



Center for Public Representation

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## **EVALUATION FRAMEWORK FOR CRISIS STANDARD OF CARE PLANS**

Many states and hospitals are issuing Crisis Standard of Care plans to inform health care providers how to make decisions on the allocation and re-allocation of medical resources in the event that scarcity requires rationing of care. These plans should be carefully scrutinized to ensure that people with disabilities, including disabled people of color, are not subject to discrimination.

This evaluation framework builds on a prior [guidance document](#) from disability and healthcare organizations discussing the application of a March 28, 2020 Bulletin from the Department of Health and Human Services' Office of Civil Rights stating that civil rights laws "remain in effect" during the pandemic.<sup>i</sup> Asking the following questions will help advocates and policymakers ensure that Crisis Standard of Care plans and other documents providing criteria for the allocation or re-allocation of scarce medical resources comply with federal disability and other civil rights laws and do not discriminate on the basis of disability.

### **1) Does the plan exclude patients from care on the basis of diagnosis or functional impairment?**

- a) Many plans exclude certain people from accessing critical care resources, such as ventilators, based on disability diagnoses or functional impairments (*e.g.*, the need for support in activities of daily living or chronic use of a ventilator).<sup>ii</sup> These exclusions are impermissible disability discrimination because they are not based on an individualized assessment that the person is unlikely to benefit from or survive treatment.<sup>iii</sup>
- b) Some plans identify certain conditions as excluding patients from receiving scarce care based on the following rationales, each of which poses disability discrimination concerns:
  - i) **Those with these conditions are too ill to likely survive the acute illness:** this may be acceptable in the context of an individualized assessment of a particular patient, but the use of a categorical exclusion denies a patient the individualized assessment required under the law. It is

well accepted that the ability to survive in the short term, with treatment for an acute illness, is a valid qualification for providing such treatment. However, the use of a categorical exclusion based on a diagnosis rather than on an individualized assessment of a particular patient may wrongly exclude patients with the diagnosis who are likely to survive.

- ii) **Those with these conditions have a one-year mortality probability so high that it is not reasonable to allocate critical care resources to them in a crisis situation:** This raises concerns, because studies show that one-year mortality predictions are often inaccurate. Moreover, medical advances can render obsolete the categorical exclusion of patients with a particular diagnosis, but the exclusion may remain in the plan due to institutional inertia.
- iii) **Those with these conditions require such a large amount of resources that it is not feasible to accommodate their hospitalization in a prolonged mass-casualty situation:** Treatment allocation decisions may not be made based on the perception that a person's disability will require the use of greater treatment resources, either in the short or long term. The law requires that reasonable modifications must be made where they are needed in order for a person with a disability to have equal opportunity to benefit from the treatment.<sup>iv</sup>

- c) Plans should include explicit statements that: a) prohibit exclusion or de-prioritization on the basis of presumed resource intensity; b) prohibit consideration of disability independent of its impact on short-term or hospital survivability; and c) reaffirm that all individuals are qualified for, and eligible to receive, lifesaving care, regardless of diagnosis, functional impairment or need for supports in activities of daily living.<sup>v</sup>

## 2) Does the plan include implicit or explicit quality of life assessments in allocating care?

- a) Assessments of the quality of life of patients with particular disabilities are discriminatory and should never be used to deny treatment.<sup>vi</sup>
- b) Many plans reference quality of life indirectly by stating that providers should consider the existence of underlying disabilities that play no role in survival probability, or the likelihood of individuals acquiring disabilities following treatment. Plans that weigh negatively certain pre-existing medical conditions or "comorbidities" that do not reduce the likelihood of a patient's short-term survival may introduce concerning value judgments. Such value judgments systemically disadvantage people with disabilities and chronic health conditions and reduce the likelihood that they will receive medically indicated care.<sup>vii</sup>

**3) Does the plan weigh intermediate or long-term survival beyond the acute care episode in allocating care?**

- a) Individuals who can recover with treatment are “qualified” to receive lifesaving care under federal disability discrimination laws. Plans that exclude or give lower priority to people based on a perception that their disabilities mean they will not survive in the intermediate or long-term discriminate based on disability.<sup>viii</sup> This is true whether assessed explicitly in the form of weighing predicted long-term survival (*e.g.* considering predicted five- or ten-year survival) or implicitly through prioritizing the number of “life-years” saved rather than the number of “lives” saved.
- b) Long-term survival projections are significantly less certain than the assessment of short-term survival. Thus, attempts to predict long-term or intermediate prognosis in the context of triage decision-making can lead to erroneous, inconsistent, and subjective decision-making. Moreover, medical innovations such as new pharmaceuticals, surgical techniques and other interventions can shift the long-term prognosis for many conditions. Many disabled individuals live years and even decades longer than predicted by medical professionals. With limited access to medical information and expert consultation, it may be impossible to accurately assess life expectancy. Predicting prognosis under these circumstances increases the likelihood that clinicians will rely on stereotypical assumptions or unconscious bias, resulting in discrimination against people with disabilities, older persons, and individuals from communities of color who are more likely to have underlying medical conditions.
- c) If a plan weighs any predictions of survival beyond the acute episode, triage clinicians should be directed to make conservative judgments, to not assume the mere existence of an underlying medical condition negatively impacts survival past the acute episode, and to not assign negative points when a patient’s prognosis is uncertain.<sup>ix</sup>

**4) Where the plan weighs short-term survival probabilities, does it require an individualized assessment based on available objective evidence?**

- a) Many plans weigh the likelihood of short-term survival in allocating scarce medical resources. While some consideration of short-term survival probability is permissible, it must be based on an individualized assessment of the patient’s particular circumstances rather than a generalized conclusion on the basis of a diagnosis.
- b) When two patients cannot be distinguished relative to short term outcome after individualized assessments are made, a non-discriminatory tiebreaker may need to be used in order to determine which patient receives the limited resource.<sup>x</sup>

**5) Are reasonable modifications made to the SOFA or other triage tool to avoid discriminatory outcomes?**

- a) Many plans rely on the use of the Sequential Organ Failure Assessment (SOFA), a measure designed to predict short-term mortality, to assess relative survival probabilities. The SOFA produces a numerical score that may be used to prioritize patients for lifesaving care. The SOFA may disadvantage specific disability categories, such as chronic ventilator users, that start at a higher SOFA score as their “baseline” condition.
- b) Individuals with other disabilities may also find their SOFA score inflated by measures that capture chronic but stable underlying conditions.<sup>xi</sup> For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity, adds points to the SOFA score when a patient cannot articulate intelligible words, even if this condition is due to a pre-existing speech disability or chronic ventilation. Patients with pre-existing motor impairments are also disadvantaged by this tool since SOFA measures a patient’s ability move in response to verbal commands.<sup>xii</sup>
- c) Plans which rely on the SOFA must provide reasonable modifications to avoid denying lifesaving care to people with disabilities, older adults and individuals from communities of color, based on levels of impairment occurring prior to the acute care episode. Modifications may include an explicit directive that baseline co-morbidities should not increase a patient’s SOFA scores unless objective medical evidence demonstrates the conditions directly impact an individual’s short-term survivability with treatment. Alternatively, if the SOFA score is used to place individuals in different priority categories, the scoring thresholds for each category could be increased for a particular patient in order to hold the patient harmless for underlying impairments that do not impact short-term survivability.<sup>xiii</sup>

**6) Does the plan permit allocation or re-allocation on the basis of anticipated or documented duration of need?**

- a) Treatment allocation decisions may not be made based on the perception that a person’s disability will require more or longer treatment in the short or long term.<sup>xiv</sup> More or longer treatment may in many instances be mandated as a reasonable modification under Section 504 and the ADA. For example, where an underlying disability means that additional time is necessary for recovery, allowing longer use of the ventilator may be a reasonable modification.<sup>xv</sup>
- b) In the context of re-allocation decisions, reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment. These may include interpreter services or other modifications or additional services needed due to a disability.

- c) Hospitals must provide information on the full scope of available treatment alternatives, including the continued provision of life-sustaining treatment, and may not impose blanket Do Not Resuscitate policies for reasons of resource constraint. Physicians may not require patients to consent to a particular advanced care planning decision in order to continue to receive services from the hospital.<sup>xvi</sup>
- d) Many plans permit prioritization on the basis of anticipated or documented duration of need, either in the initial decision to allocate a scarce medical resource or in a subsequent decision to re-allocate the resource in the event that a patient makes use of it for a greater than typical time period.<sup>xvii</sup>

**7) Does the plan protect the rights of chronic ventilator users?**

- a) Several plans limit the ability of chronic ventilator users to bring their personal ventilators with them into the hospital or other acute care setting, raising the concern that their personal ventilators may be subject to re-allocation should they need to seek acute care.<sup>xviii</sup>
- b) Doctors and triage teams must not reallocate ventilators of individuals with disabilities who use ventilators in their daily lives and come to the hospital with their personal equipment. Plans should affirmatively state that personal medical equipment, like ventilators, will not be taken or redeployed when a patient presents for hospital level of care.<sup>xix</sup>

**8) Does the plan include reasonable modifications to visitor policies when necessary to accommodate an individuals' disability?**

- a) Patients with disabilities may require reasonable modifications to have equal access to hospital care. Such modifications include interpreters, specialized assistive technology, and in-person support from family members or other caregivers. In many instances, disabled patients require the presence of their usual support person in order to effectively communicate about their care. If a patient with a disability requires the presence of a family member, personal care assistant, or similar disability service provider to physically or emotionally assist them during their hospitalization with communication or with the management of their care, this should be permitted as a reasonable modification. Hospitals can require such support people to follow COVID-19 protocols to contain the spread of infection.<sup>xx</sup>
- b) The U.S. Department of Health and Human Services, Office for Civil Rights has resolved complaints regarding strict no-visitor hospital policies, requiring hospitals and the state agencies overseeing them to provide reasonable modifications to no-visitor policies when necessary to allow equal access to medical treatment for people with disabilities.<sup>xxi</sup>

- c) The American Academy of Developmental Medicine and Dentistry (AADMD) recommends that hospitals “provide reasonable accommodations in their visitor policies for persons who need support from known and acknowledged support persons (family, community agency personnel, or other designated caregivers).” Importantly, AADMD notes that without accommodations to “no visitor” policies, physicians may be deprived of critical health care information in the triage process, and patients can experience “deleterious and sub-optimal clinical outcomes because vital bio-psycho-social information is not available to medical staff.”<sup>xxii</sup>

**9) Does the plan explicitly prohibit discrimination against people of color and other marginalized groups?**

- a) HHS has made it clear that Title VI of the Civil Rights Act also continues to apply during the pandemic, prohibiting recipients of federal financial assistance—including states and hospitals—from discriminating on the basis of race, color, and national origin. HHS has advised state and local agencies and hospitals to comply with Title VI by, among other things, adopting policies to prevent discrimination, ensuring that “existing policies and procedures with respect to COVID-19 related services (including testing) do not exclude or otherwise deny persons on the basis of race, color, or national origin,” and ensuring that “individuals from racial and ethnic minority groups are not subjected to excessive wait times, rejected for hospital admissions, or denied access to intensive care units compared to similarly situated non-minority individuals.”<sup>xxiii</sup>
- b) Many of the complaints that have been filed with OCR regarding disability discrimination in medical care also raise race and other discrimination claims.<sup>xxiv</sup> Crisis standard of care plans should take an intersectional approach and broadly prohibit public entities from discriminating and denying lifesaving medical treatment to individuals on the basis of race and other protected classes.<sup>xxv</sup> A plan should go beyond a general non-discrimination statement to identify specific areas where discrimination may occur and must be prevented.<sup>xxvi</sup>

**10) Does the plan include an appeals process for patients subject to denial or reallocation of life saving resources?**

- a) Patients, families, or clinicians may disagree with and challenge individual triage decisions (though it should be noted that providing effective communication and reasonable modifications earlier in the process will often help avoid this outcome). Procedural fairness requires the availability of an accessible, prompt, and transparent appeals mechanism to resolve such disputes. Special consideration should be made to ensure that this is done in a culturally competent manner, with racially, ethnically, culturally and linguistically diverse team members available to assist in these communications if possible, and specialized assistive technology or other reasonable accommodations available for patients and families who require it.<sup>xxvii</sup>

- b) All triage decisions should be documented in the medical record. The appeals process should be conducted and documented in sufficient detail to demonstrate that the outcome reflects a well-considered decision. All documentation related to triage decisions and appeals made during a period of crisis activation including, demographic information, medical records (electronic or paper), logs, appeals records and decision tools should be publicly reported in real time to allow for effective monitoring by responsible State entities.<sup>xxviii</sup>
- c) All individuals involved in triage decisions, oversight, and appeals must receive training on crisis standards and how to apply them, including training that addresses non-discrimination laws and awareness of implicit bias.<sup>xxix</sup>

**11) Is the plan mandatory, or does it offer discretionary guidance to hospitals?**

- a) Governors may use powers granted under their State Constitutions or applicable disaster/public health emergency authorities to issue one set of mandatory crisis standards to be observed statewide.<sup>xxx</sup>
- b) Without a binding, statewide crisis plan, the exercise of medical discretion across hospital systems will be largely unchecked, unguided, and subject to wide variation. The unavoidable result is highly subjective decision-making, undermining public trust and placing even greater responsibility and stress on treating professionals.

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<sup>i</sup> See U.S. Department of Health & Human Services, [BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 \(COVID-19\)](#), March 28, 2020; U.S. Department of Health & Human Services, [BULLETIN: Civil](#)

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[Rights Protections Prohibiting Race, Color and National Origin Discrimination During COVID-19](#), July 20, 2020; COVID-19 Healthcare Resilience Working Group, [COVID-19: Considerations, Strategies, and Resources for Crisis Standards of Care in PALTC Facilities](#), p. 7 (“Civil rights laws and regulations are not suspended or waived in the disaster context and continue to apply during the COVID-19 public health emergency.”)

<sup>ii</sup> For example:

- Tennessee initially excluded from hospital admission those with “advanced untreatable neuromuscular disease (such as ALS, end-stage MS, spinal muscular atrophy) requiring assistance with activities of daily living or requiring chronic ventilatory support.” See [March 27, 2020 OCR Complaint](#). In response to the complaint and OCR engagement, Tennessee removed these categorical exclusions. See [June 26, 2020 OCR Resolution](#); Tennessee Altered Standards of Care Workgroup, “[Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee](#),” July 2016 (updated June 2020).
- Utah previously excluded from hospital admission individuals with “known severe dementia medically treated and requiring assistance with activities of daily living.” Following a [complaint](#) and [resolution](#) with OCR, Utah revised its [Utah Crisis Standard of Care Guidelines](#), August 13, 2020 and removed all categorical exclusions.
- In an [April 8, 2020 announcement](#) of the results of a compliance review in Alabama, OCR raised concerns that the state’s use of categorical exclusion criteria may violate federal law. To resolve the compliance review, Alabama agreed “that it will not, in future CSC guidelines, include similar provisions singling out certain disabilities for unfavorable treatment or use categorical age cutoffs; and that it will also not interpret the current Guidelines in such a manner.”
- The University of Pittsburgh Medical Center’s model guidelines specify that “an allocation system should make clear that all individuals are ‘worth saving’ by keeping all patients who would receive critical care during routine circumstances eligible.” Furthermore, they note that “the use of rigid categorical exclusions would be a major departure from traditional medical ethics and raise fundamental questions of fairness.” See University of Pittsburgh School of Medicine, Department of Critical Care Medicine, “[Allocation of Scarce Critical Care Resources During a Public Health Emergency](#),” March 26, 2020, 7.

<sup>iii</sup> See [COVID-19: Considerations, Strategies, and Resources for Crisis Standards of Care in PALTC Facilities](#), *supra* n. i (“Prioritization of care, including denials of care, must be made after nondiscriminatory consideration of each situation based on the best available objective medical evidence, free from stereotypes and biases based on a person’s race, gender, disability or age—including generalizations and judgments about their quality of life or relative value to society.”); FEMA also has made clear that “medical treatment decisions, including denials of care under Crisis Standards of Care and allocation of ventilators, after an individualized consideration of each person,” must be “free from stereotypes and biases, including generalizations and judgments about the individual’s quality of life or relative value to society, based on the individual’s disability, age, race, income level, or any protected basis. This individualized consideration should be based on current objective medical evidence and the expressed views of the patients themselves as opposed to unfounded assumptions. FEMA Civil Rights Bulletin, [Ensuring Civil Rights During the COVID-19 Response](#).

<sup>iv</sup> Kentucky’s Crisis Standards states that “Given the charge to do the best for the most, saving as many lives as possible with a marked scarcity of resources, there may be situations where maximally aggressive care will not be able to be provided to every individual.” Among those excluded from hospital and ICU care are individuals who require “larger than normal” amounts of resources which make it “not feasible to accommodate their hospitalization in a prolonged mass casualty situation.” This criteria presents a very high risk of discrimination since it deprives a patient from consideration for life saving care, would most likely be implemented without an individualized assessment, and therefore based on assumptions about intensity of need or and the amount of resources a person with a disability may require in order to recover from the acute episode. “[Crisis Standards of Care: Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency](#),” March 31, 2020, 36.



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<sup>v</sup> For example:

- The revised Tennessee plan states: “categorical exclusions should be avoided. In addition, resource intensity and duration of need on the basis of age or disability should not be used as criteria.” *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee, supra* n. ii, at 8.
- The California plan states: “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. ... More time, skill, and resources may be required to care for people with disabilities, unless doing so poses a direct threat or undue burden. Reasonable accommodations may include interpreter services or other modifications or additional services needed due to a disability. ... Decisions cannot be based on generalized assumptions about a person’s disability. The mere fact that a person has diabetes, depression, an intellectual disability, or a mobility impairment, for example, cannot be a basis for denying care or making that person a lower priority to receive treatment. Treatment allocation decisions cannot be made based on misguided assumptions that people with disabilities experience a lower quality of life or that their lives are not worth living. ... A central feature of this allocation framework is that it does not use categorical exclusion criteria to bar individuals from access to critical care services during a public health emergency.... Patients who do not have a severely limited near-term prognosis for survival are given priority over those who are likely to die in the near-term, even if they survive the acute critical illness. Age, disability, or any other characteristics from the Key Points do NOT define individuals likely to die in the near-term. Co-morbid medical conditions occur in a spectrum of severity, and should only be used in allocation decisions based on the clinical decision that they will impact near-term survival.” [California SARS-CoV-2 Pandemic Crisis Care Guidelines: Concept of Operations Health Care Facility Surge Operations and Crisis Care](#) (June 2020), 5, 13, 16, 26, 27.
- The revised Utah plan, *supra* n. ii, states “Prior categorical exclusion criteria and allocation of resources based on individual patients’ long-term survival probability and resource-intensity/duration of need in these previous plans no longer apply and should be removed from existing provider CSC plans.”

<sup>vi</sup> For example:

- Oregon’s Crisis Care Guidance document provides a positive example representing a potential promising practice. This document specifies that “[I]n a public health crisis, decisions about who should receive critical care and other medical services should be based on clinical experience using objective clinical information, just as they are in non-crisis situations. Care decisions should not be based on non-clinical factors such as race, ethnicity, clinician-perceived quality of life [emphasis added], profession, social position, or ability to pay.” Oregon Health Authority, [Oregon Crisis Care Guidance](#), June 2018.
- New Hampshire crisis standards contain similar prohibitions against consideration of perceived quality of life, predictions of life expectancy, or perceived social utility. The plan’s ethical framework expressly states that rationing should not be based on “judgments that people have greater quality of life than others; predictions about baseline life expectancy (i.e., life expectancy if the patient were not facing the pervasive or catastrophic public health even related crisis), unless the patient is imminently and irreversibly dying, because rationing based on such baseline predictions would exacerbate health disparities; judgments that some people have greater “social value” than others.” [“New Hampshire Crisis Standards of Care Plan,”](#) April 17, 2020, 36.
- California’s guidelines contain similar prohibitions. *See California SARS-CoV-2 Pandemic Crisis Care Guidelines, supra* n. v, at 16-17 (plans should be designed to “ensure that no one is denied care based on stereotypes, assessments of quality of life, or judgments about a person’s ‘worth’ based on the presence or absence of disabilities or other factors...“Treatment allocation decisions cannot be made based on misguided assumptions that people with disabilities experience a lower quality of life or that their lives are not worth living.”)

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vii For example:

- In a document [since withdrawn](#), Alabama had indicated that individuals with severe or profound intellectual disability “are unlikely candidates for ventilator support.” See Alabama Disabilities Advocacy Program, “[Complaint of Alabama Disabilities Advocacy Program and The Arc of the United States](#),” letter to Roger Severino, March 24, 2020. Given that there is no evidence that intellectual disability plays any role in survival probability, this should be taken as an instance of an implicit quality of life judgment.
- Washington State’s use of “baseline functional status” (including energy, physical ability, cognition and general health) is so broad as to suggest that an implicit quality of life judgment is being made. See Washington State Department of Health, [Scarce Resource Management & Crisis Standards of Care: Overview & Materials](#), at 34-35.

viii For example:

- The University of Washington Medical Center’s Material Resource Allocation Principles and Guidelines for the COVID-19 Outbreak indicates that what should be prioritized is “healthy, long-term survival, recognizing that this represents weighting the survival of young otherwise healthy patients more heavily than that of older, chronically debilitated patients.” See University of Washington Medical Center, “[Material Resource Allocation Principles and Guidelines: COVID-19 Outbreak](#),” 2020, 1.
- Oregon permits the consideration of long-term prognosis “when multiple people have the same potential for benefit.” While we would prefer this factor be removed from consideration, their plan does specify that this is meant to serve as a tiebreaker rather than being factor into an overall score used for triage. They note that estimated long-term survival probability “should be secondary to the initial assessment of the benefit of resource use and its ability to increase the presenting patient’s baseline probability of surviving her/his acute illness or injury.” Only conditions with an estimated maximum survival of 6-12 months are considered absolute exclusion criteria in this plan. See *Oregon Crisis Care Guidance*, *supra* n. vi, at 44-45.
- While many plans restrict prioritization based on remaining life-years to a span of 1-2 years after the acute illness, the University of Pittsburgh Medical Center’s model guidelines add an intermediate prioritization level that penalizes even people with a longer expected survival. See *Allocation of Scarce Critical Care Resources During a Public Health Emergency*, *supra* n. ii, at 6. The list of examples of “major comorbid conditions with substantial impact on long-term survival” includes “malignancy with an expected < 10 year survival” and “moderately severe chronic lung disease.”
- Pennsylvania’s original Crisis Standards took into account a patient’s “prognosis for long-term survival,” assessing a patient’s comorbid conditions with the goal to “save the most life-years.” Following [advocacy by Disability Rights Pennsylvania](#) and others, [an OCR resolution](#) limited those criteria to conditions likely to cause death within 5 years. DRP’s April 16, 2020 [press release](#) describes remaining concerns with the revised plan. See [Interim Pennsylvania Crisis Standards of Care](#), April 10, 2020.
- Tennessee revised its guidelines to remove a one-year consideration and only allow for survivability consideration of no longer than “imminence of mortality.” *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee*, *supra* n. ii, at 1, 8.
- New York State’s ventilator guidelines offers a positive example representing a promising practice, indicating that their “definition of survival is based on the short-term likelihood of survival of the acute medical episode and is not focused on whether a patient may survive a given illness or disease in the long-term (e.g., years after the pandemic). By adopting this approach, every patient is held to a consistent standard. Triage decision-makers should not be influenced by subjective determinations of long-term survival, which may include biased personal values or quality of life opinions.” See New York State Department of Health, “[Ventilator Allocation Guidelines](#),” by the New York Taskforce on Life and the Law, November 2015, 34.
- California’s guidelines also explicitly commit to “the central goal of saving as many lives as possible.” *California SARS-CoV-2 Pandemic Crisis Care Guidelines*, *supra* n. v, at 20.

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<sup>ix</sup> Massachusetts provides the following directives with regard to its prediction of 1-5 year prognosis: “In these cases, clinicians should make conservative judgments regarding prognosis, relying upon individualized assessment and the most expert clinical judgment available to them. In other words, triage officers should not assign points based on the patient’s underlying conditions when the prognosis is uncertain. The mere existence of certain underlying medical conditions (including without limitation a diagnosis of end stage renal disease, a diagnosis of congestive heart failure, or a diagnosis of dementia) should not be used in and of themselves to assign points without objective, medical evidence that such conditions are of a severity that would significantly limit near term life expectancy.” [“Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,”](#) April 20, 2020, at 18, California’s guidelines include similar language. *See n. vi, above.*

<sup>x</sup> *See, e.g.,* Utah Crisis Standards of Care Guidelines, *supra* n. ii, p. 7. (“First tiebreaker: When two patients are apparently the same on all other measures at a given point in time, if one patient’s clinical trajectory is declining more rapidly than the other patient needing the same limited resource, the limited resource should be assigned to the patient with the less rapid rate of clinical decline, and thus the greatest prospect of short-term survival. Second tiebreaker: When two patients remain tied after assessment of their respective clinical trajectories, a judgment should be made of which patient has the greater prospect of short-term survival based on additional clinical judgment of patient’s record and overall presentation of relevant symptoms, combined with use of recommended assessment tools...so long as this judgment is not based on any unlawful considerations of race, color, national origin, disability, age, or sex. Third tiebreaker: When patients remain tied after consideration of clinical judgment, assign the limited resource by randomization to lottery.”)

<sup>xi</sup> For example, a person with a history of polio and respiratory insufficiency may have low PaO<sub>2</sub>/FiO<sub>2</sub> when off non-invasive mechanical ventilation. A person with rheumatoid arthritis can have chronically low platelets due to immune thrombocytopenia. People with sickle cell anemia often have chronically high bilirubin levels. A person with quadriplegia due to a spinal cord injury can have chronically low blood pressure due to autonomic dysregulation. A person with polycystic kidney disease with renal insufficiency can have chronically elevated creatinine level.

<sup>xii</sup> Massachusetts, Pennsylvania, Delaware, Tennessee, California, and Utah have all incorporated revised language on SOFA scoring in order to avoid penalizing patients for underlying disabilities or co-morbid conditions that do not impact short term survivability. *See, e.g., MA Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic, supra* n. iv, at 17; *Interim Pennsylvania Crisis Standards of, supra* n. viii, at 30; Delaware Health and Social Services, [Crisis Standards of Care Concept of Operations](#), April 28, 2020, (7.6.2Iiii); *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee, supra* n. ii, at 2, Attachment B at 5; *California SARS-CoV-2 Pandemic Crisis Care Guidelines, supra* n. v, at 26. (“GCS should not add points to the SOFA score when a patient cannot articulate intelligible words, even if this condition is due to a pre-existing speech disability or chronic ventilation. Clinicians should use clinical judgment to adjust SOFA scores downward where appropriate to account for chronic baseline levels of physiological functional impairment not caused by COVID-19, including for any temporary elevation of a score or score element caused by any patient inability to access a regularly used stabilizing device or treatment (such as a CPAP or BiPAP unit, dialysis, or specific medications).”); Utah Crisis Standards of Care, *supra* n. ii, at 5 (Assessment tools, such as the MSOFA or Revised Trauma Score, may need reasonable modifications to ensure that disability-related characteristics unrelated to short-term mortality risk do not worsen the patient’s score. For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity in the MSOFA, adds points to the MSOFA score when a patient cannot articulate intelligible words or has difficulty with purposeful movement. For patients with pre-existing speech disabilities or disabilities that effect motor movement, this may result in a higher MSOFA score even in instances where the patient’s disability is not relevant to short-term mortality risk.”)

<sup>xiii</sup> *See COVID-19: Considerations, Strategies, and Resources for Crisis Standards of Care in PALTC Facilities, supra* n. i, at 7-8 (“Reasonable modifications to clinical instruments for evaluating short-term mortality risk for prioritization purposes may be necessary for accurate use with patients with underlying disabilities.”)

<sup>xiv</sup> New York’s ventilator guidelines mostly reject the use of duration of need as an allocation criteria. Though earlier draft criteria considered utilizing resource-utilization, New York’s final criteria indicate that “resource utilization with respect to estimated duration of ventilator need as a stand-alone triage factor was rejected because it does not affect a patient’s likelihood of survival.” *See NY Ventilator Allocation Guidelines, supra* n. viii, at 85-86.

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<sup>xv</sup> For example:

- Massachusetts approaches reassessment of patient progress with ventilation in this way: “Given the clinical trajectory for any one patient is also influenced by their underlying conditions including permanent disabilities, clinicians should consider these factors when performing the reassessment and allow for variations on recovery (for example, extension to the therapeutic trial) that are in the context of the underlying condition or disability.” See *MA Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic*, *supra* n. ix, at 23.
- Delaware’s plan states that, “[r]easonable accommodations to triage protocols for individuals with disabilities should be considered, including extension of ventilator trial periods, to allow additional time for demonstrate effective progress because of their disability.” See *Crisis Standards of Care Concept of Operations*, *supra* n. xii.
- California’s plan states: “All patients who are allocated critical care services should be allowed a therapeutic trial of a duration to be determined by the clinical characteristics of the disease. The decision about trial duration should ideally be made as early in the public health emergency as possible, when data becomes available about the natural history of the disease. Trial duration should be tailored for other non-pandemic diseases and patient contexts, given the concern that patients with certain disabilities may need longer trials to determine benefit.” *California SARS-CoV-2 Pandemic Crisis Care Guidelines*, *supra* n. v, at 28.

<sup>xvi</sup> See *Utah Crisis Standard of Care Guidelines*, *supra* n. ii, 6 (“Providers may not impose blanket Do Not Resuscitate policies for reasons of resource constraint. Providers may not require patients to consent to a particular advanced care planning decision in order to continue to receive services from a facility.”)

<sup>xvii</sup> Several states use a set of guidelines developed by the Minnesota Healthcare Preparedness Program that suggest making re-allocation decisions based either on “significant differences in prognosis or resource utilization.” See *e.g.*, Minnesota Department of Health, Emergency Preparedness and Response, “[Patient Care Strategies for Scarce Resource Situations](#),” by the Minnesota Health Care Preparedness Program, April 2019, 16. This includes duration of need, with re-allocation suggested when the patient’s condition suggests a long duration of need, “e.g., ARDS, particularly in setting of preexisting lung disease (estimate > 7 days on ventilator).” As part of its resolution with OCR, Tennessee removed the Minnesota guidelines. See, OCR Resolution, June 26, 2020, *supra* n. ii.

<sup>xviii</sup> For example, the New York State Task Force on Life and the Law indicates that when chronic ventilator users arrive at the hospital “they are treated like any other patient who requires a ventilator and need to meet certain criteria to be eligible for ventilator therapy,” arguing that “if chronic care patients were permitted to keep their ventilators rather than be triaged, the policy could be viewed as favoring this group over the general public.” See *Ventilator Allocation Guidelines*, *supra* n. viii, 42. According to a 2009 report from the New York Times, state health care officials took this to mean that should a chronic ventilator user need to enter the hospital, “the guidelines call for the machine that keeps him alive to be given to someone else.” See Sheri Fink, “[Worst Case: Choosing Who Survives in a Flu Epidemic](#),” *The New York Times*, October 24, 2009, sec. Week in Review. Kansas makes use of similar criteria borrowed from the New York Task Force guidelines. The underlying meaning of these guidelines has been contested, but regardless of intent, additional clarity is needed to ensure that people with disabilities are not deprived of their ventilators if they enter an acute care setting. See Ari Ne’eman, “[Do New York State’s Ventilator Allocation Guidelines Place Chronic Ventilator Users at Risk? Clarification Needed](#),” *The Hastings Center*, April 3, 2020.

<sup>xix</sup> In contrast, Massachusetts, Delaware, Tennessee, Utah, and California expressly prohibit reallocation of personal medical equipment when a patient presents at the hospital:

- “Patient personal equipment: If a patient presents to a hospital and has personal medical equipment, such as a ventilator, that equipment will not be confiscated or used for any other patient.” See *MA Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic*, *supra* n. ix, at 26.
- “Individuals presenting for hospital level of care will not be subject to the automatic withdrawal or redeployment of personal lifesaving equipment, including ventilators, based on discriminatory

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assumptions about their intensity of need or likelihood of recovery.” See DE Crisis Standards of Care Concept of Operations, *supra* n. xii.

- “SOFA or MSOFA may be utilized in connection with an individualized assessment of the patient based on the best available objective medical evidence... This algorithm should not be construed to authorize the re-allocation of personal ventilators (defined as a ventilator brought by the patient to the acute care facility at admission to continue the patient’s pre-existing personal use with respect to a disability).” *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee*, *supra* n. ii, at Attachment B at 4.
- “Hospitals may not re-allocate a personal ventilator (defined as a ventilator brought by the patient to the acute care facility at admission to continue the patient’s pre-existing personal use with respect to a disability). This prohibition also applies to re-allocation decisions under other parts of the CSC.” *Utah Crisis Standards of Care*, *supra* n. ii at 5.
- “Individuals already on ventilators in chronic care settings should not be triaged unless they present in acute care settings and personal home ventilators belonging to, rented, or used by patients should not be reallocated to other patients.” *California SARS-CoV-2 Pandemic Crisis Care Guidelines*, *supra* n. v, at 20.

<sup>xx</sup> See, e.g. *COVID-19: Considerations, Strategies, and Resources for Crisis Standards of Care in PALTC Facilities*, *supra* n. i, at 8 (“Reasonable modifications to policies restricting visitations may be necessary to permit access to support personnel who assist people with disabilities, unless such modifications would constitute a fundamental alteration to CSC or would pose a direct threat to others... Support personnel may be paid or volunteer and may include family members who assist with communication, self-regulation and behavioral support, and other support, which an individual with a disability may require to receive equal benefit from the facility’s programs.”); New York Department of Health, [Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation](#); New Jersey Department of Health, [Support Person Permitted for a Patient with a Disability](#), April 25, 2020; California Department of Public Health, [Visitor Limitations Guidance](#), May 2, 2020; Oregon Health Authority [REVISED COVID-19 Guidance for Entry into Acute Health Care Facilities](#), April 23, 2020; *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee*, *supra* n. ii, at 8 (“...visitation policies should address, on a case-by-case basis and in consultation with treating physicians and facility medical directors, visits involving accommodations or other support for persons with disabilities”).

<sup>xxi</sup> See [OCR Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19](#); For an analysis of hospital visitor policies across the country, see [“Evaluation Framework for Hospital Visitor Policies.”](#)

<sup>xxii</sup> AADMD [“Hospitalized Patients & Designated Support Staff Policy Statement Committee on Public Policy and Advocacy.”](#) April 2020.

<sup>xxiii</sup> U.S. Department of Health & Human Services, *BULLETIN: Civil Rights Protections Prohibiting Race, Color and National Origin Discrimination During COVID-19*, *supra*, n. i.

<sup>xxiv</sup> See e.g., Arizona Complaint, page 3, available at: <http://thearc.org/wp-content/uploads/2020/07/HHS-OCR-Complaint-re-Crisis-Standards-of-Care-Arizona.pdf> (“Complainants’ constituents and members deserve equal access to medical care and should not be denied care based on their disability and need for reasonable modifications, their age and cycle of life or prognosis for long-term life expectancy, or their race or other protected status.”); [North Carolina Complaint](#), page 1 (requesting that “to address related discrimination based on race and/or age, any revised Protocol must: prohibit any implementation of the Standards that would result in discriminatory treatment or impact on populations protected by Title VI of the Civil Rights Act of 1964, the Age Discrimination Act of 1975, and Section 504 of the Rehabilitation Act of 1973.”)

<sup>xxv</sup> See, e.g., *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee*, *supra* n. ii, at 2 (“Every person has an inherent dignity and intrinsic moral worth, regardless of age, race, gender, creed, socioeconomic status, functional ability, disability or



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any other characteristic. All people deserve equal respect as human beings. With this in mind, the allocation mechanism cannot discriminate based on anything that is not directly relevant to the eligibility of individuals to receive care as established through the triage system.”); Utah Crisis Standards of Care Guidelines, *supra* n. xvi (“This 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.”); *California SARS-CoV-2 Pandemic Crisis Care Guidelines*, *supra* n. v, at 5 (“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.”); *See MA Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic*, *supra* n. ix, at 4. (“Factors that have no bearing on the likelihood or magnitude of benefit, including but not limited to 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 past or future use of resources, are not to be considered by providers making allocation decisions.”)

<sup>xxvi</sup> *See e.g., California SARS-CoV-2 Pandemic Crisis Care Guidelines*, *supra* n. v, at 23-24. (“Regardless of who communicates the [triage] decision, it may be useful to explain the medical factors that informed the decision, as well as the factors that were not relevant (e.g., race, ethnicity, disability, sex, insurance status, perceptions of social worth, immigration status, and other factors including those listed under Key Points)...Data collection should include data on morbidity and mortality outcomes to assess trends by demographic factors such as gender, race and ethnicity, geographic location, or socioeconomic status.”); *See MA Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic*, *supra* n. ix, at 11, 19. (“It may also be appropriate to explain the medical factors that informed the decision, as well as the factors that were not relevant (e.g., race, ethnicity, insurance status, perceptions of social worth, immigration status, etc.).”; “In determining the priority score for a patient, the Triage Officer(s) may by necessity as part of the evaluation have access to characteristics that have no bearing on the likelihood or magnitude of benefit (including but not limited to: race, disability, gender, sexual orientation, gender identity, ethnicity, ability to pay, socioeconomic status, perceived social worth, perceived quality of life, immigration status, or past or future use of resources). Triage Officers must not consider such characteristics in any way in making priority determinations and should be mindful of the role that implicit bias may play in decision making.”)

<sup>xxvii</sup> Massachusetts has adopted a detailed appeals process for use by patients, family members and health care agents. It includes expedited appeal of the initial prioritization of care and any subsequent withdrawal of life saving care based on the reassessment process. With regard to the communication of triage decisions, the MA plan states: “[s]pecial consideration will be made to ensure that this is done in a culturally competent manner, with racially, ethnically, culturally and linguistically diverse team members available to assist in these communications if possible, and specialized assistive technology or other reasonable accommodations available for patients and families who require it.” Detailed requirements for the documentation and reporting of these decisions are also included. *See Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic*, *supra* n. ix, 24-25.

<sup>xxviii</sup> *Id.*

<sup>xxix</sup> Pennsylvania’s Standards include requirements for triage officer crisis training, including training on implicit bias. *See Interim Pennsylvania Crisis Standards of*, *supra* n. vii, at 27. California’s guidelines also state that triage officers and health care workers should have training and expertise on bias and disability rights. *California SARS-CoV-2 Pandemic Crisis Care Guidelines*, *supra* n. v, at 9, 11, 19, 20-21.

<sup>xxx</sup> Colorado issued its Crisis Standards of Care pursuant to an Executive Order. [Executive Order D 2020 032](#) “Amending and Extending Executive Order D 2020 003 Declaring a Disaster Emergency Due to the Presence of Coronavirus Disease 2019 in Colorado,” April 8, 2020; “Subject Matter Experts Advisor Panel for the Governors Expert Emergency Epidemic Response Committee on Crisis Standards of Care Guidelines for Hospitals for the COVID-19 Pandemic,” Draft Version 0.9, April 4, 2020.