

Justice. Community. Inclusion.

Disability Rights Connecticut

"Connecticut's protection and advocacy system"

846 Wethersfield Avenue
Hartford, CT 06114

Sent Via Electronic Mail and U.S. Mail

April 2, 2020

The Honorable Ned Lamont
Office of the Governor
State Capitol
210 Capitol Avenue
Hartford, CT 06106

Attorney General William Tong
Office of the Attorney General
165 Capitol Avenue
Hartford, CT 06106

RE: COVID-19 and the Civil Rights of Connecticut Citizens with Disabilities

Dear Governor Lamont and Attorney General Tong:

I am writing today on a truly life-and-death situation that threatens citizens of Connecticut who happen to have disabilities. Your tireless work on behalf of these individuals and all of us in Connecticut is sincerely appreciated. We at Disability Rights Connecticut (DRCT)¹ are offering our efforts and expertise to prevent avoidable tragedy in our community. This letter asks that state officials take specific steps to ensure that life-saving care is not illegally withheld from disabled citizens due to discriminatory resource allocation or altered standards of care during the coronavirus pandemic.

Specifically, DRCT requests you take the following immediate action:

- issue and disseminate mandatory principles, consistent with the Connecticut Constitution, state and federal law, reaffirming 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. Medical care decisions should be based on individualized assessment of the patient based on the best available objective medical evidence; and
- designate staff from your offices, the Department of Public Health, Connecticut hospital ethics committees and representatives from the disability community to devise specific processes for operationalizing non-discriminatory allocation of resources.

¹ / Disability Rights Connecticut (DRCT) is the Protection and Advocacy System for persons with disability in Connecticut designated in accordance with Section 46a-10b of the Connecticut General Statutes.

Proposed Principles by National Council on Disability and Consortium for Citizens with Disabilities

The National Council on Disability (NCD) and the Consortium for Citizens with Disabilities (CCD) have proposed important principles for the delivery of care. We urge Connecticut to immediately adopt and disseminate mandatory statewide guidelines which clarify the following:

- 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;
- 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;
- 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;
- 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
- 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.

Guidance from U.S. Department of Health and Human Services Office for Civil Rights

On Saturday, March 28, 2020, in response to complaints filed by protection and advocacy systems in other states, the U.S. Department of Health and Human Services Office for Civil Rights issued guidance regarding this specific topic stating:

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.²

People with disabilities are, and will be, 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 Connecticut is already making efforts to protect these residents' safety and their ability to access medically necessary services. However, around the country 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.

The law in this area is clear. All public 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

² / HHS Office for Civil Rights in Action BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), March 28, 2020; <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

Affordable Care Act. These laws remain in effect. As such, 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 should be based on an individualized assessment of the patient based on the best available objective medical evidence.

Constitutional Protection in Connecticut

In Connecticut, disability rights are not merely aspirational, or the province of federal and state statutes and regulations. Rather, disability rights are protected in our Constitution which reads in pertinent part:

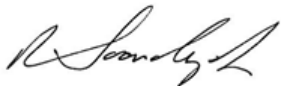
No person shall be denied the equal protection of the law nor be subjected to segregation or discrimination in the exercise or enjoyment of his or her civil or political rights **because of ... physical or mental disability.** (Emphasis Supplied)

The Connecticut Department of Public Health produced a Whitepaper in 2010 to provide an ethical framework for decision-making during lengthy public health emergencies and serve as a guide to health care providers for allocating resources and modifying standard practices. However, this document does not prescribe how scarce resources should be allocated or resolve critical questions when demand exceeds system capacity. Nor does it provide specific guidance to private hospitals and ethics committees who will be on the front lines of thousands of individual treatment decisions.³

As the Governor has so clearly indicated in recent press briefings, we are on the verge of a statewide crisis in access to care. While there is still a window of opportunity, now is the time for Connecticut to act to establish equitable, democratic and nondiscriminatory standards of care before scarcity begins driving medical decisions across the state.

DRCT stands ready to assist in these efforts and can bring to bear a range of local and national resources and expertise, including emerging best practices, to support the Governor, the Attorney General, and the Department of Public Health. At a minimum, we ask that you confirm receipt of this letter and make clear how Connecticut intends to address the disability community's concerns regarding discriminatory rationing of care. You may contact me directly at 503-502-1967 or bob.joondeph@disrightsct.org. Thank you in advance for your consideration of this important matter.

Sincerely,



Bob Joondeph
Interim Director

³ / Embedded in this Whitepaper is the principle that "[d]ecisions must: be based on trust and cooperation; respect personal liberty and privacy; be non-discriminatory, proportional and fair; and protect those who bear the greatest burdens in protecting the public good." *See* Standards of Care: Providing Health Care During A Prolonged Public Health Emergency, CT Department of Public Health October 2010; www.ct.gov/dph/standardsofcare