

April 30, 2020
Governor Andrew Cuomo
New York State Capitol
Albany, New York 12224

Dear Governor Cuomo:

On behalf of undersigned organizations, we write today to express concern with our state's plan on Ventilator Allocation Guidelines. As organizations representing people with pre-existing chronic conditions and disabilities, we are concerned that our state's plan is discriminatory and will prevent or limit life-saving care from the people we represent.

As COVID-19 continues to spread through our communities, we are facing unprecedented times. Unfortunately, our state may reach a point where need outstrips our healthcare capacity. This is a reality that we must face together. Our response cannot be based on discriminatory and outdated ideas about quality of life or the value of people with disabilities and chronic conditions to society.

On March 28, the Office for Civil Rights (OCR) at the US Department of Health and Human Services issued a bulletin regarding Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19).¹ In the bulletin, OCR reminded federally-funded health programs and activities that Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act prohibit discrimination on the basis of disability, and that these civil rights laws are still in effect. OCR continues, "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."

We are concerned that the New York plan is discriminatory and will harm the people we represent. The Exclusion Criteria used is ambiguous, open to interpretation and may inadvertently screen out a disproportionate number of individuals with disabilities. Under this plan, if a patient demonstrates Exclusion Criterion, a triage officer/committee could make the decision as to whether the patient qualifies for a ventilator. The tiered approach also creates potential to discriminate within the tiered system – as the first tier eliminates access to ventilators for patients with the highest probability of mortality. If resources continue to fall short, the second tier denies access to patients who require a high use of additional resources, including patients who also have a pre-existing illness with a poor prognosis. The third-tier patients are triaged based on criteria that are developed as needed by a committee, which could include the use of a clinical scoring system to "score" patients. Finally, the authors proposed the extubation of any patient "who might be stable, or even improving, but whose objective assessment indicates a worse prognosis than other patients who require the same resource."

To avoid discrimination, doctors or triage teams must perform a thorough individualized review of each patient and not assume that any specific diagnosis is determinative of prognosis or near-term survival

¹ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

without an analysis of current and best available objective medical evidence and the individual's ability to respond to treatment.

In other states, these plans have led to legal action. To date, advocates have filed complaints with OCR in response to plans issued in Washington,² Alabama,³ Kansas,⁴ Tennessee,⁵ Utah,⁶ and Pennsylvania,⁷ in addition to the complaint filed in our own state. Thirty-two bipartisan members of Congress have also expressed concern.⁸ In the Ventilator Allocation Guidelines it specifically points to Alabama as having a "distinguishing characteristic" in regard to its tiered triage program that New York mimics. It is worth noting that the Health and Human Services Office of Civil Rights recently informed State of Alabama and the Alabama Department of Public Health that their guidance is discriminatory, and the State of Alabama has resolved the issue.

We urge you to work with our organizations and with disability rights organizations throughout the state to write a plan that is based on individual assessments of each patient. This plan should be written in accordance with the OCR bulletin. Several of our groups have endorsed additional guidance, written by disability rights professionals, on how to implement the bulletin in states.⁹ This should also serve as additional assistance toward writing a plan that is equitable, just, and does not discriminate against the people we represent.

We look forward to working with you to develop a plan for our state. Please reach out to Jennifer Muthig with the National Multiple Sclerosis Society at Jennifer.muthig@nmss.org or 518-499-4322.

Sincerely,

National MS Society
Latino Commission on AIDS
National Organization for Rare Disorders
American Diabetes Association
American Kidney Fund
Consumer Directed Personal Assistance Association of New York State
Hemophilia Association of New York, Inc.
Coalition for Hemophilia B Inc.
Western New York BloodCare Inc.
Center for Independence of the Disabled, NY
Arthritis Foundation
Epilepsy Foundation
Independence Care System
Brooklyn's Best MS Support Group

² https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf

³ https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint_3.24.20.docx.pdf

⁴ <https://www.centerforpublicrep.org/wp-content/uploads/2020/03/Kansas-OCR-complaint-3.27.20-final.pdf>

⁵ <http://thearc.org/wp-content/uploads/2020/03/2020-03-27-TN-OCR-Complaint-re-Healthcare-Rationing-Guidelines.pdf>

⁶ <https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Utah-OCR-Rationing-Final-.pdf>

⁷ <https://www.centerforpublicrep.org/wp-content/uploads/2020/04/04.03.2020-DRP-OCR-Complaint-with-Exhibit-A-1.pdf>

⁸ <https://chrissmith.house.gov/news/documentsingle.aspx?DocumentID=406467>

⁹ https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf