



Center for Public Representation

*Together with Ari Ne’eman, Visiting Scholar at the Lurie Institute for Disability Policy at Brandeis University, and Sam Bagenstos, former Principal Deputy Assistant Attorney General for Civil Rights at the U.S. Department of Justice*

Issued April 9, 2020; updated May 6, 2020

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

Many states and hospitals are relying on the use of Crisis Standard of Care plans to inform providers how to make decisions on the allocation and re-allocation of scarce medical resources. These plans should be carefully scrutinized to ensure that people with disabilities are not subject to discrimination. This guide, which [accompanies guidance](#) from disability and healthcare organizations that expands on a [Bulletin](#) from the Department of Health and Human Services’ Office of Civil Rights, is designed to 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 rights laws.

We identify six questions to ask when evaluating Crisis Standards of Care plans and other allocation criteria, and how particular allocation criteria amount to discrimination or risk being discriminatory.

### **1) Does the plan include categorical exclusions on the basis of diagnosis or functional impairment?**

- a) Many Crisis Standard of Care plans include criteria excluding certain people from accessing critical care resources, such as ventilators. These criteria may reflect impermissible disability discrimination if they are based on disability diagnoses or on broad functional impairments (such as the need for support in activities of daily living or chronic use of a ventilator) rather than an individualized assessment that a person is unlikely to benefit from treatment.<sup>i</sup>
- b) Plans cannot make categorical exclusions on the basis of disability, as doing so precludes the possibility of a truly individualized assessment of a patient’s ability to benefit from treatment.<sup>ii</sup>

- i) Some plans have identified certain conditions as exclusion criteria based on the following rationales: a) those with these conditions are too ill to likely survive the acute illness; b) 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, and; c) 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.

Each of these rationales poses disability discrimination concerns. The first rationale (that a patient is too ill to likely survive the acute illness) 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 opportunity to receive the individualized assessment required under the law. It is well accepted that the ability to survive in the short term, with aggressive treatment for an acute illness, is a valid qualification for providing such treatment. However, the use of a categorical exclusion associating this determination with a diagnosis rather than an individualized assessment of a particular patient may erroneously exclude those within a diagnosis for which this is not an accurate judgment.<sup>iii</sup>

The second rationale (that a patient has a one-year mortality that is so high as to make it unreasonable to allocate critical care resources to that patient in a crisis) raises concerns if the evidence does not support a mortality expectation high enough to justify such an exclusion. Even if high one-year mortality is accepted as a permissible basis to exclude from critical care, medical advances may render categorical exclusion criteria arrived at on that basis obsolete even as institutional inertia maintains the categorical exclusion within guidance provided to providers.<sup>iv</sup>

The third rationale - the assumption that patients with the particular conditions will require too large an amount of resources - is not an acceptable rationale to justify an exclusion criteria. Not only does it not reflect an individualized judgment, but the need for additional resources may in many instances be mandated as a reasonable accommodation under Section 504 and the Americans with Disabilities Act.<sup>v</sup> 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. 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.

- 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 survivability; and c) reaffirm that all individuals are qualified for, and eligible to receive, lifesaving care, regardless of diagnosis, functional impairment or ADL needs.
  - d) Given the lack of adequate research on the impact of COVID-19 on survival probabilities and the need for individualized assessment, plans must avoid the use of diagnosis or functional impairment-based categorical exclusion criteria in Crisis Standards of Care plans.<sup>vi</sup>
- 2) Does the plan include implicit or explicit quality of life assessments as an allocation criteria?**
- a) Many plans may reference quality of life indirectly, by indicating that providers should consider underlying disabilities that play no role in survival probability, either by virtue of their existence prior to the receipt of treatment or the likelihood of individuals acquiring such disabilities after the receipt of treatment.<sup>vii</sup>
  - b) Assessments of the quality of life of patients with particular disabilities should never be used to deny treatment.<sup>viii</sup>
- 3) Does the plan include intermediate or long-term survival beyond the acute care episode as an allocation criterion?**
- a) Some Crisis Standard of Care plans permit the use of long-term survival beyond the acute care episode, permitting the prioritization of individuals with longer anticipated lifespans than those with shorter lifespans. This places individuals with chronic illnesses and disabilities that shorten long-term lifespan at a disadvantage for accessing treatment and fails to account for the significant uncertainty surrounding long-term survival probabilities.<sup>ix</sup>
  - b) Long-term survival projections are significantly less certain than the assessment of short-term survival. Medical innovations such as new pharmaceuticals, surgical techniques and other interventions can shift the long-term prognosis for many conditions. Incorporating comorbidities that do not reduce a patient's short-term survival prospects into an assessment of whether or not they will receive care risks incorporating concerning value judgments that will systemically disadvantage people with disabilities and chronic health conditions and reduce the likelihood that they will receive medically indicated care.

- c) Attempts to predict long-term or intermediate prognosis in the context of triage decision-making also can lead to erroneous, inconsistent, and subjective decision-making. 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, co-morbid conditions.
- d) Further, individuals who can recover from the treatment are qualified to receive it. Thus, 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
- e) Any consideration of long-term survival in plans or allocation criteria, whether it comes in the form of explicit consideration of long-term survival or implicit consideration through prioritization of number of “life-years” saved rather than the number of “lives” saved, is inconsistent with disability rights laws.<sup>x</sup>
- f) Careful scrutiny should be given to the instruments utilized to assess survival probabilities to evaluate the extent to which they are designed for the assessment of long-term survival probability, rather than survival from the acute episode in question. To the extent any predictions of short term survival beyond the acute episode are required, triage clinicians should be directed to make conservative judgments, to not assume the mere existence of an underlying medical condition negatively impacts short term survival, and to not assign points when a patient’s prognosis is uncertain.<sup>xi</sup>

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

- a) 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>xii</sup>
- b) 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. This should preclude the denial of initial access to a scarce medical resource, such as a ventilator, based on the assessment that the person will require its use for a longer period of time.<sup>xiii</sup>

- c) 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. They may also include permitting a person to continue using a ventilator for additional time where an underlying disability means that additional time is necessary for recovery.<sup>xiv</sup>
- 5) Where the plan incorporates short-term survival probabilities, does it do so in an individualized fashion consistent with available standards of evidence? Are reasonable modifications made to avoid discriminatory outcomes in triage scoring?**
- a) Many Crisis Standard of Care plans reference likelihood of short-term survival as a criterion for the allocation of scarce medical resources. Though 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 broad-based conclusion on the basis of a diagnosis.
- b) To avoid discrimination, doctors or triage teams must perform a thorough individualized review of each patient and not assume that any specific diagnosis is determinative of prognosis or near-term survival without an analysis of current and best available objective medical evidence and the individual's ability to respond to treatment.
- c) 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 life saving care. The SOFA may disadvantage specific disability categories, such as chronic ventilator users, that start at a higher SOFA score as their "baseline" condition.
- d) Individuals with underlying co-morbidities may also find their SOFA score inflated by measures that capture chronic but stable underlying conditions. 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>xv</sup>
- e) Plans which rely on the SOFA must provide for 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.

## **6) Special Consideration for Chronic Ventilator Users**

- a) Several plans appear to 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>xvi</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 symptoms of COVID-19. 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>xvii</sup>

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

- a) Patients with disabilities may require specific accommodations in communicating their needs and preferences regarding treatment, including access to interpreters, specialized assistive technology, and/or support from family members or other support staff/caregivers. In many instances, this communication can only be effectively facilitated through access to a specific individual known to, and selected by, the person receiving care. If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider, knowledgeable about the management of their care, or needs someone to physically or emotionally assist them during their hospitalization, this should be allowed with proper precautions taken to contain the spread of infection.<sup>xviii</sup>
- b) 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>xix</sup>

**8) 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 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.<sup>xx</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>xxi</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>xxii</sup>

**9) 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>xxiii</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.

For more information, please contact:

Alison Barkoff  
Cathy Costanzo  
Steven Schwartz  
Kathryn Rucker  
Center for Public Representation  
[abarkoff@cpr-us.org](mailto:abarkoff@cpr-us.org)  
[ccostanzo@cpr-ma.org](mailto:ccostanzo@cpr-ma.org)  
[sschwartz@cpr-ma.org](mailto:sschwartz@cpr-ma.org)  
[krucker@cpr-ma.org](mailto:krucker@cpr-ma.org)

Shira Wakschlag  
The Arc of the United States  
[Shira@TheArc.org](mailto:Shira@TheArc.org)

Sam Bagenstos  
[sbagen@gmail.com](mailto:sbagen@gmail.com)

Jennifer Mathis  
Bazelon Center for Mental Health Law  
[jenniferm@bazelon.org](mailto:jenniferm@bazelon.org)

Samantha Crane  
Autistic Self Advocacy Network  
[scrane@autisticadvocacy.org](mailto:scrane@autisticadvocacy.org)

---

<sup>i</sup> For example:

- Florida excludes from hospital admissions individuals with “complex disorders with significant neurological component and prognosis for imminent expected lifelong assistance with most basic activities of daily living (i.e., toileting, dressing, feeding, respiration).” See Florida Department of Health. “Pandemic Influenza: Triage and Scarce Resource Allocation Guidelines,” by the Pandemic Influenza Technical Advisory Committee, April 5, 2011, 27. [http://www.floridahealth.gov/programs-and-services/emergency-preparedness-and-response/healthcare-system-preparedness/\\_documents/acs-guide.pdf](http://www.floridahealth.gov/programs-and-services/emergency-preparedness-and-response/healthcare-system-preparedness/_documents/acs-guide.pdf).
- Tennessee excludes 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 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, 21. [https://www.tn.gov/content/dam/tn/health/documents/2016\\_Guidance\\_for\\_the\\_Ethical\\_Allocation\\_of\\_Scarce\\_Resources.pdf](https://www.tn.gov/content/dam/tn/health/documents/2016_Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf).

- Utah excludes from hospital admission individuals with “known severe dementia medically treated and requiring assistance with activities of daily living.” See Utah Department of Health, “Utah Pandemic Influenza Hospital and ICU Triage Guidelines,” by the Utah Hospitals and Health Systems Association, August 11, 2009, 5. [http://pandemicflu.utah.gov/plan/med\\_triage081109.pdf](http://pandemicflu.utah.gov/plan/med_triage081109.pdf).
- Colorado, among other states, lists as an exclusion criteria from admission or transfer to critical care “cystic fibrosis with post-bronchodilator FEV1 <30% or baseline PaO2 <55 mm Hg.” See Colorado Department of Public Health and the Environment, “CDPHE All Hazards Internal Emergency Response and Recovery Plan, ANNEX B: Colorado Crisis Standards of Care Plan,” May 10, 2018, 78. <https://cha.com/wp-content/uploads/2018/10/Crisis-Standards-of-Care-05102018-FINAL.pdf>.

<sup>ii</sup> In an April 8, 2020 announcement of the results of a compliance review in Alabama, the HHS Office of Civil Rights 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.” See HHS Office of Civil Rights., “OCR Reaches Early Case Resolution With Alabama After It Removes Discriminatory Ventilator Triaging Guidelines,” April 8, 2020. [https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-trianging.html?fbclid=IwAR0JIMVCu0goRGzW6oEaRmw-oJqqA9yy0-LNp89SDChIB-i3F2Vt-8l\\_VU](https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-trianging.html?fbclid=IwAR0JIMVCu0goRGzW6oEaRmw-oJqqA9yy0-LNp89SDChIB-i3F2Vt-8l_VU)

<sup>iii</sup> On April 16, 2020, OCR announced the resolution of a complaint against Pennsylvania based on the State’s willingness to: 1) remove criteria that automatically deprioritized persons on the basis of particular disabilities; 2) require individualized assessments based on the best available, relevant, and objective medical evidence to support triaging decisions; and 3) 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. The underlying complaint alleged that Pennsylvania’s CSC Guidelines unlawfully singled out and authorized the denial of treatment to individuals with disabilities when prioritizing access to critical care and ventilators. Advocates claimed that the Guidelines listed specific impairments or disabilities that would lead to greater deprioritization, and did not require an individualized assessment, but instead used “preexisting conditions that are disabilities” to determine a priority score. <https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html>

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, <https://www.fema.gov/media-library-data/1586893628400f21a380f3db223e6075eeb3be67d50a6/EnsuringCivilRightsDuringtheCOVID19Response.pdf>

<sup>iv</sup> For example:

- Tennessee lists “Cystic fibrosis with post-bronchodilator FEV1 <30%” as an exclusion criteria for hospital admission, as do several other states. However, research on the life expectancy of people with cystic fibrosis whose FEV1 is less than 30% shows the median survival prior to transplant at >6.5 years. Recent advances in pharmaceutical interventions may have further extended the life-expectancy of people with CF. As a result, the use of cystic fibrosis as an exclusion criteria, even with this caveat, cannot be justified on the basis of the rationale articulated within the Crisis Standard of Care Plan. See Kathleen J. Ramos et al., “Heterogeneity in Survival in Adult Patients With Cystic Fibrosis With FEV1 < 30% of Predicted in the United States,” *Chest* 151, no. 6 (2017): 1320–28, <https://doi.org/10.1016/j.chest.2017.01.019>.
- Colorado’s pediatric exclusion criteria in its 2018 Crisis Standards of Care include SMA Type I and “progressive neuromuscular disorder e.g. muscular dystrophy and myopathy, with inability to sit unaided or

---

ambulate when such abilities would be developmentally appropriate based on age” as examples of conditions with “> 80% mortality expected at 18 to 24 months.” See Colorado Department of Public Health and the Environment, “CDPHE All Hazards Internal Emergency Response and Recovery Plan, ANNEX B: Colorado Crisis Standards of Care Plan,” May 10, 2018, 82. <https://cha.com/wp-content/uploads/2018/10/Crisis-Standards-of-Care-05102018-FINAL.pdf>. Recent medical advances have made this inaccurate for SMA. The more general exclusion is likewise inaccurate – delay or inability to walk is not directly predictive of lifespan. This speaks more generally to the harms of diagnosis-based exclusion criteria - not only are they frequently not predictive of lifespan, but medical advances may render them obsolete even as institutional inertia continues to leave them in place within state and provider allocation plans. See Tamara Dangouloff and Laurent Servais. “Clinical Evidence Supporting Early Treatment of Patients with Spinal Muscular Atrophy: Current Perspectives,” *Therapeutics and Clinical Risk Management* 15: 1153-1161, <https://doi.org/10.2147/TCRM.S172291>.

- Washington State indicates “severe chronic lung disease” as a significant underlying disease that predicts poor short term survival that may impact a patient’s access to ICU care in the event of scarce resources. With no clarity about the threshold of “severity” that would be necessary to accurately predict poor survival, people with disabilities may be inappropriately denied a ventilator merely based on the triage team’s subjective judgment about their diagnosis. See Washington State Department of Health, “Scarce Resource Management & Crisis Standards of Care: Overview & Materials,” by the Northwest Healthcare Response Network, March 2020, 34-35. <https://nwhrn.org/wp-content/uploads/2020/03/Scarce-Resource-Management-and-Crisis-Standards-of-Care-Overview-and-Materials-2020-3-16.pdf>.
- Compare Pennsylvania’s statement **against** the use of exclusionary criteria based on disability: “There are compelling reasons to not use exclusion criteria. Categorically excluding patients will make many feel that their lives are “not worth saving,” leading to justified perceptions of discrimination. Moreover, categorical exclusions are too rigid to be used in a dynamic crisis, when ventilator shortages will likely surge and decline episodically during the pandemic. In addition, such exclusions violate a fundamental principle of public health ethics: use the means that are least restrictive to individual liberty to accomplish the public health goal. Categorical exclusions are not necessary because less restrictive approaches are feasible, such as allowing all patients to be eligible and giving priority to those most likely to benefit.” Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines April 10, 2020, version 2.0, 30, <https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf>

<sup>v</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, <https://www.kyha.com/assets/docs/COVID19/Update/CrisisStandardsOfCareFinal.pdf>

<sup>vi</sup> The University of Pittsburgh Medical Center’s model guidelines provide a positive example, avoiding all use of categorical exclusion criteria. They 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. [https://ccm.pitt.edu/sites/default/files/UnivPittsburgh\\_ModelHospitalResourcePolicy.pdf](https://ccm.pitt.edu/sites/default/files/UnivPittsburgh_ModelHospitalResourcePolicy.pdf).

---

<sup>vii</sup> For example:

- In a document since taken down from the state’s website, 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. [https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint\\_3.24.20.docx.pdf](https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint_3.24.20.docx.pdf). 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.
- Florida’s draft criteria from 2011 incorporates an exclusion from hospital admissions individuals with “complex disorders with significant neurological component and prognosis for imminent expected lifelong assistance with most basic activities of daily living (*i.e.*, toileting, dressing, feeding, respiration)” (*see* Florida Department of Health, “Pandemic Influenza: Triage and Scarce Resource Allocation Guidelines,” by the Pandemic Influenza Technical Advisory Committee, April 5, 2011, 27. <http://www.floridahealth.gov/programs-and-services/emergency-preparedness-and-response/healthcare-system-preparedness/documents/acs-guide.pdf>) may be best understood as an implicit quality of life judgment, as it is so broad as to have no relationship with survival probability.
- Similarly, 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,” by the Northwest Healthcare Response Network, March 2020, 34-35. [https://nwhrn.org/wp-content/uploads/2020/03/Scarce\\_Resource\\_Management\\_and\\_Crisis\\_Standards\\_of\\_Care\\_Overview\\_and\\_Materials-2020-3-16.pdf](https://nwhrn.org/wp-content/uploads/2020/03/Scarce_Resource_Management_and_Crisis_Standards_of_Care_Overview_and_Materials-2020-3-16.pdf).

<sup>viii</sup> 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 Medical Association, “Oregon Crisis Care Guidance,” by the Crisis Care Guidance Workgroup, June 2018, 7. <https://www.theoma.org/CrisisCare>.

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, <https://www.dhhs.nh.gov/documents/nh-csc-plan.pdf>

<sup>ix</sup> 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. <https://covid-19.uwmedicine.org/Screening%20and%20Testing%20Algorithms/Other%20Inpatient%20Clinical%20Guidance/Clinical%20Care%20in%20ICU/Material%20Resource%20Allocation.COVID19.docx>.
- Colorado lists “little likelihood of long-term survival” as one of the rationales used to compile the state’s list of exclusion criteria from critical care resources. *See* Colorado Department of Public Health and the

---

Environment, “CDPHE All Hazards Internal Emergency Response and Recovery Plan, ANNEX B: Colorado Crisis Standards of Care Plan,” May 10, 2018, 78. <https://cha.com/wp-content/uploads/2018/10/Crisis-Standards-of-Care-05102018-FINAL.pdf>. A recent update to Colorado’s crisis standard of care plan sets an explicit goal to “save the most life-years”, utilizing a modified Charlson Comorbidity Index Score that prioritizes individuals in part based on their likelihood of survival over the next decade. *See* Colorado Department of Public Health and the Environment. “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,” April 5, 2020, 6. <https://www.colorado.gov/pacific/cdphe/colorado-crisis-standards-care>

- 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 Medical Association, “Oregon Crisis Care Guidance,” by the Crisis Care Guidance Workgroup, June 2018, 44-45. <https://www.theoma.org/CrisisCare>.
- 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* 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, 6. [https://ccm.pitt.edu/sites/default/files/UnivPittsburgh\\_ModelHospitalResourcePolicy.pdf](https://ccm.pitt.edu/sites/default/files/UnivPittsburgh_ModelHospitalResourcePolicy.pdf). 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.” *See* Pennsylvania Department of Health. “Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines,” March 22, 2020, 30. Following advocacy by Disability Rights Pennsylvania and others, those criteria were limited to conditions likely to cause death within 5 years. DRP’s April 16, 2020 press release describes remaining concerns with the revised plan. “Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines April 10, 2020” <https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf>. *See also*, <https://www.disabilityrightspa.org/newsroom/civil-rights-complaint-filed-by-disability-rights-pennsylvania-resulted-in-progress-on-pennsylvanias-medical-rationing-guidelines/>

<sup>x</sup> New York State’s ventilator guidelines offers a positive example representing a potential 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. [https://www.health.ny.gov/regulations/task\\_force/reports\\_publications/docs/ventilator\\_guidelines.pdf](https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf).

<sup>xi</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, <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download>

<sup>xii</sup> Several states, including Colorado and Tennessee, 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 Colorado Department of Public Health and the Environment, “CDPHE All Hazards Internal Emergency Response and Recovery Plan, ANNEX B: Colorado Crisis Standards of Care Plan,” May 10, 2018, 48. <https://cha.com/wp-content/uploads/2018/10/Crisis-Standards-of-Care-05102018-FINAL.pdf>; 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, 37; [https://www.tn.gov/content/dam/tn/health/documents/2016\\_Guidance\\_for\\_the\\_Ethical\\_Allocation\\_of\\_Scarce Resources.pdf](https://www.tn.gov/content/dam/tn/health/documents/2016_Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf); 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. <https://www.health.state.mn.us/communities/ep/surge/crisis/standards.pdf>. 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).”

<sup>xiii</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 New York State Department of Health, “Ventilator Allocation Guidelines,” by the New York Taskforce on Life and the Law, November 2015, 85-86. [https://www.health.ny.gov/regulations/task\\_force/reports\\_publications/docs/ventilator\\_guidelines.pdf](https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf).

<sup>xiv</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.” “Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,” April 20, 2020, 23, <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download>

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.” Delaware Health and Social Services, Crisis Standards of Care Concept of Operations, April 28, 2020, (7.6.2Iiii), <http://>

<sup>xv</sup> Massachusetts, Pennsylvania and Delaware 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., “Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,” April 20th 2020, 17. <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download> ; “Pennsylvania’s Interim Crisis Plan,” April 10, 2020, Version 2, 30, <https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf>; Delaware Health and Social Services, Crisis Standards of Care Concept of Operations, April 28, 2020, (7.6.2Iii), <http://>

<sup>xvi</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

---

New York State Department of Health, “Ventilator Allocation Guidelines,” by the New York Taskforce on Life and the Law, November 2015, 42.

[https://www.health.ny.gov/regulations/task\\_force/reports\\_publications/docs/ventilator\\_guidelines.pdf](https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf). 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, <https://www.nytimes.com/2009/10/25/weekinreview/25fink.html>. 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, <https://www.thehastingscenter.org/do-new-york-states-ventilator-allocation-guidelines-place-chronic-ventilator-users-at-risk-clarification-needed/>.

<sup>xvii</sup> In contrast, Massachusetts and Delaware 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.” “Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,” April 20, 2020, at 26, <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download>

“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 assumptions about their intensity of need or likelihood of recovery.” [Delaware Health and Social Services, Crisis Standards of Care Concept of Operations, April 28, 2020, \(7.6.2Iiv\)](https://www.delaware.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care-concept-of-operations), <https://www.centerforpublicrep.org/wp-content/uploads/2020/05/DE-CSC-ConOps-FInal-4-29-20.pdf>

<sup>xviii</sup> See, e.g. New York Department of Health, Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation, [https://opwdd.ny.gov/system/files/documents/2020/04/doh\\_covid19\\_hospitalvisitation\\_4.10.20.pdf](https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf); New Jersey Department of Health, Support Person Permitted for a Patient with a Disability, April 25, 2020, [https://njcdd.org/wpcontent/uploads/VisitorPolicy.pdf#%5D.+?\)%5B'%22%5D\)&link\\_id=45079976764548&source\\_id=45079984840849&source\\_type=Contact](https://njcdd.org/wpcontent/uploads/VisitorPolicy.pdf#%5D.+?)%5B'%22%5D)&link_id=45079976764548&source_id=45079984840849&source_type=Contact); California Department of Public Health, Visitor Limitations Guidance, May 2, 2020, <https://www.cdph.ca.gov/Programs/CHCQ/LCP/Pages/AFL-20-38.aspx>; Oregon Health Authority REVISED COVID-19 Guidance for Entry into Acute Health Care Facilities: April 23, 2020, <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/1e2282.pdf>

<sup>xix</sup> AADMD “Hospitalized Patients & Designated Support Staff Policy Statement Committee on Public Policy and Advocacy,” April 2020, <https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e9e1cbefc832d0a6866fed4/1587420352080/Visitation-PolicyStatement.pdf>.

<sup>xx</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. “Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,” April 20th 2020, 24-25, <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download>

<sup>xxi</sup> *Id.*

---

<sup>xxii</sup> Pennsylvania’s Standards include requirements for triage officer crisis training, including training on implicit bias. “Pennsylvania’s Interim Crisis Plan,” April 10, 2020, Version 2, 27.  
<https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf>

<sup>xxiii</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,  
<https://bloximages.newyork1.vip.townnews.com/coloradopolitics.com/content/tncms/assets/v3/editorial/4/30/4309ba26-7a9e-11ea-b526-9bc3faaa4e01/5e8f81862e9080.pdf.pdf> “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.