September 23, 2020

Roger Severino, Director
Office for Civil Rights (OCR)
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC. 20201

Re: The Age Bias in Utah’s Crisis Standard of Care Tiebreaker Provision

Dear Mr. Severino,

Thank you for taking the time to speak with us last week. We appreciate the continuing leadership of the Office for Civil Rights in resolving complaints relating to Crisis Standards of Care, and your willingness to hear feedback on issues that remain of concern to us. We hope that we can be helpful going forward as your office considers the impact of Crisis Standards of Care on older adults caught in the cross hairs of this pandemic. We also appreciate your recognition of the harm that age discrimination causes and the inherent unfairness in approaches such as “fair innings” or “life years.”

As discussed during our call, the Utah Crisis Standards of Care includes a list of personal characteristics whereby the guidelines would not permit discrimination. Specifically, the Guidelines state that “[t]his protocol does not discriminate, based on race, disability, gender, sexual orientation, gender identity, ethnicity, ability to pay, socioeconomic status, perceived social worth, perceived quality of life, immigration status, incarceration status, homelessness, or exercise of conscience and religion.” See “About the Guidelines,” page 2. Notably absent is a prohibition against discrimination based on age. While it is not clear whether its omission was an oversight or a consequence of the inclusion of the aged-based “tie-breaker” provision, we think it is important to clarify that age is a protected characteristic, both under the law and within the CSC guidelines.

We do understand from your email that OCR is satisfied with the result in Utah, but we hope that you will take a fresh look at age-based tie breaker language in any future CSC subject to the complaint process at OCR. We remain concerned regarding any tie-breaker provision that relies on the use of age as a proxy for short-term survivability. Aggregate data relating to survivability may support that “younger persons generally have better short-term mortality outcomes than older persons with the same clinical conditions.” However, in part due to longstanding systemic discrimination, 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\textsuperscript{1}, yet the CSC does not favor women in the receipt of life saving health care services over men. All things being equal, reliance on such generalized data relating to disability, race, gender and age should not decide who receives limited lifesaving care.\textsuperscript{2}

Our understanding of the exceptions provided by the Age Act 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
(d) other characteristic is impractical to measure directly on an individual basis.

In the context of the Utah tiebreaker language, and assuming that age could be one characteristic that is used to approximate “short-term mortality risk,” we do not think that it would 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 Utah, 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 in the aggregate 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.\textsuperscript{3} We have seen examples of alternative methods for measuring short-term mortality risk when SOFA scores are

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  \item [\textsuperscript{1}] 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).
  \item [\textsuperscript{2}] 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
  \item [\textsuperscript{3}] 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.
\end{itemize}
\end{footnotesize}
equal (e.g. California/co-morbidities approach), and tiebreaker alternatives that simply do not use short-term mortality as tiebreaker criterion (e.g. lottery). Given these alternatives, we believe reliance on a simple age-based tiebreaker does not meet the four-prong test under regulations implementing the Age Act.

We also have some reservations regarding how providers may interpret the Utah tiebreaker language. We share your 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 (a 18 year old single adult preferred over a 35 year old mother of three). It is not clear that the language of the Utah tiebreaker on its face would prohibit these outcomes. If changes are not made to Utah’s CSC, we hope these issues will be considered and clarified in future resolutions of objections to CSCs.

We appreciate your openness to our feedback and the continued leadership of OCR on issues surrounding Crisis Standards of Care. We would like to work with OCR as you review CSCs that impact older adults and share our understanding of the importance of removing all traces of bias from this sensitive and high-stakes process. In light of the prevalence of discrimination against older adults in the healthcare context\textsuperscript{4} and the disproportionate harm suffered by older adults during the COVID-19 pandemic, we believe it is imperative that we guard against the shifting of even greater burden onto older adults in the rationing of life-saving care. Please let us know if your review of CSCs in Utah or other jurisdictions would benefit from the sharing of our aging specific analysis. We can be reached through Regan Bailey at rbailey@justiceinaging.org.

Thank you,

Regan Bailey
Gelila Selassie
Denny Chan
Justice in Aging

Alice Bers /s/
Peter Kalde
Kata Kertesz
American Society on Aging
Center for Medicare Advocacy