

November 22, 2020

The Honorable Phil Murphy
Governor of New Jersey
225 West State Street
Trenton, New Jersey 08625

Commissioner Judith M. Persichilli
New Jersey Department of Health
369 South Warren Street
Trenton, New Jersey 08608

Via Regular Mail and Electronic Mail

Dear Governor Murphy and Commissioner Persichilli:

On behalf of Disability Rights New Jersey, please allow me to wish you both a safe and happy Thanksgiving, and to thank all of the members of your staff for the work they have done on behalf of all New Jerseyans throughout the COVID-19 pandemic. If ever there was a time for us to be vigilant, put the needs of the community first, and follow the guidance of healthcare experts, it is now, and we appreciate your leadership.

We write to you today in response to the surge of COVID-19 cases across New Jersey – as of Saturday, there were 4,679 new cases along with 2,552 patients in hospitals – to *urgently request* that the Department of Health re-visit its April 11, 2020 Allocation of Critical Care Resources During a Public Health Emergency (Allocation of Critical Care Resources) policy. When this policy was announced in April, Disability Rights NJ responded by letter dated April 16, 2020 (a copy of which is attached) to thank the administration for taking action on this important issue, but also to highlight aspects of the Allocation of Critical Care Resources policy that we believe to be discriminatory.

Since the beginning of the pandemic in March, advocates in at least 12 states have filed complaints with the federal HHS Office of Civil Rights (OCR) regarding state resource allocation and rationing policies and the discriminatory impact on individuals with disabilities. See <https://www.centerforpublicrep.org/covid-19-medical-rationing/>. Like New Jersey, several of those state policies relied on or were adapted from the University of Pittsburgh Model Policy. Through the OCR complaint process, resolutions were reached that brought policies into compliance with federal civil rights laws, including Section 504 of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Act, Section 1557 of the Patient Protection and Affordable Care Act, and the Age Discrimination Act of 1975.

Advocating and advancing the human, civil and legal rights of persons with disabilities

Disability Rights NJ particularly brings to the attention of the Department of Health the Early Complaint Resolution process used in Utah, wherein OCR provided technical assistance which resulted in Utah updating its policies. Details about that resolution can be found here, <https://www.hhs.gov/about/news/2020/08/20/ocr-resolves-complaint-with-utah-after-revised-crisis-standards-of-care-to-protect-against-age-disability-discrimination.html>.

Based on our review of all of the OCR resolutions regarding allocation of critical care resource policies, Disability Rights NJ respectfully requests that the Department of Health immediately revise its Allocation of Critical Care Resources policy to ensure that it does not discriminate against persons on the basis of disability or age, and in particular, that it makes the following changes to the policy:

- Ensure that there are no exclusions or deprioritizing based on resource intensity for disability diagnosis
- Eliminate long-term survivability considerations in treatment decisions, allowing medical personnel to consider only short-term mortality
- Require that hospitals make reasonable modifications to the Sequential Organ Failure Assessment (SOFA) score to avoid penalizing people with underlying conditions that are unrelated to their ability to benefit from treatment
- Prohibit reallocation of personal ventilators of a patient who uses a ventilator in daily life to another patient whom the personnel deem more likely to benefit from the ventilator in receiving treatment

In addition, we ask that the Department of Health prohibit hospitals from imposing blanket No Not Resuscitate (DNR) policies. As we previously shared, Disability Rights NJ heard anecdotal accounts in April of incidents where nursing homes or hospitals were pressuring guardians to consent to DNRs and DNHRs without informed consent. As the numbers of COVID-19 hospitalizations increase now, it is important for the state to be clear on this issue.

As the Department revises its Allocation of Critical Care Resources policy, it is important to include individuals with disabilities and their advocates in the discussion, even if that discussion must happen on a very short timeframe. We at Disability Rights New Jersey stand ready to assist as best we can, including invoking the technical assistance of the OCR early Complaint Resolution process.

Thank you for your timely consideration of this critically important issue.

Very truly yours,
/s/ Gwen Orłowski

Gwen Orłowski
Executive Director
Disability Rights New Jersey