



August 12, 2020

Senator Gustavo Rivera
Chair, Senate Standing Committee on Health

Senator James Skoufis
Chair, Senate Standing Committee on Investigations & Government Operations

Senator Simcha Felder
Chair, Administrative Regulations Review Commission

Assembly Member Richard N. Gottfried
Chair, Assembly Standing Committee on Health

Assembly Member John T. McDonald, III
Chair, Assembly Standing Committee on Oversight, Analysis & Investigation

Assembly Member Dan Quart
Chair, Administrative Regulations Review Commission

RE: NYS Joint Legislative Hearing on COVID-19 and Hospitals

Dear Committee Chairs and Members,

The Center for HIV Law and Policy (CHLP) respectfully submits the following testimony regarding the disproportionate impact of COVID-19 on people with disabilities and the gaps in New York law on the allocation of scarce resources during emergency situations such as the coronavirus pandemic.

This testimony builds upon our letter (attached here) to Governor Cuomo and state officials in April asking Governor Cuomo to issue binding guidance protecting the rights of all New Yorkers to high quality medical care regardless of age, disability, or any other disfavored status; and advocacy by Disability Rights New York (DRNY) on this issue. We have received no response from any of the state agency leaders we reached out to regarding our concerns, and there has been no progress made on this issue. Consequently, we believe that legislative action is necessary.

CHLP is a New York-based non-profit organization that challenges barriers to the rights and health of people affected by HIV through legal advocacy, high-impact policy initiatives, and creation of

cross-issue partnerships, networks and resources. We support movement building that amplifies the power of individuals and communities to mobilize for change that is rooted in racial, gender and economic justice.

It is clear that people with disabilities, including people with chronic health problems, are especially vulnerable to coronavirus. People with disabilities also have faced a long history of discrimination and stigma in society and particularly in their medical treatment. Meanwhile, as DRNY, CHLP, and others have identified, New York's current non-binding guidance on ventilator distribution has serious gaps and is insufficient to protect the rights and lives of people with disabilities. First, they address only the allocation of ventilators, which are not the only form of essential care. COVID-19 patients living with disabilities including HIV, advanced age, and other disfavored statuses need assurances of equal access to other respiratory therapies, testing, medications, critical care beds, and staff time, which current guidance fails to adequately protect. New Yorkers also need assurances that, in times of scarcity, all state and federal laws that prevent discrimination on the basis of age, disability, race and gender will apply to the provision of critical care. Second, the ventilator policy is voluntary, creating a very real possibility that resource allocation decisions will not be uniform throughout the state and may be made on ad hoc bases in violation of fundamental principles of medical ethics and antidiscrimination laws.

This reality has led people with disabilities to fear that they will be treated as second class citizens in hospitals and to therefore avoid hospitals, even when experiencing health problems.

The Office of Civil Rights at the U.S. Department of Health and Human Services issued a bulletin (attached here) confirming that civil rights laws such as the Americans with Disabilities Act remain in effect during public health emergencies and affirming 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." Clearly these are integral rights that no attempt to avoid liability or promote flexibility can waive.

Seeing no buy-in or action from the Governor's office or the Department of Health, we propose today that the legislature **codify these rights in the Patient's Bill of Rights**. Individuals must have confidence that when they enter hospitals they will not have personal ventilators taken away or otherwise be discriminated against due to disability, age or other disfavored identities.

The right time to fix protections for vulnerable New Yorkers during an emergency is before that emergency arises, in order to ensure that the resulting policy is comprehensive and includes input from all stakeholders. The fact that New York avoided a ventilator-rationing crisis during the first wave of COVID-19 is no reason to not act with urgency to fix this now. Indeed, it is likely that we will again confront serious resource allocation issues through either a COVID-19 resurgence or another lethal virus in the near future.

Further, the legislature should **revoke Article 30-D of the Public Health Law** immunizing health care facilities from liability.

Article 30-D of the Public Health Law (Emergency Disaster Treatment Protection Act) drastically limits liability standards to the point that it essentially insulates hospitals and nursing homes and their executive leadership from criminal or civil liability. Specifically, liability would only pertain to cases in which gross negligence, reckless misconduct, or instances where intentional malfeasance has occurred, yet the law specified that those definitions do not apply to “decisions resulting from a resource or staffing shortage” as has been caused by the COVID-19 pandemic.

Stripping patients and family members of the ability to hold hospitals accountable for civil rights violations and other harm is not appropriate. Immunizing hospitals under these circumstances abandons people with disabilities and suggests that these institutions are free to violate their rights with impunity. Pandemics should not be used as a basis to encourage hospitals to put aside basic standards of care which, when followed, insulate against liability.

We urge you to repeal Public Health Law Article 30-D in its entirety.

Finally, we ask that the Legislature **hold hearings on Covid-19 responses by prisons, jails, psychiatric hospitals and other settings of confinement**. It is unconscionable that the legislature has chosen to minimize the serious situation facing inmates and staff at prisons, jails, and psychiatric facilities around the state by not holding a hearing on this subject. Information from staff and residents at these facilities reveals that efforts to protect inmates and staff from coronavirus are sorely lacking. Criminal justice stakeholders around the country have come together and agreed on a series of pragmatic life-saving [approaches](#) to the coronavirus pandemic that rely on reducing institutionalization and incarceration, and we hope that New York can change course and adopt this guidance to protect its incarcerated citizens. Prosecutors, correctional leadership, and state officials should aggressively assess who can be freed from confinement and what supports are required for these individuals to live safely in the community.

Thank you for your consideration of our testimony and your work to protect the rights of people with disabilities in New York State.

Respectfully submitted,



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Attachments:

- 1) April 13, 2020 Letter to Governor Cuomo and Commissioner Zucker
- 2) March 28, 2020 HHS OCR Bulletin



April 13, 2020

Governor Andrew Cuomo

Dr. Howard Zucker
Commissioner, New York State Department of Health

Johanne Morne
Director, AIDS Institute, New York State Department of Health

Dr. Charles Gonzalez
Medical Director, AIDS Institute, New York State Department of Health

Dr. Mitchell Katz
President and Chief Executive Officer, NYC Health + Hospitals

**RE: Essential Elements Of New York Guidelines For Allocation
Of Health Care Resources During A Pandemic**

The rapid spread of COVID-19 has quickly pushed New York City and many other cities in the United States to the precipice of an unsavory public health dilemma: how to allocate scarce resources when a pandemic has overwhelmed our existing health care infrastructure. Absent clear guidance from the state, this situation could easily lead to facilities and providers employing ad-hoc triage policies that ration critical care away from patients living with disabilities, including those with HIV, Hepatitis and related comorbidities, and older patients, based on uninformed assumptions about the relative values of their lives and life expectancies.

One example of how a lack of guidance is leading to institutional policies that could permit discrimination is a directive from the chair of NYU Langone's emergency department, which reportedly said, "For those patients who you feel intubation will not change their ultimate clinical outcome (for example cardiac arrests, some chronic disease patients at end of life, etc.) you will have support in your decision making at the department and institutional level to

withhold futile intubations.”¹ That report highlights two alarming prospects—first, that treating physicians will be tasked with making care rationing decisions, and with only the vaguest of guidance; and second, that providers might use unsupported on-the-fly assessments about quality of life and likelihood of survival based on assumptions about certain diagnoses rather than objective clinical data.²

The serious risk that critical care could be rationed away from certain patients based on unethical, illegal assumptions about their fitness to receive care has been acknowledged by the Office of Civil Rights at the federal Department of Health and Human Services, which on March 28, 2020 issued a bulletin affirming 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.”^{3 4 5}

New York’s existing guidance in this area provides a foundation to build on, but is far from sufficient to address the very serious crisis posed by COVID-19:

- First, current guidance addresses only the allocation of ventilators, which, while essential tools for fighting COVID-19, are not the only form of essential care.⁶ COVID-19 patients with disabilities, advanced age, and other disfavored statuses also need equal access to other respiratory therapies, testing, medications, critical care beds, and staff time, which current guidance fails to adequately protect.
- Second, the ventilator policy is voluntary, purportedly to provide institutions with flexibility in the event of a crisis. Though the authors urge institutions to adopt them as their own policies, they are not enforceable by the state or by a private party in litigation, creating a very real possibility that resource allocation decisions will not be uniform throughout the state and may be made on ad hoc bases in violation of fundamental principles of medical ethics.

¹ Del Valle, Lauren, “[NYU Langone Tells Emergency Doctors to Consider Who Gets Intubated, WSJ Reports](#),” CNN (April 1, 2020).

² Nor is this an unprecedented problem. One example is Dr. Laura Evans of Bellevue Hospital, featured in “[The Hardest Questions Doctors May Face: Who Will Be Saved? Who Won’t?](#)” by Sherry Fink in The New York Times on March 21, 2020. Dr. Evans recalls being asked by hospital administrators to make a list of patients to prioritize for care during Hurricane Sandy without institutional guidance.

³ The full bulletin is available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.

⁴ Notably, the ability of the Department of Health and Human Services to address discriminatory care allocation decisions might be limited by the Secretary’s March 17, 2020 declaration limiting liability of providers in provision of COVID-19 care. That declaration is available at <https://www.federalregister.gov/documents/2020/03/17/2020-05484/declaration-under-the-public-readiness-and-emergency-preparedness-act-for-medical-countermeasures>.

⁵ While these principles are rooted primarily in disability antidiscrimination law, federal and state statutory and constitutional law also clearly prohibit allocation of resources on the basis of age, sex (including sexual orientation and gender identity), race, ethnicity, national origin, or religion.

⁶ New York’s Ventilator Allocation Guidelines, which were last revised in 2015, are available here: https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf.

Clear and widely circulated guidelines also will protect dedicated, hard-working health care providers from unwarranted lawsuits and liability.⁷ Virtually everyone wants to do the right thing; what's needed is leadership that offers front line care providers consistent, objective criteria for life-and-death decision making in the event of inadequate resources.

We urge Governor Andrew Cuomo to take seriously his obligation to protect public health under the New York state constitution⁸ and employ its emergency powers^{9 10} to issue binding guidance protecting the rights of all New Yorkers to high quality medical care regardless of age, disability, and any other disfavored status.

That guidance should be governed by the following key principles.

- 1. Categorically excluding groups of patients from access to critical care without objective individualized assessments is unethical and violates federal and state anti-discrimination law.**

One thing that New York's ventilator allocation policy gets seriously wrong is that before it employs neutral criteria to determine how best to allocate resources, it explicitly excludes patients with certain health conditions from access to ventilators on that basis alone. Such categorical exclusions are unethical and suggest problematic assessments about the relative values of different kinds of lives. Categorical exclusions could lead to the denial of care to patients with persistently stigmatized conditions such as intellectual disabilities and HIV, based not on an objective, individualized assessment of their ability to benefit from care but rather from unwarranted assumptions based on a diagnosis alone.^{11 12}

⁷ A new provision of New York's public health law, Article 30-D ("The Emergency Disaster Treatment Protection Act"), PHL § 3080 *et seq.* (2020), contains a provision shielding health care providers from liability related to provision of COVID-19 related care in an emergency situation of limited resources. Significant limits on malpractice lawsuits may be legally permissible at a time when inadequate resources may require triage that limits services to those unlikely to benefit from them. However, Article 30-D cannot and should not be read as an effective override of federal and state antidiscrimination protections, such as the Civil Rights Act of 1964 and the ADA, that prohibit triage determinations based on disability, race or any class of identity that is protected under these laws.

⁸ NY CONST. art. XVII, § 3

⁹ N.Y. EXEC. LAW § 28(1) (the New York State and Local Natural Disaster and Man-Made Disaster Act).

¹⁰ N.Y. PUB. HEALTH LAW § 16.

¹¹ White, Douglas B., Lo, Bernard, A Framework for Rationing Ventilators and Critical Care Beds During the COVID-19 Pandemic, JAMA-Online (March 27, 2020), *available at* <https://jamanetwork.com/journals/jama/fullarticle/2763953> ("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. 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").

¹² An further problem is that patient concerns about being categorically-excluded from treatment could result in patients deciding not to share information with their treating physicians that would be useful in treatment.

People with disabilities have good reason to be concerned about medical discrimination based on a long history of underrepresentation in medical professions as well as countless individual and collective experiences in which medical providers themselves have misunderstood diagnoses and made assumptions about the value of a patient's life on that basis. One can easily imagine the types of patients who might be vulnerable to such treatment during the COVID-19 crisis:

- A person who has been living with HIV for decades and due to treatment interruption has a high viral load and a low CD4 count;
- A person who uses a personal ventilator to manage a disability that affects their respiratory system;
- A young person living with cystic fibrosis;
- An incarcerated person with underlying chronic conditions such as diabetes;
- An individual struggling with severe mental health issues;
- An individual with a history of any drug use or dependency.

Several federal and state laws that prohibit discrimination against people living with disabilities would bar denial of care to any of these individuals based on those conditions or circumstances. Principal among these is the Americans with Disabilities Act (ADA), which prohibits discrimination against people with disabilities in a wide range of settings, including in the provision of medical care; and Section 504 of the Rehabilitation Act of 1973, which prohibits disability-based discrimination by recipients of federal funding.¹³ Both state policies and the policies of private hospitals are covered under both laws.¹⁴ The ADA's prohibition on disability-based discrimination in the provision of health care is evident in the text of the statute and has been affirmed by the Supreme Court, most notably in *Bragdon v. Abbott*, the Court's first decision interpreting the ADA in a case challenging a dentist's refusal to provide routine dental care to a woman living with HIV.¹⁵ ¹⁶ Furthermore, in *Alexander v. Choate* the Supreme Court suggested that

¹³ 29 U.S.C. 794.

¹⁴ State policies are covered by Title II of the ADA at 42 U.S.C. § 12132. Private hospitals are covered as public accommodations by Title III of the ADA at 42 U.S.C. § 12182.

¹⁵ 524 U.S. 624 (1999).

¹⁶ In its analysis of medical providers' ADA obligations during the COVID crisis, the Disability Rights Education and Defense Fund notes that the legislative history of the passage of the ADA includes ample evidence that preventing discrimination in provision of medical care was a primary goal of the ADA. See Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability, Disability Rights Education and Defense Fund (March 25, 2020), [available at https://www.hivlawandpolicy.org/sites/default/files/%20Preventing%20Discrimination%20in%20the%20Treatment%20of%20COVID-19%20Patients-%20The%20Illegality%20of%20Medical%20Rationing%20on%20the%20Basis%20of%20Disability-DREDF.pdf](https://www.hivlawandpolicy.org/sites/default/files/%20Preventing%20Discrimination%20in%20the%20Treatment%20of%20COVID-19%20Patients-%20The%20Illegality%20of%20Medical%20Rationing%20on%20the%20Basis%20of%20Disability-DREDF.pdf).

healthcare providers cannot circumvent the requirements of the ADA by simply classifying people with disabilities as medically unqualified to receive certain types of medical care on a categorical basis.¹⁷

The protections of these federal laws apply to incarcerated people,¹⁸ to whom state officials have the additional, affirmative obligation under our state and federal constitutions to provide for all of their essential medical needs.¹⁹

New York State's Human Rights Law²⁰ and New York City's Human Rights Law²¹ also clearly establish that services may not be denied by a public accommodation on the basis of a disability diagnosis or a perceived disability.²²

Categorical exclusions of people with disabilities fly in the face of those important legal protections.

2. Decisions about provision of care must be based not on subjective assessments of quality of life or long-term prognosis, but rather on whether a given patient would benefit from treatment in the near-term.

There is no question that a patient's individual medical condition will be a consideration when deciding how to provide the best care possible under the circumstances. A just

¹⁷ 469 U.S. 287 (1985).

¹⁸ *E.g.*, Penn. Dept. of Corrections v. Yaskey, 524 U.S. 206, 209 (1998): "[Th]e ADA plainly covers state institutions *without* any exception that could cast the coverage of prisons into doubt."

¹⁹ *See, e.g.*, See Estelle v. Gamble, 429 U.S. 97, 103, 97 S. Ct. 285, 290, 50 L. Ed. 2d 251, 256 (1976) ("These elementary principles establish the government's obligation to provide medical care for those whom it is punishing by incarceration.") *See also* N.Y. Correct. Law § 45(3) (McKinney 2012) (detailing the responsibilities of the New York Commission of Corrections, including the duty to "visit, and inspect correctional facilities ... and appraise the management of such correctional facilities with specific attention to matters such as safety, security, health of inmates, sanitary conditions" and other things that affect a prisoner's well-being).

²⁰ NY EXEC § 290 ("the state has the responsibility to act to assure that every individual within this state is afforded an equal opportunity to enjoy a full and productive life and that the failure to provide such equal opportunity, whether because of ... health care not only threatens the rights and proper privileges of its inhabitants but menaces the institutions and foundation of a free democratic state and threatens the peace, order, health, safety and general welfare of the state and its inhabitants.").

²¹ New York City Administrative Code § 8-107.

²² NY State and NY City's legal protections are at least as strong as federal provisions and prohibit any discrimination that would violate the ADA and RA. *E.g.*, I.M. by L.M., 178 A.D.3d 126, 135 (1st Dept. 2019) ("State HRL disability discrimination claims are governed by the same legal standards as federal ADA claims. The City HRL is as or more protective than State and Federal discrimination laws. Given the close overlap, if a plaintiff can satisfy his or her burden under the ADA, a plaintiff will also satisfy his or her burden under the RA and the State and City HRLs") (*internal citations omitted*).

approach to making that decision, however, will not assume at the outset that certain categories of patients are less worth saving on the basis of a diagnosis, or an arbitrary age cutoff or general assumption about life expectancy, but will rather make an individualized assessment based on an objective consideration of that patient's actual current condition.²³ The appropriate question is not a patient's long-term prognosis but rather only whether critical care would be futile in the short-term.

Constructing such a triage plan is achievable. In one published example of a triage plan that successfully allocates resources without requiring discriminatory ex ante presumptions about who deserves care, hospital triage teams have clear guidance as to how to prioritize patients without embedding assumptions about categories of patients.²⁴ Such a system is actually most consistent with providing the best care and does not require that doctors provide futile care or interfere with clinical decision making; rather, it merely requires that decisions about resource-allocation be made consistent with general decisions about critical care.²⁵

3. Triage teams, with input and representation of people with disabilities, must make care allocation decisions.

One thing that New York's ventilator allocation policy absolutely gets right, and must be extended to other forms of care, is that resource-allocation decisions must be made not by a treating physician but rather by a hospital triage team that incorporates input and representation from people living with disabilities.

²³ As disability rights expert Samuel Bagenstos, professor of law at the University of Michigan, notes, "To be sure, disabilities may make it impossible or impracticable for an individual to satisfy eligibility criteria that are defined without reference to disability...But the insertion of disability into the medical rationing context is not like that. Refusing to allocate scarce treatment resources to patients with pre-existing disabilities does not rest on a simple and uncontroversial empirical question." *May Hospitals Withhold Ventilators from COVID-19 Patients with Pre Existing Disabilities?*, available at <https://poseidon01.ssrn.com/delivery.php?ID=870067088114085013031084080068064108058045018002021023103090073113114122022085080007037114118031122002109098124091024004094092057019039084049114097064074126017028004022023000125022088104083094021020068066072087004106092125004107000114121084031030096&EXT=pdf>.

²⁴ [White DB, Lo B, A framework for rationing ventilators and critical care beds during the COVID-19 pandemic, JAMA online \(March 2020\).](#)

²⁵ [White DB, Lo B, A framework for rationing ventilators and critical care beds during the COVID-19 pandemic](#) ("An allocation system should make clear that all individuals are 'worth saving' by keeping all patients who would receive critical care during routine clinical circumstances eligible, and by allowing the availability of beds and services to determine how many eligible patients receive them. It is important to note that there are some conditions that lead to immediate or near-immediate death despite aggressive therapy such that during routine clinical circumstances clinicians do not provide critical care services (e.g., cardiac arrest unresponsive to appropriate ACLS, massive intracranial bleeds, intractable shock). 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.").

Such a policy would lead to an ethical decision-making process based on objective evidence, benefiting individual patients, health care providers and care facilities generally.

- It would lead to the best decisions for patients because it would permit treating physicians to fulfill their duty of care to individual patients. As the ventilator allocation policy explains, “this framework permits attending physicians to fulfill their obligation to care for their individual patients without facing a conflict of interest; they can advocate for their patients and not also be responsible for deciding to withhold or withdraw ventilator treatment.”²⁶
- It would lead to the best decisions for facilities because it would ensure that the right people with sufficient seniority and ethical training are charged with such weighty decisions. What is needed is a healthy, seamless mix of public health ethics and clinical ethics. “A triage team with expertise in both aspects of this allocation framework should make allocation decisions. “The separation of the triage role from the clinical role is intended to enhance objectivity, avoid conflicts of commitments, and minimize moral distress.”²⁷

As a safeguard against the influence of unconscious biases and subjective assessments about quality of life in care allocation decisions, it is essential that triage teams include people with disabilities.

Despite the fact that delegating care allocation decisions to triage teams offers these clear benefits and has been recognized as the best approach in the ventilator allocation guidelines, news reports continue to circulate suggesting that treating physicians may yet be charged with making these decisions. Notably, in one such report, state officials, including Governor Andrew Cuomo, are quoted as saying that there is no universal protocol for resource allocation decisions.²⁸ This confusion points to the importance of quickly clarifying best practices and providers’ ethical responsibility to adhere to them before facilities have to make these decisions.

4. New York must issue binding guidance to ensure that all New Yorkers can safely access appropriate medical care, and that all hospital and clinic staff throughout the state understand and follow.

In a time of crisis and uncertainty, the only way to ensure that all patients have access to best practices medical care is to give providers notice as to what is expected and give

²⁶ New York’s Ventilator Allocation Guidelines, *infra* n. 5.

²⁷White DB, Lo B, *A framework for rationing ventilators and critical care beds during the COVID-19 pandemic*, JAMA, *infra* n. 17.

²⁸ Goldstein, Joseph, Rothfeld, Michael, and Weiser, Benjamin, “Patient Has Virus and Serious Cancer. Should Doctors Withhold Ventilator?,” New York Times (April 1, 2020), *available at* <https://www.nytimes.com/2020/04/01/nyregion/coronavirus-doctors-patients.html>

patients tools to advocate for their own care. Voluntary guidance accomplishes neither of those goals. As state health officials have acknowledged in reporting, the lack of binding guidance from the state necessarily leads to a patchwork of policies in which each institution is implementing its own policies or leaving providers to make ad hoc policy on the fly. Everyone involved would be better served by clarity.

Expecting even well-intentioned providers and institutions to implement best practices that have not clearly been articulated to them is an invitation to violations of the ethical obligation to provide the best care for each patient in their charge. At the same time, failing to articulate clear expectations up front may not in fact protect them from costly litigation on the back end. To the contrary, the best way to avoid litigation—which is nobody’s goal as in most cases it will come too late to meaningfully assist patients as well—is to provide clear expectations leading to the provision of high-quality care obviating the need for court-involvement.

While the hope is that clarifying expectations will actually make enforcement less costly in the long run, patients would also benefit from binding guidance that they can use to safeguard their rights when necessary. Patients, such as those with disabilities, need a recourse if they receive substandard care as a result of assumptions about their fitness or the values of their lives. To ensure that unconscious biases about the relative values of different lives are not baked into triage protocols, people living with disabilities, particularly those with a history of denial of essential services (such as those living with HIV in the earlier days of the HIV epidemic) must be included as advisors in guidance development and training.

A voluntary policy offers no such protection, while also depriving providers of clear guidance on how to best manage difficult circumstances.

5. Patients have a right to know how care rationing decisions are made.

Ethical allocations of care during a crisis should be assessed not only by measurable outcomes such as survival to hospital discharge or years of life saved, but also whether patient dignity is respected such that patients have confidence that difficult decisions,

such as who to provide and who to deny critical care, are not arbitrary or discriminatory.^{29 30 31}

The moment that a patient receives access to a ventilator is but one point on the care continuum. It is essential that patients, consistent with New York’s Patients’ Bill of Rights, are apprised of how decisions about their own treatment were made as well as their individual rights to have input in their own care and challenge unfair or unjustified decisions in a timely manner.³²

Make no mistake—the lack of such a holistic plan has tangible and dire consequences. For example, one major issue that Disability Rights New York has identified is that, without clear guidance protecting them now, many people with disabilities are avoiding seeking any medical care during a crisis for fear that they may be separated from life-sustaining medical equipment, such as a personal ventilator.³³ The fact that a significant group of patients would avoid any contact with the healthcare system clearly indicates a lack of confidence that there are safeguards to protect their rights. Surely this is the opposite of what we want in the midst of a medical crisis and could be avoided with better policies.³⁴

²⁹ Wynia, Matthew K. and Hick, John L., “If COVID-19 Gets Bad, Triage Will Be Needed. Are We Ready For That?” StatNews (March 10, 2020), available at <https://www.statnews.com/2020/03/10/covid-19-gets-bad-are-we-prepared-for-triage/>.

³⁰ See Hick, John L., Hanfling, Dan, Wynia, Matthew, and Pavia, Andrew T., *Duty to Plan: Health Care, Crisis Standards of Care, and Novel Coronavirus SARS-CoV-2*, National Academy of Medicine, available at <https://nam.edu/duty-to-plan-health-care-crisis-standards-of-care-and-novel-coronavirus-sars-cov-2/> (“Reduced to its fundamental elements, [crisis standards of care] describe a planning framework based on strong ethical principles, the rule of law, the importance of provider and community engagement, and steps that permit the equitable and fair delivery of medical services to those who need them under resource-constrained conditions.”)

³¹ See “Rapid Expert Consultation on Crisis Standards of Care for the COVID-19 Pandemic,” National Academies of Science, Engineering, and Medicine (March 28, 2020), available at <file:///Users/jacobschneider/Downloads/NAS%20guidance%20on%20health%20care%20in%20crisis.pdf> (“During a catastrophic crisis, it is vitally important to uphold the core ethical principles of fairness, duty to care, duty to steward resources, transparency in decision making, consistency, proportionality, and accountability.”).

³² Public Health Law § 2803-c(e) (“Every patient shall have the right to receive adequate and appropriate medical care, to be fully informed of his or her medical condition and proposed treatment unless medically contraindicated, and to refuse medication and treatment after being fully informed of and understanding the consequences of such actions.”).

³³ DRNY’s April 7, 2020 complaint against the New York State Department of Health outlines the illegal discriminatory impact of New York State’s Ventilator Allocation Guidelines, including the chilling effect that ventilator rationing is having on DRNY clients who are chronic ventilator users and live in the community. A copy of DRNY’s complaint can be found here: <https://www.dropbox.com/s/h3hjktvz3qxes3/2020.04.07%20-%20Ventilator%20Rationing%20-%20OCR%20Complaint%20FINAL.pdf?dl=0>

³⁴ Several centers in New York have depth of experience in caring for patients with an array of, and frequently multiple, chronic health conditions where interventions such as breathing tubes are as a matter of course based on the condition of an individual’s lungs and survivability, not on age or their multiple

6. Governor Cuomo, and New York Department of Health and Mental Hygiene guidelines, must explicitly prohibit the appropriation and reallocation of personal ventilators and other assistive technology of individuals with disabilities who seek medical care.

New York's current Ventilator Allocation Guidelines provide that chronic ventilators who seek acute medical care will have their personal ventilator entered into the larger pool of ventilators at the medical facility. This action allows medical providers to determine that a chronic ventilator user should be disconnected from their life saving assistive technology and that technology should be reallocated to another patient. Such guidance forces chronic ventilator users who live in the community to make an impossible decision: stay at home when they are sick and receive no medical care, or seek treatment and risk losing access to their personal ventilator through a likely fatal extubation. New York must address the chilling impact that ventilator rationing has on individuals with disabilities who utilize ventilators on a daily basis. It is vital that an explicit order be provided stating that separating a chronic ventilator user from ventilation support without a new device being readily available for their use for the unacceptable and illegal when done for purposes of medical rationing.

7. Patients have a right to fast and fair review of treatment decisions.

After decisions are made, a holistic plan would provide clear mechanisms for review. This necessarily includes guaranteeing that patients have a right to quickly challenge decisions to deny critical care—*here, litigation or lengthy administrative review processes are not sufficient as days and hours may matter.*

8. Hospitals must collect and promptly report data.

In order to ensure that care is not being arbitrarily and discriminatorily denied to certain patients, advocates and public health officials must have access to accurate, comprehensive, and contemporaneous information about to whom care is provided and denied. This will permit patients, advocates, and public health officials to enforce legal rights and adjust policies to meet realities.

diagnoses. These centers may offer practice models for guidelines that would be of great service to providers around the state, not just for the current COVID-19 epidemic but to inform uniform best practices going forward.

9. New York must plan better for the next crisis.

As the Hastings Center, a bioethics think tank, puts it: “ethical challenges arise when there is uncertainty about how to ‘do the right thing’ in clinical practice when duties or values conflict.”³⁵ Such uncertainty is unnecessary and could be avoided with better planning during non-crisis decisions. Failing to anticipate the current crisis has led New York to a point in which hospitals and providers lack clear guidance from the state and are being forced to develop policies ad-hoc. Such scenarios uniquely disadvantage people with disabilities and other vulnerable patients who are most likely to be arbitrarily denied essential care.

To prevent us from ever again finding ourselves in the position of trying to develop policies on the fly in the midst of a crisis, the state should implement a process for developing and periodically reviewing crisis standards of care between crises. It is essential that all stakeholders, including people with disabilities and other patient communities, are included in that process.

We stand ready to support the rapid development of these needed assurances and guidance for people living with HIV and other disabilities, as well as the dedicated health care workers who serve them. Please advise us on how we can further assist in ensuring such guidelines are in place as soon as possible.

Respectfully submitted,

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³⁵ *Ethical Framework for Health Care Institutions & Guidelines for Institutional Ethics Services Responding to the Coronavirus Pandemic*, The Hastings Center, available at <https://www.thehastingscenter.org/ethicalframeworkcovid19/>.

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HHS Office for Civil Rights in Action



March 28, 2020

BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

In light of the Public Health Emergency concerning the coronavirus disease 2019 (COVID-19), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.¹

In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.

The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, 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. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

"HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal," said Roger Severino, OCR Director. "Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism," Severino added.

¹ Due to the public health emergency posed by COVID-19, OCR is exercising its enforcement discretion in connection with the conditions outlined herein. This guidance is a statement of agency policy not subject to the notice and comment requirements of the Administrative Procedure Act (APA). 5 U.S.C. § 553(b)(A). For the same reasons explained above, OCR additionally finds that, even if this guidance were subject to the public participation provisions of the APA, prior notice and comment for this guidance is impracticable, and there is good cause to issue this guidance without prior public comment and without a delayed effective date. 5 U.S.C. § 553(b)(B) & (d)(3).

NOTE: The CDC has advised that the best way to prevent illness is to avoid being exposed to this virus: practice social distancing; clean your hands often; cover coughs and sneezes; and call your healthcare provider if you believe you may be infected. <http://www.coronavirus.gov>.

OCR remains in close coordination with federal partners to help ensure that the Nation's response effectively addresses the needs of at-risk populations. To this end and as resources allow, government officials, health care providers, and covered entities should not overlook their obligations under federal civil rights laws to help ensure all segments of the community are served by:

- Providing effective communication with individuals who are deaf, hard of hearing, blind, have low vision, or have speech disabilities through the use of qualified interpreters, picture boards, and other means;
- Providing meaningful access to programs and information to individuals with limited English proficiency through the use of qualified interpreters and through other means;
- Making emergency messaging available in plain language and in languages prevalent in the affected area(s) and in multiple formats, such as audio, large print, and captioning, and ensuring that websites providing emergency-related information are accessible;
- Addressing the needs of individuals with disabilities, including individuals with mobility impairments, individuals who use assistive devices, auxiliary aids, or durable medical equipment, individuals with impaired sensory, manual, and speaking skills, and individuals with immunosuppressed conditions including HIV/AIDS in emergency planning;
- Respecting requests for religious accommodations in treatment and access to clergy or faith practices as practicable.

Some actions or accommodations may not be required on the basis that they may fundamentally alter the nature of a program, pose an undue financial and administrative burden, or pose a direct threat.

In addition, the Secretary's March 17, 2020, Declaration under the Public Readiness and Emergency Preparedness (PREP) Act may apply with respect to some private claims arising from the use or administration of a covered countermeasure and may provide immunity from certain liability under civil rights laws. Questions regarding the scope of PREP under this guidance document should be directed to the Office of the General Counsel.

Finally, covered entities should consider adopting, as circumstances and resources allow, the following practices to help ensure all segments of the community are served:

- Making use of multiple outlets and resources for messaging to reach individuals with disabilities, individuals with limited English proficiency, and members of diverse faith communities; and
- Stocking facilities with items that will help people to maintain independence, such as hearing aid batteries, canes, and walkers.

Being mindful of all segments of the community and taking reasonable steps to provide an equal opportunity to benefit from emergency response efforts, including making reasonable accommodations will help ensure that the emergency response is successful and minimizes stigmatization.

<https://www.cdc.gov/coronavirus/2019-ncov/about/related-stigma.html>.

For information regarding how Federal civil rights laws apply in an emergency, please visit:

<https://www.hhs.gov/civil-rights/for-individuals/special-topics/emergency-preparedness/index.html>

For information regarding Emergency Preparedness Resources for Persons from Diverse Cultural Origins,

please visit: <https://www.hhs.gov/civil-rights/for-individuals/special-topics/emergency-preparedness/diverse-cultural-origins/index.html>.

COVID-19 and HIPAA

OCR issued a bulletin on February 3, 2020, providing information on the ways that covered entities and business associates may share protected health information under the HIPAA Privacy Rule during a public health emergency.

- [February 2020 HIPAA and Novel Coronavirus Bulletin - PDF*](#)

In order to ensure that healthcare providers can serve patients, including those who cannot or should not leave their homes during this emergency, OCR [announced](#) on March 17, 2020, that it will exercise its enforcement discretion and will not impose penalties for HIPAA violations against health care providers that in good faith provide telehealth using non-public facing audio or video communication products, such as FaceTime or Skype, during the COVID-19 nationwide public health emergency. This exercise of enforcement discretion applies regardless of whether the telehealth service is related to the diagnosis and treatment of health conditions related to COVID-19. OCR also issued guidance in the form of frequently asked questions in support of the good faith rendering of telehealth services.

- [Notice of Enforcement Discretion for Telehealth](#)
- [FAQs on Telehealth and HIPAA](#)

OCR also issued guidance on when the HIPAA Privacy Rule permits a covered entity to disclose the protected health information of an individual who has been infected with, or exposed to, COVID-19, with law enforcement, paramedics, other first responders, and public health authorities without the individual's authorization.

- [Guidance on Disclosures to Law Enforcement and Other First Responders](#)

Filing a Complaint with OCR

If you believe that a covered entity violated your civil rights, conscience and religious freedom, or health information privacy rights, you may file a complaint at <https://www.hhs.gov/ocr/complaints>.

Other Resources

You may send inquiries to OCRMail@hhs.gov or call the OCR toll-free phone line at (1-800-368-1019), (TTY: 1-800-537-7697) for further information.

For a list of other Federal civil rights enforcement agencies and how to file a complaint with them, please visit: <https://www.justice.gov/crt/fcs/Agency-OCR-Offices>

For resources provided by the Administration for Community Living, please visit:
<https://acl.gov/COVID-19>

COVID-19 resources are now available in American Sign Language (ASL) on CDC's YouTube page:
<https://www.youtube.com/user/CDCStreamingHealth/videos>

To see CDC updates on COVID-19, please visit:
<https://www.cdc.gov/coronavirus/2019-ncov/whats-new-all.html>

For the U.S. Department of Education's COVID-19 statement addressing stereotyping, harassment, and bullying, please visit: <https://content.govdelivery.com/accounts/USED/bulletins/27f5130>

If you would like to learn more about Civil Rights, Conscience and Religious Freedom, the HIPAA Privacy Rule and the HIPAA Security Rule subscribe to the OCR Civil Rights Listserv at:
<https://www.hhs.gov/ocr/list-serv>.

For copies of OCR documents in alternative formats, please call (800) 368-1019 or (800) 537-7697 (TDD).

If you speak a non-English language and need help with this document, call 1-800-368-1019 (TTY: 1-800-537-7697), and you will be connected to an interpreter who will assist you at no cost.

Español (Spanish)

ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [Hojas de datos - sobre las leyes en contra de la discriminación](#)
- [Derechos sobre la confidencialidad de la información sobre su salud](#)

繁體中文 (Chinese)

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1 (800) 368-1019 (TTY 文字電話：1 (800) 537-7697)。

- [事實紙頁-關於反視的法律](#)
- [您的健康資訊隱私權](#)
- [您的健康信息隱私權](#)

Tiếng Việt (Vietnamese)

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [T Thông Tin - v các điều luật chng phân biệt x](#)
- [Quyền Bảo mật Thông tin Sức khỏe của Quý vị](#)

한국어(Korean)

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1 (800) 368-1019번 (TTY: 1 (800) 537-7697번)으로 전화하십시오.

- [정보 안내서 -- 차별 금지법에 관한 정보](#)
- [개인의 의료 정보 보호 권리](#)

Tagalog (Tagalog)

PAUNAWA: Kung nagsasalita ka ng Tagalog, may mga libreng serbisyo para sa tulong sa wika na maaari mong gamitin. Tumawag sa 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [Paunawa - tungkol sa mga batas laban sa diskriminasyon](#)
- [ANG IYONG MGA KARAPATAN SA PAGKAPRIBADO NG IMPORMASYONG PANGKALUSUGAN](#)

Русский (Russian)

ВНИМАНИЕ! Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните по номеру 1 (800) 368-1019 (телетайп: 1 (800) 537-7697).

- [Информационные листки о законах, запрещающих дискриминацию](#)
- [ВАШИ ПРАВА НА ЗАЩИТУ КОНФИДЕНЦИАЛЬНОСТИ МЕДИЦИНСКОЙ ИНФОРМАЦИИ](#)

العربية(Arabic)

هاتف الصم (1 (800) 368-1019 اتصل على الرقم . إذا كنت تتحدث العربية، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان :ملحوظة
والبيكم 1 (800) 537-7697 :

Kreyòl Ayisyen (French Creole)

ATANSYON Si w pale Kreyòl, gen sèvis èd pou lang gratis ki disponib pou ou. Rele 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Français (French)

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1 (800) 368-1019 (ATS : 1 (800) 537-7697).

Português (Portuguese)

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Polski (Polish)

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Dzwon pod numer 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

- [Strony informacyjne na temat ustaw o przeciwdziałaniu dyskryminacji](#)
- [PRAWA DO OCHRONY PRYWATNOŚCI DANYCH ZDROWOTNYCH](#)

日本語 (Japanese)

注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。Call 1 (800) 368-1019 (TTY:1 (800) 537-7697).

Italiano (Italian)

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Deutsch (German)

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufen Sie uns an unter 1 (800) 368-1019 (TTY: 1 (800) 537-7697).

Persian (Farsi)

شما می اگر به زبان فارسی صحبت می کنید، خدمات یاری رسانی زبانی، بطور رایگان، در دسترس توجه
تماس بگیرید (1 (800) 537-7697) ، 1 (800) 368-1019 با شماره باشد.

Updated: April 3, 2020