

Disability Rights
RHODE ISLAND



April 29, 2020

Via email:

katja.hamler@governor.ri.gov

claire.richards@governor.ri.gov

David.Ortiz@governor.ri.gov

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

Dear Governor Raimondo:

Thank you for your ongoing and considerable efforts to address the crisis facing our state due to the coronavirus. As you know, on April 22, Disability Rights Rhode Island [wrote](#) to you regarding our concerns about the guidelines for “crisis standards of care” that you had directed RI hospitals to implement in the event of scarcity of emergency healthcare resources. Such standards of care would presumably be implemented for decision-making that could require choices as to who does and who does not receive life-saving treatment. Our April 22, 2020 letter is incorporated herein by reference.

Our letter clearly outlined federal guidance and authority that prohibits discrimination against people with disabilities in healthcare decisions, including in the event of a public emergency.

We understand that hospitals were required to submit their policies for approval to your administration by April 23, 2020. To date, we have not had any response to our April 22 letter, nor have we been provided copies of any hospital crisis standards of care. We also have not been able to locate the policies on the DOH website.

While we appreciate your public statement that you do not anticipate this kind of tragic potentiality to occur, there have been no unequivocal public statements that would actually *prohibit* such a violation of federal civil rights, from either your administration or Rhode Island hospitals. This public statement is necessary because doctors and triage teams must assume at the outset, that they are not free from bias in making critical treatment decisions. Value judgments about the fact that a patient may require minimal or extensive support in activities of daily living, uses augmentative or alternative

communication, has a sensory disability such as blindness or is deaf or hard of hearing, uses a wheelchair, or experiences a psychiatric disability are irrelevant to decisions about whether such individuals can respond to and benefit from treatment.

At this time, we write as our state's federally mandated Protection and Advocacy (P&A) agency, along with our two state-level, federally authorized partners, the Paul V. Sherlock Center on Disabilities at Rhode Island College (University Center for Excellence in Developmental Disabilities) and the Rhode Island Developmental Disabilities Council, as well as the undersigned state advocacy organizations. Together, we jointly and respectfully request that you issue a clear and unequivocal directive to prohibit any discriminatory treatment of individuals with disabilities in accessing emergency and/or life-saving treatment.

Specifically, we ask that you issue a directive that includes the following:

- People with disabilities must have an *equal opportunity* to receive life-sustaining treatment.
- ***Doctors or triage teams must perform a thorough individualized review of each patient and must 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.*** This means that the mere fact that a patient may have a diagnosis of, for example, intellectual disability, autism, cystic fibrosis, diabetes, cancer, spina bifida, spinal muscular atrophy, neurological disorder or schizophrenia cannot be a basis, in part or in whole, for denying care or making that person a lower priority to receive treatment.
- ***Doctors must not assume that any specific diagnosis or disability indicates a poor prognosis for near-term survival or an inability to respond to treatment.*** People with disabilities regularly outlive the prognoses doctors ascribe to them, often by decades. Protocols that equate survival with "health" or the absence of chronically debilitating symptoms will be discriminatory.
- ***Doctors and triage teams must not reallocate ventilators of individuals with disabilities who use ventilators in their daily lives and come to the hospital with symptoms of COVID-19.*** Individuals with disabilities who use ventilators in their daily lives must be allowed to continue to use this personal equipment if they receive COVID-19 treatment at a hospital.
- ***Reasonable modifications must be made whenever needed by a person with a disability to have equal opportunity to benefit from the treatment.*** These include interpreter services, access to nonvisual information or other modifications or additional services needed due to a disability. They also include permitting a person to continue using a ventilator for additional time where an underlying disability means that additional time is necessary for recovery.

As Governor, you can ensure that people with disabilities have full and equal access to emergency healthcare and life-saving treatment, during the current pandemic, and any future crises.

Please feel free to contact Morna Murray, mmurray@drri.org, 401-831-3150 with any questions or clarifications. We appreciate your efforts and actions in this matter and look forward to your response.

Respectfully,

Morna A. Murray, J.D.
Executive Director
Disability Rights Rhode Island

Amy Grattan, Ph.D.
Executive Director
Paul V. Sherlock Center on Disabilities at Rhode Island College

Kevin Nerney
Executive Director
Rhode Island Developmental Disabilities Council

Advocates in Action
Rhode Island's Statewide Self-Advocacy Organization

Steven Brown
Executive Director
American Civil Liberties Union of Rhode Island

Joanna Scocchi
Director
The ARC Rhode Island Family Advocacy Network

Debra L. Sharpe
Executive Director
Brain Injury Association of Rhode Island

Tina Spears, M.P.A
Executive Director
Community Provider Network of Rhode Island

Marc Anthony Gallucci, Esq.
Executive Director
Ocean State Center for Independent Living

Kim M. Einloth
Kiernan O'Donnell
Co-Chairs
Rhode Island Employment First Task Force