Center for Public Representation

April 22, 2020
By electronic mail

Governor Charles Baker
Lt. Gov. Karyn Polito
Attorney General Maura Healey
Senate President Karen Spilka
Speaker of the House Robert DeLeo
Secretary Marylou Sudders

Dear Governor Baker and other distinguished State officials:

We write to you again on behalf of The Arc of Massachusetts, the Brain Injury Association of Massachusetts, the National Alliance on Mental Illness, Massachusetts, Massachusetts Families Organizing for Change, the Western Massachusetts Recovery Learning Community, the Metro-Boston Recovery Learning Community, the Southeast Learning Recovery Community, the Disability Policy Consortium, the Boston Center for Independent Living, the Charles Hamilton Houston Institute for Race and Justice, the New England Chapter of Paralyzed Veterans of America, Greater Boston Legal Services, Prisoner Legal Services, the Disability Law Center, and Paul Lanzikos, as well as four individuals with significant disabilities – Paul Spooner, James Bostic, Cindy Marty Hadge, and David V – regarding the Massachusetts Crisis Standards of Care (hereafter "Standards"). The views set forth in this letter are also supported by a long list of other advocacy and legal services organizations, as well as academics and other leaders with regard to disability, aging, and communities of color.

We appreciate the Administration's ongoing crisis response, including its recent efforts to address concerns we and other disability, aging and racial justice advocates raised about the original Crisis Standards. The revised Standards, issued on April 20, 2020, include several important changes. However, we believe that serious problems remain, including some that are inconsistent with federal civil rights laws and constitute prohibited discrimination on the basis race, age, and/or disability. Rather than filing a complaint with the HHS Office of Civil Rights (OCR), we would prefer to work with the Administration to resolve these problems through further revisions to the Standards in the near future.

Given the reasonable expectation that we will experience a resurgence of epidemic conditions this fall and winter, an opinion expressed in recent commentary by federal health officials, we would hope that necessary revisions to the Crisis of Care Standards be fully in place soon, and no later than this summer. This will allow individual health care institutions and systems to make adjustments and modifications to their standards, policies, protocols, and practices as well as provide necessary time to communicate with their stakeholders and to train appropriate personnel before the next crisis period is underway.

First, we support the following the changes made in the revised Standards:

- the removal of certain criteria that penalize individuals with underlying co-morbid conditions believed to impact their long-term prognosis;
- explicit references to the need to guard against disproportionate impacts on disadvantaged populations, including by unconscious bias, in triage decision-making;
- instructions that baseline levels of impairment prior to an acute care episode not increase SOFA scores meant to assess short-term survivability with treatment;
- statements on the importance of making conservative judgments regarding prognosis, based on individualized assessments, and the most expert clinical judgment available, and not the mere existence of certain underlying conditions;
- directives to provide reasonable accommodations to triage protocols, and in the communication of treatment and triage decisions to patients and families;
- clarification that a patient presenting at the hospital with personal medical equipment such as a ventilator will not have that equipment confiscated or used for any other patient; and
- the collection and reporting of data to DPH.

Based on the changes made to date, we believe it is possible to work together to resolve the remaining problems in the Standards, and to eliminate any risk of unintended discrimination. Assuming nothing significant changes in the pace or locations of infections and deaths from COVID–19 in the Commonwealth, such discussions would hopefully obviate the need for a formal complaint to OCR. To that end, this letter lays out the rationale for additional revisions, and suggests a process and timetable for further dialogue and revisions.

1) Eliminate predictions of five year prognosis

As we noted in our earlier correspondence, attempts to predict intermediate and long-term prognosis can lead to erroneous, inconsistent, and subjective decision-making in violation of federal anti-discrimination laws. Accurate predictions of life expectancy of less than 5 years are extremely difficult, even under normal circumstances. In the context of expedited emergency triage decision-making, it is near impossible. There is little evidence in the medical literature and professional research to support the reliability of such predictions. Moreover, a number of doctors with whom we have conferred expressed their rejection of the reliability of such projections and their concern about the associated risk of implicit bias toward, and discriminatory impact on, people with disabilities, older persons, and individuals from communities of color who are more likely to have underlying, co-morbid conditions.

Moreover, as noted by many other advocates, organizations, and legislators who objected to the initial version of the Standards, the underlying conditions which are used to make these predictions penalize persons with disabilities and individuals from communities of color for pre-existing conditions and related healthcare disparities. This approach is inconsistent with the admonitions in the revised Standards to not consider co-morbid conditions.

Triage decisions are inevitably made with limited medical information, and limited time to seek expert clinical judgments. These challenges are exacerbated by a lack of objective methods for assessing five year prognosis.[1] As a result, predictions made in this context will be largely based on subjective – or at least not well informed – assumptions about the individual, their age, diagnoses or underlying medical conditions. Retaining this criterion in the Standards will increase the likelihood that individuals with disabilities, older adults, and people of color with serious underlying conditions will be denied lifesaving care based on their disabilities and discriminatory assumptions about their overall life expectancy. This is precisely the outcome OCR has prohibited in its March 28, 2020 Bulletin.[2]

By maintaining a penalty for individuals based on the allegedly "near term" prognosis of five years, the revised Standards continue to reinforce inequities in access to health care, and risk importing unconscious bias into the triage process. Similarly, attempts to predict even "near term" prognosis will lead to inconsistent and subjective decision-making, higher rates of clinical error, and discriminatory allocation of care.

Finally, five years of life is not inconsequential or insignificant. To affected individuals, and those who love them, this may be time to see children or grandchildren grow and graduate from school, to complete one's life work, to care for family and friends, to enrich the lives of others, and to continue to contribute to society. For these reasons alone, penalizing individuals with life expectancies of less than 5 years is disrespectful and discriminatory.

Therefore, we recommend the Standards eliminate any consideration of intermediate term prognosis (5 year life expectancy), and limit any consideration of individual patient longevity to medical conditions that are highly likely to result in death in less than one year. Massachusetts should adopt the portion of the New York State triage model[3] which assesses "the short-term likelihood of survival of the acute medical episode," and not whether a patient may survive another illness or disease years after the pandemic. Under this approach, every patient is treated in accordance with a consistent standard of care, and triage decision-makers are not asked to

---

[1] The Standards acknowledge that in some cases there will not be "valid prognostic data" available to determine whether or to what extent an underlying condition significantly limits "near-term" prognosis. Although triage officers are expressly cautioned not to assign points when prognosis is uncertain, no further guidance is provided, making it highly likely that underlying conditions will be considered and result in negative de-prioritization. Nor do the Standards offer an objective, reliable, or consistent predictive method.

[2] *See*, https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.

[3] 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.

make predictions based on insufficient information, or subjective assumptions about survival in the years following treatment.

Of course, predictions, when they do occur, must be made with caution, as part of an individualized assessment. If there is not objective medical evidence supporting the high likelihood of death in less than one year, no points should be added to the individual's triage score.

2) Eliminate provisions that discriminate on the basis of age

The revised Standards continue to include the stated goal of saving "life years," and explicitly invoke age as a basis for the allocation of scare medical resources if two individuals have the same SOFA scores. This "tie-breaker" provision violates the Affordable Care Act's anti-discrimination provisions, as well as the Age Discrimination Act of 1975, which establishes that "no person ... shall, on the basis of age, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any program or activity receiving Federal financial assistance." 42 U.S.C. § 6102; 34 C.F.R. § 110.10(a).

The American College of Physicians has rejected the use of "number of life years," instead recommending that hospitals make resource allocation decisions

> based on patient need, prognosis (determined by objective scientific measures and informed clinical judgment) and effectiveness (i.e., the likelihood that the therapy will help the patient recover). Allocation of treatments must maximize the number of patients who will recover, not the number of "life-years," which is inherently biased against the elderly and the disabled.[4]

The continued focus on "life years" also jeopardizes individuals with disabilities and people of color such as those in African American[5] and Native American[6] communities who experience lower life expectancies due to well-documented social disparities and systemic health inequities.

Patients who were born and grew up in poverty are also more likely, through no fault of their own, to have life-limiting medical problems due to lack of access to basic health care, environmental hazards, crime, hazardous work or unemployment, and many other factors. Moreover, these disadvantaged patients are more likely to come from racial or ethnic groups that are victims of other forms of wrongful discrimination, or to have disabilities that have subjected them to discrimination in access to health care. The life-years approach to allocating care cannot easily accommodate such considerations, and instead exacerbates these inequities.

---

[4] Available at https://www.acponline.org/acp-newsroom/internists-say-prioritization-allocation-of-resources-must-not-result-in-discrimination.

[5] *See,* Allan S. Noonan, et al., Improving the Health of African Americans in the USA: An Overdue Opportunity to for Social Justice, 37 Oub. Health Rev. 12 (2016) available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5810013/.

[6] Indian Health Service, Fact Sheet: Disparities, at https://www.ihs.gov/newsroom/factsheets/disparities/.

Therefore, we recommend the elimination of this tie-breaker provision, and the inclusion of older adults among the group of individuals for whom hospitals are instructed to guard against social inequities and disproportionate negative impacts.

3) Clarify affirmative obligations to make reasonable accommodations to visitor policies

The revised Standards acknowledge that patients with disabilities may require specific accommodations in communicating their needs and preferences regarding treatment, including access to interpreters and specialized assistive technology. In many instances, this communication can only be effectively facilitated through access to a specific individual known to, and selected by, the person receiving care. If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider, knowledgeable about the management of their care, or needs someone to physically or emotionally assist them during their hospitalization, this should be allowed with proper precautions taken to contain the spread of infection.[7]

Recently, the American Academy of Developmental Medicine and Dentistry (AADMD) recommended that hospitals "provide reasonable accommodations in their visitor policies for persons who need support from known and acknowledged support persons (family, community agency personnel, or other designated caregivers)."[8] Importantly, AADMD notes that without these accommodations, physicians may be deprived of critical health care information in the triage process, and patients can experience serious negative outcomes:

> "No Visitors" policies may result in deleterious and sub-optimal clinical outcomes because vital bio-psycho-social information is not available to medical staff. Agency personnel and family caregivers who have this type of information can provide it stat when on site in the patient's room or floor. Such persons also may serve as the patient's medical proxy when legally eligible. Such designated support personnel are not passive "visitors," they can provide vital information that can impact clinical decisions and outcomes. Such information may include previous hospitalization information, preferences for therapeutics, sensory accommodations, fall prevention, swallowing and feeding techniques, positive behavioral tactics, and other personal care information not readily available from hospital intake notes. They may also provide communication support between the patient and hospital staff or implement specialized support strategies to aid the patient to comply with clinical treatments.

For these reasons, visitor restrictions should be specifically listed among the hospital policies and procedures where reasonable accommodations are required under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

---

[7] *See, e.g.* New York Department of Health, Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation, available at https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf.

[8] This statement on the rationale for revised visitor policies for hospitalized patients with Intellectual and Developmental Disabilities (IDD) can be found at https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e9e1cbefc832d0a6866fed4/1587420352080/Visitation-PolicyStatement.pdf.

Finally, accommodations in the provision of community supports may be necessary to allow the appropriate discharge of individuals with significant support needs post-hospitalization.

4) Ensure an accessible, transparent and accountable triage process

We support the revised Standards' requirement that facilities document triage decisions and appeals made during a period of crisis activation, including demographic information. We urge DPH to require the proactive reporting of this information in real time, rather than simply upon request.

It is also critical that this information be made public in a way that allows interested communities and organizations to evaluate the efficacy of the Standards throughout their period of application, the extent to which their application at the local level complies with federal law, and whether further guidance and oversight is needed to ensure Massachusetts residents do not experience disparate impacts or unconscious bias based on disability, age or race.

Finally, we continue to believe that each hospital's triage protocols and the appeal procedures must be shared with the Administration and posted publicly on both DPH's and the hospitals' websites for the benefit of individual patients and their health care agents/families.

Conclusion

The organizations and individuals listed above believe that significant problems remain with the revised Standards, including reliance on triage criteria which violate federal law. Rather than seek the intervention of OCR at this time, we would prefer to work with the Administration to make additional revisions to the Standards. We request a meeting in the near future between representatives from our coalition and key state officials to address the above revisions. We hope that this dialogue would both resolve our concerns and avoid the need for a formal complaint. We would appreciate a commitment within the next ten days to schedule such a meeting.

As part of that dialogue, we would hope to formalize a process for further community input and ongoing monitoring of the Standards, understanding that even if the current surge does not overwhelm hospital capacity, there remains a real risk that future spikes in transmission could trigger the implementation of crisis standards of care.

Finally, we urge the Administration to publicly report any activation of crisis standards of care, and related data concerning the implementation of those standards, pursuant to the April 20, 2020 Order of the Department of Public Health, as part of the Department's ongoing commitment to monitor quality of service delivery and equitable implementation of the Standards.

We look forward to meeting with administration officials as we all mutually work to ensure what is best for the Commonwealth's residents.

Thank you for your attention and prompt response.

Sincerely,

Kathryn L. Rucker
Cathy E. Costanzo
Steven J. Schwartz
Robert D. Fleischner
Center for Public Representation
22 Green Street
Northampton, MA 01060
413-586-6024
krucker@cpr-ma.org
ccostanzo@cpr-ma.org
sschwartz@cpr-ma.org

Linda Landry
Rick Glassman
Disability Law Center
11 Beacon Street, Suite 925
Boston, MA 02108
617-723-8455
llandry@dlc-ma.org
rglassman@dlc-ma.org

Daniel S. Manning
Greater Boston Legal Services
197 Friend Street
Boston, MA. 02114
dmanning@gbls.org

Regan Bailey
Denny Chan
Gelila Selassie
Justice In Aging
1101 I Street, NW, Suite 1100
Washington, DC 20036
202-683-1990
rbailey@justiceinaging.org
dchan@justiceinaging.org
gselassie@justiceinaging.org

Justin J. Lowe
Health Law Advocates
One Federal Street, 5th Floor
Boston, MA 02110
617-275-2981
jlowe@hla-inc.org

Phillip Kassel
Caitlin Parton
Mental Health Legal Advisors Committee
24 School Street, Suite 804
Boston, MA 02108
617-338-2345
pkassel@mhlac.org
cparton@mhlac.org

Ruth A. Bourquin
Jessica Lewis
American Civil Liberties Union
Foundation of
Massachusetts, Inc.
211 Congress Street
Boston, MA 02110
617-482-3170
RBourquin@aclum.org
JLewis@aclum.org

Mark Larsen
Mental Health Litigation Division
Committee for Public Counsel Services
44 Bromfield Street
Boston, MA 02108
mlarsen@publiccounsel.net

Ivan Espinoza-Madrigal
Lawyers for Civil Rights
61 Batterymarch Street
5th Floor
Boston, MA 02110
iespinoza@lawyersforcivilrights.org

Cc: Daniel Tsai, Acting Secretary, EOHHS; Joan Mikula, Commissioner, DMH; Monica Bharel, M.D., Commissioner, DPH; Jane Ryder, Commissioner, DDS; Toni Wolf, Massachusetts Rehabilitation Commission; Elizabeth Chen, PhD, Secretary of the Executive Office of Elder Affairs; Michael Wagner, MD FACP, Chief Physician Executive, Wellforce; Torey McNamara, Secretary, Massachusetts Public Health Council