Disability Rights
RHODE ISLAND

The Designated Protection and
Advocacy System for Rhode Island

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April 22, 2020

The Honorable Gina M. Raimondo
Office of the Governor
Providence, RI 02903

Director Nicole Alexander-Scott, MD, MPH
Rhode Island Department of Health
Providence, RI 02908

RE: Crisis Standards of Care

Dear Governor Raimondo and Director Alexander-Scott:

Thank you for the April 18, 2020 response to our letter of the same date, which requested a copy of the Department's guidance to hospitals regarding Crisis Standards of Care. We appreciate that the Department has been engaging in a dynamic process with acute care hospitals in the state and with bioethics experts from Brown University, and that you have provided this recent guidance to hospitals for use in their continuing development of individual Crisis Standards of Care. We understand these individual plans will be forwarded to the Department by April 23, 2020.

Based on the guidance shared, we have further concerns regarding individual patients' rights and how preexisting conditions and impairments would be considered in determining an individual's priority for access to scarce resources. We also have requested some additional clarification and copies of documents referenced in the guidance.

At the outset, we note an overarching concern. While we have provided questions and commentary, the guidance upon which we have done so is, in our opinion, broad and in some cases, vague. It is not possible to determine, from the guidance provided, whether the state has a specific policy (as do many other states) regarding crisis standards of care.

If there is a specific state policy underlying the guidance, we request a copy of that policy at this time.

Our comments follow the order of topics within the guidance.

Underlying Assumptions

We recommend that non-discriminatory principles be specifically listed here, including the requirement that reasonable accommodations are necessary for equal access to care and must be provided by hospitals.

Section 1. i. acknowledges that some patients will refuse life sustaining medical resources and refers to a process of "using shared decision-making with their physician." It is not clear what "shared decision-making with physician" means with respect to informed consent. It is solely an individual's right to consent to a proposed medical decision. It is important to emphasize that in order to give informed consent to voluntarily refusing life-sustaining medical resources, some individuals with disabilities will need accommodations, for example, the presence of support person or family member to assist with understanding information and/or communicating a decision.

Clarification of Ethical Standards

We appreciate your recommendation against the use of fundamentally discriminatory factors in developing a "patient score" for resource allocation. In addition to the guidance issued by the Office of Civil Rights (OCR) of the U.S. Department of Health and Human Services (HHS) mentioned in our April 18 letter, we also wanted to highlight FEMA's Civil Rights Bulletin,[1] which similarly promotes non-discriminatory and patient-driven decisions, so that providers:

> Make medical treatment decisions, including denials of care under Crisis Standards of Care and allocation of ventilators, after an individualized consideration of each person, free from stereotypes and biases, including generalizations and judgments about the individual's quality of life or relative value to society, based on the individual's disability, age, race, income level, or any protected basis. This individualized consideration should be based on current objective medical evidence and the expressed views of the patients themselves as opposed to unfounded assumptions.

Because you referred to "[s]tatewide adoption of an underlying ethics guidance statement" it was not clear whether the state has already created a specific ethics guidance statement. If such a guidance statement exists, we request a copy at this time.

Intention of Crisis Standards of Care

We strongly disagree with the state's directive to healthcare professionals and hospitals to abandon the principle of patient-focused care in favor of public-focused care, as well as asking hospitals to provide a rationalization for that conversion. Maximization of population survival is not consistent with the basic tenets of individual rights. Setting standards that do not take into consideration a person's distinct, individual circumstances leads to a disparate impact on those who have disabilities, as well as other disadvantaged groups.

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[1] See FEMA Civil Rights Bulletin: Ensuring Civil Rights During the COVID-19 Response (April 13, 2019) at https://www.fema.gov/media-library-data/1586893628400-f21a380f3db223e6075eeb3be67d50a6/EnsuringCivilRightsDuringtheCOVID19Response.pdf.

State and federal anti-discrimination laws, which require an individualized assessment using objective evidence rather than assumptions, protect individuals' freedom and autonomy. As HHS/OCR stated in its recent Bulletin, federal disability rights laws "protect the equal dignity of every human life from ruthless utilitarianism."[2]

Directing hospitals and healthcare providers to set consistent standards for clinicians, and concomitant expectations for the public, patients, and families based on the above principles, advances the very ruthless utilitarianism that OCR warns against, and devalues individuals and their rights.

Process for Allocation

The guidance appears to indicate that hospitals will be using their own scales and assessments of "likelihood of survival" in determining the need for a scarce resource. While the Clarification of Ethical Standards section recommends against using pre-existing health status, quality of life, life expectancy and social value as factors, it is not clear whether the likelihood of survival *from the acute COVID-19 condition will be the only factor assessed*. Some assessment standards used by other states have considered discriminatory factors – either explicitly or implicitly. For example, in a recent resolution of a HHS/OCR complaint regarding Crisis Standard of Care guidelines, Pennsylvania agreed to remove criteria that automatically deprioritized persons based on their particular disabilities.[3] Pennsylvania had utilized assessments that negatively weighted pre-existing conditions and co-morbid illnesses.

In your continuing review of hospital Crisis Standards of Care plans, we request that you ensure that assessments scales and standards do not use explicit or implicit discriminatory factors.

The guidance provides that hospital plans have a clear mechanism for the interaction of the clinical team with the "triage team" that also allows for appeal or reconsideration. We request that you ensure that hospitals:

- make these mechanisms public, so that patients and their loved ones will understand these important processes;
- specifically provides the patient and/or their representatives a process to appeal decisions (rather than only the clinical team); and
- specifically provides a process for further review/reconsideration of a decision by the RI Department of Health.

Prioritization

While it is appropriate that, "[d]isease-specific exclusion criteria should be avoided," adding the qualification, "if possible," does not eliminate consideration of pre-existing conditions. Specifically, all persons should be eligible for, and qualified to receive, lifesaving care regardless of the presence of an underlying disability or co-morbid conditions. Every patient should be treated as an

[2] See OCR, Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-2019) at 2 (Mar. 28, 2020), https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.

[3] See HHS/OCR April 16, 2020 press release https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html, and the complaint from Disability Rights Pennsylvania and other advocates https://www.disabilityrightspa.org/newsroom/covid-19-civil-rights-complaint-filed-against-pennsylvanias-medical-treatment-rationing-guidelines/

individual, not a diagnosis. This means that the mere fact that a patient may have a diagnosis cannot be a basis (in part or whole) for denying care or making that person a lower priority to receive treatment.

The reference to "clinical factors listed in the other documents" that should be incorporated into the "survivability assessment" is unclear. It is unknown what these "other documents" are, if they are generated by the state, and what "specific scales" may be factored in the "4-tier level of priority table."

We request copies of any such documents at this time.

The rationale that a patient is too ill to likely survive the acute illness may be acceptable in the context of an individualized assessment of a particular patient, but the use of a categorical exclusion denies a patient the opportunity to receive the individualized assessment required under the law.

We appreciate your ongoing work and commitment to these critical issues. Please do not hesitate to contact me if you have any questions regarding our letter. I can be reached at mmurray@drri.org, 401-831-3150.

Sincerely,

/s/ Morna A. Murray

Morna A. Murray, J.D.
Executive Director

cc: Director Kathryn Power, Department of Behavioral Healthcare, Developmental Disabilities and Hospitals.