



Center for Public
Representation

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By Electronic Mail

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Thank you for the courage and selflessness shown by health care professionals in the face of this growing health care crisis. We appreciate all that you as leaders of your respective organizations are doing to rapidly mobilize resources to meet the needs of people affected by the COVID-19 pandemic. Like all Americans, persons with disabilities and their advocates are heart-broken that we may face insufficient lifesaving resources in the difficult days and weeks to come. Because we are all too aware of the risk of discrimination faced by our community, both young and old, we write to offer support, feedback and resources to assist health care systems as you work to design and implement triage assessment protocols.

We have already written to Governor Baker stressing the need to ensure that triage guidelines comport with civil rights laws including Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA).¹ As you know, on March 28, 2020, the US Health and Human Services' Office of Civil Rights issued guidance prohibiting disability discrimination in HHS funded health programs, including the delivery of lifesaving care during the COVID-19 outbreak.² Importantly, the OCR bulletin directs 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. 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.

We know that you are working hard under difficult circumstances to operationalize principles of fairness and nondiscrimination in the delivery of health care. To comport with federal

¹ The letter from family, professional, and advocacy organizations is enclosed and available electronically at <https://www.centerforpublicrep.org/news/cpr-and-local-partners-send-letter-to-governor-on-need-for-statewide-guidelines-preventing-discriminatory-allocation-of-life-saving-medical-care/>

² This bulletin is available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>; *see also*, <https://www.disabilitycoop.com/2020/03/30/trump-administration-says-disability-no-reason-to-deny-covid-19-care/28065/>.

nondiscrimination law and emerging best practices, we recommend that triage assessment guidelines:

1) include an explicit statement prohibiting consideration of disability independent of its impact on survivability;

The National Council on Disability³ and the Consortium for Citizens with Disabilities⁴ have articulated important principles for the delivery of care which can form the basis of such a statement.

2) remove any categorical exclusion on the basis of diagnosis, functional impairment or ADL needs;

Often diagnostic or functional exclusions are based on misplaced assumptions regarding people with disabilities, the nature of their conditions, and the value of their lives. As the widely consulted “Pittsburgh model” makes clear, all individuals should be eligible for, and qualified to receive, lifesaving care regardless of the presence of underlying disabilities or co-morbid conditions.⁵ Adhering to this standard is not incompatible with the triage assessment process.

3) rely on individualized assessments based on objective medical evidence;

Triage protocols which assess patients “comparative ability to benefit” from treatment can be vulnerable to conscious or unconscious bias and misperceptions about the level of resources a person with underlying disabilities may require to survive the virus. The use of evidence-based assessment tools increases credibility and public confidence in the objective and individualized nature of these assessments.

4) replace vague criteria that are likely to screen out or disparately impact people with disabilities;

Assessments which score patients based on “*life-limiting co-morbidities*” or “*long term prognosis*” increase the likelihood that individuals with disabilities, including those living full and successful lives in the community, will be denied lifesaving care. Even protocols which equate survival with “health,” or the absence of chronically debilitating symptoms, risk importing quality of life criterion into the triage process.⁶ Any consideration of physical, developmental, cognitive, or psychiatric co-morbidities should be tied to prognosis for hospital survival and discharge. Attempts to predict longer term prognosis will lead to inconsistent, subjective decision-making and higher rates of clinical error.

³ Available at <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>

⁴ Available at <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>.

⁵ See, <https://ccm.pitt.edu/?q=content/model-hospital-policy-allocating-scarce-critical-care-resources-available-online-now>

⁶ See, *COVID-19 Triage and Disability: What Not to Do*. Joseph Stramondo, PhD, Bioethics.net, March 30, 2020, available at ...<http://www.bioethics.net/2020/03/covid-19-triage-and-disability-what-not-to-do/>

5) clarify that individuals will not be subject to the withdrawal or removal of lifesaving equipment based solely on disability;

Some hospitals in other states are being criticized for plans to take ventilators away from people in the community who routinely use this equipment, should they present for acute care.⁷ These policies have triggered civil rights complaints, and are creating perverse disincentives for affected individuals to seek appropriate medical care. All hospitalized patients should expect to receive an individualized medical assessment, without fear that their personal medical equipment will be automatically redeployed based on assumptions about their intensity of need or likelihood of recovery.

6) consider reasonable accommodations/modifications of the triage protocol for people with disabilities;

Certain triage criteria, such as limitations on how long patients may stay on a ventilator without demonstrated improvement, may have a disproportionate, negative impact on individuals with disabilities. Triage protocols should have the flexibility to offer accommodations to patients who are expected to recover, but may require additional time to demonstrate effective progress because of their disability.

7) provide disabled patients with effective methods of communication;

Patients with disabilities may require specific accommodations in communicating their needs and preferences regarding treatment, including interpreters and specialized assistive technology. It is critical that all reasonable steps be taken to ensure guardians, family members, and health care agents are afforded the opportunity to communicate regularly with the individual, their treating clinicians, and the triage assessment team through whatever telephonic or video technology is most accessible to the person and their supporters.

8) establish a meaningful, accessible and participatory appeal process.

Although triage assessments are made in real time, there are models that afford patients and families the opportunity to question the accuracy of priority scoring and prompt recalculation by triage assessment teams to ensure protocols are applied based on the best available medical information.⁸

Decisions to withdraw or reallocate scarce resources such as mechanical ventilation are more dependent on clinical judgment and should involve a more robust appeal process. In all instances, it is critical that the triage assessment protocol is shared with the individual and their agents/family, that the appeal process is transparent and easy to use, and that the outcome is explained by the responsible triage officer.

⁷ OCR Complaints filed against the states of Washington, Alabama, Kansas and Tennessee can be found at <https://www.centerforpublicrep.org/news/cpr-and-partners-file-additional-complaints-regarding-illegal-disability-discrimination-in-treatment-rationing-during-covid-19-pandemic/>

⁸ See, <https://ccm.pitt.edu/?q=content/model-hospital-policy-allocating-scarce-critical-care-resources-available-online-now>, p.4.

Thank you for your consideration of these recommendations. We are available to speak with you and members of your association involved in triage protocol development. You can reach us by contacting Kathryn Rucker, Center for Public Representation, at krucker@cpr-ma.org or Rick Glassman, Disability Law Center, at rglassman@dlc-ma.org.

Sincerely,

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