EXAMINING HOW CRISIS STANDARDS OF CARE MAY LEAD TO INTERSECTIONAL MEDICAL DISCRIMINATION AGAINST COVID-19 PATIENTS



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Black, Indigenous and People of Color, disabled people, higher weight people,¹ and older adults have historically experienced and continue to experience discrimination by medical professionals. In health care settings, members of these communities face pervasive negative biases and inaccurate assumptions about their value, quality of life, capacity to communicate and make decisions, and likelihood of survival.

During the COVID-19 pandemic, these biases can have serious and even deadly consequences. Such biases may be exacerbated when hospitals are faced with scarce resources and must make decisions about which critically ill patients should receive treatment. The "crisis standards of care" which are used by many states and hospitals to make these decisions, have too often reflected these biases. It is crucial that these standards be tailored to avoid unlawful discrimination.

Michael Hickson's Story



The death of <u>Michael Hickson</u> is just one example of a tragedy that raises questions about the impact of race and disability bias in decisions about who receives lifesustaining treatment. It highlights the need for crisis standards of care guidelines that address such biases.

When Michael Hickson was admitted to the hospital for COVID-19, he was not alone. His wife of 18 years stayed by his side. Hickson, a 46-year-old Black father of five with multiple disabilities—quadriplegia, cortical blindness, and a brain injury—died of complications from COVID-19 after contracting the virus in a nursing facility. In consultation with medical professionals, a court-

appointed guardian, discontinued Hickson's medical treatment, including hydration and nutrition for six days, over the objection of his wife. In the decision to end treatment, the doctor told Mrs. Hickson that treatment was futile because her husband did not "have much of" a quality of life due to his disabilities. The recorded conversation between Mrs. Hickson and the doctor went as follows:

Doctor: So as of right now, his quality of life – he doesn't have much of one.

Melissa Hickson: What do you mean? Because he's paralyzed with a brain injury, he doesn't have quality of life?

Doctor: Correct.

Sarah McSweeney's Story

The death of <u>Sarah McSweeney</u>, 45, raises similar questions about the role of medical bias in the care and treatment of people with significant disabilities. McSweeney entered the hospital with a high temperature and trouble breathing. It is reported that doctors did not view McSweeney as having a "quality of life" due to her inability to speak verbally, walk, or otherwise interact directly with the health care providers. As a result, her medical providers pressured her caregivers to revise her documented wishes from receiving all life-saving treatment to a do not resuscitate order. Though her caregivers pushed back against these attempts, McSweeney ultimately died of aspirational pneumonia—a condition usually considered to be treatable.

Designing Non-Discriminatory Crisis Standards of Care

Advocacy groups have been working to identify and address discriminatory provisions in crisis standards of care around the country. This guide provides: (1) an explanation of what crisis standards of care are and how they may perpetuate discrimination; (2) the principles that should apply to crisis standards of care to prevent discrimination; (3) the civil rights laws that apply to the use of crisis standards of care; and (4) recommended strategies to ensure the non-discriminatory application of crisis standard of care guidelines.

I. <u>ABOUT CRISIS STANDARDS OF CARE</u>

What are crisis standards of care?

Crisis standards of care are plans developed by states or hospitals concerning how to make decisions about allocating scarce medical resources. These plans provide guidance about the factors to consider in determining who gets priority when there are not enough medical resources to distribute, such as during a pandemic.

How may crisis standards of care be applied during the COVID-19 pandemic?

Many states and hospitals have developed crisis standards of care to plan for situations where there may not be enough resources to provide life-saving COVID-19 treatment to everyone who needs it. Crisis standards of care may be invoked to decide who receives a ventilator or an Intensive Care Unit bed, for example, if these resources are rationed due to shortages. In some cases, individual medical providers have made their own decisions about allocating scarce medical treatment apart from any formalized crisis standards of care.

Are there concerns that some crisis standards of care may reflect unlawful discrimination?

Yes. As discussed further below, while crisis standards of care typically prioritize patients who are more likely to survive hospitalization, many have included provisions that discriminate based on disability, age, and race in violation of civil rights laws. For example, some crisis standards of care have categorically excluded or given lower priority to people living with particular disabilities. Others have excluded or given lower priority to people based on a speculative presumptions they are unlikely to live more than five years. Sometimes, these standards give lower priority to people based solely on age, even where the individual could benefit from treatment and survive.

Disabled people of color may also be disproportionately denied life-saving care when crisis standards of care are in effect. These groups often experience higher rates of health conditions, as a result of poorer medical treatment, medical neglect, and lower availability of medical facilities and resources in communities of color. The higher incidence of health problems makes it more likely that disabled people of color will be denied treatment if medical treatment is rationed during the pandemic using discriminatory crisis standards of care.

What is "intersectional discrimination?"

As discussed further below, crisis standards of care may discriminate against people due to biased assumptions physicians tend to hold regarding people of color, people with disabilities, higher weight people, and older adults. When people have more than one status associated with bias in medicine, they face discrimination that is layered, compounded, and distinct. For example, disabled people of color face dual discrimination, especially where the state or hospital has authorized exclusion of certain individuals in its crisis standards of care. For purposes of this discussion, we refer to this as "intersectional discrimination," where individuals may face discrimination based on their overlapping identities or circumstances.

II. PRINCIPLES FOR CRISIS STANDARDS OF CARE

The lives of Black, Indigenous and People of Color, disabled people, higher weight people, and older adults are equally worthy as the lives of others.

Discrimination based on disability is pervasive in the medical profession.² Nondisabled medical professionals frequently presume that disabled people have a lower quality of life, reflecting a lack of understanding about how people with significant disabilities can live fully, enjoy their lives as much as anyone else, achieve as much or more than others, and where necessary develop alternative strategies to accomplish goals that others assume are off-limits to them.³

- i. Discrimination based upon race is pervasive in the medical profession. Health professionals often provide worse care to African Americans when compared to whites experiencing the same health conditions.⁴ Communities of color are systematically allocated fewer health care resources than white communities.⁵
- ii. Black, Indigenous and People of Color are likely to experience intersectional discrimination due to both racial bias and biased assumptions regarding the value of the lives of disabled people.
- iii. Black, Indigenous and People of Color, disabled people, higher weight people, and older adults must have an equal opportunity to receive life-saving treatment.⁶
- iv. Yet crisis standards of care in many states would, if implemented, subject individuals to discrimination in receiving life-saving care based on disability, age, and race or ethnicity alone or in combination.
- v. Many crisis standards of care discriminate on their face, excluding or giving lower priority to individuals based on having certain disabilities, on age, on presumed life expectancy or remaining "life years", on the intensity or duration of treatment that an individual is presumed to need, or on a presumption that the individual has a lower quality of life due to a disability.⁷
- vi. These standards would result in denials of life-saving treatment to people with disabilities and older adults who could benefit from and survive COVID-19 treatment. They would also result in disproportionate denials of life-saving treatment to Black, Indigenous and People of Color who could benefit from and survive treatment.
- vii. Individuals who are likely to survive hospitalization for COVID-19 should not be disqualified from receiving treatment based on concerns about their age, disabilities, life expectancy, quality of life, or resources they may require for treatment.
- viii. Doctors also lack the ability to predict, with accuracy, how a disability will impact a person's life expectancy. Studies show that doctors are unable to accurately predict how long an individual with a particular disability or health condition will live,⁸ and countless disabled people have lived far longer than doctors predicted.
- ix. Physicians who exclude individuals from treatment or give them lower priority based on disability or age when the individuals are likely to survive treatment violate antidiscrimination laws, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and the Age Discrimination Act.
- x. Physicians who exclude individuals from treatment or give them lower priority based on race or ethnicity when they are likely to survive treatment violate Title VI of the Civil Rights Act of 1964 and Section 1557 of the Affordable Care Act.

III. MEDICAL BIAS AND COVID-19

Crisis standards of care have often reflected a bias against disabled people and older adults. They typically prioritize care towards patients who are younger and do not have disabilities, excluding or de-prioritizing those who have certain health conditions, those who are presumed unlikely to survive in the intermediate or long term, and those presumed to require greater resources to survive the acute episode of illness. Crisis standards of care, therefore, may direct medical resources away from those with certain disabilities due to medical bias, which can be conscious or unconscious.

The significance of this bias is compounded by the reality that disabled people and older adults are disproportionately affected by the pandemic. According to a report issued by the Senate Health, Education, Labor, and Pensions Committee:

While very few states are disaggregating data related to COVID-19 by disability status, an independent analysis showed as of June 2020, people with intellectual disabilities and autism in Pennsylvania were twice as likely to die from COVID-19, and people with developmental disabilities in New York were 2.5 times as likely to die compared to COVID-19 patients without disabilities. Another independent study found that individuals with developmental disabilities between the ages of 18 and 74 had a death rate from COVID-19 of nearly twice that of their same-age peers without disabilities.⁹

People of color may also be disparately impacted by discriminatory crisis standards of care. Black and Indigenous people have higher rates of disability than other race and ethnic groups, so are more likely to be evaluated adversely under treatment rationing protocols.¹⁰ Fourteen percent of African-Americans have a disability while only 11 percent of non-Hispanic whites and eight percent of Latinos do.¹¹

Similarly, people of color are more likely to have underlying conditions that are highly correlated with COVID-19 complications and increased risk of death. According to the CDC, severe illness from COVID-19 is correlated with type 2 diabetes, chronic kidney disease, sickle cell disease, and being higher weight, among other disabilities. People of color are more likely than white people to have each of these medical conditions. For example, Black people experience higher prevalence of diabetes, kidney failure, and sickle cell disease than white people; Hispanic people are more likely to have diabetes or kidney failure compared to non-Hispanic white people; and American Indian and Alaska Native people are almost three times more likely to be diagnosed with diabetes and 1.6 times more likely to be diagnosed with chronic liver disease compared to white people.

Public health researchers have come to recognize "that discrimination and structural racism are key contributors to inequity in health behaviors and outcomes."¹² Racial disparities in health such as the pervasiveness of poverty,¹³ chronic health conditions, and higher mortality rates—though often attributed to the behavior of individuals or groups—stem from decades of systemic inequities in education, employment, housing, and access to health care and health insurance.¹⁴ For example, in 2017, 10.6 percent of African Americans, were uninsured compared with 5.9 percent of non-Hispanic whites, a rate twice that of non-Hispanic whites.¹⁵ Access to health insurance correlates with the quality of health (and perceptions of one's health). Consider the rates of health insurance in conjunction with self-reports of quality of health: 13.8 percent of African Americans reported having fair or poor health compared with 8.3 percent of non-Hispanic whites.¹⁶

Black, Indigenous, and People of Color experience food¹⁷ and housing insecurity at higher rates than Whites. Structural racism in access to credit, for example, has forced communities of color to rent as opposed to own their homes, leaving them susceptible to predatory landlords, environmental toxins, and the inability to accumulate wealth relative to non-Hispanic whites.¹⁸ During the pandemic, this has meant higher rates of eviction for Black, Indigenous, and People of Color.¹⁹ In the aggregate, these socio-economic factors situate Black, Indigenous, and People of Color, particularly those with disabilities, as high risk for the contraction of COVID-19 and related complications.

Additionally, LGBTQIA+ people also experience high rates of certain diseases – including asthma and diabetes – that place them at risk of getting COVID-19 or experiencing poorer outcomes related to the virus.²⁰ And people in poverty are less able to treat disabling conditions and to mitigate their impact: Limited access to high quality medical care and early intervention may mean that a condition goes untreated longer and has potentially more severe long-term effects.²¹

Further, as discussed above, medical bias already leads providers to provide worse care, or even no care, to patients of color. Studies show that health professionals provide less aggressive pain management and treatment to African Americans when compared to whites experiencing the same health conditions.²² This bias has been widely documented in the context of the pandemic, as both anecdotal evidence from around the country and data shows hospitals turn patients seeking care for COVID-19 symptoms at higher rates than white patients.²³ For example, data collected by the Virginia Department of Health showed that non-Hispanic whites are admitted to emergency departments in the Central Region of Virginia at a higher rate than other races.²⁴ Thus, bias very likely prevents providers from administering life-saving care to marginalized communities.

Together with strained medical resources and implicit medical bias, higher rates of pre-existing conditions that make COVID-19 deadlier may lead providers to deny critical care to people of color, disabled people, or people who live at the intersections of these identities.

IV. CRISIS STANDARDS OF CARE AND CIVIL RIGHTS LAW

All doctors must adhere to a "standard of care" in the provision of medical care. In general, a standard of care means the care provided is consistent with that of other competent physicians in their community. There is no universal standard of care, but physicians must adhere to federal civil rights laws in the provision of care.

Likewise, states often create their own crisis standards of care, through regulation or special order. These crisis standards permit physicians to forgo typical treatment, in order to better allocate scarce medical resources, such as ventilators or special medications. For example, although the usual standard of care may require physicians to intubate patients with respiratory failure, a crisis standard of care permits physicians to deny this care to some patients under certain circumstances.

Although states may appropriately encourage or require the use of crisis standards of care, those standards must still comply with federal civil rights laws, which remain in effect. Some standards of care discriminate on their face against people with disabilities, in clear violation of state and federal anti-discrimination laws. Other crisis standards of care are not, on their face, discriminatory or unlawful. However, the risk of unlawful discrimination against disabled people and people of color is outsized due to medical bias, especially when crisis standards of care are in effect. States, hospitals, and advocates must therefore remain vigilant that patients' civil rights are zealously protected and upheld during the pandemic.

A. The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act

i. What are medical providers' duties under the ADA and Section 504 when crisis standards of care are in effect.⁹

Medical providers must be aware of their duties under the ADA, as well as Section 504 of the Rehabilitation Act. Both laws prohibit discrimination on the basis of disability under any program or activity receiving federal financial assistance, even while crisis standards of care are in effect. Title III of the ADA, specifically, prohibits discrimination based upon disability in places of public accommodation, such as hospitals and doctors' offices:

No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to) or operates a place of public accommodation.²⁵

As summarized by one federal court, "[d]iscrimination in public accommodation can take the form of the denial of the opportunity to receive medical treatment, segregation unnecessary for the provision of effective medical treatment, unnecessary screening or eligibility requirements for treatment, or provision of unequal medical benefits based upon the disability."²⁶

Title II of the ADA similarly prohibits states and local governments from discriminating against people with disabilities.²⁷ ADA regulations provide that:

A public entity shall not impose or apply eligibility criteria that *screen out or tend to screen out* an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.²⁸

Despite these clear directives, many crisis standards of care discriminate in that they "screen out or tend to screen out" certain groups from receiving life-saving care. For example, in a document since taken down from the state's website, Alabama indicated that individuals with severe or profound intellectual disability "are unlikely candidates for ventilator support."²⁹ Crisis standards of care that exclude or give lower priority of care to people with certain medical conditions also violate the ADA. The ADA protects against discrimination based on conditions such as "orthopedic, visual, speech, and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV disease (whether symptomatic or asymptomatic), tuberculosis, drug addiction, and alcoholism."³⁰ Yet, in Tennessee, the state initially excluded from COVID-19 treatment and critical care 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 ventilator support."³¹ Such standards are likely unlawful under the ADA.

ii. What types of discrimination are prohibited by the ADA and Section 504?

Federal law prohibits practices that outright discriminate by directly targeting a specific group of people, such as a policy that excludes people with ALS from receiving ventilator care. However, civil rights laws, like the ADA and Section 504, also prohibit policies that appear neutral on their face, but have a discriminatory impact. Thus, even crisis standards of care that are neutral can be applied in a discriminatory manner. This is especially true where bias may lead physicians to disproportionately exclude disabled people of color from receiving life-saving care under the guise of applying a neutral crisis standard of care.

B. The Age Discrimination Act of 1975 (the Age Act)

The Age Act prohibits discrimination based on age in federally funded programs.³² Federal regulations also prohibit discrimination on the basis of age in programs or activities receiving federal funds from Health and Human Services (HHS).³³

Actions otherwise prohibited by the Age Act may be allowed, if these actions are part of the actor's "normal operation" and the action is based on "reasonable factors other than age" as determined by the following four-part test:³⁴

(a) age used to measure or approximate another characteristic;

(b) other characteristic must be measured or approximated for the normal operation of the program or activity to continue;

(c) other characteristic can be reasonably measured or approximated by use of age; and

(d) other characteristic is impractical to measure directly on an individual basis. $^{\scriptscriptstyle 35}$

Many crisis standards include age-based "tiebreakers" that discriminate against older adults. Tiebreakers occur when two or more patients have similar clinical prognoses but limited resources are available for both patients. In that instance, age would be used to "break the tie," such that the older patient loses access to potentially lifesaving treatment, even if they would otherwise survive. Crisis standards may try to use age as a proxy for short-term survival. However, this is inconsistent with the Age Act's fourpart test since individualized, clinical assessments can and must be used to determine survivability. Furthermore, crisis standards by their very nature are only activated outside of the "normal operation of the program or activity," thus prohibiting agebased tiebreakers under the Age Act.

C. Title VI of the Civil Rights Act

Title VI of the Civil Rights Act prohibits discrimination against people on the basis of race, color, and national origin by federally funded health care providers. Thus, crisis standards of care that tend to exclude patients of color may violate this law.³⁶ Although no crisis standards of care have explicitly excluded people of color, many give lower priority to patients with pre-existing conditions that disproportionately impact people of color. For example, Pennsylvania's Interim Crisis of Care listed heart failure, chronic lung diseases, and end stage renal disease as medical conditions that would give a lower priority score to patients with these diseases.³⁷ However, Black people experience kidney failure at three times the rate of white people, and Black and Hispanic people have the highest incidence rates of heart failure.³⁸ Patient advocates and providers should therefore be cognizant that utilizing specific co-morbidities as determinants for ventilator support and other medical interventions may disproportionately deny care to people of color in violation of Title VI.

Second, as discussed above, medical bias against people of color is rampant throughout the U.S. healthcare system. Physicians harboring such bias may deny patients of color life-saving care, even when their white counterparts have similar prognoses. This is especially likely when resources are limited. However, patients' civil rights must be guarded, particularly when they are most vulnerable to discriminatory treatment.

D. Section 1557 of the Affordable Care Act

Section 1557 of the Affordable Care Act prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in: (1) any health program or activity, any part of which receives funding from HHS, (2) any program or activity that HHS administers under Title I of the ACA, such as the federally-facilitated marketplace, and (3) health insurance marketplaces and all plans offered by issuers that participate in those marketplaces.

V. STRATEGIES FOR ERADICATING DISCRIMINATORY ALLOCATION OF PATIENT CARE RESOURCES

Because medical bias is likely to lead to the denial of care for vulnerable patients, providers and public health officials should employ the following strategies to ensure health care resources are equitably distributed:

1) Any entity developing or implementing crisis standards of care must ensure that those standards do not create the potential to exclude protected classes of people in violation of civil rights laws. Health care professionals cannot ignore the enormous risk of discrimination disabled people, people of color, and people at the intersections of these identities face. Crisis standards of care should thus acknowledge this potential, identify discriminatory practices in the allocation of health care resources, and expressly reject any such practices.

2) Crisis standards of care must set forth the protection of patients' civil rights as guiding principles. Rather than solely prioritizing saving younger, nondisabled people, providers must give equal prioritization to the protection of their patients' rights to be free from discrimination in all forms.

3) Crisis standards of care must encourage and require anti-racist and anti-ableist training for health care providers. Even where crisis standards of care expressly reject discrimination, physician bias may nonetheless lead them to discriminatorily deny patients care on the basis of their race or disability status. It is therefore critical that physicians receive training in how to distribute health care resources in a manner that is both anti-racist and anti-ableist.

4) Crisis standards of care cannot exclude or deprioritize individuals for treatment unless the individual is unlikely to survive COVID-19 treatment in the short term. Because nearly every other measure of a patient's medical condition will cause physicians to discriminatorily deny care to disabled patients and people of color, physicians must consider only a patient's ability to survive COVID-19 treatment in the short term—that is, through the acute episode of illness.

5) Crisis standards of care cannot make categorical exclusions on the basis of disability or pre-existing conditions. Doing so is a clear violation of the aforementioned civil rights statutes, and are therefore prohibited.

6) Assessments of the quality of life of patients with particular disabilities should never be used to deny treatment. Plans must steer clear of criteria that screen out people with disabilities based on quality of life considerations, which would violate the rights of people with disabilities under Title II and Title III of the ADA. Instead, consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities.

7) Hospitals must not ration care based upon long-term survival probability. Some plans ration care based upon an estimate by a physician of a patient's long term surviva given their pre-existing disabilities. Allocating care based on such estimates of long-

term survival violate federal disability rights laws.³⁹ Moreover, physicians are unable to correctly predict how long any person has left to live, making this is a flawed strategy for allocating resources. Therefore, hospitals must not ration care based on determinations of a patient's long-term survivability.

8) Treatment allocation decisions may not be made based on the perception or reality that a person's disability may require the use of greater treatment resources, either in the short or long term. Under Titles II and III of the ADA and Section 504, reasonable modifications must be made to ensure patients with a disability have an equal opportunity to benefit from COVID-19 treatment. These may include interpreter services, or other modifications or additional services needed because of a disability. Plans that do not allow for variations in recovery that consider the perhaps lengthier time for those with disabilities to recover can violate disability laws.

9) Provide reasonable access to patient support persons. Patient advocacy is an important tool that individuals can use to combat discriminatory treatment. Hospitals must generally allow family, community agency personnel, or other designated caregivers to visit patients with disabilities who need extra support at the hospital. In most circumstances, allowing visitation under these circumstances, with appropriate protection, will be a reasonable modification required by the ADA and Section 504.

VI. CONCLUSION

There is no question that the pandemic exposed existing health inequities and the deeply entrenched medical bias that has led to many poor outcomes. Though wellmeaning, crisis standards of care have massive potential to exacerbate these biases and inequities by directing health resources away from people of color, disabled people and individuals who live at the intersection of marginalized identities. However, if guided by the above civil rights principles, it is possible to ensure resources are equitably distributed in alignment with federal laws.

¹ Higher weight people are disproportionately people of color and people with disabilities, and are often perceived as people with disabilities.

² See, e.g., Samuel R. Bagenstos, Who Gets the Ventilator? Disability Discrimination in COVID-19 Protocols. Medical-Rationing 130 Yale L.J. Forum (2020).1. https://papers.ssrn.com/sol3/papers.cfm?abstract id=3559926; David Carlson, Cindy Smith, Nachama Wilker, Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights, National Disability Rights Network and Disability Washington Rights p.40 (2012).http://ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.p df; Jasmine E. Harris, The Frailty of Disability Rights, 169 U. L. REV. Online 29, 33 (2020), at https://scholarship.law.upenn.edu/cgi/viewcontent.cgi?article=1232&context=penn law review online].

³ See, e.g., Rebecca Sohn, Large Majority of doctors hold misconceptions about people with disabilities, survey finds, STAT, Feb. 1, 2021, <u>https://www.statnews.com/2021/02/01/large-majority-of-doctors-hold-misconceptions-about-people-with-disabilities-survey-finds/</u> (citing recent study in which 82% of doctors surveyed reported a belief that people with significant disabilities have a worse quality of life than people without disabilities).

⁴ See, e.g., Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, and M. Norman Oliverb, "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites," Proceedings of the National Academy of Science 113, no. 16 (April 19, 2016): 4,296–301, <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4843483/</u>

⁵ American Academy of Family Physicians, Institutional Racism in the Health Care System (July 2019), https://www.aafp.org/about/policies/all/institutional-racism.html.

⁶ See California Department of Public Health, California SARS-CoV-2 Pandemic Crisis Care Guidelines (June 2020) ("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."), https://tinyurl.com/CA-crisisstandards

⁷ See "Evaluation Framework for Crisis Standard of Care Plans," https://tinyurl.com/y2wojtfb.

⁸ See, e.g., Joao Gabriel Rosa Ramos, et al., Prognostication in urgent intensive care unit referrals: a cohort study, BMJ Supportive & Palliative Care (2018); Catherine S. Hibberd and Gerald M. Y. Quan, Accuracy of Preoperative Scoring Systems for the Prognostication and Treatment of Patients with Spinal Metastases, International Scholarly Research Notices (2017); Nicola White, et al. A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? 11:8 PLOS One (Aug. 2016); Stephanie Cheon, *et. al*, The accuracy of clinicians' predictions of survival in advanced cancer: a review, 5:1 Ann Palliat Med 22 (2016); Kevin M.Y.B. Leung, MD, *et al.*, Challenging the 10-year rule: The accuracy of patient life expectancy predictions by physicians in relation to prostate cancer management, 6:5 Canadian Urological Ass'n J. (Oct. 2012); Irene J Higginson and Massimo Costantini, Accuracy of prognosis estimates by four palliative care teams: a prospective cohort study, I:1 BMC Palliative Care (Mar. 2002).

⁹ "COVID-19 & ACHIEVING HEAL TH EQUITY: Congressional Action Is Necessary To Address Racism And Inequality In The U.S. Health Care System." *Senate HELP Committee*, U.S. SENATE COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS RANKING MEMBER PATTY MURRAY (D-WA), Sept. 2020, https://tinyurl.com/SenateHELP.

¹⁰ "Infographic: Adults with Disabilities: Ethnicity and Race." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, 16 Sept. 2020, https://tinyurl.com/CDC-disabilities.

¹¹ Goodman, Nanette, et al. "Financial Inequity: Disability, Race, and Poverty in America." *National Disability Institute*, https://tinyurl.com/Disabilityrace.

¹² Angela M. Odoms-Young, Examining the Impact of Structural Racism on Food Insecurity:

Implications for Addressing Racial/Ethnic Disparities, 41 Fam Community Health 1, 2 (2018).

¹³ Jessica Semega et al., "Income and Poverty in the United States: 2019" (Washington: U.S. Census Bureau, 2020), available at

https://www.census.gov/content/dam/Census/library/publications/2020/demo/p60-270.pdf (finding that Black, Latinx, and Indigenous communities comprised a majority of the 34 million people living in poverty in 2019).

¹⁴ Sofia Carratala and Connor Maxwell, *Fact Sheet: Health Disparities By Race and Ethnicity*, Center for American Progress, May 7, 2020, *available at*

https://cdn.americanprogress.org/content/uploads/2020/05/06130714/HealthRace-

factsheet.pdf?_ga=2.227274653.1883193698.1611885172-1034168289.1609556806.

¹⁵ *Id.* (citation omitted).

¹⁶ *Id.* at 1-2.

¹⁷ Angela M. Odoms-Young, *Examining the Impact of Structural Racism on Food Insecurity: Implications for Addressing Racial/Ethnic Disparities*, 41 Fam Community Health 1, 1 (2018) (documenting the "persist[ant] gap in the prevalence of food insecurity between people of color and whites"). For example, food insecurity rates for both non-Hispanic Black and Hispanic households were at least twice that of non-Hispanic white households. *Id.*

¹⁸ Jaboa Lake, *The Pandemic Has Exacerbated Housing Instability for Renters of Color*, Center for American Progress, Oct. 30, 2020, at

https://www.americanprogress.org/issues/poverty/reports/2020/10/30/492606/pandemic-exacerbated-housing-instability-renters-color/.

¹⁹ *Id*.

²⁰ COVID-19 & ACHIEVING HEAL TH EQUITY, supra.

²¹ Financial Inequity, supra.

²² See e.g. Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, and M. Norman Oliverb, "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites," Proceedings of the National Academy of Science 113, no. 16 (April 19, 2016): 4,296–301, <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4843483/</u>

²³ Eligon, John, and Audra. "Questions of Bias in Covid-19 Treatment Add to the Mourning for Black Families." *The New York Times*, The New York Times, 10 May 2020, https://tinyurl.com/yydcbgno; Grubbs, Vanessa. "The Health Care System Has the Black Community in a Choke Hold." *California Health Care Foundation*, 5 Aug. 2020, https://tinyurl.com/CHCFbias.

²⁴ "COVID-19 Like Emergency Department Visits by Race & Ethnicity – Updated." *Virginia Department* of *Health.*, 17 July 2020, www.vdh.virginia.gov/coronavirus/2020/06/16/cli_ed_race_eth/.

²⁵ 42 U.S.C.A. § 12182 (a)

²⁶ *Howe v. Hull*, 873 F.Supp. 72, 78 (N.D.Ohio,1994) (citing 42 U.S.C. § 12182(b)(1)(A)(i), § 12182(b)(1)(A)(iii), § 12182(b)(2)(A)(i), § 12182(b)(1)(A)(ii))

²⁷ 42 U.S.C. §§ 12131-12134.

²⁸ 28 C.F.R. § 35.130(b)(8)

²⁹ 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://tinyurl.com/AL-Complaint

³⁰ 28 CFR 36.104 (1)(iii)

³¹ See March 27, 2020 OCR Complaint, https://tinyurl.com/DisabilityTN. In response to the complaint and OCR engagement though, Tennessee removed these categorical exclusions See June 26, 2020 OCR Resolution: https://tinyurl.com/y5jdkkpu; 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), https://tinyurl.com/TNGuidance ³² 42 U.S.C. § 6102.

³³ 45 CFR § 91.3; 45 C.F.R. § 92.4.

³⁴ 45 CFR § 91.14.

³⁵ 45 C.F.R. § 91.13.

³⁶ Disparate impact violations of Title VI are enforced by the federal government. See 28 C.F.R. § 42.104(b)(2) (DOJ); 45 C.F.R. § 80.3(b)(2) (HHS) (both stating that federally funded entities may not "utilize criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, color, or national origin.").

³⁷ "Interim Pennsylvania Crisis Standards of Care." *New York Times*, Pennsylvania Department of Health, https://tinyurl.com/Penn-crisis.

³⁸ African Americans and Kidney Disease." *National Kidney Foundation*, 16 Feb. 2018, www.kidney.org/news/newsroom/factsheets/African-Americans-and-CKD; Bahrami, Hossein, et al. "Differences in the Incidence of Congestive Heart Failure by Ethnicity: the Multi-Ethnic Study of Atherosclerosis." *Archives of Internal Medicine*, U.S. National Library of Medicine, 27 Oct. 2008, www.ncbi.nlm.nih.gov/pmc/articles/PMC3038918/.

³⁹HHS's Office for Civil Rights resolved complaints challenging crisis standards of care used by the state of North Carolina and the North Texas Mass Critical Service as violative of disability rights laws after those entities agreed, among other things, to eliminate provisions that made a patient's long-term life expectancy a factor in allocating life-saving treatment.