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Gwen Orlowski, Executive Director

April 16, 2020

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

Via scanned email to [redacted]

Re: April 11, 2020, DoH Allocation of Critical Care Resources Guidance

Dear Commissioner Persichilli:

I write on behalf of Disability Rights New Jersey (DRNJ), the state designated protection and advocacy agency. By letter dated April 3, 2020 to Governor Murphy, DRNJ raised serious concerns that any state policy or guidance regarding the rationing of medical services or equipment be 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 as well as the March 28, 2020 federal Office of Civil Rights bulletin. I have attached a copy of the letter for your reference. The Department of Health issued its guidance, the Allocation of Critical Care Resources During a Public Health Emergency (the Resource Allocation Plan), on April 11, 2020, and on April 14, 2020, a call with stakeholders was held to review the guidance and answer questions.

First, DRNJ extends its heartfelt thanks and appreciation to you, Governor Murphy, and the administration for all of your efforts to address the current health crisis, including this guidance. We are mindful of the responsibility that rests on your shoulders as the state develops its guidance to address the potential for scarce medical resources. We recognize and sincerely appreciate the efforts to make an allocation policy that does not discriminate against individuals with disabilities, but nevertheless, DRNJ continues to have questions and concerns. Please allow this letter to follow up on several of the questions and concerns asked during the April 14th call and request that the Department provide answers in the next few days, in anticipation of New Jersey's COVID-19 peak, anticipated on April 25th:

- **ADVISORY COMMITTEE:** The Governor and Department of Health relied on the advice and counsel of a professional advisory committee to assist with the adoption of the Resource Allocation Plan. Can the Department please share the members of that professional advisory committee? Did any self-advocates, individuals with disabilities or

persons with lived experience serve as committee members? In addition, was any disability-focused advocacy group a member of the committee or otherwise consulted?

- **NOTIFYING THE PUBLIC AND INDIVIDUAL PATIENTS ABOUT THE ALLOCATION POLICY:** The guidance from the Department does not provide for a clear notice from a hospital whether it has adopted the Department's allocation guidelines or decided to apply its own policies. Individuals, therefore, may not know which hospitals have adopted this allocation policy, whether their hospital has begun triaging resources, or whether the policy is being applied to them specifically. Under the current guidance, the hospital would not notify the patient of the existence or operation of this policy until after it has decided to withhold critical care. Will the Department issue any further guidance about notice to the public, patients, families regarding specific hospital adoption of this policy or its own policy?

- **DISCRIMINATORY DISPARATE IMPACT OF THE SEQUENTIAL ORGAN FAILURE ASSESSMENT SCORE (SOFA) AND LONG-TERM SURVIVAL STANDARDS:** Even though the Department's plan for the Allocation of Critical Care Resources During a Health Emergency states that it does not categorically exclude people with disabilities, the use of SOFA scores as a prediction of short-term survival has an unintended disparate discriminatory impact against people with disabilities. An individual with a disability that impacts the SOFA score is deprioritized purely as a result of the disability while an individual without a disability has an inherent advantage. For example, an individual who is a chronic ventilator user starts with a higher SOFA score as a baseline condition. Similarly, a disability that causes a shorter life expectancy renders that person less likely to be allocated scarce resources than a non-disabled person, and therefore, may be inconsistent with disability rights laws.

- **THE RESOURCE ALLOCATION PLAN LACKS A MEANINGFUL APPEALS PROCESS:** The Resource Allocation Plan recognizes that procedural fairness requires the availability of an appeals mechanism to resolve disputes, but the appeals process outlined in the Resource Allocation Plan fails to provide a meaningful opportunity to challenge an individual triage decision. At a minimum, a fair process must include notice, an opportunity to be heard, and a decision by a neutral decision maker. The Resource Allocation Plan requires none of these elements. Specifically, (1) the Resource Allocation plan does not require a specific time, place or manner for informing the individual and/or family of the triage decision, the basis of the triage decision or even the right to appeal; (2) the Resource Allocation Plan limits the reason for appeal of the initial triage decision only to the calculation of the SOFA score or to the use or non-use of the long-term survival "tiebreaker"; and (3) the Resource Allocation Plan does not require the appeal to be decided by a neutral tribunal. Even where the decision is to withdraw life-saving equipment (where the Relocation Assistance Plan calls for a more

"robust" appeals process), the plan lacks a notice framework, severely limits the basis for appeal, and states that the review of the triage committee is final.

- **THE RESOURCE ALLOCATION PLAN FAILS TO ADDRESS THE USE OF AN INDIVIDUAL'S OWN PERSONAL LIFE-SAVING EQUIPMENT:** DRNJ is concerned that there is nothing in the Resource Allocation Plan regarding the use and potential withdrawal of an individual's own person ventilator or life-saving equipment. Although this question was asked during the conference call, and you answered that this policy would not be used when an individual presents at a hospital with a personal ventilator, the actual policy is silent as to this issue. As a result, there is no specific prohibition against withdrawing a disabled patient's own life-saving equipment that they use on a day to day basis and giving it to another patient with a lower SOFA score. This fact can (and perhaps should) influence a decision by the disabled person whether or not to seek medical treatment in the first place.

To the extent possible, DRNJ requests responses to these questions/concerns early next week.

Finally, we bring to your attention an additional area of concern for disability and aging advocates that is related to the allocation of critical care resources: we have received anecdotal accounts of several hospitals adopting hospital-wide Do Not Attempt Resuscitation (DNAR) policies for all COVID-19 patients, regardless of the patient's expressed wishes, potentially contrary to 42 C.F.R. §482.13 – Condition of Participation: Patient's Rights. While CMS's COVID-19 Blanket Waivers for Health Care Providers, updated April 15, 2020, waives several of the requirements of this regulation, it does not appear to waive the requirements related to notification for discontinuance of patient care and hospital adherence to a patient's advanced directive. DRNJ continues to review this issue, but brings it to the Department's attention now because of the potential gravity of a hospital wholesale DNAR policy for COVID-19 patients.

Once again, Disability Rights New Jersey is appreciative of the tireless work of the Department of Health, as well as all state agencies in this emergency – thank you. Please do not hesitate to contact me at [redacted] or (609) 292-9742 if you have questions regarding this matter or would like additional information. Thank you for your attention to this matter.

Sincerely,

/s/ Gwen Orlowski

Gwen Orlowski
Executive Director