

April 3, 2020

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

Re: Guidelines to Address Potential Rationing of Medical Services

Dear Governor Murphy:

Disability Rights New Jersey (DRNJ) is designated as New Jersey's protection and advocacy system for individuals with disabilities. DRNJ advocates for the human, civil, and legal rights of individuals with disabilities.

DRNJ is very appreciative of your ongoing efforts to avoid shortages of medical equipment and ensure that all New Jersey residents have access to needed medical treatment. DRNJ is concerned about how individuals with disabilities, including those with psychiatric, developmental, intellectual, and physical conditions who contract COVID-19, will be served if rationing is required.

People with disabilities are at high risk of contracting COVID-19, particularly those who are in congregate residential programs, state-operated institutional settings, prisons and jails, and long-term care facilities. We recognize and appreciate that state officials are already making efforts to protect these residents' safety and their ability to access medically necessary services. We would like to take this opportunity to urge you and your administration to consider the civil rights implications of any proposed guidelines as they concern people with disabilities.

All state and private entities overseeing the delivery of life-saving medical interventions must make treatment decisions consistent with the non-discrimination requirements of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. Yet around the country national and state advocacy groups are confronting outdated and discriminatory policies on emergency resource allocation in which individuals with specific disabilities or functional impairments can be denied access to, or subjected to the removal of, medically necessary ventilators.¹

¹ Office of Civil Rights complaints filed against the States of Washington and Alabama can be found at <https://www.centerforpublicrep.org/news/cpr-and-partners-file-second-complaint-regarding-illegal-disability-discrimination-in-treatment-rationing-during-covid-19-pandemic/>

In response to such policies, the National Council on Disability (NCD)² and the Consortium for Citizens with Disabilities (CCD)³ have proposed important principles for the delivery of care. In keeping with those national organizations, and consistent with our respective organizations' missions, we urge the State to immediately adopt and disseminate mandatory statewide guidelines which clarify the following:

- 1) that the ADA and Section 504 require government decisions regarding the allocation of treatment/life-saving resources to be made based on individualized determinations, using current objective medical evidence, not generalized assumptions about a person's disability;
- 2) that the ADA and Section 504 prohibit treatment allocation decisions based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living;
- 3) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person with a disability has a lower prospect of survival;
- 4) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person's disability will require the use of greater treatment resources; and
- 5) that a person is "qualified" for purposes of receiving COVID-19 treatment if he or she can benefit from the treatment (that is, can recover) and the treatment is not contraindicated.⁴

The Office of Civil Rights of the United State Department of Health and Human Services issued a bulletin on March 28, 2020, titled "Civil Rights, HIPPA and the Coronavirus Disease 19 (COVID-19)" (available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>). The Office of 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 by HHS-funded health programs and activities. These civil rights protections remain in effect in emergency situations like the present one.

In regard to any rationing of care, the OCR bulletin states 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. Decisions by covered entities concerning whether an individual is a candidate for treatment

² See, Letter of National Council to Roger Severino, Director, Office for Civil Rights, U.S. Department of Health & Human Services, March 18, 2020, available at <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>

³ CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

⁴ See, Consortium of Citizens with Disabilities, letter to Secretaries of EOHHS and the Office of Civil Rights, March 20, 2020, available at <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>

The Honorable Phil Murphy

Page 3

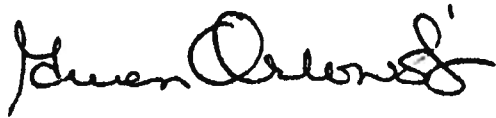
April 3, 2020

should be based on an individualized assessment of the patient based on the best available objective medical evidence.”

The lives of people with disabilities are inherently valuable, and under the law, they have an equal right to health care treatment. When developing guidelines for rationing life-saving medical treatment, the above principals must be followed as required by law. Furthermore, please ensure that all of these guidelines are followed by all health care providers in the State so that individuals with disabilities receive equal access to health care treatment.

In this time of crisis, we should strive to make sure that all people in New Jersey are served and protected. Should you wish to discuss these issues in greater detail, please feel free to contact me.

Sincerely,

A handwritten signature in black ink, appearing to read "Gwen Orłowski". The signature is fluid and cursive, with a large initial "G" and "O".

Gwen Orłowski,
Executive Director

GO/md

cc: Judith Perischilli, Commissioner of NJ Department of Health
New Jersey Hospital Association
Eddy Bresnitz, M.D.
Michael J. Solomon, M.D., Medical Society of New Jersey