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FACT SHEET

Combatting Discriminatory Crisis Standards of Care

SEPTEMBER 2020

Crisis Standards of Care (CSC) are policies used to help providers ration medical care should medical resources like beds, ventilators, and medication, become scarce. Several states and hospital systems have developed crisis standards long before the COVID-19 pandemic. However, due to a surge in COVID-19 cases across the country, and reports of hospitals being overwhelmed and under-resourced, several crisis standards have been updated to respond to the COVID-19 crisis.

Older adults and People with Disabilities (PWD) often worry their lives will not be considered worth saving due to implicit and explicit prejudice about their perceived "worth" or quality of life. Older adults of color and PWD of color also have the added fear from systemic racism leading to massive health disparities. The Department of Health and Human Services determined: "treatment decisions, including denials of care under crisis standards must be made after nondiscriminatory consideration of each person, free from stereotypes and biases based on disability or age – including generalization 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." Unfortunately, crisis standards often include discriminatory provisions, making it more difficult for older adults, people with disabilities, and communities of color to access life-saving treatment, in violation of the American with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), Age Discrimination Act of 1975 (the Age Act), and Title VI of the Civil Rights Act of 1964 (Title VI).

Common Discriminatory Provisions

Failure to provide modifications to short-term survival assessments

Several policies use Sequential Organ Failure Assessment (SOFA) scores to assess a patient's prognosis and risk of immediate mortality. SOFA scores use a series of tests to measure physical, neurological, cognitive, and verbal functioning. This can disproportionately harm PWD with functional limitations and may result in an unfavorable SOFA score due solely to their underlying condition and not their actual prognosis. Modified SOFA (MSOFA) scores measure a patient's baseline functioning, and then conduct subsequent assessments assigning scores based on the patient's baseline. This ensures the MSOFA is not applying a patient's unrelated disability as declining health.

Long-term survivability

Several crisis standards consider a patient's long-term survivability, instead of survival to hospital discharge. These provisions often prioritize "saving life years" over saving lives generally. Long-term survivability always harms older adults and people with disabilities, is much more difficult to accurately assess compared with immediate survivability, and disproportionality harms communities of color. People of color suffer higher rates of comorbidities that reduce life expectancy. These disparities exist due to socioeconomic barriers and systemic racism, including in access to healthcare, nutrition, housing, and economic security. Preventing communities of color from accessing life-saving treatment due to the existence of comorbid conditions that occur due to health disparities unjustly exacerbates those health inequities. To prevent unjust considerations of comorbidities, medical rationing decisions should only determine if the patient's likelihood of surviving the immediate illness or injury based on an individualized clinical assessment.

Exclusionary criteria

Categorical exclusions explicitly prevent people with certain conditions from receiving medical resources if demand exceeds supply. This disproportionately harms older adults and people with disabilities since it excludes life-saving treatment solely based on a diagnosis with no individualized assessment. For example, "people with severe dementia," "advanced untreatable neuromuscular disease," or "requiring assistance with activities of daily living" may be excluded from receiving treatment. Some standards also include age-based categorical exclusions, such that a patient belonging to a certain age category (e.g. 65-79 or 80+) may be denied care just because they belong in a particular age category. The Department of Health and Human Services Office for Civil Rights (OCR) issued resolutions removing categorical exclusions from crisis standards.

Age-based tiebreakers

In the event two or more patients have similar clinical assessments (e.g. MSOFA scores), crisis standards may include provisions to "break the tie." Tiebreakers should be determined fairly, like using a lottery or other random allocation, to avoid discrimination based on age, disability, race, or any other impermissible factor. As with categorical exclusions, age-based tiebreakers are based on generalized assumptions, not individualized, clinical assessments. However, OCR has not definitively issued a statement against using age as a tiebreaker at this time.

Resource intensity, resource allocation, and Do Not Resuscitate (DNR) orders

Crisis standards may try to preserve resources by deprioritizing patients perceived as requiring high-intensity resources. These generalized assumptions about resource intensity harm older adults and people with disabilities who may require greater resources. The implication that people using high intensity resources are less deserving of treatment violates reasonable accommodation mandates under Section 504 and the ADA. Similarly, in the event of resource scarcity, providers cannot "steer" or encourage patients into DNRs or require patients to sign DNRs prior to receiving services. Crisis standards should also ensure that patients entering facilities with their own equipment (e.g. ventilators) will not have their personal equipment re-allocated to other patients.

Failure to provide disability accommodations

Hospitals and other acute care facilities have issued strict no-visitation policies to prevent the spread of COVID-19. However, crisis standards should include provisions to accommodate patients with disabilities, including modifications to visitation policies to allow support persons. Support persons differ from social visitors—they provide the patient with personal care, assist with activities of daily living, or help the patient communicate with medical providers. Support persons are critical to a patient's care team and must be allowed into the facility to provide care.

What Should Be Included in Crisis Standards

1. Antidiscrimination provision prohibiting decisions based on race, ethnicity (including national origin and language spoken), age, disability status (including weight-related disabilities and chronic medical conditions), gender and gender identity, sexual orientation, ability to pay, weight/size, homelessness, and perceived self-worth or quality of life.
2. Training for providers on crisis standards, including antidiscrimination training and implicit bias.
3. Reasonable accommodations for disabilities, including modifications to visitation policies.
4. Opportunities to appeal triage decisions.
5. Availability of crisis standards, with accommodations for individuals with Limited English Proficiency or visual and auditory limitations.
6. Guaranteed use of personal equipment (e.g. ventilator) without reallocation.
7. Random allocation (e.g. lottery) for tiebreakers, if tiebreakers are used.
8. Determination of immediate survivability based on individualized clinical assessments using best available medical evidence.

Additional Resources

- Summary of California's Revised Crisis Care Guidelines
- HHS Office for Civil Rights Bulletins
- Justice in Aging Care Rationing
- Center for Public Representation Medical Rationing