



Perspective

Respecting Disability Rights — Toward Improved Crisis Standards of Care

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In times of emergency, many legal strictures can flex. For example, to enable hospitals to respond to Covid-19, the Department of Health and Human Services (HHS) recently waived a swath

of federal regulatory requirements. But though officials' emergency powers are extensive, the ability to discard antidiscrimination protections is not among them. A hallmark of our legal system is that our commitment to prohibiting invidious discrimination remains steadfast even in times of emergency.

Pressure is put on that commitment when the need arises to triage patients to receive scarce medical resources such as ventilators and intensive care unit beds. As states and hospitals plan for surges of Covid-19 cases, they have had to make difficult choices, some of which have prompted criticism. In March and April 2020, disability rights advocacy groups and persons with disabilities filed

complaints with the HHS Office of Civil Rights (OCR) alleging that guidelines put forth by Alabama, Kansas, New York, Pennsylvania, Tennessee, Utah, and Washington illegally discriminated against persons with disabilities (see table). Guidelines from Massachusetts have provoked similar concerns. Analysis of these complaints suggests that policymakers and hospitals can take several key steps to honor commitments to anti-discrimination principles while appropriately stewarding scarce resources during a public health emergency.

In the bull's-eye of complaints by disability rights advocates are policies that base triage decisions on quality-of-life judgments or exclude patients with specific con-

ditions that constitute disabilities. For instance, Alabama's now-rescinded guidelines called for hospitals to withhold ventilators from patients with "severe or profound mental retardation," "moderate to severe dementia," or "severe traumatic brain injury." Utah's guidelines recommend excluding patients with advanced neuromuscular diseases "requiring assistance with activities of daily living or requiring chronic ventilatory support."

One principle underlying the complaints should attract little controversy: as a legal and ethical matter, patients must not be categorically excluded from access to treatment because of a disability. Rather, reflecting established legal precedent, HHS guidance states that "whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence."¹ Decisions about access

Disability Rights Advocates' Objections to States' Critical Care Allocation Frameworks.*		
State	Complainants and Form of Complaint	Complainants' Objections
Alabama	Alabama Disabilities Advocacy Program, The Arc of the United States: Complaint to OCR	State plan (now withdrawn and replaced) ordered hospitals to "not offer mechanical ventilator support for patients" with "severe or profound mental retardation," "moderate to severe dementia," or "severe traumatic brain injury."
Kansas	Disability Rights Center of Kansas, Topeka Independent Living Center, person with a disability: Complaint to OCR	State guidelines exclude from admission or transfer to critical care patients with "Advanced untreatable neuromuscular disease" "Advanced and irreversible immunocompromise" "Metastatic malignant disease with poor prognosis" (Guidelines also list other bases for exclusion not mentioned in the complaint.) Guidelines could permit withdrawal of ventilators from persons who use them regularly and seek acute care in order to reallocate them to others.
Massachusetts	Center for Public Representation: Letters to governor and state hospital and medical associations	Triage scoring protocol considers "life-limiting comorbidities" and "long-term prognosis" regardless of their relation to short-term survival or an individual's ability to benefit from treatment. Guidelines' core principles of maximizing efficiency in allocation and life-years saved are inherently biased against persons with disabilities. (Revised guidelines released April 20, 2020, use only "near-term survival.")
New York	Disability Rights New York: Letter to governor, complaint to OCR	State's 2015 ventilator allocation guideline (now under review) will disproportionately disqualify persons with disabilities "simply because they have underlying conditions that may intensify symptoms and slow recovery." Guideline does not prohibit the categorical deprioritization of such persons. Guideline could permit withdrawal of ventilators from persons who use them regularly and seek acute care in order to reallocate them to others.
Pennsylvania	Disability Rights Pennsylvania, 10 other disability advocacy organizations: Complaint to OCR	Triage scoring protocol in state's interim guidelines considers long-term prognosis, scored using "major" or "severely life-limiting" coexisting diagnoses (including moderate or severe dementia, cancer with <10 yr predicted survival, and moderately severe or severe chronic lung diseases), regardless of whether these conditions affect short-term survival or ability to respond to treatment. (Revised draft guidelines released April 13, 2020, mention only near-term prognosis.)
Tennessee	Disability Rights Tennessee, 9 other disability and patient advocacy organizations, persons with disabilities: Complaint to OCR	State's 2016 guidelines advise hospitals to exclude from admission or transfer any person with "Severe and irreversible chronic neurologic disease with persistent coma or vegetative state" "Acute severe neurologic event with minimal chance of functional neurologic recovery" (e.g., traumatic brain injury, severe hemorrhagic stroke, hypoxic ischemic brain injury and intracranial hemorrhage) "Known, severe, end-stage dementia, medically treated and requiring assistance with ADLs" "Advanced untreatable neuromuscular disease (e.g., ALS, end-stage MS, spinal muscular atrophy)" requiring assistance with ADLs or chronic ventilatory support "Incurable metastatic malignant disease" (Guidelines also list other bases for exclusion not mentioned in the complaint.)
Utah	Disability Law Center, person with a disability: Complaint to OCR	State guidelines advise hospitals to consider excluding from admission or transfer to critical care patients with "Severe and irreversible chronic neurological condition with persistent coma or vegetative state" "Known severe dementia" requiring assistance with ADLs "Advanced untreatable neuromuscular disease" requiring assistance with ADLs or chronic ventilatory support "Incurable metastatic malignant disease" "End-stage organ failure" meeting specified criteria "Acute severe neurologic event with minimal chance of functional neurologic recovery," including traumatic brain injury (Children:) "progressive neuromuscular disorder, e.g. muscular dystrophy and myopathy, with inability to sit unaided or ambulate" at the usual level for children of that age Cystic fibrosis with specified lung function criteria (Complaint omits that these conditions may be exclusion criteria only if "deemed to impact short-term survival.") Guidelines recommend using the ASA score, which includes "functional impairment" due to severe disease, in triage scoring system.
Washington	Disability Rights Washington, 2 other disability advocacy organizations, person with a disability: Complaint to OCR	State plan (still under development) will "Assess factors such as age, health, and likelihood of survival" Consider "baseline functional status" Follow existing plan at UWMC in seeking to maximize overall "healthy, long-term survival," which requires weighting the survival of "young otherwise healthy patients more heavily than that of older, chronically debilitated patients"

* ADLs denotes activities of daily living, ALS amyotrophic lateral sclerosis, ASA American Society of Anesthesiologists, MS multiple sclerosis, OCR Department of Health and Human Services Office of Civil Rights, and UWMC University of Washington Medical Center.

to treatment must consider not whether someone has a disability, but rather the patient's prospects of benefiting from treatment. Excluding patients on the basis of preexisting functional impairments that do not necessarily limit their survival prospects, as Utah does, is tantamount to excluding people on the basis of disability and is probably illegal.

Policies like Alabama's and Utah's appear to make quality-of-life judgments about particular disabilities, a legally and ethically problematic move. HHS's guidance states that "persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities,"¹ which is in line with older HHS guidance limiting use of quality-of-life assessments in Medicaid benefit design. Those guidance documents reflect awareness of biases in how the public evaluates the quality of life of persons with disabilities — a problem that also affects physicians' judgments. Ethically speaking, such biases justify excluding quality of life as a triage criterion.

The complaints also object, with reason, to incorporating long-term life expectancy into allocation decisions. For instance, they allege that initial triage-scoring guidelines developed by Pennsylvania and Massachusetts unfairly used long-term life expectancy as a criterion by considering the number of life-years saved. (Both states subsequently revised their guidelines.) Whether disability law permits basing triage decisions on long-term life expectancy is unclear. It is ethically preferable to avoid doing so because long-term life expectancy is negatively af-

ected by some disabilities and by social circumstances — such as poverty and poor access to health care. Thus, using long-term life expectancy would probably unfairly disadvantage some persons with disabilities and exacerbate other health disparities. Moreover, predictions of long-term life expectancy are much more uncertain and prone to bias than predictions of short-term survival.

Where some complaints have veered off the mark is in suggesting that it's unfair and illegal to consider patients' near-term prognosis in allocation decisions (e.g., to assign lower priority to patients who are expected to die within a year from an end-stage condition even if they survive the acute illness). Disability rights advocates in Pennsylvania, for instance, urge that the prognosis must be ignored except for "immediate-term survivability" (i.e., ability to survive the acute illness); advocates in Washington similarly contend that only the ability to survive Covid-19 with treatment is relevant. A recent letter from eight U.S. senators goes further, suggesting that if a person has a "non-negligible" probability of survival, even large differences in probability of survival should be ignored.²

Consideration of near-term prognosis is accepted in medical ethics and clinical practice. The American Medical Association's guidance on allocating limited resources recommends that decisions be based on "likelihood and anticipated duration of benefit." Frameworks for allocating transplantable organs, a process overseen by HHS, include near-term duration of benefit as a criterion. The National Council on Disability's recent report on disabilities and organ transplantation did not

reject the use of near-term benefit in organ allocation. And on April 16, 2020, the OCR approved revised Pennsylvania triage guidelines that incorporate assessment of near-term prognosis.

Allocation guidelines that ignore near-term prognosis can produce outcomes inconsistent with considered moral judgments about responsible stewardship of scarce resources. For example, a patient with advanced metastatic pancreatic cancer who is expected to die within weeks would be given the same priority for ventilator treatment as a patient who is visually impaired but has no conditions affecting near-term prognosis. As in this example, incorporating near-term prognosis will usually benefit patients with disabilities more than random selection, "first-come, first-served" rules, or ignoring prognosis entirely because most disabilities do not materially affect near-term prognosis.

Use of evidence-based predictions about hospital survival and near-term prognosis is also supported by case law.³ Cases finding illegal discrimination in medical decisions involve factually unsupported, categorical judgments, such as exclusion of a deaf patient from prenatal care,⁴ whereas evidence-based predictions have been upheld.⁵

The need for triage guidelines and processes during emergencies is undeniable. Properly designed guidelines can save more lives — including those of patients with disabilities — and counter the predictive and other decisional biases that may affect physicians' bedside decisions. But guidelines must be attentive to the interests of persons with disabilities.

Our analysis suggests six guideposts that states and hospi-

tals should follow to respect disability rights. Four relate to criteria for decisions. First, do not use categorical exclusions, especially ones based on disability or diagnosis. Second, do not use perceived quality of life. Third, use hospital survival and near-term prognosis (e.g., death expected within a few years despite treatment) but not long-term life expectancy. Fourth, when patients who use ventilators in their daily lives (e.g., home ventilation) present to acute care hospitals, their personal ventilators should not be reallocated to other patients.

The fifth recommendation, designate triage officers as the decision makers and train them to respect disability rights, is procedural. Triage officers must assess patients individually on the basis of objective medical evidence, not stereotypes or assumptions. To this end, some experts propose that the information available to triage officers exclude all patient characteristics not relevant to prognosis for hospital and near-term survival.

Finally, include disability rights advocates in policy development and dissemination. Doing so shows respect, helps avoid paternalism, augments procedural fairness, and may produce substantively better guidelines. It may also help avoid ambiguities in guidelines that invite misapprehension and speculation. For example, some states' guidelines use vague terms like "life-limiting" that may be intended to reference duration of benefit but also connote quality-of-life judgments. Involving disability rights advocates can help in avoiding potentially inflammatory language and ensure (e.g., by issuing accessible FAQs) that the public understands how guidelines will (and will not) be operationalized. These steps can help the health care system to honor its commitments to antidiscrimination principles while properly stewarding scarce resources.

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