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Via Electronic Mail OCRComplaint@hhs.gov

U.S. Department of Health and Human Services
Office for Civil Rights
200 Independence Avenue, SW Room 509F
Washington, DC 20201

Attn: Roger Severino, Director c/o Centralized Case Management Operations

Re: OCR Complaint No. CU-20-379158: April 7, 2020 Complaint filed by Disability Rights New York against the New York State Department of Health concerning the 2015 Ventilator Allocation Guidelines Published by the New York State Task Force on Life and the Law and the New York State Department of Health (the “2015 Ventilator Allocation Guidelines”)¹

Dear Director Severino:

The New York Civil Liberties Union (the “NYCLU”) writes to you in support of the complaint submitted to the U.S. Department of Health and Human Services Office for Civil Rights (“OCR”) on or about April 7, 2020 by Disability Rights New York (“DRNY”) against the New York State Department of Health (“NYSDOH”) concerning the 2015 Ventilator Allocation Guidelines.²

DRNY’s complaint alleges that the NYSDOH 2015 Ventilator Allocation Guidelines contain serious gaps that discriminate against people with preexisting disabilities and place them in potentially life-threatening positions in violation of the Americans with Disabilities Act (“ADA”), 42 U.S.C. § 12101, et seq., and Section 504 of the Rehabilitation Act of 1973 (“Section 504”), 29 U.S.C. § 794, et seq. The 2015 Ventilator Allocation Guidelines, as written, will have the unintended consequence of disproportionately disqualifying many people with disabilities from ventilator access simply because they have underlying conditions that may intensify symptoms and slow recovery, which violates both the ADA and Section 504.³

¹New York State Task Force on Life and the Law New York State Department of Health, *Ventilator Allocation Guidelines*, Nov. 2015, https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf. Accessed 15 Apr. 2020.

² The NYCLU, is the New York State affiliate of the American Civil Liberties Union and is a nonprofit, nonpartisan organization with eight chapters, regional offices, with more than 180,000 members and supporters across the state. The NYCLU works to defend and promote the fundamental principles, rights and constitutional values embodied in the Bill of Rights of the U.S. Constitution and the Constitution of the State of New York. Our work includes defending the long-established rights of all New Yorkers to be free from discrimination on the basis of disability.

³ See DRNY Complaint ¶¶ 4,5, 44, 53-54.

The NYCLU believes that these issues are of critical importance to New Yorkers with disabilities during the COVID-19 pandemic. New York hospitals and other medical facilities need clear guidance that they may not prevent people with disabilities from accessing health care, including obtaining ventilator support, simply because they have underlying conditions that may intensify symptoms or slow recovery as such actions would be discriminatory, illegal and actionable. In this letter, we explain why OCR must act promptly on DRNY’s complaint, why the lack of clear and binding guidelines on the allocation of scarce health care resources is likely to exacerbate discrimination against individuals with disabilities in obtaining health care, and the 2015 Ventilator Allocation Guidelines are discriminatory and not sufficient. Accordingly, we support DRNY’s request that New York immediately issue clear and binding guidelines that all health care facilities and health care professionals must follow that do not discriminate against people with disabilities seeking acute healthcare in New York State during the COVID-19 pandemic.

OCR Should Expedite Its Investigation

OCR already has acknowledged the serious risk that persons with disabilities face when medical care must be triaged. *See* OCR Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) issued by the U.S. Department of Health and Human Services on March 28, 2020 (the “OCR March 28, 2020 Bulletin”).⁴ The OCR March 28, 2020 bulletin affirms that “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 or age.”⁵ Yet OCR’s urgent admonition to the medical professions has not been acknowledged by NYSDOH, and NYSDOH has not circulated OCR’s guidance to New York State health care facilities and health care professionals.⁶ Nor has Governor Andrew Cuomo or NYSDOH formally issued mandatory statewide guidance on allocation of scarce medical resources during this pandemic.⁷

It is especially important that OCR act expeditiously on DRNY’s complaint as critical provisions relating to health care facilities and providers that could allow for discrimination were buried in the New York State budget, enacted on April 3, 2020. The new Emergency or Disaster Treatment Protection Act (EDTPA) confers complete immunity from liability on health care facilities and professionals during the COVID-19 crisis. The EDTPA took effect immediately upon passage of the budget and is retroactive to Governor Cuomo’s March 7, 2020, COVID-19 emergency declaration.⁸

Under the EDTPA, health care facilities and professionals now have broad immunity from state civil or criminal liability for any harm or damages alleged to have been sustained as a result of an act or omission for services that relates to the diagnosis, prevention, or treatment of COVID-19;

⁴ HHS Office for Civil Rights in Action, *Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)*, 28 March 2020, <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>. Accessed 15 Apr. 2020.

⁵ In the March 28, 2020 OCR Bulletin, OCR appropriately noted federal and state constitutional and statutory law also prohibit allocation of resources on the basis of age, sex (including sexual orientation and gender identity), race, ethnicity, national origin, or religion.

⁶ *See* DRNY Complaint ¶¶ 6, 55, 80, 88.

⁷ *Id.* *See also* discussion below at 3.

⁸ *See* S. S07506, 2020 Senate Assemb., at 346 (NYS 2020), https://assembly.state.ny.us/leg/?default_fld=&leg_video=&bn=S07506&term=0&Summary=Y&Text=Y. Accessed 15 April 2020.

assessment or care of an individual with a confirmed or suspected case of COVID-19; or the care of any other individual who presents for health services during the period of the COVID-19 emergency declaration, particularly where the health care facility or professional claims a shortage of resources, including ventilators, was the basis for their actions. Without clear guidance, this perception of immunity may lead providers to disregard the rights of people with disabilities during the crisis.

Due to the Lack of Clear Guidance Harmful Stereotypes of People with Disabilities Have Likely Already Influenced Treatment Decisions

The history of disability discrimination and bias in the medical community must inform OCR's consideration of DRNY's complaint and lead OCR to mandate NYSDOH to issue uniform statewide guidelines to ensure non-discriminatory rationing of critical medical care, such as ventilators. As OCR is well aware, studies have repeatedly documented a persistent bias on the part of medical providers against people with disabilities and, notably, a persistent failure of medical providers to fully appreciate the value and quality of life with a disability.⁹ These problems are reinforced by the dramatic underrepresentation of disabled people in the health professions.

High stakes medical decisions are some of the most difficult choices made by healthcare professionals. However, healthcare decisions are influenced by more than just medical facts. Instead, innumerable social factors influence these decisions, as well as time, expertise, finances, supplies, and other factors. When stakes are high and resources are low, medical decisions can especially be influenced by a patient's race, gender, sexuality, age, religion, citizenship, and financial background in ways that can both be detrimental and unfairly prejudicial to a person's well-being. Disability status is also an important factor that influences the decisions of medical professionals providing life sustaining health care.¹⁰

Discrimination is not always driven by malice. Stereotypes about disability are often so ingrained in the thought process of the medical professionals that they do not realize they are discriminating against people with disabilities. In the case of disability discrimination, the discriminating provider often claims he or she simply tried to do what was in the patient's best interest, and does not view the actions that were or were not taken as discriminatory. For example, as the National Council on Disability has reported, doctors often make decisions about the "futility of treatment," for example, that are based on implicit biases about the quality of life and inherent worth of people with disabilities. Hospital or emergency room physicians often prematurely attempt to force palliative or hospice care on patients with a disability with treatable diseases—or they delay care in medical emergencies to first determine the patient's code status, presuming that a primary care physician would have (or should have) encouraged a DNR order for patients with certain disabilities. As but one example cited to by the National Council, a 20-year old man with physical and intellectual disabilities was denied treatment for a serious wound and bone infection because his

⁹ See, e.g., Carlson, David, et al., *Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights*, National Disability Rights Network and Disability Rights Washington, May 2012, at 40, http://ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf. Accessed 15 Apr. 2020.

¹⁰ See e.g., Okoro CA, et al., *Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016*. MMWR Morbidity and Mortality Weekly Report vol. 67, 32:882–7, 17 Aug. 2018, <https://doi.org/10.15585/mmwr.mm6732a3>. Accessed 15 Apr. 2020, examining characteristics of noninstitutionalized adults with six specific disability types (hearing, vision, cognition, mobility, self-care, and independent living), to assess disability-specific disparities in health care access.

physicians asserting that he was not a candidate for IV antibiotics; they recommended withholding supplemental fluids and nutrition, and issuing a DNR order. When he received IV antibiotics to stabilize his condition, he was able to receive aggressive wound treatment which resolved the infection and permitted him to return safely to his home in the community.¹¹

It is not hard to see how stereotypes of disability persist in the medical community. The National Council on Disability found significant discrimination against people with disabilities by the medical profession, including discrimination in organ transplants, quality-adjusted life years, and medical futility.¹² A recent medical study showed that large segments of the medical community, in multiple geographic locations, refuse even to treat patients with disabilities.¹³ A quarter of doctors in the study refused to schedule an appointment with potential patients who used wheelchairs.¹⁴ Another recent survey confirmed that physicians “demonstrated superficial or incorrect understanding” of the ADA and other anti-discrimination laws.¹⁵

Research has shown that disabled patients “experience health care disparities, such as lower rates of screening and more difficulty accessing services, compared to people without disabilities.”¹⁶ Medical professionals have historically deprioritized the delivery of treatment to people with disabilities due to their negative views, which continue to make it more difficult for people with disabilities to get treatment. The policies at Elmhurst Hospital in Queens, New York – where the medical professionals were permitted to unilaterally designate coronavirus patients as DNR and/or DNI, against the wishes of the patient or family until the policies were revealed by Washington Post reporters – demonstrate that these stereotypes and negative views of people with disabilities continue to influence care during the pandemic.

NYSDOH Must Issue Strong Guidance to New York Healthcare Providers Clarifying How to Prevent Discriminatory Rationing of Health Care Assets to People with Disabilities

It is against the backdrop of longstanding disability discrimination, and concomitant “ableist” bias in the medical community, set forth above, that OCR must mandate that New York State clarify how to prevent the discriminatory rationing of health care to people with disabilities under the 2015 Ventilator Allocation Guidelines.¹⁷ NYSDOH must issue guidance that corrects the following

¹¹ National Council on Disability, *Bioethics and Disability Report Series: Medical Futility and Disability Bias*, 20 Nov. 2019, https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf. Accessed 15 Apr. 2020.

¹²*Id.*

¹³ Chen, Pauline W., *Disability and Discrimination at the Doctor's Office*, New York Times, 23 May 2013, <https://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/>, citing Lagu T, et al., *Access to Subspecialty Care for Patients With Mobility Impairment: A Survey*, *Ann Intern Med.* 158:441–446, 19 March 2013, <https://doi.org/10.7326/0003-4819-158-6-201303190-00003>. Accessed 15 Apr. 2020.

¹⁴ *Id.*

¹⁵ Agaronnik, Nicole D, et al., *Knowledge Of Practicing Physicians About Their Legal Obligations When Caring For Patients With Disability*, *Health Affairs* vol. 38, 4, Apr. 2019, <https://doi.org/10.1377/hlthaff.2018.05060>. Accessed 15 Apr. 2020.

¹⁶ Iezzoni LI. *Eliminating health and health care disparities among the growing population of people with disabilities.* *Health Aff. (Millwood)* vol. 30, 10:1947–54, Oct. 2011, <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2011.0613>. Accessed 15 Apr. 2020.

¹⁷ Governor Cuomo and NYSDOH have created enormous confusion about the operability of the 2015 Ventilator Allocation Guidelines. Neither Governor Cuomo nor NYSDOH have reinforced the obligations of New York State health care providers to comply with the non-discrimination principles set forth in the OCR March 28, 2020 Bulletin. At Elmhurst Hospital, a New York City Health + Hospital facility in the “epicenter of the epicenter” in Queens, New York, a protocol “was communicated to staff on Saturday and again on Sunday and was shared with The Washington Post,”

aspects of the 2015 Ventilator Allocation Guidelines that, as written, could lead to the denial of life-sustaining services to people with disabilities during this pandemic:

- The 2015 Ventilator Allocation Guidelines do not rest on the presumption that all patients who are eligible for ICU services during ordinary circumstances remain eligible for ICU services in a pandemic event.
- The 2015 Ventilator Allocation Guidelines contain exclusion criteria based on age, disabilities, and other factors.¹⁸
- The 2015 Ventilator Allocation Guidelines do not ensure that all patients receive individualized assessments by clinicians, based on the best available objective medical evidence and not based on generalized assumptions about a person’s disabilities.
- The 2015 Ventilator Allocation Guidelines do not ensure that no one is denied care based on stereotypes, assessments of quality of life, or judgments about a person’s “worth” based on the presence or absence of disabilities or other factors.
- While it is appropriate to evaluate the possibility of a person’s survival in allocation decisions, the 2015 Ventilator Allocation Guidelines do not mandate that that consideration must be based on the prospect of surviving the condition for which the treatment is designed – in this case, COVID-19 – and no other disabilities. The 2015 Guidelines impose a protocol utilizing the Sequential Organ Failure Assessment (“SOFA”) system. While a SOFA score is based solely on clinical factors and does not consider personal values or subjective judgments, individuals with preexisting conditions are by default going to receive higher (worse) SOFA scores than individuals without disabilities, meaning these individuals with disabilities will be less likely to receive life-saving care. Individuals with disabilities may live day-to-day without any complications, but with a condition that presents abnormalities in one or more of the six key organs and systems measured using SOFA. These individuals are completely disadvantaged in a triage situation prior to considering any symptoms that result directly from COVID-19.

that would allow doctors “to unilaterally designate coronavirus patients as DNR and/or DNI — do not intubate — which means they will not be eligible for a ventilator, even if it goes against the wishes of the patient or family. Getting the agreement of a second doctor is ‘optimal,’ the guidance states, but is not required. The language of the ethical framework states that if the order is in effect, doctors have no ‘no obligation to offer or initiate’ the treatment, allowing them to make decisions on a case-by-case basis.” Cha, Eunjung, et al., *Faced with a crush of patients, besieged NYC hospitals struggle with life-or-death decisions*, Washington Post, 31 March 2020,

<https://www.washingtonpost.com/health/2020/03/31/new-york-city-hospitals-coronavirus/>. Accessed 15 Apr. 2020.

¹⁸ During a public health emergency, clinicians should still make clinical judgments about the appropriateness of critical care using the same criteria they use during normal clinical practice. There are compelling reasons to not use exclusion criteria. Categorically excluding patients will make many feel that their lives are “not worth saving,” leading to justified perceptions of discrimination. Moreover, categorical exclusions are too rigid to be used in a dynamic crisis, when ventilator shortages will likely surge and decline episodically during the pandemic. In addition, such exclusions violate a fundamental principle of public health ethics: use the means that are least restrictive to individual liberty to accomplish the public health goal. *See, e.g.*, American Public Health Association, *Public Health Code of Ethics*, https://www.apha.org/-/media/files/pdf/membergroups/ethics/code_of_ethics.ashx. Accessed 15 Apr. 2020. Categorical exclusions are not necessary because less restrictive approaches are feasible, such as allowing all patients to be eligible and giving priority to those most likely to benefit.

- The 2015 Ventilator Allocation Guidelines do not mandate that treatment allocation decisions cannot be made based on the perception that a person’s disability will require the use of greater treatment resources.
- The 2015 Ventilator Allocation Guidelines do not call for the communication of triage decisions to patients and/or their next of kin as a required component of a fair allocation process that provides respect and dignity for persons.
- With respect to patient due process rights, the 2015 Ventilator Allocation Guidelines do not endorse an on-going appeals process that will provide the greatest patient protection against unjust denial of life-sustaining treatment to people with disabilities. Rather the 2015 Ventilator Allocation Guidelines call for a highly constrained “hybrid” system of review which combines “limited on-going individual appeals with retrospective, periodic review.” The 2015 Ventilator Allocation Guidelines provide that individual appeals are be limited to procedural/technical injustices only (e.g., when a withdrawal decision was made without considering all relevant clinical triage criteria) that could remedy a potential injustice prior to the implementation of a triage decision.”¹⁹ But NYSDOH has issued guidance that hospitals must suspend visitation, except in very limited circumstances, during the COVID-19 pandemic.²⁰ Visitation constriction provisions were not evaluated during the development of the appeals process endorsed in the 2015 Ventilator Allocation Guidelines. Those appeals processes must now be reassessed in light of the fact that patients effectively have no one to advocate for them or to assist them to advocate for themselves. People with cognitive impairments due to intellectual and developmental disabilities, people with dementia, people with altered mental status due to a mental health challenge are all at very real risk of disability discrimination in the rationing of scarce resources during this pandemic.²¹
- Finally, and perhaps worst of all, the 2015 Ventilator Allocation Guidelines actively call for the removal of a ventilator from a person who lives in the community and who utilizes a ventilator on a daily basis when that person seeks medical care and treatment in an acute medical facility. The 2015 Ventilator Allocation Guidelines force a person who utilizes this equipment on a daily basis in the community to choose whether or not to access medical

¹⁹ See Chapter 4, *Implementing New York State’s Ventilator Allocation Guidelines: Legal Considerations*, Section VI. Appeals.

²⁰ NYSDOH issued its first health advisory suspending all visitation on March 18, 2020. On March 27, 2020, NYSDOH issued updated guidance specific to obstetrical and pediatric settings. On April 10, 2020, NYSDOH issued additional updated guidance specific to “patient support persons, or family members/and or legal representatives of patients in imminent end-of-life situations.” The April 10, 2020 updated guidance is available at https://coronavirus.health.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_041020-002.pdf. Accessed 15 Apr. 2020.

²¹ Under the updated NYSDOH April 10, 2020 guidance, support persons are allowed, under certain circumstances, to accompany persons with cognitive impairment in order to “avoid negative health outcomes unrelated to the COVID-19 public health emergency.” Hospitals are reported as non-compliant with this newly issued support guidance and are still denying access to supporters. But, even if admitted, these supporters are not officially there to participate in any process that addresses rationing of critical health care. Similarly, the updated April 10, 2020 guidance permits a family member and/or legal representative to attend a person in “imminent end-of-life situations,” defined as a “patient who is actively dying, where death is anticipated within less than 24 hours.” While permitting the family member/legal representative to attend a person at end-of-life may permit participation in decision making around withholding and withdrawal of life-sustaining treatment, the family member/legal representative has not been afforded rights to participate in any decision making around rationing of critical health care at the initial hospitalization or during the course of treatment in advance of the patient being deemed to be “actively dying.”

treatment as seeking out such medical treatment exposes them to the very real risk that their ventilator could be “commandeered” for the public good, resulting in their being taken off their life-sustaining medical equipment when seek treatment.²²

Conclusion

Accordingly, we urge OCR to expedite its investigation into the matters raised by DRNY’s complaint and to do so in a way that is open and transparent to the public.

We also urge OCR to mandate that New York State immediately do the following:

- (1) issue clear and binding guidelines that all health care facilities and health care professionals, statewide, must follow with respect to the allocation of scarce health care resources during this pandemic, specifying that:
 - (a) the guidelines must establish a critical care triage treatment protocol for the entire state grounded in obligations that include the duty to care, duty to steward resources, distributive and procedural justice, and transparency;
 - (b) the guidelines must not violate federal, state and local civil rights laws that prohibit discrimination against people with disabilities and/or other disfavored status including age, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), and Section 1557 of the Affordable Care Act (ACA); and
 - (c) the guidelines must diminish the chances that implicit bias will significantly influence what should otherwise be sound and fair medical decisions;
- (2) issue the March 28, 2020 OCR Bulletin to all hospitals, health care facilities and healthcare providers in New York State;
- (3) include the people who will be affected by these guidelines in both the deliberative process that will inform the drafting of such guidelines and the oversight process relating to the ongoing implementation of such guidelines;
- (4) ensure that all patients have access to tools to advocate for their own care during the COVID-19 pandemic; and
- (5) ensure that NYSDOH clarify any confusion that exists in the medical and disability communities by publicly retracting the provisions of the 2015 Ventilator Allocation

²² So called “commandeering” of ventilators from ventilator-dependent individuals who live in “chronic care” facilities was not endorsed by the 2015 Allocations Guidelines. However, ventilator-dependent individuals who live in the community are treated differently when they present at an acute-care, i.e. hospital, seeking treatment. The 2015 Ventilator Allocation Guidelines provide as follows: “the Task Force determined that ventilator-dependent chronic care patients are subject to the clinical ventilator allocation protocol only if they arrive at an acute care facility for treatment. Once they arrive at a hospital, they are treated like any other patient who requires ventilator therapy. This policy balances the need to protect vulnerable populations with the principle of treating all patients in need of a ventilator equally.” See New York State Task Force on Life and the Law New York State Department of Health, *Ventilator Allocation Guidelines*, Nov. 2015, https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf. Accessed 15 Apr. 2020.

Guidelines that would allow medical facilities to take away a chronic ventilator user's personal ventilator when they enter a health care facility seeking medical care.

Ultimately, the question of how to ration critical medical equipment and treatment when those resources are insufficient must rest on an individualized assessment of each person's likelihood to survive if offered whatever medical services are in limited supply. The assessment must be based on an individual's specific functioning, and not upon bias-informed assumptions based on a person's pre-existing condition or specific diagnosis. These standards would still enable the system to deflect limited available treatment away from both people who are expected to recover without such treatment and people who are not expected to recover with such treatment.

Thank you for your consideration of our support of DRNY's complaint.

Respectfully submitted,



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Deputy Legal Director



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