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Center for Public Representation

February 11, 2021

Dear Secretary Sudders,

We write to you today to express our continued concern regarding the Massachusetts Crisis Standards of Care, which were recently revised in October 2020 (October CSC). While the revisions addressed many concerns raised by the disability community, it continues to demonstrate bias in the rationing of life saving care against older adults. Older adults are protected from discrimination in healthcare and the Office for Civil Rights at HHS has rejected age biased CSCs in numerous states. We urge you to revisit this language to bring the State's policy into compliance with Section 1557 of the Patient Protection and Affordable Care Act and the Age Discrimination Act of 1975 (the Age Act). The undersigned previously alerted you of the discriminatory language found in the prior version of the Crisis Standard of Care in our letters of April 14, 2020 and June 5, 2020, with further correspondence directed to the Massachusetts Crisis Standards of Care Advisory Group on September 28, 2020. The October CSC addressed some of the issues raised, but still includes an age-based tie breaker, fails to include age in the protected classes covered by non-discrimination provisions, and considers prognosis up to one year after hospital discharge. Each of these provisions discriminates against older adults. We hope that we can continue to work together to create a nondiscriminatory CSC.

I. Age-Based Tie Breakers Deny Life Saving Care Based Solely on Age

The October CSC tie breaker language removed the draconian life-cycle considerations and categorical age-based factors, but it continues to allow age to be the sole reason for denial of healthcare. The tie breaker language also discriminates against people with disabilities through the inclusion of related criteria; relying on "frailty" and "severe underlying medical condition" as basis for denial of care.<sup>1</sup> Here, age is considered alone without any related clinical findings related to recovery from the acute event and is a singular basis for denial of care. The criteria rely on age as a proxy for short-term survival where individualized considerations of survival (which already reflect the impact of age on the person's body) have already been considered. The addition of age here results in a double

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<sup>1</sup> The new tie breaker language states "There may be multiple patients with the same absolute priority score who, based on individual patient characteristics not accounted for by SOFA, are deemed to have substantially different prospects for survival of the acute illness. **Such individual patient characteristics may include, for example, age, progressive frailty and severe underlying medical condition for which there is objective medical evidence.** To the extent that several patients with the same priority score are deemed to have substantially different prospects for survival of the acute illness, priority may be given to the patients with the higher likelihood of surviving the acute illness." (emphasis added).

counting of that impact and is discriminatory against older adults and violative of Section 1557 of the ACA and the Age Act. The inclusion of age in this section is made more problematic by the *failure* to include age in the list of characteristics that should not be used to discriminate in making healthcare allocations elsewhere in the October CSC.

We continue to have serious concern regarding any tie-breaker provision that relies on the use of age as a proxy for short-term survivability. Aggregate data relating to survival may support that “younger persons generally have better short-term mortality outcomes than older persons with the same clinical conditions.” This cannot support denial of care based on age where older adults experience longstanding systemic discrimination.<sup>2</sup> In the aggregate, data also support that people who do not live with certain disabilities generally have better short-term mortality outcomes, as well as persons of certain races. In fact, women have better short-term mortality outcomes for COVID-19 survival than men<sup>3</sup>, yet the October CSC does not favor women in the receipt of life saving health care services over men. Reliance on such generalized data relating to protected characteristics -- disability, race, gender and age -- should not decide who receives limited lifesaving care when individuals present with equivalent conditions.<sup>4</sup>

While the Age Act has certain exceptions, they do not support the use of age as a tiebreaker. The regulation’s four-part test necessitates that all criteria must be met for an exception to apply. 42 C.F.R. § 91.13.

- (a) age used to measure or approximate another characteristic;
- (b) other characteristic must be measured or approximated for the normal operation of the program or activity to continue;
- (c) other characteristic can be reasonably measured or approximated by use of age; and

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<sup>2</sup>*Ageism and its clinical impact in oncogeriatrics: state of knowledge and therapeutic leads*; Clinical Interventions in Aging 2015:10 117–125 (“Yet it should be remembered that “advanced” age alone should not be a contraindication for treatments that can increase a patient’s quality of life or significant extend a patients survival. Consequently, although it is undeniable that some health changes appear with age... these changes are not contraindication for receiving treatment: instead they point to the need to adapt them to elderly people.”). *See also, Ageism as a Risk Factor for Chronic Disease*, Julie Ober Allen, The Gerontology Society of America, <https://academic.oup.com/gerontologist/article-abstract/56/4/610/2605514>; *COVID-19 Pandemic and Ageism: A Call for Humanitarian Care*, Christopher C. Colenda *et al*, JAMDA, <https://doi.org/10.1016/j.jamda.2020.05.054> 1525-8610/\_ 2020 American Association for Geriatric Psychiatry,

<sup>3</sup> <https://www.frontiersin.org/articles/10.3389/fpubh.2020.00152/full>. (men more at-risk for death from COVID-19 independent of age); <https://www.brookings.edu/blog/up-front/2020/05/15/covid-19-much-more-fatal-for-men-especially-taking-age-into-account/> (showing significant gender gap in death rates across all age ranges).

<sup>4</sup> Guidance of the Health Care Resilience Taskforce (composed of HHS, FEMA, and the Army Corps of Engineers), “Crisis Standards of Care and Civil Rights Laws,” states that “[t]reatment decisions, including denials of care under CSCs, must be made after nondiscriminatory consideration of each person, free from stereotypes and biases based on disability or age—including generalizations and judgments about the quality of life, or relative value to society, concerning disabilities or age. This individualized consideration should be based on current objective medical evidence and the views of the patients themselves as opposed to unfounded assumptions.” Issued April 14, 2020, <https://files.asprtracie.hhs.gov/documents/crisis-standards-of-care-and-civil-rights-laws-covid-19.pdf>

(d) other characteristic is impractical to measure directly on an individual basis.

Regulations governing the Age Act make clear that age can legally be used in public benefits only when providing special benefits to older adults and children, not to deny care based on age:

42 C.F.R. § 91.17 Special benefits for children and the elderly.

If a recipient operating a program or activity provides special benefits to the elderly or to children, such use of age distinctions shall be presumed to be necessary to the normal operation of the program or activity, notwithstanding the provisions of § 91.13.

In the context of the October CSC tiebreaker language, and even when assuming that age could be one characteristic that is used to approximate “short-term mortality risk,” the age-related denial of care cannot overcome each of the four prongs of the test. For age to be an appropriate measure, it must be used to measure or approximate another characteristic; it must be a reasonable measure for that characteristic, and it must be impractical to measure that characteristic directly. In October CSC, for example, reliance on age as the tiebreaker is purportedly using age as a proxy for short-term survival. However, the terms of the tiebreaker language require an *actual individualized measure* of the clinical basis for assessing likelihood of short-term survival *prior* to applying the tiebreaker, making a proxy duplicative of the individualized result and essentially counting twice the impact a person’s age has on his or her body (both by direct measurement and by proxy).

Similarly, we question whether a proxy for short-term survival is necessary to the normal operation of the program or activity. The CSCs are not operational under normal conditions, nor are they statutory creations, so it is not clear that age-based criteria could ever be applied. However, if age could be considered, the age-based criteria are not necessary.<sup>5</sup> In our prior correspondence, we have shared examples of alternative methods for measuring short-term mortality risk when SOFA scores are equal (e.g. California, New York and New Hampshire), and tiebreaker alternatives that simply do not use short-term mortality as tiebreaker criterion (e.g. lottery). Given these alternatives, we believe reliance on an age-based tiebreaker is not necessary and therefore does not meet the four-prong test under regulations implementing the Age Act.

We have serious reservations regarding how providers may interpret the tiebreaker language. We hope that the context surrounding the tiebreaker provision would militate against the blunt use of age to ration care, but we remain concerned that the imprimatur of the state’s CSC for the use of age, even as a last-resort criterion, is likely to lead to arbitrary decision-making and reinforce personally-held ageist notions of “fair innings” that unfairly devalue the lives of older people. Similarly, a blunt preference for youth could lead to denial of care where the age difference is just a few years (a 73-year-old preferred over a 76-year-old) or where the choice may be perceived as indefensible by the community (an 18-year-old single adult preferred over a 35-year-old mother of three). It is not clear that the language of the October CSC tiebreaker on its face would prohibit these outcomes.

## II. Older Adults Experience Deep Seated Ageism, Sexism, and Racism in Healthcare

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<sup>5</sup> Reliance on age may not even be the best approximation of short-term survivability when other characteristics, such as gender, might be even more accurately predictive, see footnote 1.

The October CSC does not clearly list age as a protected characteristic which cannot be the basis of the denial of healthcare. Older adults face pervasive discrimination in the healthcare context, which is why they were expressly included in federal non-discrimination protections. The language from the October CSC fails to list age as a prohibited consideration:

“Healthcare providers making allocation decisions should not consider characteristics that have no bearing on the likelihood or magnitude of benefit. Such factors include but are not limited to race, disability, gender, sexual orientation, gender identity, ethnicity, ability to pay or insurance status, socioeconomic status, perceived social worth, perceived quality of life, immigration status, incarceration status, homelessness, and past or future use of resources. These factors should not be used to limit care, and efforts must be made to ensure that the application of the framework does not result in negative impact on individuals from these groups or with these characteristics.”

Section 1557 of the Patient Protection and Affordable Care Act prohibits discrimination based on age by health care entities. The CSC should clearly state that age should not be considered in and of itself. This is necessary to bring the policy into alignment with similar protections that are expressly included, such as race, disability, gender – all of which have similar bearing on the likelihood of benefit from treatment. Massachusetts rightly determined that these corollaries reflect long-term disparities in health care and expressly chose to prohibit consideration of them in deciding life or death treatment decisions. Age-based discrimination is well documented and similar protections should be expressly included for older adults. “The COVID-19 pandemic has placed a spotlight on the deleterious effects of deep-seated ageism, sexism, and racism on older Americans.”<sup>6</sup> Justification for these experiences should not be codified in state policy.

The impact of COVID 19 on older adults cannot be overstated – many have died, but what is less studied is how much that is reflective of age alone versus numerous layers of bias and disparities impacting older adults in the healthcare system.

If older patients had equal access to quality health care, housing, and social support, it might be that age bears very little on COVID-19 outcomes. But there are reasons for skepticism about the existing data. First, “soft rationing” has likely occurred, where older individuals were simply not recommended for transfer to a higher acuity setting, or were transferred later and more gravely ill, and died without ever being considered for a scarce resource. And second, the explicit use of age in triage protocols—either as a categorical exclusion, or as a secondary tie-breaker under a “life years saved,” “survivability” or “fair innings” rationale— further frustrates the ability to assess the extent to which the physiology of age impacts COVID-19 survival, rather than the triage protocols themselves that deprioritize the elderly.<sup>7</sup>

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<sup>6</sup> *Recovering from the COVID-19 Pandemic: A Focus on Older Adults*, Nancy Morrow-Howell, MSW, Ph et al, Journal of Aging and Social Policy, 2020, VOL. 32, NOS. 4–5, 526–535  
<https://doi.org/10.1080/08959420.2020.1759758>; see also

<sup>7</sup> *Embedding the Problems Does Not Make Them Go Away*, Teneille R. Brown , Leslie P. Francis & James Tabery (2020) The American Journal of Bioethics, 20:7, 109-111, DOI: 10.1080/15265161.2020.1779864  
<https://doi.org/10.1080/15265161.2020.1779864> ; see also, *Why the fair innings argument is not persuasive*, Michael M Rivlin, BMC Medical Ethics, 2000, 1:1; <http://www.biomedcentral.com/1472-6939/1/1>

III. “Short-Term” Prognosis of Requiring One-Year Benefit is Arbitrary and Will Lead to Denial of Care to Older Adults

The October CSC directs health providers to look to short-term survival from the acute event but defines that to mean that the *duration of the benefit must be at least one year*. Specifically, it states:

“By accounting only for prognosis for surviving the acute illness and surviving one year beyond the acute illness, and not focusing on long-term life expectancy, the framework attempts to mitigate the impact disparities caused by social inequity.”

While professing to limit prognosis to survival to discharge, in fact it extends that prognosis to the longer term of one year. The October CSC requires that an assessment be made that the individual will live for one year post discharge, and this equates to a one-year prognosis requirement and does not align with Office for Civil Rights guidance and resolutions in other states. In the resolution of a complaint filed against Tennessee, OCR’s resolution resulted in language clearly articulating the prohibition on long-term prognosis beyond risk of imminent mortality<sup>8</sup>: Tennessee “removed language permitting the use of a patient’s long-term life expectancy as a factor in the allocation and re-allocation of scarce medical resources, instead indicating that providers should consider only risk of *imminent mortality*.”

We invite you to revisit the language in the October 2020 Crisis Standards of Care and to meet with us to discuss how best to bring the state into compliance with the Age Act while fashioning a workable health care rationing protocol. We are assessing what if any additional action we may take to ensure that older adults in Massachusetts are not wrongfully denied care. Please contact Regan Bailey at [rbailey@justiceinaging.org](mailto:rbailey@justiceinaging.org) by February 25, 2021 if you are open to further discussion.

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<sup>8</sup> *OCR Resolves Complaint with Tennessee After it Revises its Triage Plans to Protect Against Disability Discrimination*, June 26, 2020, <https://www.hhs.gov/about/news/2020/06/26/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against-disability.html>