



May 8, 2020

The Honorable Ned Lamont
Governor of the State of Connecticut
The Capitol, 210 Capitol Ave
Hartford, CT 06106

Dear Governor Lamont:

On behalf of the undersigned organizations representing people with chronic conditions and disabilities, thank you for your considerable efforts to address the coronavirus (COVID-19) crisis. We write today to comment on the state's document titled "Standards of Care: Providing Health Care During A Prolonged Public Health Emergency"¹ and to request the state of Connecticut adopt a policy that clearly directs health care providers across the state to refrain from discriminating against people with pre-existing chronic conditions and disabilities in the provision of treatment during the COVID-19 emergency.

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 health care 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 Our response cannot be based on discriminatory and outdated ideas about quality of life or the value of people with disabilities and chronic conditions to society.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).² 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 have seen discriminatory plans issued by some states that would ultimately harm the people we represent if implemented. In certain states, these plans have led to legal action. To date, advocates have

¹ <https://portal.ct.gov/-/media/Departments-and-Agencies/DPH/dph/legal/StandardsOfCarefinalpdf.pdf?la=en>

² <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

filed complaints with OCR in response to plans issued in Washington,³ Alabama,⁴ Kansas,⁵ Tennessee,⁶ Pennsylvania,⁷ Utah,⁸ New York,⁹ and Oklahoma.¹⁰ Thirty-two bipartisan members of Congress have also expressed concern.¹¹

We are concerned that Connecticut's standards of care guide, as currently written, fails to protect individuals with underlying conditions. In particular, this guide allows for re-allocation of ventilators from patients who rely on this equipment in daily life. We urge you to work with our organizations, as well as disability rights organizations in Connecticut to develop a plan that is centered on individual assessments of each patient and 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.¹² 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 that safeguards the health and affirms the rights of those in Connecticut living with disabilities and pre-existing conditions. If you have any questions regarding this letter, or if we may provide further information, please don't hesitate to contact Michael Finley with the Epilepsy Foundation at 860-346-1924 or michael@epilepsyct.com.

Sincerely,

American Diabetes Association
Arthritis Foundation
Connecticut Hemophilia Society
Cystic Fibrosis Foundation
Epilepsy Foundation of Connecticut
National Multiple Sclerosis Society
National Organization for Rare Disorders
New England Bleeding Disorders Advocacy Coalition
New England Hemophilia Association

³ https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf

⁴ https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint_3.24.20.docx.pdf

⁵ <https://www.centerforpublicrep.org/wp-content/uploads/2020/03/Kansas-OCR-complaint-3.27.20-final.pdf>

⁶ <http://thearc.org/wp-content/uploads/2020/03/2020-03-27-TN-OCR-Complaint-re-Healthcare-Rationing-Guidelines.pdf>

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

⁸ <https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Utah-OCR-Rationing-Final-.pdf>

⁹ <https://www.dropbox.com/s/h3hjktdvz3qxes3/2020.04.07%20-%20Ventilator%20Rationing%20-%20OCR%20Complaint%20FINAL.pdf?dl=0>

¹⁰ <http://okdlc.org/wp-content/uploads/2020/04/4.21-Oklahoma-OCR-Complaint-Final.pdf>

¹¹ <https://chrissmith.house.gov/news/documentsingle.aspx?DocumentID=406467>

¹² https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf