No. 21-2212

IN THE
United States Court of Appeals
for the Second Circuit

NOT DEAD YET, NMD UNITED, DISABILITY RIGHTS NEW YORK, MICHELLE BROSE, MIKE VOLKMAN, JESSICA TAMBOR, PERI FINKELSTEIN, INDIVIDUALLY AND ON BEHALF OF A CLASS OF ALL OTHERS SIMILARLY SITUATED,

PLAINTIFFS-APPELLANTS,

—v.—

KATHY HOCHUL, GOVERNOR OF THE STATE OF NEW YORK, IN HER OFFICIAL CAPACITY, HOWARD A. ZUCKER, COMMISSIONER OF THE NEW YORK STATE DEPARTMENT OF HEALTH, IN HIS OFFICIAL CAPACITY,

DEFENDANTS-APPELLEES,

APPEAL FROM THE UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF NEW YORK
IN CASE NO. 20-CV-4819 (GRB),
U.S. DISTRICT JUDGE GARY R. BROWN

BRIEF OF AMICUS CURIAE
NATIONAL DISABILITY RIGHTS NETWORK IN SUPPORT OF
PLAINTIFFS-APPELLANTS AND IN SUPPORT OF REVERSAL

BRIDGET A. CLARKE
ANDREW J. DHUEY
456 Boynton Avenue
Berkeley, CA 94707
(510) 528-7755

Attorneys for Amicus Curiae, National Disability Rights Network

January 17, 2022

RULE 26.1(a) DISCLOSURE STATEMENT

Amicus is a non-profit corporation. It has no parent corporations and, as it has no stock, no publicly held company owns 10 percent or more of its stock.

RULE 29(a)(2) PERMISSION TO FILE AMICUS BRIEF

Pursuant to Fed. R. App. P. 29(a)(2), amicus certifies that all parties have consented to the filing of this amicus brief.

TABLE OF CONTENTS

Page

TABLE OF AUTHORITIES

Page

CASES

STATUTES

ACTS OF CONGRESS

RULES

OTHER AUTHORITIES

INTEREST OF AMICUS CURIAE[1]

I. Amicus Curiae National Disability Rights Network

The National Disability Rights Network (NDRN) is the non-profit membership organization for the federally mandated Protection and Advocacy (P&A) and Client Assistance Program (CAP) agencies for individuals with disabilities. The P&A and CAP agencies were established by the United States Congress to protect the rights of people with disabilities and their families through legal support, advocacy, referral, and education. There are P&A's and CAP's in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Territories (American Samoa, Guam, Northern Mariana Islands, and the US Virgin Islands), and there is a P&A and CAP affiliated with the Native American Consortium which includes the Hopi, Navajo and San Juan Southern Paiute Nations in the Four Corners region of the Southwest. Collectively, the P&A and CAP agencies are the largest provider of legally-based advocacy services to people with disabilities in the United States.

II. Why This Case Matters to NDRN

This case is about ensuring that people who rely on ventilators each day for their survival are not discriminated against by an emergency preparedness plan that, in times of triage, calls for taking away their ventilators and giving them to other people deemed

[1]Pursuant to Fed. R. App. P. 29(a)(4)(E), amicus certifies that: (i) no counsel for a party authored this brief in whole or in part; (ii) no such counsel or party made a monetary contribution to fund the preparation or submission of this brief; and (iii) no person other than amicus and its counsel made any such monetary contribution.

more likely to survive. In addition to being unethical and impractical, the plan is illegal. It discriminates on its face against chronic ventilator users in violation of the Americans with Disabilities Act (ADA), the Affordable Care Act (ACA) and Section 504 of the Rehabilitation Act (RA).[2]

Despite other states revising their emergency preparedness plans to avoid discriminating against people with disabilities, the Defendants-Appellees refuse to do so. Their refusal is harmful not only to people with disabilities in New York State, but throughout the country, given that New York State is viewed as a national leader on such policies.[3]

ARGUMENT

NDRN submits this amicus curiae brief in support of reversal of the district court's order dismissing Plaintiffs-Appellants' complaint (Order). The subject of that complaint is the discriminatory emergency preparedness plan: a set of guidelines adopted by the New York State Department of Health (DOH) to direct the process of allocating ventilators

---

[2]*See* Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, 130 Yale L.J. Forum (May 27, 2020) https://www.yalelawjournal.org/forum/who-gets-the-ventilator (the ADA, RA, and ACA "all prohibit healthcare providers from discriminating against qualified individuals with disabilities because of their disabilities"; a COVID-19 plan that explicitly de-prioritizes people with pre-existing disabilities for access to life-saving treatment violates these prohibitions "on its face").

[3]*See* A-110 (Noting that since publication of an earlier version of New York State's plan, "numerous other states have developed triage plans for ventilator allocation, many incorporating aspects of the protocol presented in" New York's earlier plan). "A-" citations herein are to the Joint Appendix filed by Plaintiffs-Appellants.

during a pandemic (Guidelines). The Guidelines' allocation criteria disadvantage chronic ventilator users and single them out as a source of ventilators for others: if a chronic ventilator user seeks care in a hospital for any reason during a time of triage, they risk having their ventilator taken away and given to someone else. The Guidelines so provide even though a chronic ventilator user will die if left extubated, and even though their personal ventilator may provide little or no benefit to another patient. The Guidelines themselves recognize these facts, and even acknowledge that their provisions "place ventilator-dependent individuals in a difficult position of choosing between life-sustaining ventilation and urgent medical care."[4]

Because the Guidelines target people who rely on ventilators, there is little doubt that they violate the ADA, ACA and RA. Defendants-Appellees' maintenance of these facially illegal Guidelines as their only plan for ventilator reallocation during a pandemic is itself a cognizable injury. This fact becomes even more apparent when the lived experience of ventilator-dependent people during the pandemic is considered. Each day that the Guidelines remain on the books, and as hospitalizations surge and healthcare resources are stretched thin, chronic ventilator users live with the imminent threat that, should they need to go to the hospital for some reason, any reason, they will die because their personal ventilator will be removed and given to someone else.

The Order in effect dictates that adjudication of Plaintiffs-Appellants' claims on their merits be delayed until the Guidelines have actually been implemented. But doing so

[4]A-100.

would not only perpetuate the harms that the Guidelines are already causing, but likely entail sacrificing the life of one or more chronic ventilator users. It is also likely that waiting until that moment would put the judiciary in an extremely challenging situation, requiring decision and review of the claims on an expedited basis and during catastrophic circumstances. For these reasons, the Order must be reversed.

I. Under the Guidelines, a Chronic Ventilator User Risks Losing Their Ventilator Upon Entering a Hospital for Any Reason

The Guidelines unequivocally state that a chronic ventilator user who "arrive[s] at the hospital" during a time of triage may have their personal ventilator removed and reallocated to someone "deemed most likely to survive with ventilator treatment."[5] The likelihood-of-survival determination is made based on "clinical criteria," specifically, a mechanical sequential organ failure assessment (SOFA) score. The ultimate decision regarding whether the chronic ventilator user gets to keep their personal ventilator is made not by the doctor attending to that person, but by a "triage officer/committee" based on that person's SOFA score.[6] Chronic ventilator users are disadvantaged in the SOFA scoring system by the fact that the lungs of a ventilator-dependent person "are not functional without a ventilator."[7] They consequently face a significant risk of being left without any ventilator, leading to their death.

[5]A-99 to A-101, A-111 to A-112.

[6]A-73, A-111 to A-112.

[7]A-117 to A-118, A-119 (n.121).

The Guidelines draw a distinction "between acute and chronic care facilities."[8] "Patients using ventilators in chronic care facilities [*i.e.*, not hospitals] are not subject to the clinical protocol,"[9] *i.e.*, they are not at risk of having their ventilators removed and reallocated. However, "[i]f such patients require transfer to an acute care facility [a hospital], then they are assessed by the same criterial as all other patients, and the possibility exists that these patients may fail to meet criteria for continued ventilator use."[10] Similarly, "ventilator-dependent individuals who reside in the community" will "not be denied access to their ventilators," but could lose them "upon their arrival at an acute care facility."[11]

While the Guidelines do not call for entering people's homes to remove their personal ventilators, chronic ventilator users are treated very differently once they enter a hospital. At that point, they may become a source of ventilators for other patients. No logical justification for this approach appears in the Guidelines. Instead, it is simply asserted that if people entering a hospital were allowed "to keep their ventilators rather than be triaged, the policy could be viewed as favoring [chronic ventilator users] over the general public."[12] But it is the chronic ventilator users who are disfavored: they risk losing

[8]A-99.

[9]A-99.

[10]A-99.

[11]A-101.

[12]A-101.

their ventilators (and dying) when they enter the hospital, while members of the general public face no equivalent risk upon entry.

The Guidelines are not limited in their application to chronic ventilator users who come into the hospital due to infection with SARS-CoV-2. A ventilator user entering the hospital seeking treatment for *any* condition could "be triaged."[13] For example, under the Guidelines, "a 32-year-old man with cystic fibrosis entering the hospital with appendicitis in the midst of a flu pandemic, who 'brought with him the mechanical ventilator that helps him breathe,' " would likely have " 'the machine that keeps him alive . . . be given to someone else.' "[14]

In sum, under the Guidelines, if a person relies on a personal ventilator and shows up at a hospital for care at a time when there is a ventilator shortage, they are at grave risk of losing their personal ventilator. It is only by staying home that a chronic ventilator user can be certain that their personal ventilator will not be removed and reallocated.

---

[13]*See* A-101.

[14]Ari Ne'eman, *Do New York State's Ventilator Allocation Guidelines Place Chronic Ventilator Users at Risk? Clarification Needed*, The Hastings Center (Apr. 3, 2020), https://www.thehastingscenter.org/do-new-york-states-ventilator-allocation-guidelines-place-chronic-ventilator-users-at-risk-clarification-needed/ (quoting Sheri Fink, *Worst Case: Choosing Who Survives in a Flu Epidemic,* New York Times (Oct. 24, 2009), http://www.nytimes.com/2009/10/25/weekinreview/25fink.html?ref=influenza.). Note that Sheri Fink's 2009 article is cited with seeming approval by the Guidelines. *See id.;* A-80 (n.6).

II. The Lived Experience of Chronic Ventilator Users Shows the Real-World Harms Caused by the Guidelines Right Now

The real-world harm caused by the Guidelines cannot be overstated.[15] During a pandemic, the Guidelines put a person who relies on their ventilator for their daily survival in a position akin to that of an involuntary organ donor: someone who lives with the imminent threat that, should they end up in a hospital, they will be required to donate to someone else the mechanism that acts as their lungs. And they are deterred from seeking needed medical treatment – itself an existential threat. Singling out chronic ventilator users for sacrifice only serves to heighten their lived experience of being devalued by society.

a. Personal Ventilators Are Necessary for Their Users' Survival and Are Akin to Vital Organs, but They Are Not Likely Useful to Other Patients in a Triage Situation

Personal ventilators are used by individuals "in their homes, whether that be private homes in a community or in long-term care environments, such as group homes and nursing homes."[16] The former group of ventilator users includes "ventilator-dependent individuals who reside in the community, rather than in institutions," while the latter

---

[15] *See* Joel Michael Reynolds et al., *Against Personal Ventilator Reallocation*, Cambridge Quarterly of Healthcare Ethics (Oct. 2, 2020), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7642499/ ("It is hard to overstate the personal terror wrought from the suggestion that [personal ventilators] could be taken away in a triage process, but to fully appreciate *why* this causes such terror requires better understanding the lived experience of long-term ventilator users."; emphasis in original).

[16] *Id*.

group includes people who reside in "chronic care facilities," as discussed in the Guidelines.[17]

Chronic ventilator users, including the individual plaintiffs and putative class members in this case, have disabilities[18] affecting their ability to breathe on their own, and necessitating daily use of personal ventilators. For example, as a result of Charcot Marie-Tooth disease, Plaintiff Michelle Brose "is completely ventilator dependent and uses a ventilator 24 hours per day because she cannot breathe on her own."[19] Plaintiff Mike Volkman also uses a ventilator 24 hours per day due to spinal muscular atrophy.[20] Plaintiff Jessica Tambor uses a ventilator about 12 hours per day, needing it as a result of a spinal cord injury.[21] And because of Muscular Dystrophy, Plaintiff Peri Finkelstein "is completely ventilator dependent and uses a ventilator 24 hours per day . . . ."[22] If a chronic ventilator user such as Ms. Brose, Mr. Volkman, Ms. Tambor or Ms. Finkelstein were to

[17]A-99, A-101.

[18]A-19 to A-20, A-22 to A-23 (plaintiffs are "qualified individual[s] with a disability within the meaning of" the ADA, RA and ACA).

[19]A-19.

[20]A-20.

[21]A-22.

[22]A-23.

have their ventilator removed, they would die immediately or soon after.[23] The Guidelines acknowledge this terrifying fact.[24]

For a long-term user, their personal ventilator "is not something which merely interferes (positively) in pulmonary function, but which *realizes* livable pulmonary function for them."[25] Thus, taking away their personal ventilator for placement in a hospital's "allocation pool" is "akin to seizing [their] vital organ for public use . . . ."[26] As one chronic ventilator user has explained:

> My vent is part of my body – I cannot be without it for more than an hour at the most due to my neuromuscular disability. For clinicians to take my vent away from me would be an assault on my personhood and lead to my death . . . . I deserve the same treatments as any patient. As a disabled person, I've been clawing my way into existence ever since I was born. I will not apologize for my needs.[27]

---

[23]*See* A-20 (taking away Ms. Brose's ventilator would result in her "imminent death"), A-22 (same for Mr. Volkman and Ms. Tambor), A-24 (same for Ms. Finkelstein).

[24]A-100 ("if the ventilator is removed from a person known to depend on it, s/he will not survive, regardless of the reason requiring hospitalization").

[25]Reynolds, *supra* note 15 (emphasis in original).

[26]*Id.*; *see also* Ne'eman, *supra* note 14 (people with disabilities who bring their ventilators with them into the hospital are in effect "bring[ing] in their own lungs").

[27]Ari Ne'eman, *'I Will Not Apologize for My Needs,'* New York Times (Mar. 23, 2020), https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html (internal quotation marks omitted); *see also* Reynolds, *supra* note 15 ("long-term ventilator use" leads to "bodily incorporation of the ventilator"). Even a member of the task force that wrote the Guidelines has come to recognize that a personal ventilator is in effect part of one's body and, as such, should not be reallocated. *See* Joseph J. Fins, *Disabusing the Disability Critique of the New York State Task Force Report on Ventilator Allocation*, The Hastings Center (Apr. 1, 2020), https://www.thehastingscenter.org/disabusing-the-disability-critique-of-the-new-york-state-task-force-report-on-ventilator-allocation/ (a personal ventilator is "part and parcel

Indeed, for many long-term ventilator users, their ventilator becomes part of their social identity as well.[28] Personal ventilators are not only essential to functioning in "acute situations, but across one's future life course, *and* they are part of one's relational narrative identity."[29]

There "are many types of ventilators with different functionalities."[30] Consistent with their long-term use in service of the needs of particular individuals, *personal* ventilators "may not be usable even if they were to be reallocated to the general resource pool" at a hospital in a time of triage.[31] Consequently, as recognized by the Guidelines, their reallocation "may offer little additional benefit" to a hospital's general resource pool.[32] Additionally, unlike chronic ventilator users, who "often have specialized

---

of that person" and as "such [should not be] subject to being commandeered in a crisis. It [is] theirs, not the collective's.").

[28]Reynolds, *supra* note 15 ("the experience of long-term ventilator users" leads to the conclusion that their personal ventilators "should be considered as an *integrated technology"* that is "part of one's social identity"; emphasis in original); *see also id*. ("*taking away someone's personal ventilator is a direct assault on their bodily and social integrity*"; emphasis in original).

[29]*Id*. (emphasis in original).

[30]Joseph J. Fins, *New York State Task Force on Life and the Law Ventilator Allocation Guidelines: How Our Views on Disability Evolved,* The Hastings Center (Apr. 7, 2020), https://www.thehastingscenter.org/new-york-state-task-force-on-life-and-the-law-ventilator-allocation-guidelines-how-our-views-on-disability-evolved/.

[31]A-100 to A-101.

[32]A-101; *see also* Fins, *supra* note 30 (explaining that "ventilators in chronic use by patients" would "offer little additional benefit" to others).

expertise in how to adjust their ventilators for changing needs,"[33] hospital staff "may not be familiar with the operation of" personal ventilators.[34]

b. The Guidelines Have a Chilling Effect on Chronic Ventilator Users When It comes to Seeking Needed Medical Treatment, Further Jeopardizing Their Lives

The risk of losing one's personal ventilator upon entering a hospital in New York State has had a chilling effect when it comes to chronic ventilator users seeking needed medical attention.[35] Discussion of reallocation of personal ventilators "has been covered in the media and implanted as a concern in disability communities."[36] These discussions have "struck fear into long-term ventilator users and their loved ones that [has] rippled across disability communities."[37] The same is all the more true for the Plaintiffs-Appellants, thanks to the Guidelines. The Guidelines have caused them wide-spread fear, motivating at least one plaintiff (Ms. Finkelstein) "not to leave her house for months."[38]

The Guidelines themselves acknowledge this impact, noting that the "policy to triage upon arrival" at a hospital "may deter" chronic ventilator users "from going to" a

---

[33]Reynolds, *supra* note 15.

[34]A-101 (n.75).

[35]It is important to note that needing medical care at a hospital is a frequent occurrence for some chronic ventilator users. *See, e.g.*, A-20, A-21 ("Mr. Volkman has been admitted to the hospital nine times since he started using his ventilator" in 2015), A-23 ("Ms. Finkelstein has spent a significant amount of time in the hospital.").

[36]Reynolds, *supra* note 15.

[37]*Id.*

[38]*See* A-13, A-19 to A-25, A-27 to A-28 (*see especially* ¶¶ 59-60, 72-73, 81, 90-96 (describing plaintiffs' fears regarding hospital admission caused by the Guidelines)).

hospital "for fear of losing access to their ventilator . . . ."[39] This places "ventilator-dependent individuals in a difficult position of choosing between life-sustaining ventilation and urgent medical care."[40]

As discussed *infra* in section IV., a triage situation can arise quickly during this pandemic and with little warning – something that is obvious to anyone who follows the news. Consequently, for a New York State resident who relies on their ventilator, choosing to stay away from hospitals during the pandemic is a rational decision "based on a well-founded fear of being sacrificed 'for the greater good' "[41] – but is also a decision that could lead to their demise.

c. The Guidelines Harm Chronic Ventilator Users by Devaluing Their Lives, Reinforcing a Long History of Disregard and Disparagement of People with Disabilities

There is a long history in this country of discrimination against people with disabilities with respect to the provision of health services, based often on "stereotypical assumptions" about them and attribution to them of "inferior social status."[42] Because of that history "of disregard, disparagement, and far worse forms of treatment," the mere

---

[39]A-101.

[40]A-100; *see also* Reynolds, *supra* note 15 (the possibility "that one could go to the hospital to receive acute care services and end up without access to the life-sustaining device that they have constant access to at home . . . is a valid deterrent to going to the hospital when otherwise necessary").

[41]Ne'eman, *supra* note 27.

[42]*See* 42 U.S.C. §12101(a)(3), (6), (7) (ADA findings and purposes); *see also* Bagenstos, *supra* note 2 ("there is ample evidence of widespread bias against people with disabilities among medical professionals").

suggestion of personal ventilator reallocation is harmful to people with disabilities.[43] Indeed, "ventilators have become a focal point of resource triage debates and advocacy in many disability communities and have in many ways taken on symbolic meaning amounting to the perception of one's social worth – whether people are 'worth saving' and whether they live 'lives worth living' . . . ."[44]

As discussed in section II.a. *supra,* the Guidelines recognize that a personal ventilator is needed for the very survival of its user, but it may not be usable to save the life of another patient. That is, if a chronic ventilator user's personal ventilator is removed and given to someone else, there is no guarantee that the recipient will benefit from that ventilator (or survive). But the death of the donor is a certainty.

Members of the Task Force were apparently aware of these facts:

> Some argued that this strategy was contrary to the aim of saving the most lives because denying ventilator therapy to a ventilator-dependent person is different from denying the ventilator to someone who has a high probability of mortality who might have qualified for a ventilator under non-pandemic circumstances. Thus, if the ventilator is removed from a person known to depend upon it, s/he will not survive, regardless of the reason requiring hospitalization.[45]

And yet the decision was made to include "this strategy" in the Guidelines.

---

[43]Reynolds, *supra* note 15.

[44]*Id.*

[45]A-100. Similarly, the Guidelines recognize that a pitfall of such a ventilator allocation system is "quality of life judgments that may impose on the rights of the disabled" (A-72), and that "likely fatal extubations of stable, long-term ventilator-dependent patients" would make "victims of the disabled." A-100.

One can only conclude that underlying the Guidelines is an assumption that the life of the person with disabilities who is extubated is worth less – that their life does not count toward the Guidelines' "goal of saving the most lives."[46] The Guidelines thus harm Plaintiffs-Appellants by devaluing them, further perpetuating a long history of societal disregard and disparagement.

III. Defendants-Appellees Cannot Avoid Liability for their Discriminatory Guidelines by Labeling Them Voluntary and Nonbinding

Defendants-Appellees seek to avoid liability for the harms caused by the Guidelines based on their labeling as "voluntary and non-binding"[47] – a strategy seemingly aimed at achieving their implementation while leaving people with disabilities with no recourse. A reading of the Guidelines reveals Defendants-Appellees' intent that hospitals follow the Guidelines as written, as well as their belief that hospitals will in fact follow them. Unless this Court intervenes, hospitals will look to the Guidelines as intended, with disastrous results for chronic ventilator users.

---

[46]*See* A-61; *cf. OCR Issues Bulletin on Civil Rights Laws and HIPAA Flexibilities that Apply During the COVID-19 Emergency*, U.S. Dept. of Health & Human Services (Mar. 28, 2020), https://public3.pagefreezer.com/content/HHS.gov/31-12-2020T08:51/https:/www.hhs.gov/about/news/2020/03/28/ocr-issues-bulletin-on-civil-rights-laws-and-hipaa-flexibilities-that-apply-during-the-covid-19-emergency.html (the ADA, RA and ACA "remain in effect" during the pandemic, and "persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities").

[47]A-261.

Throughout the Guidelines are statements establishing that they are the State of New York's plan for how ventilators are to be allocated during a pandemic.[48] They were promulgated by the New York State Task Force on Life and the Law (Task Force) at the direction of the DOH.[49] In his introduction to the Guidelines, the DOH Commissioner recognizes that the Guidelines are intended to fulfill the DOH's "responsibility" to "plan" for a pandemic, and that such responsibility includes "guidance on how to ethically allocate limited resources (*i.e.*, ventilators)" during a pandemic.[50] The Guidelines purport to provide "detailed clinical ventilator allocation protocols" for "implementation . . . in New York State."[51] In fact, they were promulgated because hospitals "requested detailed procedural advice from the State."[52]

The clear intent in promulgating the Guidelines was that they "be implemented Statewide."[53] Indeed, their authors express pride in the fact that their predecessor guidelines "have impacted greatly the delivery of health care in New York," while indicating confidence that the Guidelines will "ensure that the State is adequately and appropriately prepared" for a pandemic.[54] The DOH Commissioner predicted that the

---

[48]*See, e.g.*, A-54, A-57, A-60 to A-61, A-67.

[49]A-57, A-67.

[50]A-57.

[51]A-58.

[52]A-67.

[53]A-65; *see also* A-111 (the "ventilator allocation protocol applies to all patients . . . in all acute care facilities Statewide").

[54]A-59.

Guidelines would be followed "by other states" as well,[55] while the Guidelines note that prior versions of "New York's innovative guidelines were . . . widely cited and followed by other states."[56]

Despite opting to label the Guidelines as nonbinding, the DOH and Task Force expressed their belief that hospitals throughout the State would follow them:

> Although it has been argued that voluntary guidelines may offer an insufficient guarantee of consistency, facility representatives stress that they are eager to follow State-level guidance and do not seek wide latitude in devising their own policies. Hospitals have expressed a preference for State guidance over drafting their own policies.[57]

The clear message is that the Guidelines are *the* "State guidance" that hospitals had been seeking and will follow.

And there is no reason to believe that hospitals will *not* follow the Guidelines. Apart from earlier versions of the Guidelines also drafted at the direction of the DOH, the Guidelines appear to be the *only* ventilator allocation guidelines promulgated by a New York State entity. Defendants-Appellees have not pointed to *any* other guidelines that would direct how personal ventilators are to be distributed in the State in a time of triage. They have not advised New York State hospitals or other healthcare providers that they should *not* follow the Guidelines. Nor have the Guidelines been revised since they were

---

[55]A-57. This hope has unfortunately become reality: other states have used the Guidelines as their model. *See, e.g.,* Ne'eman, *supra* note 14 (Kansas used "criteria modeled after the New York Task Force's").

[56]A-60.

[57]A-265.

promulgated in 2015, despite assurances that they would be revised "as societal norms change and clinical knowledge advances."[58] Regardless of how labeled or characterized, the Guidelines remain the only New York State guidance on personal ventilator reallocation.

Thus far, Defendants-Appellees have refused to reassure chronic ventilator users that the Guidelines will *not* be used against them should they be admitted to a hospital in the State. Despite a direct request by Plaintiff-Appellant Disability Rights New York, Defendants-Appellees have refused to state "that a chronic ventilator user would never be extubated without having another ventilator available for their use."[59] Their refusal indicates that while Defendants-Appellees seek to avoid liability for their discriminatory Guidelines, they do *not* seek to avoid their implementation.

Other members of the disability community have also called for revision or clarification of the Guidelines to eliminate the possibility of reallocation of personal ventilators.[60] In response, a former member of the Task Force proffered his own interpretation: that the Guidelines would only require removal of someone's ventilator when that person needed "a more sophisticated ventilator" due to "a new severe illness."[61]

---

[58]*See* A-57.

[59]A-28.

[60]*See, e.g.,* Ne'eman, *supra* notes 14, 27.

[61]Fins, *supra* note 27; *see also* Fins, *supra* note 30 ("*It wasn't so much that they would lose their ventilator but rather need something more*."; emphasis in original). The Task Force member endorsed this interpretation of the Guidelines as "discriminating but *not* discriminatory." Fins, *supra* note 27 (emphasis in original).

But the plain language of the Guidelines does not support this interpretation.[62] While this Task Force member may have intended that the Guidelines "not view the personal ventilators of people using them chronically as being subject to a collective allocation,"[63] that is simply not how the Guidelines read.[64] And if this Task Force member's interpretation is correct, then Defendants-Appellees should say so.[65]

[62]*See also* Ne'eman, *supra* note 14 (This "is a distinction that appears nowhere in the Task Force's 272-page guidelines.").

[63]Fins, *supra* note 30.

[64]Indeed, if the Task Force's intent were to remove a personal ventilator *only* when a chronic user needed a better ventilator, then it would not make sense for the Guidelines to state that permitting personal ventilator users to keep their ventilators would discriminate against nondisabled members of the public. *See* A-101.

[65]*See also* Ne'eman, *supra* note 14 (They "should revise their language to offer clarity on that point as quickly as possible.").

IV. Triage Conditions Triggering Application of the Guidelines Could Happen at Any Time, Necessitating Adjudication of Plaintiffs-Appellants' Claims Now

According to Order, before this case can be adjudicated, someone must be about to lose their personal ventilator or have already lost it (and died).[66] But the threat that a hospital will implement the Guidelines is ever-present. The pandemic is not over. Surges in cases can happen quickly and with little warning, triggering triage protocols.[67]

Recently, the Delta and Omicron variants have fueled massive surges in new cases.[68] In New York State, cases increased by more than 80 percent over two weeks in mid-December 2021.[69] No doubt there will be other variants of concern in the future.[70]

---

[66] *See* A-327 to A-328.

[67] *See* Dylan Scott, *Covid-19 Surges Spark Chain Reactions that Strain US Hospitals Everywhere*, Vox (Dec. 28, 2021), https://www.vox.com/coronavirus-covid19/22849829/covid-omicron-variant-cases-surge-us-hospitals ("One hospital being overwhelmed isn't a one-hospital problem, it's an every-hospital problem. Even if your community is not awash with Covid-19 or if most people are vaccinated, a major outbreak in your broader region, plus all the other patients hospitals are treating in normal times, could easily fill your hospital, too.").

[68] *See* Campbell Robertson et al., *The U.S. Faces Another Covid Christmas as Omicron Fuels a Rise in Cases*, New York Times (Dec. 20, 2021), https://www.nytimes.com/2021/12/20/us/us-holidays-omicron-cases.html.

[69] *Id*.

[70] Ed Yong, *America Is Not Ready for Omicron*, The Atlantic (Dec. 16, 2021), https://www.theatlantic.com/health/archive/2021/12/america-omicron-variant-surge-booster/621027/ ("more variants can still arise"; "Omicron 'doesn't look like the end of it.' ").

Even for public health experts, predicting when the pandemic might be over is a fraught enterprise. And there will be more pandemics in the future.[71]

Ventilator shortages have occurred throughout the pandemic. Early on, Governor Cuomo felt compelled to take dramatic steps to secure ventilators, including by authorizing "the National Guard to take control of excess community ventilators," and multiple hospitals sought unused ventilators from a Long Island nursing home.[72] More recently, there have been ventilator shortages amid spread of the Delta variant.[73]

As of mid-December, hospitalizations have been rising in 42 states,[74] and the U.S. health-care system "*is already overwhelmed*, in a way that is affecting all patients,

---

[71]Michael Penn, *Statistics Say Pandemics Are More Likely than We Thought*, Duke Global Health Institute (Aug. 23, 2020), https://globalhealth.duke.edu/news/statistics-say-large-pandemics-are-more-likely-we-thought (" 'large pandemics like COVID-19 and the Spanish flu are relatively likely' ").

[72]Reynolds, *supra* note 15.

[73]*See*, *e.g.*, *Surge in COVID Cases Causing Concern*, Aurora News-Register (Dec. 14, 2021), https://www.auroranewsregister.com/news/surge-covid-cases-causing-concern (as a result of "the Delta surge," some Nebraska "referral hospitals are seeing a shortage of ventilators and have reached out to the state to assist with a solution"); *see also* Shamane Mills, *COVID-19 Straining Wisconsin Hospitals as Delta Variant Makes Patients Sicker Longer*, Wisconsin Public Radio (Dec. 2, 2021), https://www.wpr.org/covid-19-straining-wisconsin-hospitals-delta-variant-makes-patients-sicker-longer ("A record number of patients are on ventilators"); Annie Ropeik, *380 Mainers Hospitalized with COVID-19 as of Monday, with Near Record Number in Critical Care*, Spectrum News (Dec. 20, 2021), https://spectrumlocalnews.com/me/maine/news/2021/12/20/record-number-of-maine-covid-patients-in-critical-care (Maine "is just below its peak totals for patients on ventilators and those hospitalized overall.").

[74]Yong, *supra* note 70.

COVID or otherwise."[75] The much more contagious Omicron variant is likely to lead to more ventilator shortages, thanks to the speed of its spread – which increases the likelihood that a hospital will experience a sudden influx of patients – and at a time when a hospital may already be overwhelmed with Delta patients.[76] Omicron's rapid spread shows how quickly circumstances can change for the worse, creating a triage situation where the Guidelines suddenly become applicable.

Given these realities of the pandemic – especially how quickly circumstances can worsen – it makes no sense to wait until the Guidelines are actually implemented before adjudicating Plaintiffs-Appellants' claims. Doing so would only serve to prolong the ongoing harms experienced by Plaintiffs-Appellants, and would likely mean that at least

---

[75]*Id.* (emphasis in original); *see also* Jenn Schanz, *Coronavirus Omicron Variant in Michigan: What You Need to Know*, WXYZ Detroit (Dec. 10, 2021), https://www.wxyz.com/news/coronavirus/coronavirus-omicron-variant-in-michigan-what-you-need-to-know ("The Omicron variant has shown up at a time when 'hospitals continue to teeter on the edge, many of them at or near capacity.' ").

[76]Yong, *supra* note 70 ("Omicron is spreading so quickly that a small proportion of severe cases could still flood hospitals."); Robertson, *supra* note 68 (Omicron is "stunningly infectious" and its " 'uncontrolled spread . . . could quickly overwhelm hospital capacity' "; in New England, the rise in cases has coincided with "an uptick in the number of hospitalizations and deaths"); Schanz, *supra* note 75 (hospital admissions in Michigan were already "up 88% in [November] and now [Omicron] poses more problems"; at least one Michigan hospital "is considered at triage level red, unable to take patients from other hospitals"); Amelia Templeton, *Oregon Officials: Omicron Could Overwhelm Sate Hospitals; Response to Focus on Boosters, Testing and Treatment*, OPB (Dec. 17, 2021), https://www.opb.org/article/2021/ 12/17/oregon-health-leaders-governor-kate-brown-covid-19-omicron-variant/ (the Omicron surge could peak with "two and three times the number of COVID-19 patients hospitalized as during" the Delta surge; Omicron "is likely less virulent" but that is not "enough to protect [Oregon] against a wave of hospitalizations given the variant's extreme transmissibility and immune escape").

one of them would have their ventilator removed and die before this case could be heard. It is also likely that waiting until that moment would put the judiciary in an extremely challenging situation: being called upon to resolve these claims on an expedited basis amid an even more dire set of pandemic-related circumstances than the current ones. Judicial doctrines of standing and ripeness have never required courts to wait for such calamity before exercising their remedial powers. The Constitution "is not a suicide pact."[77]

V. Chronic Ventilator Users Apparently Were Not Part of the Process Leading to Creation of the Guidelines; They Should Have Been

Ventilator shortages during a pandemic are not surprising. There is no excuse for planning that fails to address adequately the risk of these shortages. And it is unconscionable as well as ineffective to attempt to mitigate such shortages by forcing chronic ventilator users to relinquish their personal ventilators. Instead, planning for a pandemic must take into account the needs of people with disabilities. The best way to do so is to include them in the planning process.

The Guidelines recognize that during a pandemic, "there will not be enough ventilators in the State to meet the demand."[78] They disproportionately place the burden caused by foreseeable ventilator shortages on chronic ventilator users – forcing them to make the ultimate sacrifice in a time of triage. Such a decision

---

[77] *Kennedy v. Mendoza-Martinez*, 372 U.S. 144, 160 (1963).

[78] A-71; *see also* A-85 to A-86 (a dangerous pandemic with a "dramatic increase in patients requiring ventilator therapy" is a "foreseeable event").

> results not from scarcity as a natural fact, but from two societal decisions: first, the decision to fail to maintain an adequate stock of ventilators to serve all patients who would need them if a pandemic breaks out; second, the decision, once a pandemic breaks out, to use patients' pre-existing disabilities as a basis for denying them the use of those devices.[79]

But people with disabilities should not be required to sacrifice their lives during a healthcare emergency in order to increase the odds that others may survive.[80] To do so is particularly abhorrent given that people with disabilities "already experience disadvantage as a result of societal discrimination, and . . . disproportionately lack access to the political and health-system processes that frame policies concerning medical rationing."[81]

While the Guidelines emphasize "the importance of genuine public outreach, education, and engagement" as being "critical to the development of just policies and the establishment of public trust,"[82] it does not appear that any chronic ventilator users served on the Task Force or otherwise participated in the process of creating the Guidelines.[83]

Including chronic ventilator users in that process would have "show[n] respect, help[ed] avoid paternalism, augment[ed] procedural fairness, and may [have] produce[d]

---

[79]Bagenstos, *supra* note 2 (footnote omitted).

[80]*See id*. ("allowing scarcity of ventilators, while imposing the life-or-death costs of that scarcity most heavily on disabled people . . . bespeaks a failure of democratic legitimacy")

[81]*Id.*; *see also* 42 U.S.C. §12101(a)(3) (noting the persistence of discrimination against people with disabilities in health services).

[82]A-68.

[83]There was at least one member of the Task Force with disabilities: Adrienne Asch, who died in 2013 and was blind. A-69; *Adrienne Asch,* Wikipedia (last edited Nov. 1, 2021), https://en.wikipedia.org/wiki/Adrienne_Asch Ms. Asch argued against reallocation of personal ventilators. *See* Fins, *supra* note 27.

substantively better guidelines."[84] It is safe to assume that had the Task Force included chronic ventilator users, the Guidelines would have been much less likely to discriminate against them.[85]

VI. This Is Not a "Peculiar" Case; Complaints Filed with the Office of Civil Rights about Similar Ventilation Reallocation Policies Have Led to Their Revision

Finally, it is important to note that while the Order describes this case as "creative, if peculiar,"[86] it is anything but. On the contrary, during the pandemic, many complaints have been filed with the Office for Civil Rights (OCR) at the United States Department of Health and Human Services based on similar discriminatory policies promulgated in other

[84]Michelle M. Mello et al., *Respecting Disability Rights – Toward Improved Crisis Standards of Care*, The New England Journal of Medicine (Jul. 30, 2020), https://www.nejm.org/doi/full/10.1056/NEJMp2011997.

[85]*See* Bagenstos, *supra* note 2 (a process that included people with disabilities "would not lead to" using "patients' pre-existing disabilities as a basis for denying them the use of" ventilators); *see also* Fins, *supra* note 30 (describing the impact of Adrienne Asch as a Task Force member).

[86]A-326.

states.[87] Plaintiffs-Appellants filed this lawsuit only after attempts at resolving an OCR complaint based on the Guidelines failed.[88]

Because of obvious ADA, ACA and RA violations, many pandemic-related OCR administrative cases have been resolved in favor of people with disabilities, resulting in revised policies that have included specific prohibitions on the reallocation of personal ventilators. For example, in response to an OCR complaint, Tennessee updated its crisis standards of care plan in June 2020 by incorporating

> language stating that hospitals should not re-allocate personal ventilators brought by a patient to an acute care facility to continue pre-existing personal use with respect to a disability. Under this language, long term ventilator users will be protected from having a ventilator they take with them into a hospital setting taken from them to be given to someone else.[89]

Prohibitions on reallocation of personal ventilators have appeared in resolutions of other OCR complaints, and when the OCR has provided "technical assistance" to entities

---

[87] *See* Bagenstos, *supra* note 2 (describing OCR administrative cases involving discriminatory guidelines from Alabama, Tennessee, Washington State, Kansas, Pennsylvania, and Utah involving illegal disability-based distinctions in allocating scarce resources during the pandemic, including ventilators); *COVID-19 CSOC 50 State Overview* (last visited Jan. 13, 2022), https://docs.google.com/spreadsheets/d/1dIgfl-VGYocxGpOBMw-2WKbYsYCV8iGnmtg3qPYQiRw/edit#gid=0 (spreadsheet with links to OCR complaints regarding healthcare rationing and/or related discriminatory policies in various states).

[88] A-28.

[89] *OCR Resolves Complaint with Tennessee after It Revises Its Triage Plans to Protect Against Disability Discrimination*, U.S. Dept. of Health & Human Services (Jun. 26, 2020), https://www.hhs.gov/guidance/document/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against.

seeking to avoid discriminatory policies, in: Utah;[90] North Carolina, Texas regional health groups and the Indian Health Service;[91] Arizona;[92] and Oregon.[93]

CONCLUSION

"To allow discrimination against the disabled, even when there isn't enough to go around, is simply wrong."[94] And it is illegal. The harms caused by having the

---

[90] *OCR Resolves Complaint with Utah after It Revised Crisis Standards of Care to Protect Against Age and Disability Discrimination*, U.S. Dept. of Health & Human Services (Aug. 20, 2020), https://public3.pagefreezer.com/content/HHS.gov/31-12-2020T08:51/https://www.hhs.gov/about/news/2020/08/20/ocr-resolves-complaint-with-utah-after-revised-crisis-standards-of-care-to-protect-against-age-disability-discrimination.html (incorporating same language used by Tennessee regarding no reallocation of personal ventilators).

[91] *OCR Provides Technical Assistance to Ensure Crisis Standards of Care Protect Against Age and Disability Discrimination*, U.S. Dept. of Health & Human Services (Jan. 14, 2021), https://www.hhs.gov/about/news/2021/01/14/ocr-provides-technical-assistance-ensure-crisis-standards-of-care-protect-against-age-disability-discrimination.html (incorporating same language used by Tennessee regarding no reallocation of personal ventilators).

[92] *OCR Provides Technical Assistance to the State of Arizona to Ensure Crisis Standards of Care Protect Against Age and Disability Discrimination*, U.S. Dept. of Health & Human Services (May 25, 2021), https://www.hhs.gov/about/news/2021/05/25/ocr-provides-technical-assistance-state-arizona-ensure-crisis-standards-care-protect-against-age-disability-discrimination.html ("Inclusion of language ensuring that long-term ventilator users will be protected from having a ventilator they bring with them into a hospital setting taken from them to be given to someone else.").

[93] *Principles in Promoting Health Equity During Resource Constrained Events*, Oregon Health Authority (Dec. 7, 2020), https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le3513.pdf ("Patients who are chronically ventilator-dependent outside of the critical care context should not have their ventilators withdrawn in order to extend supplies" and "the baseline need for a ventilator should be excluded from consideration when allocating scarce resources in a public health crisis").

[94] Ne'eman, *supra* note 27.

discriminatory Guidelines on the books should not be minimized. To do so would be to perpetuate ongoing societal devaluation of the lives of people with disabilities, as well as place the lives of chronic ventilator users at grave risk – risk of death from actual removal of their personal ventilators and risk of death caused by avoiding needed medical care for fear of losing their ventilators. Without reversal of the Order, not only will these harms continue, but there is no reason to believe that the Guidelines will not be followed, with disastrous results.

For the forgoing reasons, NDRN submits this brief in support of reversal of the Order.

Date: January 17, 2022

Respectfully submitted,

/s/ Bridget A. Clarke

BRIDGET A. CLARKE (Cal. Bar #161320)
ANDREW J. DHUEY (Cal. Bar #161286)
456 Boynton Avenue
Berkeley, CA 94707
(510) 528-7755
baclarke@comcast.net

Attorneys for Amicus Curiae
National Disability Rights Network

CERTIFICATE OF COMPLIANCE WITH WORD LIMIT

This brief complies with: (1) the type-volume limitation of Fed. R. App. P. Rule 29(a)(5) and Local Rule 29.1(c) because it contains 6,672 words, excluding the parts exempted by rule; and (2) the typeface requirements of Fed. R. App. P. Rule 32(a)(5) and the type style requirements of Fed. R. App. P. Rule 32(a)(6) because the body of the brief has been prepared in 14-point Times New Roman font using Microsoft Word 2016.

Date: January 17, 2022 /s/ Bridget A. Clarke