Disability Rights RHODE ISLAND

The Designated Protection and Advocacy System for Rhode Island

March 30, 2020

The Honorable Gina M. Raimondo
Governor of Rhode Island
State House
82 Smith Street
Providence, RI 02903

Dear Governor Raimondo:

Thank you for your continued leadership during this crisis.

Disability Rights Rhode Island is Rhode Island's federally mandated Protection & Advocacy (P&A) system. We have been working cooperatively with our governmental partners during this difficult time to ensure that Rhode Islanders with disabilities have equal access to all programs and services, including access to health care.

We write regarding our letter of March 19, 2020, requesting, among other actions, that you "issue a directive … prohibiting discrimination against people with disabilities in offering COVID-19 treatment" through rationing of care or treating the lives of people with disabilities as of less value than others. As of today, Rhode Island has 408 documented cases of COVID-19, 41 people hospitalized, and 4 individuals who have died.

As this crisis unfolds with daily changes, the Office of Civil Rights (OCR) of the U.S. Department of Health and Human Services issued a directive on March 28, 2020, to medical providers regarding their obligations under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the Affordable Care Act. In pertinent part, it provides:

> "In light of the Public Health Emergency concerning the coronavirus disease 2019 (COVID-19), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.
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> In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else."

In 1990 Congress acted to combat the widespread and persistent discrimination against people with disabilities in the United States with the implementation of the Americans with Disabilities Act (ADA). Title II of the ADA prohibits state and local governments from discriminating against people with disabilities. Title III prohibits discrimination in places of public accommodation, such as hospitals, clinics, and doctor's offices.

Applying the principles of the ADA, the guidance from HHS OCR, as well as other federal, state, and local laws, to the allocation of scarce medical treatment during a crisis requires the following be included in any guidance your office and the RI Department of Health (RIDOH) provide to healthcare practitioners in order to avoid discriminatory outcomes:

1. Treatment allocation decisions must be made based on individualized determinations, using current objective medical evidence, and not based on generalized assumptions about a person's disability.

2. Treatment allocation decisions cannot be made based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living.

3. Treatment allocation decisions cannot be made based on the perception that a person with a disability has a lower prospect of survival. While the possibility of a person's survival may receive some consideration in allocation decisions, that consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities.

4. Treatment allocation decisions cannot be made based on the perception that a person's disability will require the use of greater treatment resources. Reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment.

Additionally, RIDOH must directly address the potential chilling impact that ventilator rationing will have on individuals with disabilities who utilize ventilators on a daily basis. Proper procedures may require that an individual be removed from their personal ventilator to a hospital ventilator. However, a chronic ventilator user should never be removed from ventilation support for reasons of rationing. It is vital that explicit guidance from RI DOH to medical providers clearly set forth that such actions are never acceptable. A ventilator user can never be disconnected from ventilation support without a new device being readily available for their use.

As this crisis intensifies, there have been reports in the media that healthcare providers are facing "excruciating decisions" in terms of the availability of hospital beds, ventilators, and other emergency resources. We urge that all pertinent state partners take the necessary steps to ensure people with disabilities have equal access to all necessary healthcare and resources.

We ask that you immediately direct RIDOH to take the necessary steps outlined above to ensure that medical providers have proper guidance and to prevent the discriminatory rationing of healthcare.

We hope that your administration can ensure that individuals with disabilities are not discriminated against in treatment planning guidelines or policies.

Sincerely,

Morna A. Murray

Morna A. Murray
Executive Director

cc: Nicole Alexander-Scott, MD, MPH, Director of RI Department of Health

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