Via Email: Nicole.alexanderscott@health.ri.gov

May 19, 2020

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

Re: April 27, 2020 Crisis Standards of Care Guidelines

Dear Director Alexander-Scott:

We write in response to your release of the above referenced Crisis Standards of Care (CSC) Guidelines, and in follow-up to our prior correspondence regarding their development. As expressed in your opening letter, we share your hope that Rhode Island hospitals will never need to implement these CSC Guidelines. We also expect that this period of lockdown should serve to fully appraise us of the needs we have for any additional outbreaks.

However, because these CSC Guidelines now exist and remain a possibility for the future, we want to alert you to the adverse impact their implementation will have on people with disabilities and older adults, and the need for revisions.

The CSC Guidelines reference the framework established by the Institute of Medicine (now the National Academy of Medicine) for the development of these standards, and we note that the authors of that framework encourage the use of a transparent and inclusive public engagement process[1] prior to the finalization of standards. We ask you to consider our comments and recommendations as part of that public engagement process, and to revise the current CSC Guidelines in order to ensure that people with disabilities are equitably treated.[2]

1. **Provisions in the CSC Guidelines adversely impact people with disabilities and older adults.**

As drafted, Rhode Island's CSC Guidelines ("Guidelines") are open to inconsistent interpretation and application of triaging criteria, which adversely impacts individuals with disabilities and older adults.

[1] See Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response, available at https://www.ncbi.nlm.nih.gov/books/NBK201072/#sec_0006.

[2] We appreciate your responsiveness to the concerns of the disability community in making revisions on May 8, 2020 to the Department's "Health Care Facilities Visitation Policy."

Conflicting statements regarding consideration of disability and age in resource allocation

The Guidelines reference the Institute of Medicine's ethical principles that should ground any Crisis Standards of Care, and include the principle of Consistency (Distributive Justice). This principle ensures consistent treatment across populations and among individuals including those with disability, pre-existing conditions, and those who are aged.[3] The Guidelines subsequently provide a Clarification of Ethical Principles for Rhode Island. Rhode Island's Distributive Justice principle recognizes "every patient's right to equitable access to beneficial care," and acknowledges the need for transparent criteria for allocating resources that are free from influence by inappropriate factors such as race, gender, socioeconomic status, or sexual identity.[4]

Notably, disability and age are missing from this Rhode Island list of inappropriate factors to consider in making resource allocation decisions. This omission of disability and age appears intentional, as the triage processes and criteria subsequently described authorize explicit and implicit consideration of disability and age in allocating scarce resources.

Exclusion of individuals with disabilities and older adults from access to triaged resources

Patients who are screened for "a medical condition associated with a short life expectancy" will be excluded from accessing a critical resource through the triaging process "regardless of their current acute illness."[5] Excluded individuals will only have access to palliative care. Because "short life-expectancy" is not defined, hospitals and clinicians are free to interpret the term and make subjective judgments regarding its meaning. Many people with disabilities as well as those who are aging have a medical condition or combination of conditions that can shorten their life expectancies, or are perceived as having such a condition(s). They are therefore at risk of being excluded from accessing triaged resources due to the subjectivity of this standard or misperceptions. Additionally, although examples of medical conditions that warrant exclusion from the triage process are listed in Appendix A, the listed criteria for conditions are very problematic.[6] The listed criteria:

- have uncertain meaning and application, as in the measures for cardiac arrest;
- fail to take into account pre-existing impairments, such as a limitation in mobility or speech, which would impair a person's motor response to an assessment of traumatic brain injury; and
- do not account for individualized differences in function and adaptability that may occur despite a person having a particular clinical measure.

Inappropriate consideration of disability and age as factors in triage

The focus on longer-term survivability is carried over into the triaging process itself. Patients "who are most likely to survive to hospital discharge *and beyond*,"[7] will be prioritized for access to triaged resources. This standard encourages hospitals to consider factors beyond survival of the current acute illness, in effect authorizing triage decisions that consider longevity and prognosis. As mentioned above, people with disabilities and older adults either have or are perceived to have conditions that

[3] Guidelines at page 4.
[4] *Id* at page 7.
[5] *Id* at page 18.
[6] *Id* at page 23.
[7] *Id* at page 18.

impact their longevity, and will thus be disparately treated if longevity is prioritized in the triaging process.

Appendices B through E list acceptable common triage tools available for hospital use. These tools rely on criteria that have the potential to seriously disadvantage individuals with disabilities and older adults.

One of these tools, the Clinical Frailty Scale,[8] negatively rates individuals who are dependent on others for assistance in completing Activities of Daily Living (ADLs) and/or personal care. This tool is discriminatory on its face. It discriminates against many individuals with disabilities and older adults who, because of functional limitations, depend on the assistance of others to complete typical everyday tasks. Other tools, like the SOFA (the Guidelines indicate the Rhode Island health care community has agreed to use SOFA),[9] do not take into account pre-existing conditions and disabilities, including those that are stable, or which prevent the individual from actually performing measured tasks. For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity in the SOFA, adds points when a patient cannot articulate intelligible words, even if this condition is due to a pre-existing speech disability. Patients with pre-existing motor impairments are also disadvantaged by this tool's measures, which assess movement in response to pain or verbal commands.

In establishing tiers for triage, the Guidelines prioritize those who have higher likelihood of survival. Level 1 individuals will have the highest level of access to resources. Level 2 individuals will have access to treatment after all patients in Level 1 have received treatment. Level 2 individuals are those "whose likelihood of survival is intermediate and/or uncertain." This is a vague standard that promotes inconsistent decisions and unequal access to care for individuals who are perceived as having less likelihood of survival due to pre-existing conditions or disabilities that may be life limiting or are perceived to be so.

Limitations on the ability to appeal Triage Team Decisions

A patient may only appeal a hospital triage decision that involves a "procedural/technical injustice."[10] As an example of a procedural/technical injustice, the Guidelines refer to a triage decision that does not consider all of the relevant triage criteria. Limiting the ability to appeal to procedural errors only, eliminates the ability of an individual to assert that the triage team failed to assess appropriately the impact of their disability or pre-existing condition. For example, an individual would be unable to assert that hospital team erred in assessing triage criteria because they did not take into account a pre-existing condition that resulted in a different triage score, or erred in concluding that an individual had a limited prognosis based solely on diagnostic criteria and not on an individualized assessment.

[8] *Id* at page 30.
[9] *Id* at page 19.
[10] *Id* at page 10.

2. Civil Rights Laws Governing the Use of the CSC Guidelines

As affirmed by federal agencies, "[c]ivil rights laws and legal authorities remain in effect, and cannot be waived, during emergencies" including the current COVID-19 crisis.[11]

Americans with Disabilities Act (ADA)

Title II of the Americans with Disabilities Act (ADA) prohibits the state from excluding people with disabilities from its programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Implementing regulations promulgated by the United States Department of Justice (DOJ) define unlawful discrimination under Title II to include:

- using eligibility criteria that screen out or tend to screen out individuals with disabilities;
- failing to make reasonable modifications to policies and practices necessary to avoid discrimination; and
- perpetuating or aiding discrimination by others. 28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8).

Moreover, DOJ has explicitly instructed that Title II of the ADA applies to emergency preparedness efforts of state and local governments, writing:

> One of the primary responsibilities of state and local governments is to protect residents and visitors from harm, including assistance in preparing for, responding to, and recovering from emergencies and disasters. State and local governments must comply with Title II of the ADA in the emergency- and disaster-related programs, services, and activities they provide.[12]

Title III of the ADA applies to places of public accommodations (including hospitals). It prohibits the use of eligibility criteria that screen out persons with disabilities and the provision of unequal services, and requires covered entities to make reasonable modifications in policies, practices, or procedures to afford access to services for people with disabilities. 42 U.S.C. §§ 12181-12189; 28 C.F.R. §§ 36.201(a), 36.202, 36.301(a), 36.302(a).

The Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act similarly *bans* disability discrimination by recipients of federal financial assistance, including Rhode Island state agencies and most hospitals and health care providers. 29 U.S.C. § 794(a). The breadth of Section 504's prohibition on disability discrimination is co-extensive with that of the ADA. *See, e.g., Frame v. City of Arlington*, 657 F.3d. 215, 223 (5th Cir. 2011) ("The ADA and the Rehabilitation Act are generally interpreted *in pari materia*.").

[11] 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 and HHS Office of Civil Rights Bulletin (March 28, 2020) at https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.

[12] *See*, DOJ, Emergency Management Under Title II of the Americans with Disabilities Act at 1 (July 26, 2007), available at https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm.

The Patient Protection and Affordable Care Act (ACA)

Section 1557 of the ACA provides that no health program or activity that receives federal funds may exclude from participation, deny the benefits of their programs, services or activities, or otherwise discriminate against a person protected by the Age Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or by Section 504 of the Rehabilitation Act, 42 U.S.C. § 18116; 45 C.F.R. §§ 92.101(a), 92.101(b)(2)(i). This includes an obligation to make reasonable modifications in policies, practices, and procedures necessary to avoid disability discrimination. 45 C.F.R. § 92.205.

3. Revisions are required to the CSC Guidelines to comply with Civil Rights laws: Recommendations

Using criteria that consider survival beyond discharge will have a disparate impact on people with disabilities and older adults

By using criteria linked to survival beyond the acute illness that resulted in hospitalization, the Guidelines set up a process for hospitals to: (1) screen out people with disabilities and older adults from being considered eligible for triaged resources, or, if found eligible; (2) deny people with disabilities and older adults access to triaged resources by assigning them to a lower tier level.

Allowing hospitals to screen out individuals with a "short life expectancy" from triage, and to prioritize those "who are most likely to survive hospital discharge *and beyond,"* sets up a process for subjective decision-making regarding the prognosis for individuals with pre-existing conditions and may lead to the inevitable conclusion of poor survivability. It is highly likely that individuals with disabilities will be perceived as having limited life expectancies, based on discriminatory assumptions about their conditions, or misperceptions about the value and utility of their lives.[13] Federal discrimination laws prohibit using criteria in this way to screen out people from services based on their disability diagnosis or age.

To avoid a disparate impact on people with disabilities and older adults, the state should eliminate the use of these life expectancy linked criteria in these Guidelines.

Allowing the use of a triage tool that ties scores to functional limitations is discriminatory

One of the triage tools within Appendix B's list of acceptable tools for hospital use is the Clinical Frailty Scale. This tool negatively rates individuals who are dependent on others for assistance in completing ADLs and/or personal care. On its face, this tool discriminates against many individuals

[13] *See generally*, NAT'L COUNCIL ON DISABILITY, MEDICAL FUTILITY AND DISABILITY BIAS 29 (Nov. 20, 2019) ("Several studies have demonstrated that health care providers' opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people. For example, one study found that only 17 percent of providers anticipated an average or better quality of life after a spinal cord injury (SCI) compared with 86 percent of the actual SCI comparison group. The same study found that only 18 percent of emergency care providers imagined that they would be glad to be alive after experiencing a spinal cord injury, in contrast to the 92 percent of actual SCI survivors.") (footnotes omitted), available at https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf.

with disabilities and older adults who, as a result of functional limitations, depend on the assistance of others to complete these tasks. By using this scale, hospitals would be free to deprioritize many people with disabilities as well as to deprioritize based on age for triage based on a variety of functional limitation, including people with mobility, cognitive, and sensory limitations.

The state should eliminate the discriminatory "Clinical Frailty Scale" from its Guidelines.

Failing to require the provision of reasonable accommodations to an individual's disability and reasonable modifications of the triage process will result in discriminatory decisions

The Guidelines do not mention federal law requirements to make reasonable accommodations for people with disabilities. Nor do they remind hospitals of their federal and state anti-discrimination obligations to make reasonable modifications to their policies and practices when necessary to allow persons with disabilities to enjoy the benefits and services they provide. For instance, individuals with disabilities may need additional time for treatment to be effective due to pre-existing conditions.[14] The failure to modify a protocol or make accommodation for this need would have a negative impact on individuals who are no less likely to recover, but may do so more slowly due to their pre-existing disability. Similarly, individuals who are admitted to the hospital with a personal ventilator should never have them reallocated or removed for another individual.

People with disabilities may also be disadvantaged in the triage process, when their pre-existing conditions are not considered in assigning a triage tool score. As mentioned above, the SOFA tool does not take into account pre-existing conditions and disabilities, including those that are stable, or prevent the individual from actually performing a measured task. Hospitals who use the SOFA and other triage tools should ensure that accommodation are made, so that the scores of patients with pre-existing conditions that impact performance measures are adjusted to take their disabilities into account.

The state should revise its Guidelines to ensure that hospitals do not discriminate by failing to make appropriate accommodations in their treatment and triage decisions for individuals with disabilities.

Failing to allow consideration of disability-related grounds for appeal

The Guidelines only permit an appeal of a hospital triage decision that involves "procedural/technical injustice." As noted above, limiting the ability to appeal to procedural errors only, eliminates the ability of an individual to assert that the triage team failed to assess appropriately the impact of their disability. For example, an individual would be unable to assert that hospital team erred in assessing triage criteria because they did not take into account a pre-existing condition that resulted in a different triage score, or erred in concluding that an individual had a limited prognosis based solely on diagnostic criteria and not on an individualized assessment. Allowing more substantive grounds for

[14] *See* Clarissa Kripke, Patients with Disabilities: Avoiding Bias When Discussing Goals of Care, 93 Am. Fam. Physician 192 (2017) available at https://www.aafp.org/afp/2017/0801/p192.html (patient with cognitive limitations and chronic conditions "recovering slowly from an acute, temporary illness" mistakenly referred to hospice due to undue concerns reflecting stereotypical assumptions).

appeal of triage team decisions will ensure that individuals with disabilities will have an opportunity to assert rights guaranteed by federal Civil Rights laws.

The state should allow appeals that are based upon disability-related grounds, not merely "procedural/ technical injustice."

Furthermore, in exercising its oversight of these Guidelines, we urge the Department to ensure individuals have the opportunity to seek further review of triage appeals decisions, beyond those involving withdrawal of life support, as currently limited in the guidance.[15] Individuals may be just as grievously and irreparably harmed by decisions that exclude them from treatment or de-prioritize their access to treatment.

Other states have developed Crisis Standards of Care that promote equal access to triaged resources for individuals with disabilities, and eliminate consideration (and speculation) regarding survivability beyond discharge. We attach for your reference Delaware's Crisis Standards of Care Concept of Operations.

We appreciate your consideration of our comments and hereby request to meet with those who drafted these Guidelines to ensure revisions are made to protect individuals with disabilities from disparate and/or illegal treatment under the law

Please feel free to respond to Morna Murray, mmurray@drri.org, 401-831-3150.

Respectfully,

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[15] Guidelines at page 17.

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cc: Honorable Gina M. Raimondo, Governor of Rhode Island
Kathryn Power, Director, RI Department of Behavioral Healthcare, Developmental Disabilities and Hospitals

Attachment: Delaware Crisis Standards of Care, April 25, 2020