

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW



Center for Public Representation



Strategic Action
Planning Group on Aging

January 3, 2022

Dear Dr. Hunsaker Ryan,

We write today to share our concerns regarding the Crisis Standards of Care (CSC) and their impact on older adults, including older adults with disabilities and older people of color. We are concerned that implementation of the triage protocol will result in harm to this population and may violate federal civil rights laws. We recognize the difficulties inherent in crafting a policy to allocate scarce resources during a pandemic while protecting the civil rights of patients who enter the health care setting having experienced differing levels of healthcare throughout their lives.¹ We recognize the prior work undertaken to improve the Colorado CSC and commend the latest version for specifically forbidding categorical exclusion criteria based on age, race, or other social factors.² We do believe, however, that the CSC requires further revisions in order to avoid having a discriminatory impact on older adults, people of color, and people with disabilities.

¹ *Racial Equity in Crisis Standards of Care—Reassuring Data or Reason for Concern?* E.C. Cleveland Manchanda et al, JAMA Network Open. 2021;4(3):e214527. doi:10.1001/jamanetworkopen.2021.4527

² The Strategic Action Planning Group on Aging, a signor to this letter, has attached an appendix outlining the areas of recommendations that have been made since its inception that are related to and support the requested changes to the recently revised Crisis Standards of Care.

The current CSC relies on age and age-correlated criteria in the tie breaker language which could lead to the inappropriate and discriminatory denial of medical care, including life-saving treatment interventions. First, we have serious concerns regarding any tie-breaker provision that uses age as a proxy for survivability, as age is a heterogeneous category and cannot form a reliable basis for predicting prognosis with treatment. Ageism in healthcare is prevalent and results in significant harm, further increasing the potential for unconscious bias to enter into these triage decisions.³ We have identified four additional areas where CSC provisions, if applied as written, could result in discriminatory outcomes for older adults, including those with disabilities and older adults of color: 1) tying estimated prognosis, and particularly intermediate and long term survivability, to triage decision-making; 2) reliance on of age, or age and disability correlated factors in CSC assessment tools; 3) utilization of do not resuscitate orders; and 4) the consideration of intensity and duration of treatment needs without provisions for reasonable accommodations. In addition, we note other areas where the CSC could better ensure that the rights of older adults are protected: reliance on blinded data and legal protections language.

This letter sets out the legal basis for this assessment, the ways in which the Colorado CSC is inconsistent with complaint resolutions and guidance issued by the federal Health and Human Services' Office of Civil Rights (OCR), the specific CSC provisions at issue, and potential options for addressing and preventing discriminatory allocation of scarce resources in Colorado.

Federal Civil Rights Protections for Older Adults

Our review of the CSC is informed by the federal civil rights laws protecting older adults and people with disabilities. Section 1557 of the Patient Protection and Affordable Care Act prohibits discrimination based on age by health care entities, 42 U.S.C.A. § 18116. Section 1557 incorporates other federal civil rights protections and applies them in the healthcare arena, including protections based on age, race, disability and sex by incorporating protections from several key civil rights statutes, including the Age Discrimination Act of 1975 or Age Act (42 U.S.C. § 6102, 42 U.S.C. § 6102), title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Rehabilitation Act (section 794 of Title 29).

The Age Act applies to healthcare settings (through Sec 1557 of the ACA) and establishes that

³ *Ageism against older adults in the context of the COVID-19 pandemic: an integrative review*. MF Silva et al. Rev Saude Publica. October 2020; 2021;55:4. <https://doi.org/10.11606/s1518-8787.2021055003082> (Inequities in resource allocation, derogatory references to older adults, and relief for this age group presenting more risk of mortality”); *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>; *Six Propositions against Ageism in the COVID-19 Pandemic*, Ehni & Whal, 2020. JOURNAL OF AGING & SOCIAL POLICY 2020, VOL. 32, NOS. 4-5, 515-525 <https://doi.org/10.1080/08959420.2020.1770032>, (“The risk of developing severe illness from COVID-19 and of dying from it increases with age. This statistical association has led to numerous highly problematic policy suggestions and comments revealing underlying ageist attitudes and promoting age discrimination.”).

“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.

Title II of the ADA prohibits public entities (such as state and local governments) from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Section 504 of the Rehabilitation Act similarly bans disability discrimination by recipients of federal financial assistance, including Colorado agencies and most hospitals and health care providers. 29 U.S.C. § 794(a).

Actions by the Office on Civil Rights at DHHS

Across the country, advocates for older adults, people with disabilities, and racial justice advocacy groups have filed complaints with OCR concerning discriminatory health care rationing. As a result, OCR has investigated how various CSC can work to deny access to care for persons covered by federal civil rights laws. It has issued a series of statements following the resolution of each complaint, and these statements detail HHS’s requirements for reducing or eliminating bias in CSCs. The most recent resolutions were in Tennessee⁴, Arizona⁵, Texas⁶ and Utah⁷ and included these prohibitions and patient protections:

- Prohibition on the use of **a patient's long-term life expectancy** as a factor in the allocation and re-allocation of scarce medical resources and instead **consider only risk of imminent mortality**;
- Prohibition on the use of **resource-intensity and duration of need as criteria** for the allocation or re-allocation of scarce medical resources;
- Inclusion of **reasonable modifications to the use of clinical instruments** for assessing likelihood of short-term survival when necessary for accurate use with patients with underlying disabilities;
- Inclusion of new protections against providers "**steering**" **patients into agreeing to the withdrawal or withholding of life-sustaining treatment**, clarifying that patients may not be subject to pressure to make particular advanced care planning decisions; and

⁴ <https://www.hhs.gov/guidance/document/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against>

⁵ <https://www.hhs.gov/about/news/2021/05/25/ocr-provides-technical-assistance-state-arizona-ensure-crisis-standards-care-protect-against-age-disability-discrimination.html>

⁶ <https://www.hhs.gov/about/news/2021/01/14/ocr-provides-technical-assistance-ensure-crisis-standards-of-care-protect-against-age-disability-discrimination.html>

⁷ <https://public3.pagefreezer.com/content/HHS.gov/31-12-2020T08:51/https://www.hhs.gov/about/news/2020/08/20/ocr-resolves-complaint-with-utah-after-revised-crisis-standards-of-care-to-protect-against-age-disability-discrimination.html>

- Inclusion of language ensuring that **long-term ventilator users** will be protected from having a ventilator they bring with them into a hospital setting reallocated to someone else.

COLORADO’S CRISIS STANDARDS OF CARE

As set out in detail below, the Colorado CSC are inconsistent with federal civil rights law and well-established OCR positions in several respects. The CSC is therefore likely to result in discriminatory outcomes for Colorado residents, including the perpetuation of unconscious bias and long-standing inequalities in access to health care.

Long Term Survival Considerations

The CSC exceeds OCR’s recommended measure of survivability to discharge in several ways. First, it prioritizes all care based on Life Years Saved, which allocates scarce resources (e.g. ventilators) based on predicted survival of 1-5 years. Projections of intermediate and long-term survivability have been shown to be unreliable even under normal standards of care. In the triage context, they are even less accurate and more likely to rely on discriminatory assumptions or bias against older adults, those with disabilities, and under-represented minorities. Second, the CSC introduces different and potentially conflicting standards for prognosis and life expectancy based on the type of health care being provided, a distinction which may be more conceptual than concrete given how denials of routine care can lead to greater acuity and patient risk. For instance, the CSC includes a statement on page 6 that Triage decisions should focus on short and near-term outcomes (<1 year). Yet, the criteria for survival related services appear inconsistent within the document. Life Years Saved applies to ventilators and has a predicted survival of 1-5 years on page 10, but on page 15 ventilators require looking at a 30 day to 1 year survival. Finally, the CSC relies on the Modified Charlson Comorbidity Index to help predict survivability – a tool that is facially biased given its use of categorical age classifications and inclusion of diagnosis-based criteria that count against people with underlying disabilities.⁸

After OCR provided technical assistance on this same issue, Arizona revised its CSC to include a “Prohibition on the use of a patient’s long-term life expectancy as a factor in the allocation and re-allocation of scarce medical resources.” OCR’s Tennessee resolution included greater context around the limitations of considering long term survival. Tennessee’s revised CSC 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. In Texas the two regional CSCs approved by

⁸ This tool specifically penalizes older adults with disabilities such as Dementia, adding points if the person needs any assistance with IADLs or ADLs. Persons with dementia under this tool include anyone with chronic cognitive deficit requiring assistance with instrumental activities of daily living or activities of daily living. The Charlson tool, and by application the Colorado CSC, devalues people for care if they meet this low bar.

OCR relied primarily on likelihood of survival to hospital discharge and “near-term survival” from the hospitalizing illness or injury.⁹

This CSC’s initial acknowledgment of the limited reliability of long-term prognosis and its likely harm to protected classes should consistently guide survival considerations throughout the document, resulting in revisions that tie all triage decisions to a consistent standard based on individual, objective medical evidence and the likelihood of survival to discharge.¹⁰

Assessment Tools

The Colorado CSC relies on problematic assessment tools in the allocation of scarce resources. The Modified Charlson Comorbidity Index will add points based on age and Dementia diagnosis, and thereby reduce access of older adults to needed care. Similarly, recent studies regarding the Sequential Organ Functional Assessment (SOFA) have found that it under estimates the likelihood of survival of Black patients.¹¹ This finding, combined with long term concerns about the SOFAs inclusion of chronic stable conditions in persons with disabilities, raise serious questions regarding state reliance on this tool. To date, we are unaware of an alternative short term assessment tool to recommend in the alternative. Some health systems have committed to applying clinical judgment with an eye toward the limitations of the tool before relying on it for the allocation of a scarce resource. Similarly, the California CSC specifically noted the limitations of the SOFA tool: “If an objective, validated COVID specific scoring system which predicts survival becomes available, this may be used in place of the SOFA or mSOFA score, provided that the system does not use as a factor age, disability, or other characteristics listed in Key Points.”¹²

⁹ <https://www.hhs.gov/about/news/2021/01/14/ocr-provides-technical-assistance-ensure-crisis-standards-of-care-protect-against-age-disability-discrimination.html>; <https://www.dallas-cms.org/tmainis/dcms/assets/files/communityhealth/MCC/NTMCCGuidelines011121.pdf>; https://www.strac.org/files/Incident%20Specific/2019nCoV/STRAC_Crisis_Guidelines_v1.5_Jan_2021_OCR_Seal.pdf

¹⁰ The New Hampshire CSC may provide useful language on this. It specifically limits the term of survival to be considered with a clear articulation of the equity concerns at stake.

The assessment of near-term survival should 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. Assessment of survival and assignment of a priority score should not include subjective assessments such as quality-of-life or intrinsic worth. New Hampshire CSC, May 27, 2020, p. 4.

¹¹ Tolchin B, *et al.* (2021) Racial disparities in the SOFA score among patients hospitalized with COVID-19. *PLoS ONE* 16(9): e0257608. <https://doi.org/10.1371/journal.pone.0257608>; Roy S, *et al.* (2021) The potential impact of triage protocols on racial disparities in clinical outcomes among COVID-positive patients in a large healthcare system. *PLoS ONE* 16(9): e0256763. <https://doi.org/10.1371/journal.pone.0256763>

¹² Key Points: Healthcare decisions, including allocation of scarce resources, cannot be based on age, race, disability (including weight-related disabilities and chronic medical conditions), gender, sexual orientation, gender identity, ethnicity (including national origin and language spoken), ability to pay, weight/size, socioeconomic status, insurance status, perceived self-worth, perceived quality of life, immigration status, incarceration status, homelessness, or past or future use of resources.

OCR has addressed limitations in assessment tools in several states. In Arizona, OCR required the “inclusion of reasonable modifications to the use of clinical instruments for assessing likelihood of short-term survival when necessary for accurate use with patients with underlying disabilities.” Similarly, the OCR resolution of the Utah complaint included language stating that reasonable modifications to the use of the state's primary instrument for assessing likelihood of short-term survival should be made when necessary for accurate use with patients with underlying disabilities. Such reasonable modifications ensure that people with disabilities are evaluated based on their actual mortality risk, not disability-related characteristics. Each of these resolutions were issued before the recent studies relating to the inaccuracy of the SOFA in assessing survival of Black patients, so OCR has not weighed in on that information to date.

Do Not Resuscitate Orders

OCR has required that states include specific instructions that patients and families not be steered toward or pressured to accept a DNR order as a condition of accessing care. In Arizona, the OCR has required the “inclusion of new protections against providers "steering" patients into agreeing to the withdrawal or withhold life-sustaining treatment, clarifying that patients may not be subject to pressure to make particular advanced care planning decisions. Nor can providers require patients to consent to a particular advanced care planning decision in order to continue to receive services from a facility. Studies have shown that some older adults have internalized societal ageism and will forgo care as a result of such pressure.¹³ We encourage Colorado to include these explicit protections in the CSC.

In addition, Colorado’s DNR language regarding an obligatory DNR and the withholding of treatment (such as CPR) other than the resource that is in limited supply (such as dialysis), where the patient did not meet CSC criteria for that treatment, do not seem to logically flow from the limitation on resources and may result in the denial of services that are not scarce (see p. 21). We would appreciate more clarity around the thinking underlying this provision.

Intensity and Duration

The CSC considers intensity and duration of treatment in several areas. In the context of mechanical ventilation, “if a patient is progressively worsening despite maximal ventilator support, consideration for re-allocation can be made earlier based on the CSC Triage Team’s assessment.” CO CSC p 19. Because CO’s Triage Scoring uses the Charleson tool, which adds points for age, this factor’s reliance on CSC Triage Score is biased against older adults in violation of OCR resolution and the Age Act. The OCR resolution in Arizona prohibited the use of resource-intensity and duration of need as criteria for the allocation or re-allocation of scarce medical resources.

Colorado’s provisions regarding mechanical ventilation also fail to prohibit the removal of a personal vent and reallocation to another patient. OCR has required an affirmative statement

¹³ Six Propositions against Ageism in the COVID-19 Pandemic , JOURNAL OF AGING & SOCIAL POLICY 2020, VOL. 32, NOS. 4–5, 515–525, <https://doi.org/10.1080/08959420.2020.1770032>

regarding reallocation: “Inclusion of language ensuring that long-term ventilator users will be protected from having a ventilator they bring with them into a hospital setting taken from them to be given to someone else.”¹⁴

Other areas of concern

Blinded Decision Making

“When making triage decisions, the triage team should ideally be blinded to factors such as race, ethnicity, primary language, religion, insurance status, ability to pay, housing status, VIP status, etc. if appropriate. When deciding which patient should receive a ventilator or be admitted to a critical care bed, demographic and socioeconomic factors should not affect triage decision-making.” Colorado Crisis Standard of Care, page 6.

This provision of the CSC suggests that the review be “blind” rather than identifying and addressing known inequities. We recommend that Colorado not eliminate social factors from the information in a file under review. The failure to access information relating to race will not, for example, negate the lifelong impact of racial inequities on that person’s access to care or the related impact on their health.¹⁵

Legal Protections

The CSC details liability protections for healthcare providers but fails to inform providers of the civil rights protections for patients. OCR has made clear that federal civil rights protections apply during the public health emergency.¹⁶ We recommend that the CSC expressly include a statement of the federal civil rights protections enjoyed by patients during the pandemic or other public health emergency.

Conclusion

For the reasons discussed above, we caution against the reliance on age as a proxy for likelihood of survival given the significant ageism prevalent in society and the weighing of the impact age has on the body in individualized assessments. Generalized data relating to protected characteristics -- disability, race, gender and age -- should not decide who receives limited lifesaving care. There are applicable federal standards, and other State CSC models, that can be

¹⁴ See <https://www.hhs.gov/about/news/2021/01/14/ocr-provides-technical-assistance-ensure-crisis-standards-of-care-protect-against-age-disability-discrimination.html>; <https://public3.pagefreezer.com/content/HHS.gov/31-12-2020T08:51/https://www.hhs.gov/about/news/2020/08/20/ocr-resolves-complaint-with-utah-after-revised-crisis-standards-of-care-to-protect-against-age-disability-discrimination.html>

¹⁵ see *Policy Solutions for Reversing the Color-blind Public Health Response to COVID-19 in the US*, Marisa K. Dowling, MD, MPP, JAMA July 21, 2020 Volume 324, Number 3; see also Preliminary Framework for Equitable Allocation of COVID 19 Vaccine, the National Academies of Science, Engineering, and Medicine, page 39, (demographic info appropriate to ensure equity).

¹⁶ HHS Office for Civil Rights in Action, Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 ra

used to remedy these issues, and to ensure that Colorado residents are not inadvertently subjected to discriminatory health care rationing – now or in the future.

We appreciate the opportunity to raise these issues with you and to look forward to meeting with you to discuss them more fully. We are hopeful that we can work together to come up with language that assists healthcare providers manage an untenable situation while ensuring that the civil rights of older adults, persons with disabilities and people of color are protected.

Sincerely,

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