




EMERGENCY LEGAL PREPAREDNESS AND RESPONSE Overview

Legal & Regulatory Challenges to Crisis Standards of Care (CSC) in Response to COVID-19

As numbers of confirmed COVID-19 cases soar, key U.S. jurisdictions are experiencing overwhelming surge from patients seeking testing and requiring hospitalization. Researchers estimate that in coming months up to 20 million patients may require hospitalization, and over 4 million will require intensive care such as ventilators (vents).¹ An article published last week in the *New England Journal of Medicine* found that the number of patients needing ventilation could range between 1.4 and 31 patients per vent.² These and other foreseeable shortages require implementation of crisis standards of care (CSC), which requires allocation decision based on public health needs, and not just what is optimal for individual patients, to save the most lives.

The National Academies of Science, Engineering and Medicine (NASEM) define CSC as a “substantial change in usual health care operations and the level of care it is possible to deliver,” triggered by a formally declared pervasive or catastrophic disaster.³ CSC activates specific legal or regulatory powers and protections for health care workers (HCWs) in allocating and utilizing scarce medical resources including vents. Apportioning resources raises concerns, however, that rationing is based on discrimination against protected groups. In Seattle, a 2009 plan to ration critical resources was rejected after a report found that because of “institutional racism in the health care system,” the metrics for some groups, like African Americans and immigrants, would be skewed.⁴

There are no uniform federal guidelines for rationing care. Instead, states have adopted varying CSC policies. Considering the severe shortages, most plans include specific provisions for vents. Some plans require doctors to “color code” who gets vents based on their likelihood of being saved;⁵ others utilize a lottery system.⁶ Some states have no guidelines at all. Many of the plans prioritize patients most likely to survive immediate illness and with a better chance of long-term survival considering age, disability status, or other factors. Plans have been characterized as violative of the Americans with Disabilities Act (ADA), the federal Rehabilitation Act, the Affordable Care Act (ACA), and federal anti-discrimination laws enforced by the Department of Health and Human Services’ (HHS) Office for Civil Rights (OCR). Following complaints filed by groups in Alabama, Kansas, Tennessee, and Washington, OCR announced that civil rights protections will remain in effect during the COVID-19 pandemic.



Alabama's Emergency Operations Plan includes provisions managing access to vents during a declared public health emergency.⁷ The protocol lists several health conditions, including heart failure and respiratory failure, for which providers should "not offer mechanical ventilator support."⁸ Additionally, "persons with severe mental retardation, advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support."⁹ On March 24, the Alabama Disabilities Advocacy Program filed a complaint with OCR, alleging discrimination against people with intellectual and cognitive disabilities in that the plan "specifically singles out and excludes certain people with intellectual disabilities from access to [vents] in the event of rationing."¹⁰ Alabama health authorities have since clarified their plan.

Kansas Department of Health and Environment guidelines¹¹ state that, in the event of scarce resources to treat COVID-19, individuals who use vents on a regular basis, and who require acute care, may have their vents removed and reallocated to other people if they "fail to meet criteria." The Disability Rights Center of Kansas and Topeka Independent Living Center filed an OCR complaint¹² on March 27, alleging disability discrimination. Of particular concern is that hospitals would be able to remove vents from patients with "advanced untreatable neuromuscular disease," "advanced or irreversible immunocompromise," and some forms of cancer to reallocate vents so other patients more likely to survive long-term.¹³

Tennessee guidelines for rationing scarce resources exclude people with advanced neuromuscular disease who require assistance with activities of daily living or chronic vent support from accessing critical care, including vents.¹⁴ The guidelines further exclude people with metastatic cancer, dementia, and traumatic brain injuries from necessary care. On March 27, Disability Rights Tennessee and others filed a similar OCR,¹⁵ alleging "[a] diagnosis should not determine anyone's right to individual medical judgment or leave people afraid to seek professional help because their care will be based on assumptions about a condition."¹⁶

Guidance distributed by the Washington State Department of Health recommends that triage teams consider transferring hospital patients with "loss of reserves in energy, physical ability, cognition and general health" to outpatient or palliative care.¹⁷ Age, underlying disease conditions, and likelihood of survival will be evaluated in determining which patients receive full access to care, and those provided "comfort care," with the expectation that they will die. The statewide guidance ensures a uniform response so that individual providers have make difficult decisions alone. On March 23, Disability Rights Washington filed an OCR complaint¹⁸ alleging that the guidelines illegally discriminate against people with disabilities because they prioritize "treating people who are younger and healthier" and leave "those who are older and sicker – people with disabilities – to die."¹⁹

Similar letters criticizing other state guidelines have also been sent to the governors of Massachusetts²⁰ and Pennsylvania.²¹ On March 28, HHS OCR issued a bulletin on civil rights laws that apply during the COVID-19 emergency.²² Director Roger Severino stated that the office was opening investigations to ensure that state-mandated rationing plans "are fully compliant with civil rights law."²³ The investigations will evaluate state CSC plans to "make sure they are consistent with the current state of the law."²⁴ Labeling some CSC measures "ruthless utilitarianism," Severino stated that "persons with disabilities, with limited English skills and older persons should not be put at the end of the line for health care during emergencies."²⁵ If OCR determines that rights have been violated, states would be granted a specific time period to correct the violation or provide a plan of correction,²⁶ including changing the policy or procedure.²⁷

The bulletin also clarified that HHS Secretary Alex Azar's prior statement on March 17²⁸ providing immunity from legal liability to those developing or using medical countermeasures to fight the disease, "may apply with respect to some private claims arising from the use or administration of a covered countermeasure and may provide immunity from certain liability under civil rights laws."²⁹

SUPPORTERS



Robert Wood Johnson Foundation

The Network for Public Health Law is a national initiative of the Robert Wood Johnson Foundation. The Network provides information and technical assistance on issues related to public health laws and policies.

This document was developed by Erica N. White, Senior Legal Researcher, and J.D. Candidate (2021) and James G. Hodge, Jr., J.D., L.L.M., Director, Network for Public Health Law – Western Region at the Sandra Day O’Connor College of Law, Arizona State University. The legal information and guidance provided in this document do not constitute legal advice or representation. For legal advice, please consult specific legal counsel in your state.

March 2020

- ¹ Margot Sanger-Katz, et al., *These Places Could Run Out of Hospital Beds as Coronavirus Spreads*, N.Y. TIMES, March 17, 2020, available at <https://www.nytimes.com/interactive/2020/03/17/upshot/hospital-bed-shortages-coronavirus.html>.
- ² Robert D. Truog, et al., *The Toughest Triage – Allocating Ventilators in a Pandemic*, N. Engl. J. Med. Perspective, published online March 23, 2020.
- ³ Inst. of Med. of the Nat’l Acads., *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations* 3 (2009).
- ⁴ Public Engagement Project on Medical Service Prioritization During an Influenza Pandemic, September 2009, available at https://s3.amazonaws.com/publicassets/docs/seattle_public_engagement_project_final_sept2009.pdf.
- ⁵ Weaver, *supra* note 2.
- ⁶ Joanne Kenen, *A Lottery for Ventilators? Hospitals Prepare for Ethical Conundrums*, POLITICO, March 27, 2020, available at <https://www.politico.com/news/2020/03/27/ventilators-coronavirus-lottery-152574>.
- ⁷ Annex to ESF 8 of the State of Alabama Emergency Operations Plan, *Criteria for Mechanical Ventilator Triage Following Proclamation of Mass-Casualty Respiratory Emergency*, available at https://adap.ua.edu/uploads/5/7/8/9/57892141/alabamas_ventilator_rationing_plan.pdf.
- ⁸ *Id.*
- ⁹ *Id.*
- ¹⁰ Letter from Alabama Disabilities Advocacy Program to Roger Severino, Director, Office for Civil Rights, RE: Complaint of Alabama Disabilities Advocacy Program and the Arc of the United States (March 24, 2020), available at https://adap.ua.edu/uploads/5/7/8/9/57892141/al-ocr-complaint_3.24.20.pdf.
- ¹¹ Guidelines for the Use of Modified Health Care Protocols in Acute Care Hospitals During Public Health Emergencies, revised August 2010, available at http://www.kdheks.gov/coronavirus/toolkit/Kansas_Modified_Protocols_for_Hospitals_in_Public_Health_Emergencies.pdf.
- ¹² Letter from Disability Rights Center of Kansas to Roger Severino, Director, Office for Civil Rights, RE: Complaint of Disability Discrimination Filed by the Disability Rights Center of Kansas, the Topeka Independent Living Center, and Tessa Goupil (March 27, 2020), available at <https://www.centerforpublicrep.org/wp-content/uploads/2020/03/Kansas-OCR-complaint-3.27.20-final.pdf>.
- ¹³ *Id.*
- ¹⁴ Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee, revised July 2016, available at https://www.tn.gov/content/dam/tn/health/documents/2016_Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf.
- ¹⁵ Letter from Disability Rights Tennessee to Roger Severino, Director, Office for Civil Rights, RE: Complaint of Erin Brady Worsham, Jean Marie Lawrence, Toni Corbin, John and Pam Bryan, Jennifer Aprea, Disability Rights Tennessee, the Tennessee Disability Coalition, The Arc

Tennessee, The Arc of the United States, Civil Rights Education and Enforcement Center, Disability Rights Education and Defense Fund, Autistic Self Advocacy Network, Epilepsy Foundation of Middle & West Tennessee, National Kidney Foundation, and National Multiple Sclerosis Society (March 27, 2020), available at <http://thearc.org/wp-content/uploads/2020/03/2020-03-27-TN-OCR-Complaint-re-Healthcare-Rationing-Guidelines.pdf>.

¹⁶ *Id.*

¹⁷ Washington State Department of Health, Scarce Resource Management & Crisis Standards of Care, available at https://nwhrn.org/wp-content/uploads/2020/03/Scarce_Resource_Management_and_Crisis_Standards_of_Care_Overview_and_Materials-2020-3-16.pdf.

¹⁸ Letter from Disability Rights Washington to Roger Severino, Director, Office for Civil Rights, RE: Complaint of Disability Rights Washington, Self Advocates in Leadership, The Arc of the United States, and Ivanova Smith Against the Washington State Department of Health (WA DOH), the Northwest Healthcare Response Network (NHRN) and the University of Washington Medical Center (UWMC) (March 23, 2020), https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf.

¹⁹ *Id.*

²⁰ Letter from the Center for Public Representation to Governor Charles Baker (March 26, 2020), available at https://www.dlc-ma.org/wp-content/uploads/2020/03/3.26.20.ltr_rationing_of_care.pdf.

²¹ Letter from Disability Rights Pennsylvania to Governor Wolf, Re: Assuring People with Disabilities Have Non-Discriminatory Access to Health Care for COVID-19 Treatment (March 27, 2020) available at <https://www.disabilityrightspa.org/wp-content/uploads/2020/03/03.27.2020-DRP-Health-Care-Allocation-Letter.pdf>.

²² HHS Office for Civil Rights, Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), March 28, 2020, available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.

²³ Sheri Fink, *U.S. Civil Rights Office Rejects Rationing Medical Care Based on Disability, Age*, N.Y. TIMES, March 28, 2020, <https://www.nytimes.com/2020/03/28/us/coronavirus-disabilities-rationing-ventilators-triage.html>.

²⁴ *Id.*

²⁵ Fink, *supra* note 24.

²⁶ U.S. Dep't of Health and Human Services, What to Expect: How OCR Investigates a Civil Rights Complaint, available at <https://www.hhs.gov/civil-rights/filing-a-complaint/what-to-expect/index.html>.

²⁷ *Id.*

²⁸ Declaration Under the Public Readiness and Emergency Preparedness Act for Medical Countermeasures Against COVID-19, available at <https://www.federalregister.gov/documents/2020/03/17/2020-05484/declaration-under-the-public-readiness-and-emergency-preparedness-act-for-medical-countermeasures>.

²⁹ Bulletin, *supra* note 23.