

May 7, 2020

The Honorable Chris Sununu  
Governor of New Hampshire  
State House  
107 North Main Street  
Concord, NH 03301

Dear Governor Sununu:

On behalf of the undersigned organizations representing people with disabilities and chronic conditions, thank you for your considerable efforts to address the coronavirus (COVID-19) crisis. We write today to request New Hampshire adopt a policy that clearly directs health care providers across the state to refrain from discriminating against people with disabilities and chronic conditions in the provision of treatment during the COVID-19 emergency.

We are facing unprecedented times as COVID-19 continues to spread through our communities. It is possible New Hampshire may reach a point where need outstrips health care capacity and any response to resource shortages cannot be based on discriminatory and outdated ideas about quality of life or the value added to society by people with disabilities and chronic conditions. While federal laws – including the American with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act – broadly protect people against discrimination in receiving care, direction is needed to ensure equal access to life-saving treatment. People living with disabilities and chronic conditions must not be denied treatment or deprioritized for COVID-19 care under medical triage or crisis standards currently under development or already being implemented.

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).<sup>1</sup> 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 with the discriminatory plans issued by some states that will harm the people we represent. In certain states, these plans have led to legal action. To date, advocates have filed complaints with OCR in response to plans issued in Washington,<sup>2</sup> Alabama,<sup>3</sup> Kansas,<sup>4</sup> Tennessee,<sup>5</sup> Pennsylvania,<sup>6</sup> Utah<sup>7</sup>, New York<sup>8</sup>, and Oklahoma.<sup>9</sup> Thirty-two bipartisan members of Congress have also expressed concern.<sup>10</sup>

We are pleased your Executive Order #33, issued on April 17<sup>th</sup>, activated the New Hampshire Crisis Standards of Care Plan<sup>11</sup>, which outlines a process for updating the statewide Crisis Standards of Care clinical guidelines for COVID-19 specifically. As the State Disaster Medical Advisory Committee and the State Triage Committee begin to develop these clinical guidelines, we urge these committees to work with our organizations and disability rights organizations to develop guidelines that are 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.<sup>12</sup> This should also serve as additional assistance toward writing guidelines that are equitable, just, and does not discriminate against the people we represent. As mentioned in that document, any clinical guidelines should state:

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

We look forward to working with you to develop clinical guidelines for the state that safeguards the health and affirms the rights of New Hampshire's citizens living with disabilities and chronic conditions. If you have any questions regarding this letter, or if we may provide further information, please don't hesitate to contact Heidi Ross with the National Organization for Rare Disorders at [HRoss@rarediseases.org](mailto:HRoss@rarediseases.org) or 202-588-5700.

Sincerely,  
American Diabetes Association  
Arthritis Foundation  
Cystic Fibrosis Foundation  
Epilepsy Foundation New England  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
New England Bleeding Disorders Advocacy Coalition  
New England Hemophilia Association  
New Hampshire Rare Action Network  
New Hampshire Rare Disorders Association  
New Hampshire Council for Youths with Chronic Conditions

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

2 [https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint\\_3-23-20-final.pdf](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](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/2020/04/04.03.2020-DRP-OCR-Complaint-with-Exhibit-A-1.pdf>

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

8 <https://www.dropbox.com/s/h3hjktvz3qxs3/2020.04.07%20-%20Ventilator%20Rationing%20%20OCR%20Complaint%20FINAL.pdf?dl=0>

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

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

11 <https://www.dhhs.nh.gov/documents/nh-csc-plan.pdf>

12 [https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals\\_FINAL.pdf](https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf)