



Center for Public
Representation

June 30, 2020
By Electronic Mail

Secretary Marylou Sudders
Executive Office of Health and Human Services
One Ashburton Place, 11th Floor
Boston, MA 02108

Re: MA Crisis Standards of Care

Dear Secretary Sudders:

Our coalition is looking forward to meeting with you on July 8, 2020, and to continuing our discussion of the Massachusetts Crisis Standards of Care. Not surprisingly, the landscape surrounding COVID-19 management and response has continued to evolve over the last two months, as advocates, medical professionals and state governments gain more knowledge and experience with issues arising during the pandemic.

Since we last communicated with the Administration, several states have issued new and revised crisis standards that provide models for avoiding age, race and disability discrimination, including California's [Crisis Care Guidelines](#) and New Hampshire's [Crisis Standards of Care](#). These two documents address difficult ethical and clinical decisions with criteria that avoid discrimination and reflect appropriate attention to health inequities.

More than 15 jurisdictions have issued statewide policies on reasonable accommodations for persons with disabilities. Significantly, and as discussed further below, the U.S. HHS Office of Civil Rights (OCR) has continued to clarify its expectations in this area through a complaint [resolution](#) negotiated in [Connecticut](#). And within the last week, OCR has resolved a complaint against the state of Tennessee, approving a short-term survivability standard that differs markedly from the resolution of the Pennsylvania complaint. We expect these new developments will inform our conversation next month, and guide how the Commonwealth uses this opportunity to continue to improve its Crisis Standards and related policies.

We are aware of the DPH Commissioner's June 19th rescission order. However, we recognize that the standards themselves are still available, and will continue to influence decision-making in the Commonwealth's health care facilities. In the event that a new emergency is declared and crisis standards are activated, which seems increasingly likely given the recent surge in cases around the country, the Administration should be poised to respond quickly with a document that effectively mitigates existing health inequities and protects the civil rights of persons with disabilities, older adults, institutionalized and incarcerated persons, and communities of color.

Use of Short Term Prognosis as Triage Criteria

On June 26, 2020, OCR issued a [press release](#) announcing a resolution of its third complaint dealing with crisis standards of care. As a result of the OCR negotiation process, Tennessee has eliminated longer-term survivability as a consideration in the allocation of scarce resources. Instead, OCR approved Tennessee's revised standards, "[Guidance for the Ethical Allocation of Scarce Resources During a Community-Wide Public Health Emergency](#)," that allows medical personnel to consider only the "imminence of mortality," or survivability with treatment, when making triage assessments which would deny life-saving treatment.¹ The policy also requires reasonable modifications to the Sequential Organ Failure Assessment (SOFA), in order to ensure that people with disabilities are evaluated based on their actual mortality risk, and not disability-related characteristics unrelated to their likelihood of survival. Appendix. B at 5.²

Numerous studies have shown that attempts to predict life expectancy and prognosis are often inaccurate and unreliable, even under normal standards of care.³ In the triage context, these predictions can be even more fraught, relying on imperfect information, mistaken stereotypes and assumptions about diagnosis and quality of life, and other forms of unconscious bias.⁴

¹ Notably, the revised Tennessee plan also requires the following:

- 1) that medical personnel may not reallocate a patient's personal ventilator, brought to the acute care facility for continued pre-existing personal use, to another patient deemed more likely to benefit from ventilator treatment;
- 2) that individuals cannot be excluded from medical treatment based solely on a diagnosed disability or because they require more time or resources to recover due to age or disability; and
- 3) that visitor policies in long term care settings should address reasonable accommodations or other supports for persons with disabilities, consistent with state and federal law.

² "For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity in the SOFA, adds points to the SOFA score when a patient cannot articulate intelligible words or has difficulty with purposeful movement. For patients with pre-existing speech disabilities or disabilities that effect motor movement, this may result in a higher SOFA score even in instances where the patient's disability is not relevant to short-term mortality risk." Id.

³ See, Life Expectancy Estimates: A Survey of Research on Prognosis, available at <https://www.centerforpublicrep.org/wp-content/uploads/Life-Expectancy-Studies-Crisis-Std-of-Care-for-Covid-19-6.30.20.pdf>

⁴ See, e.g., Colin A. Zestcott, et al. *Examining the presence, consequences, and reduction of implicit bias in health care: A narrative review*, 19 *Group Processes & Intergroup Relations* 528, 529 (2016), (citing multiple studies showing that implicit bias and stereotypes impact judgment and behavior of health care providers when interacting with patients from minority populations); National Council on Disability, *Medical Futility and Disability Bias*, *Bioethics & Disability Series* 1, 29 (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."); Lynne D. Richardson, et al., *Racial and Ethnic Disparities in the Clinical Practice of Emergency Medicine*, 10 *Acad. Emergency Med.* 1184, 1184-85(2003), ("Situations, such as the emergency department (ED), that are characterized by time pressure, incomplete information, and high demands on attention and cognitive resources increase the likelihood that stereotypes and bias will affect diagnostic and treatment decisions."); Catherine L. Auriemma, et al., *Eliminating Categorical Exclusion Criteria in Crisis Standards of Care Frameworks*, *Am. J. of Bioethics* 1(2020)("Even when purportedly 'objective' criteria are employed to allocate health care resources, subjective notions of the quality or desirability of life with disabilities may play an

As the [New England Journal of Medicine](#) recently noted:

In effect, CSCs that deprioritize people with coexisting conditions or with a higher likelihood of death within 5 years penalize people for having conditions rooted in historical and current inequities and sustained by identity-blind policies. In the United States, black, poor, disabled, and other disadvantaged people have shorter life expectancies than white and able-bodied Americans. If maximizing life-years is the prime directive, their lives will be consistently deprioritized as compared with already-advantaged groups.⁵

By negotiating a resolution that limits use of prognosis criteria to short term survivability with treatment, OCR has made clear that State crisis standards should strive to eliminate the risk of inaccurate and discriminatory criteria, especially among people with disabilities and communities of color. Although OCR has not yet had the opportunity to resolve a complaint based on racial discrimination in crisis standards, research shows that people of color are more likely to have co-morbid medical conditions and shorter life expectancies due to historical inequities in access to health care and exposure to environmental and social conditions that compromise health. These communities, people with disabilities and older adults in congregate or other long term care settings, and individuals in prisons and jails, are already disproportionately impacted by COVID-19 in Massachusetts.⁶ It is critical that they not be placed at further risk, or deprioritized for care, based on factors attributable to systemic discrimination and unrelated to their ability to survive with treatment.⁷

influential role. These negative biases and assumptions often result in the devaluing of the lives of people with disabilities which contributes to health care inequities and discrimination in multiple sectors of society.”)

⁵ *Inequity in Crisis Standards of Care* Emily Cleveland Manchanda, M.D., M.P.H., Cheri Couillard, M.A., and Karthik Sivashanker, M.D., M.P.H., N. Engl. J. Med., May 13, 2020.

⁶ According to data released by DPH on June 19, 2020, Black people accounted for 14.4% of all reported cases but only 7.2% of the population; Hispanic persons made up 29.3% of all cases and 12.2% of the population; and white persons are 71.5% of the population but only 45.3% of all cases. Additionally, DPH reported that the cities with the highest rates of cases are primarily cities with large communities of color.

⁷ People of color are more likely to experience bad health outcomes than white people due to the effects of structural racism in our society. See Yaryna Serkez, Who Is Most Likely to Die From the Coronavirus? New York Times (Jun. 4, 2020). If left unrevised, the crisis standards will compound the effects of structural and intentional racism. According to a report produced by the Massachusetts Health Disparities Council, these disparities are explained first and foremost by non-medical factors, including personal characteristics such as income, education, occupation, or social position, as well as community factors including neighborhood safety, pollution, availability of fresh groceries, density of package stores, and the built environment (including parks, and characteristics that lend themselves to “walkability”). Available at <https://www.mass.gov/files/documents/2016/08/qz/disparities-in-health-2011.pdf>

We appreciate Commissioner Bharel’s commitment to eliminate health inequities,⁸ and we are aware that the DPH COVID-19 Health Equity Advisory Group has recently issued recommendations aimed at equitable access to health care resources and services and prevention of inequities and disproportionate negative outcomes. Revising crisis standards criteria that will have a discriminatory impact based on race and disability, and which specifically discriminate on the basis of age and long term prognosis, is an essential step towards that goal.

Other crisis standards demonstrate that it is not necessary to focus on survival rates beyond the short term (significant likelihood of death in less than 1 year) and that using only shorter-term survival is feasible and can help reduce discrimination as compared to reliance on longer term survival predictions.⁹ The New Hampshire State Triage Committee’s Crisis Standards of Care Clinical Guidelines released was a [draft report](#) on May 27, 2020,¹⁰ which is currently out for public comment. It recommends that:

near-term survival ... be based on objective clinician assessment for the presence of severe life limiting conditions with predicted survival of less than one year. Assessment of comorbidities with the goal of predicting long-term survival carries the risk of unwarranted discrimination on the basis of age, race, disability, and socioeconomic status, and is not recommended.

Id. at 4.¹¹

The State of California recently revised its [Crisis Care Guidelines](#), making clear that triage decisions “should be based on medically relevant prognostic factors for surviving the acute critical illnesses,” (*Id.* at 20), and cautioning that “underlying health conditions should not form the basis of the determination regarding the immediate or long-term survivability of the patient.” *Id.* at 22. California’s Guidelines also emphasize the importance of training in “[a]voiding implicit and explicit bias, including with regard to age, disability, sex, gender identity, sexual orientation, immigration status...” and “...diminishing the impact of social inequalities on health outcomes.” *Id.* at 21. This type of training is necessary here in Massachusetts, regardless of whether crisis standards are invoked, but should be mandatory in the event our health care facilities need to allocate scarce life-saving resources.

⁸ *New data on state’s coronavirus cases, deaths show stark racial divide*, Boston Globe, June 19, 2020; available at https://www.bostonglobe.com/2020/06/19/nation/new-data-states-coronavirus-cases-deaths-show-stark-racial-divide/?s_campaign=breakingnews:newsletter

⁹ New York State triage model assesses “the short-term likelihood of survival of the acute medical episode,” New York State Department of Health, “Ventilator Allocation Guidelines,” by the New York Taskforce on Life and the Law, November 2015, 34, available at https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf.

¹⁰ The final version of the New Hampshire Crisis Guidelines will be posted at <https://www.dhhs.nh.gov/dphs/cdcs/covid19/crisis-soc-medical-ad-comm.htm>

¹¹ The New Hampshire clinical guidelines go on to state, “[a]ssessment of comorbidities with the goal of predicting long-term survival carries the risk of unwarranted discrimination on the basis of age, race, disability, and socioeconomic status, and is not recommended. Assessment of survival and assignment of a priority score should not include subjective assessments such as quality-of-life or intrinsic worth.”

Make the Exclusive Focus Saving Lives

As States have revised their CSCs over the past two months, several have adopted “saving lives” as the exclusive criteria for allocating limited resources. For instance, California’s revised CSC Guidelines explicitly establishes a single goal of “saving as many lives as possible.” *Id.* at 20. Focusing exclusively on this goal minimizes the risk of implicit bias and avoids the discriminatory impact of resource allocation based upon health inequities.

Avoid Use of Age as a Tie Breaker

The revised Massachusetts’ CSC still included age as a “tie breaker” when making painful decisions concerning life-saving treatment. As noted in the June 5, 2020 letter from our colleagues at Justice in Aging, Greater Boston Legal Services, The Center for Health Law Policy and Innovation and the Center for Medicare Advocacy, the use of age as a criterion for determining access to life-saving care is prohibited by the Age Discrimination Act.¹²

Significantly, California’s revised crisis guidelines now include age as a protected characteristic upon which allocation decisions cannot be made (*Id.* at 5), and have eliminated age as a tie breaker. New Hampshire adopts a similar focus on number of lives saved, and contains no tie breaker, or other triage criteria, based on age.

Steps to Avoid Rationing

Now that the initial surge has modestly subsided, there is time to consider what has been learned and take proactive steps to be better prepared for any new rise in COVID-19 infections. Three actions that can and must be taken, include: (1) expanding and maintaining the readiness of stockpiles of supplies and equipment; (2) use of non-invasive ventilation and sharing of ventilators, when shortages arise; (3) coordinating and sharing resources with local, regional, and statewide partners or health care organizations. *Id.* at 7-9, 11.

Require Hospitals to Appoint an Ombudsman or Disability Accommodations Specialist

Recent experience has demonstrated considerable variability between hospitals’ implementation of CSC principles, guidelines, and accommodations. For vulnerable populations and persons with disabilities, it is particularly important that there be at least one trained and available point person or ombudsperson to trained to assist patients in communicating requested accommodations. This role also should include the resolution of complaints regarding the denial or implementation of such accommodations, and the provision of staff training on disability and the reasonable accommodation process. The name and contact information for this individual should be posted as part of the facility’s policies on reasonable accommodations and visitor access. California’s CSC requires each hospital to appoint an ombudsman or reasonable

¹² See also, LEAVE BEHIND RESOURCES ON AGE-RELATED ISSUES FOR MA CSC MEETING (attached).

accommodations specialist to fulfill these responsibilities. Massachusetts should do the same. *Id.* at 17.

Reasonable Accommodations to Restrictive Visitor Policies

Over the last two months, an increasing number of jurisdictions have issued specific statewide guidance on the provision of reasonable accommodations when individuals with disabilities require outpatient, emergency, inpatient, and long term care during the pandemic.¹³ This guidance is necessary because strict hospital no-visitor policies instituted due to COVID-19 are harming individuals with disabilities by undermining their ability to communicate their needs and preferences, to understand the treatment options being offered, and to fully participate in their care. The absence of similar, comprehensive guidance here has negatively affected individuals in our community.¹⁴

One critical component of these reasonable accommodation policies is the availability of essential support persons, and specific recognition of the critical role they play in ensuring individuals' access to care and treatment.¹⁵ These supporters are not visitors. They facilitate communication with treating professionals, and provide necessary emotional and behavioral supports that allow individuals with disabilities to participate in their treatment.

Recently, Massachusetts Department of Public Health issued a [Memorandum](#) on hospital visitors, creating a limited exception to visitor policies for “companions” of individuals with intellectual or physical disabilities, provided they adhere to hospital screening requirements. Not only does this Memorandum exclude persons with other types of disabilities from the same accommodation, it fails to explain that designated support persons can be essential to ensuring that patients with disabilities are able to exercise their rights to access and benefit from the services of the state or private entity.¹⁶

¹³ An analysis of these policies and their respective strengths, can be found at https://www.centerforpublicrep.org/wp-content/uploads/Disability-Org-Guidance-on-COVID-19-Hospital-Visitation-Policies_5-14-20_Final.pdf

¹⁴ See, e.g., <https://www.npr.org/2020/05/17/857531789/federal-government-asked-to-tell-hospitals-modify-visit-bans>

¹⁵ An essential or designated support person may be a family member, personal care assistant, similar disability service provider, or other individual knowledgeable about the management of their care, to physically or emotionally assist them or to ensure effective communication during their stay in such Facility, provided proper precautions are taken to contain the spread of infection.

¹⁶ See, e.g., 42 U.S.C. §§ 12131-12134. Unlawful discrimination under Title II includes, inter alia: 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). 28 CFR 35.130(b).

Ironically, it was a similarly narrow policy that prompted CPR, Disability Rights Connecticut, and their partners to file the first Office of Civil Rights [Complaint](#) about discriminatory visitor policies. That complaint against the State of Connecticut, and a separate individual complaint against Hartford Hospital,¹⁷ were resolved by the OCR on June 9, 2020. Through its [press release](#), and the [revised policy](#) negotiated with Connecticut officials, OCR has made clear that hospitals, and the state agencies that oversee them, must modify their visitor policies to ensure people with disabilities have equal access to treatment, in keeping with their rights under the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act.

Issued as an order of the Public Health Department, Connecticut's policy applies to inpatient and outpatient settings, and covers a wide range of disabilities including altered mental status, physical, intellectual or cognitive disabilities, and people with communication barriers or who need behavioral supports. It requires that covered health care settings: (1) allow designated support persons to accompany and stay with any disabled patient that may need that support; (2) provide supporters with available personal protective equipment (PPE); (3) allow them to leave and re-enter the hospital, subject to hospital screening procedures; and (4) permits more than one supporter to be designated if the individual's hospital stay is going to exceed 24 hours.

In light of these additional statewide policy models, and OCR's position on the need for consistent, broadly applicable accommodations for individuals with disabilities, we urge the Commonwealth to issue a similar, statewide order.¹⁸ A model reasonable accommodation policy prepared by the Disability Law Center and the Center for Public Representation is attached for your consideration.

Thank you for considering these supplemental materials, and for your commitment to ensuring the Massachusetts Crisis Standards reflect our collective goals to promote equity and assure non-discrimination in the delivery of health care. As a result of our conversation, we hope to identify a set of next steps that we can pursue collaboratively together. We recommend these steps

Section 504 of the Rehabilitation Act similarly bans disability discrimination by recipients of federal financial assistance, including Massachusetts' state agencies and most hospitals and health care providers. 29 U.S.C. § 794(a).

¹⁷ This complaint alleged discriminatory treatment of a 73-year-old patient with speech and short-term memory disabilities. She required in-person supports to effectively communicate with her medical providers, but that requested accommodation was denied.

¹⁸ The [California SARS CoV-2 Crisis Care Guidelines](#) also reference the need for reasonable accommodations to visitor policies when crisis standards are in effect:

Given the visitor limitations imposed for infection control reasons during COVID-19, reasonable modifications should be made to permit a disabled or older patient to bring a family member, personal care attendant, communicator, or other helper to the hospital with them. Further, hospitals should ensure effective communication for people with disabilities including people who are deaf, people with non-verbal language, people with intellectual and developmental disabilities (I/DD), and people with Alzheimer's or another form of dementia. Hospitals should ensure that they have an appointed Disability Accommodations Specialist or ombudsperson who has the responsibility and authority to ensure that older adults and people with disabilities receive needed accommodations needed for effective COVID treatment.

Id. at 14.

include: (1) the revision of crisis standards to focus on short term survivability and lives saved, removing the current reliance on age as a tie breaker; (2) the issuance of a comprehensive statewide policy on reasonable accommodations in health care settings; and (3) the implementation of specific recommendations from the DPH Health Equity Advisory group.

Sincerely,

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