ventilators in New York are "encumbered" by those who are undergoing or recovering from surgical procedures, in addition to disabled people in nursing homes, other long-term care facilities, hospices, or private settings (i.e., acute as well as chronic use). One outcome of ventilator rationing—understood in an extended sense—was thus a larger number of deaths than usual from heart attacks and other cardiac issues; more people arrived at hospitals "dead on arrival," and the refrigerator trucks handled those deaths as well as those from COVID. Not only were "elective" cardiac surgeries canceled, but many people experiencing heart problems stayed home as a result of fear or confusion about when to go to the hospital. While activists have protested the possibility of certain disabled people losing their backup ventilators to rationing, there has hardly been any comment about the loss of life from ventilators being shifted away from those who required heart and lung surgeries to those who were newly ill from COVID. As the workgroup participants asked in 2006, who is considered disabled? Is everyone who requires a ventilator (at least temporarily) disabled?

The question was also raised among members of the workgroup of whether ventilators were being overemphasized as a technical fix to the complex problems of public health during a pandemic. How dominant was ventilator allocation in the overall state plan? How much money and time would be spent on ventilator allocation as opposed to, say, vaccines—which would certainly save more lives? Powell and Chuang point out that ventilators turned out not always to be appropriate for the specific impacts of COVID-19, and the use of ventilators and cardiopulmonary resuscitation (CPR) was sometimes medically futile. "By focusing on cure, and specifically on ventilators, we lacked appropriate planning for the predictable and large numbers of fatalities" (Powell and Chuang 2020, 64). Although ventilators help save some lives, they do not provide an automatic "cure" for COVID. In fact, certain types of ventilators as well as prolonged mechanical ventilation are linked to high mortality rates—and ventilators can also leave people with additional lung injuries (Tsaplina and

Stramondo 2020). Elsewhere, Powell has noted that futile mechanical ventilation can lead to a painful or "bad death" (Foggatt 2020).

What Is Allocation?

Allocation was often used synonymously with rationing and triage in the documents I reviewed, partly because allocation requires (or becomes) rationing when resources are scarce. The 2007 draft guidelines narrate certain ethical premises related to rationing about which the workgroup had disagreed in 2006. But even the exclusion chart and scoring criteria in the 2007 draft, which appear to be objective and neutral, had been the subject of much debate.

Regarding who might be favored or excluded in the first step of an allocation protocol, the 2006 workgroup discussed whether health-care workers, especially those risking their lives to help others during a pandemic, should be prioritized for ventilators if they themselves fell ill. Ultimately the committee felt that too many essential workers were involved in health care—nurses, cleaners, food servers, administrators—to make this kind of determination. In the transcript of the taped discussion, there did not seem to be unanimous consensus on the criteria for excluding a person from access to a ventilator either, even though the draft guidelines released the following year proposed a list that included cardiac arrest, cancer, severe chronic lung disease, dialysis dependence, and evidence of a "severe, irreversible neurologic event." In the workgroup, one presenter noted that basing triage "on pre-existing conditions inherently puts an uneven burden on the groups of patients that it's dealing with": "since many of those pre-existing conditions unevenly affect different social groups—disabled, AIDS patients, cirrhotics—I think then that it's internally inconsistent to say we can't value life and social worth, but then making criteria which inherently sort of do value life and social worth" (NYS Workgroup 2006). In the public commentary on the 2007 draft guidelines that resulted from the workgroup meeting, dialysis as a criterion for exclusion generated the most pushback. From nephrologists to advocates at the National Kidney Foundation, people wrote to the Task Force, the DOH, or the email hotline (panflu@health.state.ny.us) to explain the internal diversity of dialysis patients, treatments, and outcomes and to protest "dialysis dependence" as a potential reason for ventilator

denial during a pandemic. At a meeting to discuss the draft guidelines in Erie County, health-care workers in attendance pointed out that "hospital staff would find exclusion of patients they treat routinely, such as dialysis patients, to be difficult" (NYS DOH 2006–8). In response, the 2015 guidelines were amended to remove this criterion.

For the second step of the protocol, the workgroup debated using SOFA scoring as a way to assess the short-term mortality of patients in emergency settings, denying ventilators to those with worse (i.e., higher) scores even if they had passed the initial exclusion criteria. Meeting participants queried whether the SOFA measures would even be suitable for the unknown pandemic to come. In the context of privatized health care, others pointed out that SOFA was pragmatic because it was not proprietary, unlike so many other commercial testing systems that would be too expensive to apply widely during a pandemic. Some noted that SOFA scoring might simply be irrelevant during a pandemic: if a hundred people were waiting in an ICU for a ventilator to become available, the system would essentially revert to first come, first served. Furthermore, emergency medical services (EMS) frequently intubated patients in ambulances or in their homes. Would EMS have time to comply with the scoring protocols or to coordinate with hospital ERs and ICUs regarding the patients waiting in line?

SOFA scoring was also to be applied at fixed intervals *after* a ventilator was in use, with patients who showed worsening scores having their ventilators reallocated to newly arriving patients with better scores. The timing and cutoffs for this repeat scoring, and the idea of extubation itself, became a major topic of debate among the workgroup. The 2007 draft guidelines reflect this uncertainty, noting that the workgroup "struggled with the notion of removing less-ill patients from ventilators, particularly those who might recover with continued mechanical ventilation" (NYS Workgroup 2007, 17). However, the guidelines clarified that chronic-care facilities should "not be subjected to acute care triage guidelines" (NYS Workgroup 2007, 29). In other words, disabled people using ventilators in their homes or in a chronic-care facility would not be triaged under this proposal (as has commonly been misunderstood); however, any ventilator user entering a hospital or other acute facility would be subject at that point to the same protocols as everyone else. One participant in the 2006 meeting pointed out the potential ableism

of employing any fixed pattern of repeat SOFA scoring: "If people could argue that because their disability differently affects their recovery, the medical criteria should be applied to them differently." Another suggested that it would be "reverse discrimination against the critically ill" *not* to apply the protocols to everyone requiring ventilation (NYS Workgroup 2006). Some workgroup members speculated about exclusion and extubation protocols leading to riots and violence against doctors and nurses, as well as mental health issues for at-risk people, family members, and health-care workers.

Although the use of exclusion criteria and SOFA scoring to withhold or withdraw ventilators from individuals has dominated disability activism during COVID-19, the working group also spent a great deal of time discussing regional allocation. For instance, if New York City was "hit first," would rural hospitals have to transfer ventilators to the city? How would those hospitals get their ventilators back if they needed them? If rural or smaller hospitals typically send patients requiring specialist care to major health centers in the city, would they have to deny their patients access to urban resources during pandemic "lockdowns"? The workgroup was also concerned about poverty and other forms of inequality creating a vastly unfair pattern of allocation between different hospitals, even in a single city, with wealthier people able to "hospital shop." This inequality pertained to disability in unexpected ways, with wealthy and "well-organized" disability rights and disease advocacy groups likely to obtain *more* resources and better care than disabled and nondisabled New Yorkers and migrants in low-income neighborhoods. To convey a sense of the debate, since the meeting transcripts are no longer archived, I offer a few outtakes from the 2006 workgroup meeting:

> Not all hospitals are created equal.
>
> Hospitals with more limited resources might not be able to buy or rent supplemental ventilators either before or during the crisis. State pandemic plans should assess how to balance the differences among facilities in their ability to pay for and provide surge capacity.
>
> Are all these assets automatically going to arrive at the places that need it, or are hospitals going to need to go into the market to make up the

gap, and if that's true, then your cash-starved hospitals aren't going to find vendors who want to deal with them.

Hospitals in less affluent neighborhoods typically serve a far larger population base. Thus, a system of rationing that permits wide variation between hospitals in different areas will likely result in excess mortality for the poor.

Ventilators are a symbol, they don't treat the patients, they're a piece of equipment and I really hope that we're thinking about doctors and nurses who know how to take care of these important assets to help patients survive.

To what extent do you think there is a potential for people buying themselves out of the system, in other words setting up private ventilator clinics or some other deal? It's going to happen, it's New York, it's the US, it's a capital, it's a market-driven system.

If there is pandemic flu, it's not going to stop at New York's borders, and the crisis of demand and the crush of demand especially if Connecticut and New Jersey haven't yet begun to meet the challenge of what might happen, is that people will simply cross the bridges and tunnels and come to New York for treatment. I can't imagine if they have a New Jersey address, a sick person will be turned away.

People who have been not well served by the healthcare system until now are likely to have chronic conditions which are going to weigh against them in whatever triage system we set up, so it's not really possible to create just plans and programs in an unjust system.

Community participation doesn't always increase justice because some people are much more organized, specific disease group advocates are, in fact, extremely well organized, much more so than the vulnerable poor so that's just to flag the fairness of that.

The revised 2015 guidelines, which became so influential and controversial, built on the 2007 draft that derived from these conversations, as

well as from public commentary emailed to the DOH or collected during focus-group sessions organized by members of the Task Force (NYS Task Force 2015; Han and Koch 2020). Relatively few people emailed their reactions to the publicly posted 2007 draft, which Powell partly attributed to "fatigue for the public in hearing of the pandemic flu" (Powell 2022). The Research Associates, a "market intelligence strategy" company, summarized the results of a December 2008 focus-group meeting in Albany, in which participants were asked to debate scenarios for allocating ventilators to incarcerated people versus police officers, citizens versus undocumented immigrants, and medical versus nonmedical professionals, as well as the potential exclusion of those with "self-inflicted illnesses." Participants varied widely in their opinions, underscoring the need for guidelines with a "clinical algorithm" and greater public education (Research Associates 2009, 2–3, 5). The 2015 revision, chaired by Susie Han of the NYS Task Force (Powell having by then stepped down from the role), maintained the overarching goal of "saving the most lives." SOFA scoring was also maintained, albeit with more specificity regarding timing and metrics and an attempt to restrict exclusion criteria to measures of "short-term mortality," as opposed to more descriptive phenomena such as dialysis use or metastatic malignancy. Mainly, the 2015 revisions entailed new pediatric and neonatal plans and an expanded analysis of legal issues.

In 2020, although New York State did not invoke the guidelines, unequal access to ventilators derived jointly from the absence of statewide protocols and from disparate hospital arrangements, with hospitals either implementing ad hoc plans or voluntarily following the guidelines (despite their biases). Prior and current members of the Task Force have written about the "disarray" in New York hospitals before vaccines became available, resulting from a void in state guidance, with the planning burden placed on departments and already-overwhelmed medical staff (Powell and Chuang 2020; Fins 2020c; Han and Koch 2020). Examples abounded in 2020 of inefficient or unequal allocation between institutions—a topic of much conversation at the workgroup meeting that was not reflected or easily condensed into the guidelines. For instance, it was widely reported that Elmhurst Hospital in Queens—an early "epicenter within an epicenter" of the COVID-19 pandemic—quickly exceeded double capacity in early March 2020, while hospitals just twenty

minutes away still had open beds (Dwyer 2020).[5] Powell and Chuang also note that allocation of protective equipment was not well thought out; thus, hospices, which had ventilators and staffing and could have admitted patients with COVID, were not able to until workers received personal protective equipment (PPE) (2020, 4).

The 2006 workgroup had also warned that the different divisions within a given hospital would probably diverge in their interpretation of triage protocols; for instance, it would always be "the job of the physician to advocate for their patient and so the ICU physician is going to have to advocate for their patient. The ER physician is going to be advocating for their patients" (NYS Workgroup 2006). One physician told me that their New York hospital system created its own ECMO allocation guidelines early in the COVID-19 pandemic, which potentially involved withholding treatment from those who would have received it in nonpandemic times. They had not been aware of the 2015 state guidelines until they read an article about them in the newspaper. At the weekly meetings of the ECMO programs in their system, it soon became clear that some sites were following the internal guidelines more stringently than others. With disposables running out, moreover, the larger hospitals were not reallocating materials throughout the system as they were supposed to. The ECMO physicians were under conflicting pressures from other departments within their hospitals—with managers demanding that the guidelines be adhered to for labor, cost, or legal reasons and ER doctors and intensivists calling "over and over," day and night, to beg for the rules to be waived on behalf of particular patients. In fact, this physician recalled one of the hospital bioethicists—a member of the Task Force—advocating on behalf of a patient who did not meet the hospital's own criteria for ECMO, a sign of just how difficult it is to shift from the model of autonomy (patient and physician) to a population-based or distributive-justice approach. At the same time, all of the hospitals participated in the online COVID database and dashboard hosted by the Extracorporeal Life Support Organization (ELSO), so they could keep track of patient outcomes under different treatment conditions around the world—a kind of tool not considered during the making of the 2007 and 2015 guidelines, which ideally would allow allocation plans to be revised in real time.

Other Task Force members have now documented occasions when ventilator rationing following the 2015 guidelines did occur in New York

at the outset of the pandemic. Fins, for one, argues, "Although the official line from the state was that there were enough ventilators to go around, the reality was that the system buckled. . . . At the peak of the surge, multiple patients were potentially in need of intubation. Not all could be helped" (2020c, 141, 143). He quotes an April 2020 listserv post from an ethicist at Lincoln Hospital, who wrote, "I work at a city hospital in the South Bronx in one of the parts of town most impacted by covid. We came up to the brink 3 weeks ago with no available ventilators of any kind at which time we implemented step 1 exclusion criteria triage (NY State Ventilator Allocation Guideline, 57). Fortunately, the only patients withdrawn from ventilators that day (without advance directive or family permission) were those with true physiologic futility" (Fins 2020c, 144). Many similar stories of rationing in spring 2020 are no doubt forthcoming, from the perspectives of patients as well as health-care workers—despite hospital efforts to silence staff on this issue.[6]

Conclusion: Toward Disability Distributive Justice

Disability activists and scholars have responded to 2020 by demanding new state protocols, revised with input from disabled people. For instance, Ari Ne'eman and colleagues have now called for a reinterpretation of "short-term mortality risk" as the supposedly objective basis of exclusion and withdrawal criteria. While they support the principle of optimizing the number of lives saved—in distinction from Asch's random lottery approach—they argue that "short-term mortality risk should be interpreted narrowly to avoid unnecessarily screening out of individuals with disabilities and to reduce the risk of bias from more subjective longer-term judgments. Our preferred standard would be survival to hospital discharge" (Ne'eman et al. 2021, 834). The 2015 New York State guidelines have yet to be updated, however, and activists have experienced significant setbacks regarding their hopes for revision. For instance, Not Dead Yet, Disability Rights New York, and Neuromuscular Disability Support United recently lost a lawsuit they filed in 2020, demanding that the New York State Ventilator Allocation Guidelines be amended to prevent chronic ventilator users from having their devices reallocated in acute-care settings (Pierson 2022).

Other activists have protested specific elements of SOFA scoring, such as the Glasgow Coma Scale, which measures "consciousness" through eye, motor, and verbal responses and can inappropriately lower the scores of people with speech and motor impairments (DREDF 2020). Along similar lines, Harald Schmidt, Dorothy Roberts, and Nwamaka Eneanya have highlighted the racial bias in the creatinine measure that is also part of SOFA scoring, explaining that "creatinine is higher in Black communities because of higher rates of chronic kidney disease, due to higher rates of diabetes and high blood pressure that are best understood as the consequences of health inequities and structural racism" (2021, 127). Ne'eman and colleagues point out that the state of Massachusetts recently modified its CSC guidelines by reducing the weight given to creatinine within SOFA scoring; they suggest that "this represents a precedent-setting extension of the disability rights framework of reasonable modifications to other systemic inequities" (2021, 841).

These scoring protocols take on even greater significance with the rise of automated/AI (artificial intelligence) systems in health care, which employ decision trees using numeric data like SOFA scores—offering another layer of technological solutionism to the existing misconception that ventilators alone "save lives" (Whittaker et al. 2019). I attended several online hospital-management seminars during the first two years of the pandemic and note the increase of proposals for automating everything from decisions about extubation to distributing patients among hospitals—on the basis of minimal data entry by doctors and nurses.[7] At the same time, the New York guidelines and their reliance on SOFA scoring have come under intense scrutiny from other corners of the scientific community. A team of biostatisticians and pulmonary doctors at NYU recently published a study simulating triage with the 2015 guidelines, using medical records from March–July 2020. They found that most "rationing" occurred not at the first step (exclusion criteria) or the second step (SOFA scoring to decide whether to assign or withhold a ventilator) but at the third step—where ventilators were extubated and reallocated after repeat SOFA scoring. The authors expressed concern "that NYVAG [New York Ventilator Allocation Guidelines] might ration ventilators away from patients with a high chance of survival (44.4%) toward newly intubated patients with a lower chance of survival (34.8%)"—the problem being that SOFA scores miss "prognostic

nuances" that health-care providers or triage committees could better assess with a wider range of information (Walsh et al. 2023).

Much of the critical analysis and disability activism surrounding ventilator allocation remains focused on withholding/withdrawing devices from individuals. As many chapters in this volume show, disabled people are experts on rationing, especially in a privatized context that generates artificial scarcity around health care, not to mention an ableist context where implicit triage is the norm (Trowe 2022). Disabled people brought this expertise to the COVID-19 pandemic—and emergency conditions of genuine scarcity—in advocacy and mutual-aid projects such as #ICUgenics and #NoBodyIsDisposable. Patty Berne of Sins Invalid coined the latter phrase before the pandemic, uniting fat and disability activists, to protest the logic of "disposability" that inflects US economic, health, and housing policies for disabled people. #NoBodyIsDisposable became an intersectional and multipronged campaign against "triage discrimination" from the first year of COVID-19. The campaign includes the vital open-access publication "Know Your Rights Guide to Surviving COVID-19 Triage Protocols," a toolkit that offers detailed and clear instructions about necessary legal documents, the cities that have favorable laws, how to find an advocate and engage with triage committees, items to bring to the hospital, and how to request and interpret the contract for one's personal medical equipment (#NoBodyIsDisposable 2020).

Contemplating queer/crip mutual aid strategies as another type of response to health-care shortages and rationing, Emily Watlington describes a work by disability artist Alex Dolores Salerno in chapter 14 of this volume, consisting of a coded phrase embroidered onto a pillowcase (translated as, "Please be discreet, carefully disguising any medication words"; see figure 14.2, also in color in figure P.15). Regarding the Facebook mutual-aid group where this phrase was initially posted, Watlington writes, "The group hoped to enable resource sharing for medication and hormones at a time when these became especially difficult to access, with mass layoffs resulting in lost insurance and with the new risks involved in going to doctors' appointments or pharmacies. But, in an effort to evade surveillance—since sharing prescriptions, no matter how necessary, is illegal—participants were asked to write in code, replacing letters with special characters to evade search or algorithmic detection" (Watlington, chapter 14 in this volume). Might future crip mutual-aid

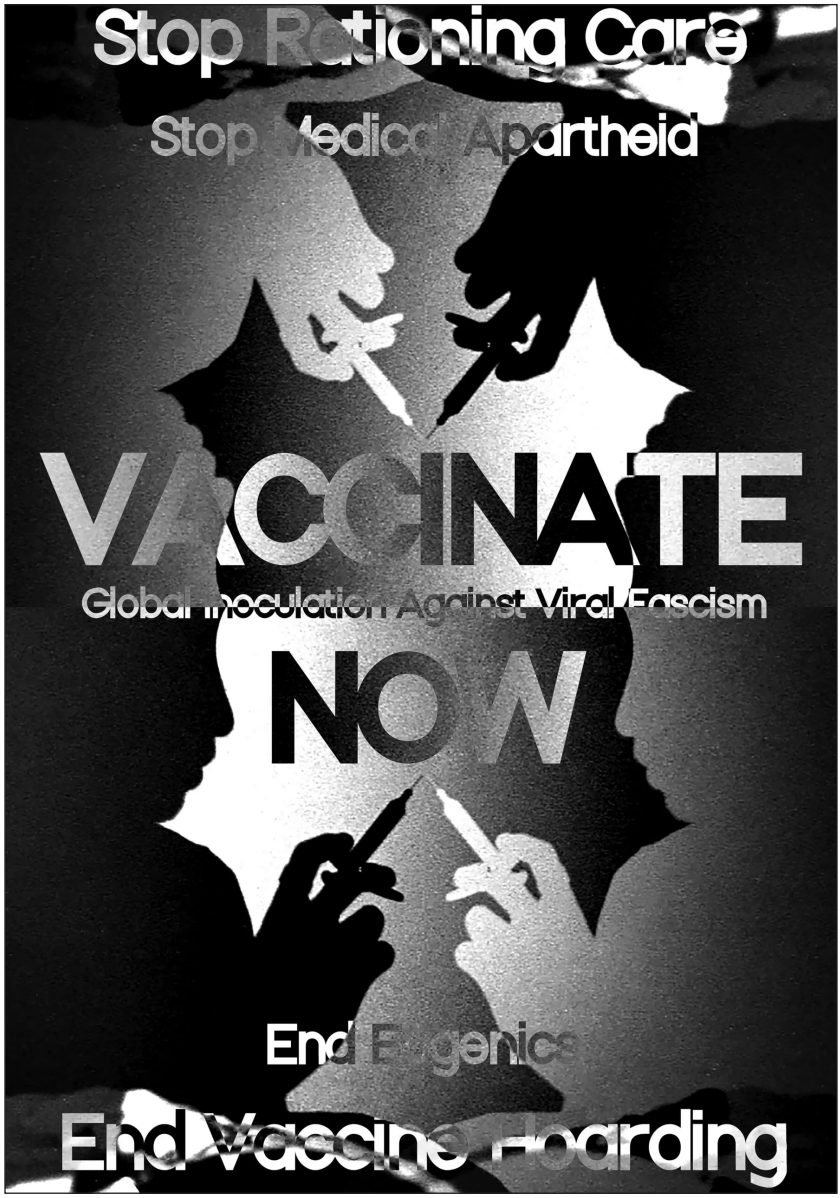

Figure 5.3. *Pareidolia (Vaccinate Now)*, 2021, Brothers Sick (Ezra Benus and Noah Benus). A black-and-white poster of silhouettes holding syringes. Written above the figures in varying font sizes from top to bottom are "Stop Rationing Care," "Stop Medical Apartheid," "Vaccinate Now," "Global Inoculation Against Viral Fascism," "End Eugenics," and, at the bottom of the image, "End Vaccine Hoarding."

projects emerge around "oxygen inequity" and the limited, unequal availability of ventilators, oxygen concentrators, disposables, and oxygen itself (Ross and Wendel 2023)?

The question remains as to how disability expertise might be extended to regional or population-based allocation. Medicine and disability rights are often at odds with each other, yet both have been dominated by an "autonomy model," focused on the individual, which creates friction for distributive justice projects with a social or societal orientation. Some of this friction is a necessary and urgent check on biased or profiteering state and managerial protocols for distributing labor and resources. Building on the disability justice movement and the cosmos of mutual aid, what remains to be imagined—and will be required of the disability ethicists and activists who contribute to the next set of ventilator allocation guidelines—is a theory of *disability distributive justice*. As the collective project of *How to Be Disabled in a Pandemic* insists, cripping distributive justice requires thinking across disability identification, disability activism, and those groups of people who are marked by class, race, and citizenship status for debilitation—and then written off for their "comorbidities" in pandemic times.

NOTES

1 In April 2020, *Politico* reported on a similar allocation plan in a memo sent by Northwell Health management to its clinical staff (Eisenberg and Goldenberg 2020).

2 The Task Force is a smaller group of roughly twenty people. Current members, some of whom have served decades-long terms, are listed at the New York DOH website (NYS DOH, n.d.). The full list of 2006 ventilator clinical workgroup participants can be found in an appendix to the 2007 draft guidelines (NYS Workgroup 2007).

3 To address the legal liability issues of out-of-state practitioners and those working outside their fields of training, Fins explains, "With intense lobbying from medical groups and the health bar, the governor inserted the Emergency or Disaster Treatment Protection Act (EDTPA) of 2020 into the state budget, which was signed into law on April 3, 2020. The EDTPA extended limited civil and criminal liability in the context of the public health emergency retroactive to March 7, 2020" (2020c, 143).

4 For a personal reflection on post-COVID home oxygen-concentrator use in New York City in 2021, see Pow 2023.

5 In this *New York Times* article, Dwyer quotes Governor Andrew Cuomo as saying, "We don't really have a public health care 'system,' we have a system of hospitals."

6 Ethicists' predictions about age- and disability-based rationing at their hospitals in spring 2020 are also instructive. See, for instance, an interview with Arthur Caplan of NYU Langone in which he tells a reporter for *The Atlantic*, "So you're probably putting kids first and then you're probably putting younger people over much older people just because age is a predictor of resilience. . . . Then you move to tiebreakers like, are you a health-care worker, broadly defined. . . . Some people are going to be worried about, if you're psychotic or mentally ill, how could we manage you, even if we tried to put you on a ventilator, would you disrupt the unit, imperil other people, do you need more resources, that kind of thing. So you'd be watching that, too" (Hamblin 2020).

7 See, for instance, the Rotman School of Management (2022) seminar on "Data Analytics in Healthcare."

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