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# Identifying And Exploring Bias In Public Opinion On Scarce Resource Allocation During The COVID-19 Pandemic

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**ABSTRACT** The COVID-19 pandemic offers an opportunity to examine public opinion regarding the allocation of scarce medical resources. In this conjoint experiment on a nationally representative sample of US adults, we examined how a range of patient characteristics affect respondents' willingness to allocate a ventilator between two patients with equal likelihood of short-term survival and how this differs by respondents' attributes. Respondents were 5.5 percentage points less likely to allocate a ventilator to a patient with a disability than to a nondisabled patient. Disability bias was correlated with older age cohorts and higher education levels of respondents. Liberal and moderate respondents were more likely to give a ventilator to Black and Asian patients than to White patients. Conservatives were much less likely to allocate a ventilator to transgender patients than to cisgender patients. These findings demonstrate the importance of bias mitigation and civil rights enforcement in health policy making, especially under conditions of scarcity.

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The Americans with Disabilities Act (ADA) of 1990 sought to alleviate discrimination against people with disabilities by codifying disability-based protections into civil rights law. Coupled with the ADA Amendments Act of 2008, which clarified that the definition of *disability* should be interpreted broadly (encompassing well-controlled chronic conditions, such as diabetes, alongside more obvious disabilities), the ADA is an important tool for addressing discrimination against people with disabilities in health care.

In spite of these protections, people with disabilities experience more denial of care, more negative treatment by health care providers, and worse health outcomes compared to people without disabilities.<sup>1-3</sup> Recent work suggests that these disparities result, in part, from clinicians' beliefs that people with disabilities have lower quality of life than nondisabled people.<sup>2,3</sup> Mem-

bers of the general public may hold similar beliefs, and these attitudes might contribute to public policies that discriminate against people with disabilities. Yet existing scholarship has paid little attention to understanding the nature of disability bias among the general public.

This gap in the research limits understanding of the role of disability bias in public policy. Before distributing resources to specific recipients, policy makers engage in what scholars call "anticipatory feedback," attempting to gauge the popularity and political feasibility of policies according to the public's assessment of each group's deservingness and their willingness to sustain sacrifices to benefit (or punish) members of target populations.<sup>4</sup> Public perceptions also influence policy making more directly by shaping the views, agendas, and behaviors of the bureaucrats who implement policy.<sup>5,6</sup>

Previous research found that the public prioritizes people with disabilities when it comes to

the allocation of cash assistance.<sup>7,8</sup> Less is known, however, about contexts involving the allocation of scarce medical resources. In contrast to the redistribution of taxpayer funds in the form of cash assistance,<sup>9</sup> one might expect that in a pandemic, many will understand themselves as being in direct competition with others for resources should they become sick. COVID-19 might therefore trigger feelings of anxiety, discomfort,<sup>10,11</sup> and even anger toward people with disabilities—all emotions that are likely to be stimulated when people feel that they are competing for scarce resources or when they believe that others are being given special privileges.<sup>10-12</sup>

Because of the large numbers of patients in the US who had COVID-19 during spikes, hospitals have faced acute shortages of ventilators, beds, medications, and other critical care resources, leading to the creation or activation of policies regarding crisis standards of care.<sup>13</sup> Such policies are intended to provide guidance to health care providers about how to allocate scarce resources during a public health emergency. These policies have often incorporated potentially discriminatory provisions ranging from categorically excluding people with specific disabilities from care to applying prioritization criteria (such as expectations for long-term survival or lower resource use) that disadvantage people with disabilities by giving them lower priority.<sup>13-16</sup>

Concerns about discrimination in the implementation of crisis standards of care have prompted state and federal oversight activities by both legislators and regulators during the pandemic, including guidance from the Department of Health and Human Services (HHS) Office for Civil Rights on the application of disability civil rights law to implementing crisis standards of care.<sup>14-16</sup> In response, crisis standards of care plans have evolved considerably to remove provisions that discriminate on the basis of disability.<sup>13</sup>

Regulators seeking evidence to inform civil rights enforcement in health care can benefit from empirical data on the nature of prejudice against specific populations. Public opinion research has examined preferences regarding crisis standards of care policy making, but these studies have typically used methodologies that are susceptible to social desirability bias;<sup>17</sup> surveyed non-US populations; or inquired about broad allocative principles, such as whether patients should be deprioritized because of long-term life-expectancy, without tying them to specific disabilities.<sup>18-20</sup> This lack of specificity in studying public opinion is a major limitation of previous work, as the social construction of a particular disability may trigger different responses than broad ethical principles would.

To address these limitations and to examine the extent to which disability bias has emerged in the allocation of scarce resources during the COVID-19 pandemic, we conducted a conjoint experiment on a nationally representative sample of the US public. Conjoint experiments were initially developed by business scholars to uncover specific attributes driving product preferences.<sup>21</sup> Political scientists have applied this methodology as a way to understand bias toward groups.<sup>22-24</sup> In our study, survey respondents made a series of choices between two personal profiles that randomly varied on multiple dimensions of interest. This method mitigates social desirability bias by allowing respondents to avoid acknowledging any specific characteristic as the reason for choosing a hypothetical individual for the allocation of benefits or burdens.<sup>22-24</sup> Respondents thereby reveal hidden preferences that they might not otherwise acknowledge. Findings from our conjoint experiment shed light on how various patient attributes affect the public's beliefs regarding who should receive access to scarce medical resources during the COVID-19 pandemic.

## Study Data And Methods

The Institutional Review Board of Miami University (Oxford, Ohio) approved this study.

**CONJOINT STUDY DESIGN** We presented respondents with a choice scenario in which they would have to select which one of two patients with an equal likelihood of short-term survival would get a hospital's last available ventilator (for a sample conjoint choice task, see online appendix exhibit 1).<sup>25</sup> The patients in the scenario varied randomly along several characteristics, including gender (cisgender man, cisgender woman, transgender man, transgender woman), race (White, Black, Asian), age (chosen from the following ranges: 21-31, 41-51, 65-75), employment status before the COVID-19 outbreak (employed, unemployed), whether the patient followed Centers for Disease Control and Prevention (CDC) social distancing guidelines<sup>26</sup> (followed, did not follow), and disability status.

If the patient had a disability, respondents were told the name of the disability and received a brief description, including information about its impact on life expectancy (lower long-term life expectancy, can have a normal life span) and typical onset (present from birth, can get it at any time, manifests in young adulthood) (appendix exhibit 2).<sup>25</sup> We tested six disabilities (type 2 diabetes, congenital heart defect, paraplegia, intellectual disability, traumatic brain injury, bipolar disorder) that were selected because they vary in ways that allowed us to explore whether

# The public's willingness to deprioritize disabled patients reflects bias against disabled people regardless of life expectancy.

respondents' choices varied between patients with physical or mental disabilities, those with lower and normal long-term life expectancy, and those with different times of disability onset. Although some previous public opinion research about ventilator allocation has asked respondents about broad allocative principles,<sup>18–20</sup> we believe that inquiring about specific disabilities is more likely to elicit a response consistent with real-world responses to specific allocative dilemmas.

**SAMPLE** Using the polling firm YouGov, we surveyed respondents from January 29 to February 4, 2021—a period during which COVID-19 case counts remained high and vaccine access was limited. By recruiting respondents through multiple methods (mainly targeted online advertising), YouGov maintains a panel of respondents who have agreed to take its surveys. The firm uses email solicitation to invite participants to complete surveys electronically.

YouGov ensured that respondents were representative of the total US adult population by matching its panelists to a target sample from the Census Bureau's 2018 American Community Survey. After matching, YouGov used propensity score weighting and poststratification to correct for any remaining differences between the matched survey sample and the target sample (see notes in appendix exhibit 3 for details).<sup>25</sup>

Our final sample consisted of 2,500 respondents, using the weights provided by YouGov (see appendix exhibit 3).<sup>25</sup> Each respondent was presented with four iterations of the choice scenario, resulting in 10,000 binary choices for analysis. Before conducting the study, we used the Sawtooth Guideline for Conjoint Power Analysis to ensure that our sample size was sufficient to detect a 5-percentage-point change in the dependent variable for main effects and interactions.<sup>27</sup>

**ANALYSIS** We hypothesized that respondents would be more likely to deny ventilators to patients with disabilities than to patients without disabilities. We also hypothesized that respondents would deprioritize patients with lower long-term life expectancy and patients with non-congenital disabilities (that is, those that did not begin at birth). We classified each disability as physical or mental (see appendix exhibit 2)<sup>25</sup> to test our hypothesis that mental disabilities would be deprioritized more than physical disabilities. Drawing on theories of intersectionality (which posit that intersecting axes of marginalization produce inequalities that are different from the results of each axis on its own), we hypothesized further that patients who were marginalized along multiple dimensions would experience compounded bias greater than the sum of each individual dimension added together.<sup>28</sup> We categorized as marginalized the following patient groups: cisgender women, transgender men, transgender women, Black people, Asian people, people with disabilities, unemployed people, and people over age sixty-five. All hypotheses were preregistered with the Center for Open Science's Open Science Framework.<sup>29</sup>

Consistent with established norms for conjoint experiments, we used multivariate linear regression incorporating all randomized traits as covariates. We also tested interactions between patients' disability status and respondent demographics (gender, race and ethnicity, age cohort, education), as well as respondents' self-reported political ideology and importance of religion (see appendix exhibit 4 for respondent characteristic questions).<sup>25</sup> Our analyses used the weights provided by YouGov. As a robustness check, we produced unweighted analyses with standard errors clustered at the respondent level. These analyses produced substantively similar results (see appendix exhibits 12–16).<sup>25</sup>

**LIMITATIONS** We acknowledge several limitations. Although our representative sample can be generalized to the US public, the data should not be taken as representing particular categories of professionals such as clinicians, crisis standards of care policy makers, elected officials, or regulators. Because we aggregated individual disabilities into categories for analysis on the basis of their disability (physical, mental), impact on long-term life expectancy, and typical onset, specific disabilities may have driven some results. Therefore, we did not generalize conclusions to a broader category if a finding was driven only by a single disability (for example, if we found through incorporating individual disabilities into our regression that only diabetes showed an effect, whereas other acquired disabilities did not, we did not generalize the effect

to all acquired disabilities).

Although we were able to identify the causal effect of the randomly assigned patient attributes on the likelihood of being allocated a ventilator, we could not identify causal effects of respondent attributes because we could not randomly assign respondents to particular demographic categories as we did the hypothetical patients. We could highlight correlations between respondents' attributes (such as education level) and a lower likelihood of selecting certain kinds of patients, but we could not know for sure whether these attributes were causing the change or whether the relationship was driven by an unobservable factor.

Finally, we note that there are inherent tradeoffs between forced-choice questions, such as those in our conjoint experiment, and open-ended ones. Open-ended questions would have allowed respondents to express detailed opinions on their preferred systems for fair allocation of a ventilator. However, the responses yielded from our conjoint design are less susceptible to social desirability bias and more likely to identify hidden preferences.

## Study Results

**IMPACT OF DISABILITY AND OTHER PATIENT CHARACTERISTICS** As reflected in exhibit 1, respondents were 5.5 percentage points ( $p < 0.001$ ) less likely to allocate a ventilator to a patient with a disability than to a patient without a disability (details found in appendix exhibit 5).<sup>25</sup> The level of deprioritization did not significantly vary by disability category (appendix exhibit 6).<sup>25</sup> Respondents were also less likely to allocate a ventilator to transgender patients, patients ages 41–51 and 65–75, patients who had been unemployed before the pandemic, or patients who did not follow CDC guidelines (all at  $p < 0.001$  significance). Contrary to our hypothesis, respondents were 5.2 percentage points more likely to select Black patients ( $p < 0.001$ ) than they were to select White patients. Also contrary to our hypotheses, there were no significant differences in respondents' allocation decisions for patients with lower versus normal life expectancies ( $p = 0.511$ ), acquired versus congenital onset ( $p = 0.405$ ), or physical versus mental disabilities ( $p = 0.670$ ) (see appendix exhibit 6).<sup>25</sup> We also found no significant interactions between the marginalized patient identities other than disability (see above) and individual disabilities or between those identities and disability aggregated across types (appendix exhibits 7 and 8).<sup>25</sup> We did, however, find a significant interaction between prior employment status and acquired disability ( $p = 0.048$ ;

## Our results show that completing higher education does not prevent disability bias and may instead be associated with it.

appendix exhibit 7).<sup>25</sup>

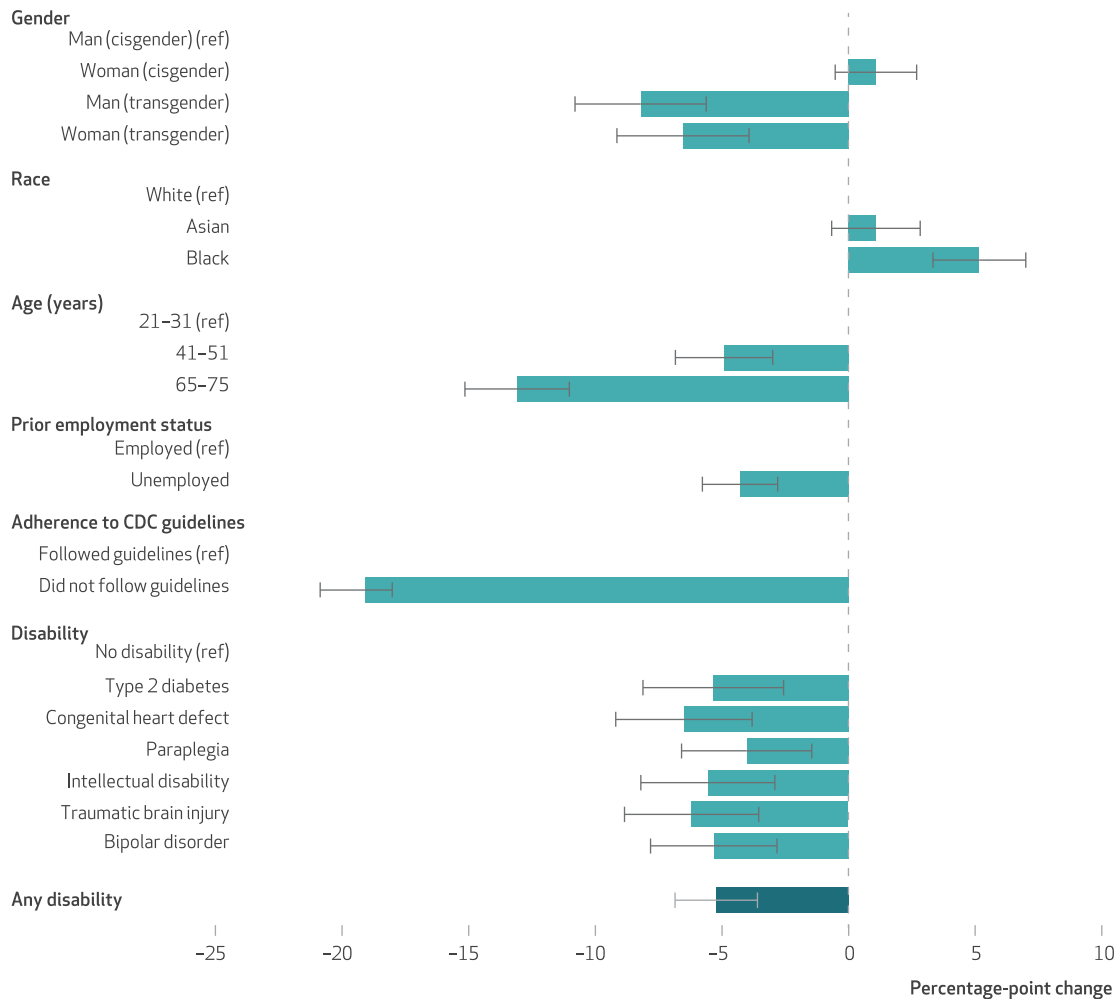
**ASSOCIATION OF RESPONDENT DEMOGRAPHICS WITH DISABILITY BIAS** We found that disability bias varied by respondent age and education level. Exhibit 2 shows that respondents from younger age cohorts displayed less bias toward disabled patients, with respondents in the youngest age cohort (Generation Z, born 1997–2012) almost 20 percentage points more likely ( $p < 0.001$ ) to select disabled patients than respondents in the oldest cohort (the Silent Generation, born before 1946) (see appendix exhibit 9).<sup>25</sup> Exhibit 2 also shows that respondents with college and postgraduate degrees deprioritized disabled patients to a greater extent than those whose education was limited to high school or less. Respondents with the highest level of education (postgraduate degrees) were 6.7 percentage points less likely ( $p = 0.017$ ) than those with a high school diploma or less to select a disabled patient (appendix exhibit 9).<sup>25</sup>

Respondents for whom religion was important were considerably less likely to deprioritize patients with disabilities than nonreligious respondents ( $p = 0.009$ ), although this effect did not extend to bipolar disorder ( $p = 0.658$ , see appendix exhibits 9 and 10)<sup>25</sup> and was slightly short of conventional significance levels for mental disabilities more broadly ( $p = 0.054$ , see appendix exhibit 9).<sup>25</sup> We also found that conservative respondents deprioritized disabled patients overall more than liberal respondents ( $p = 0.024$ ), but paraplegia ( $p = 0.007$ ) and bipolar disorder ( $p = 0.026$ ) were the only specific disabilities for which there was a statistically significant difference between conservatives and liberals (see appendix exhibits 9 and 10).<sup>25</sup> Hispanic respondents were less likely than White respondents to deprioritize patients with lower life expectancy ( $p = 0.029$ ) or with acquired ( $p = 0.022$ ) and physical ( $p = 0.038$ ) disabilities (see appendix exhibit 9).<sup>25</sup> A robustness check that included additional controls for respondent-



**EXHIBIT 1**

**Marginal impact of patients' demographic characteristics, employment, Centers for Disease Control and Prevention (CDC) guideline adherence, and disability status on their likelihood of being selected by respondents to receive a ventilator, 2021**



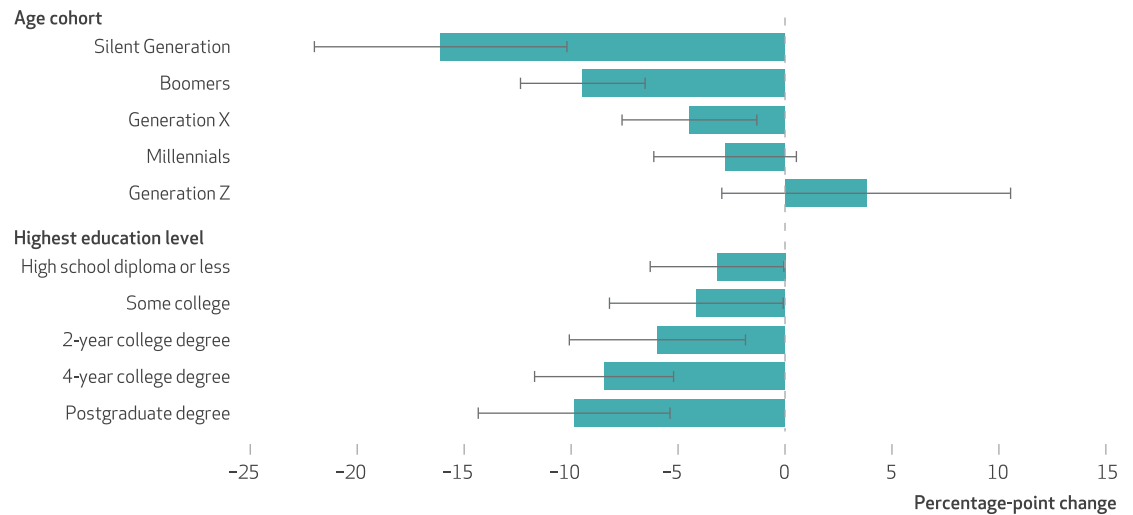
**SOURCE** Original analysis of authors' conjoint experiment data, January 29–February 4, 2021. **NOTES** Results are from a conjoint experiment on a representative sample of US residents. The x axis reflects marginal impact on likelihood of receiving a ventilator for each patient characteristic relative to the reference category in each domain. Both coefficients and confidence intervals are from a multivariate linear regression predicting choosing a patient for a ventilator. All *p* values are significant ( $p < 0.01$ ) except those for cisgender woman ( $p = 0.189$ ) and Asian race ( $p = 0.225$ ). Employment status refers to the patient's status before the COVID-19 pandemic. "CDC guidelines" refers to the CDC's social distancing guidelines for the COVID-19 pandemic. The sample conjoint task and definitions of disabilities used are in appendix exhibits 1 and 2 (see note 25 in text). The "any disability" coefficient comes from a separate regression in which all patient disability types were aggregated in an indicator variable.

level characteristics did not substantively alter our results (see appendix exhibit 11).<sup>25</sup>

**RACIAL PREFERENCE AND TRANSGENDER BIAS ASSOCIATED WITH POLITICAL IDEOLOGY** Exhibit 3 examines the interaction between respondent political ideology and two patient attributes: race and gender (also see appendix exhibits 15 and 16).<sup>25</sup> We found that liberal and moderate respondents prioritized Asian and Black patients relative to White patients. Liberal respondents, for instance, were 5.4 percentage points more likely ( $p = 0.014$ ) than conservative respondents to select Asian patients and 7.6 percentage

points more likely ( $p = 0.001$ ) to select Black patients. When we examined the marginal impact of varying patient race by respondents' political ideology (reflected in exhibit 3), we found that these differences reflected preference for Asian and Black patients on the part of liberal and moderate respondents, whereas conservative respondents were equally likely to select patients of any race. We also found that bias against transgender patients was driven by differences in ideology, with conservatives 18.6 percentage points less likely to select a transgender man ( $p < 0.001$ ) and 14.3 percentage points less likely

## EXHIBIT 2

**Marginal change in respondents' likelihood of choosing a disabled person relative to a nondisabled person to receive a ventilator, by respondent age cohort and education level, 2021**

**SOURCE** Original analysis of authors' conjoint experiment data, January 29–February 4, 2021. **NOTES** Results are from a conjoint experiment on a representative sample of US residents. Confidence intervals (represented by whiskers) are calculated from two distinct multivariate regressions (one interacting disability with respondent age cohort, the other with respondent education level). All *p* values are significant ( $p < 0.05$ ) except Millennials ( $p = 0.10$ ) and Generation Z ( $p = 0.270$ ). Age cohorts were defined as follows: Silent Generation (born before 1946), Boomers (born 1946–64), Generation X (born 1965–80), Millennials (born 1981–96), and Generation Z (born 1997–2012). Education categories refer to the highest level of education completed by the respondent. Specific age and education questions are in appendix exhibit 4 (see note 25 in text).

to select a transgender woman ( $p < 0.001$ ) than they are to select a cisgender man.

## Discussion

**IMPLICATIONS FOR POLICY AND PRACTICE** To address concerns regarding disability discrimination in the allocation of scarce resources during COVID-19, in March 2020 the HHS Office for Civil Rights issued guidance informing providers that “assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities” cannot be used to allocate resources.<sup>30</sup> Subsequent guidance prohibited other discriminatory forms of prioritization in crisis standards of care policy making, including denial of care because of anticipated lower long-term life expectancy or greater resource use, while making clear that providers may prioritize based on short-term mortality risk.<sup>16</sup>

In debates surrounding crisis standards of care policy making, some have argued that patients with diminished long-term life expectancy should be deprioritized relative to patients with a typical anticipated lifespan, claiming that policy makers should “consider the number of years of life saved” in addition to the number of lives saved.<sup>31</sup> Our findings suggest that public support

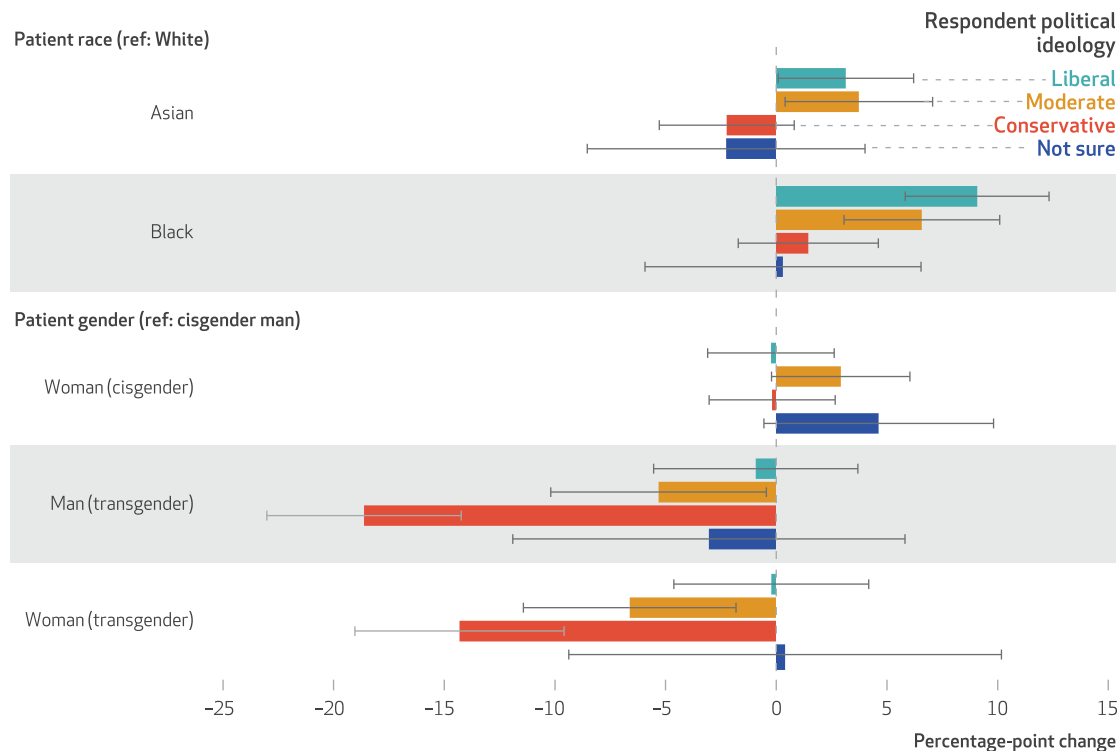
for deprioritizing disabled people with diminished life expectancy is not distinguishable from general bias against patients with disabilities, including those with normal life expectancy. Rather than a desire to “save the most life years” (itself impermissible according to recent HHS guidance),<sup>16</sup> the public’s willingness to deprioritize disabled patients reflects bias against disabled people regardless of life expectancy. The data presented here did not allow us to identify underlying motivations; however, these findings would be consistent with discrimination motivated by quality-of-life judgments.

Although our experiment focused on ventilator allocation, it highlights the existence of biases against people with disabilities that may have implications for other areas of policy and practice, especially when resources are scarce. For example, disability bias may play a role in informing public policy decisions regarding access to and prioritization for organ transplantation and other scarce medical resources. Further research is needed to understand to what extent our results generalize to other contexts.

Our findings underscore the importance of bias mitigation in health policy making. Such measures might include, but should not be limited to, efforts to include people with disabilities on triage teams and hospital ethics committees,

**EXHIBIT 3**

**Marginal change in respondents' likelihood of choosing a patient to receive a ventilator, by patient race and gender and respondent political ideology, 2021**



**SOURCE** Original analysis of authors' conjoint experiment data, January 29–February 4, 2021. **NOTES** Results are from a conjoint experiment on a representative sample of US residents. The x axis reflects the marginal impact of a patient's race and gender on the likelihood of receiving a ventilator by respondents' political ideology relative to the reference groups. All *p* values are significant (*p* < 0.05) for race except the impact of Asian patient race for respondents with conservative political ideology (*p* = 0.152), Asian patient race for respondents who answered "not sure" regarding political ideology (*p* = 0.481), Black patient race for respondents with conservative political ideology (*p* = 0.365), and Black patient race for respondents who answered "not sure" regarding political ideology (*p* = 0.922). For gender, the only *p* values that are significant at the 0.05 level are the impact of a patient being a transgender man for respondents with moderate political ideology (*p* = 0.033) and respondents with conservative political ideology (*p* < 0.001), as well as the impact of a patient being a transgender woman for respondents with moderate political ideology (*p* = 0.007) and respondents with conservative political ideology (*p* < 0.001). Results, including confidence intervals (represented by whiskers), are based on a single multivariate linear regression predicting choosing a patient for a ventilator. The specific question on respondents' ideology are in appendix exhibit 4 (see note 25 in text).

anti-bias training for triage team members, regular review of potential disparities in health outcome data, and greater investment in civil rights protection. Policy makers could also consider making additional investments in federally funded protection and advocacy programs, which provide legal assistance and advocate for systemic change in each state to protect the rights of people with disabilities.<sup>32</sup> Although the protection and advocacy system has played an important role in enforcing disability rights laws during the COVID-19 pandemic, no dedicated funding stream currently supports protection and advocacy activities specific to health care more broadly; as a result, the resources available for populations not covered by other funding are limited. By authorizing an ongoing, health care-specific protection and advocacy funding

stream, Congress could enhance efforts to address disability discrimination in health care.

**RELATIONSHIP BETWEEN DISABILITY BIAS AND RESPONDENTS' EDUCATION AND AGE**

Our results also yield important insights about how different portions of the public view the deservingness of people with disabilities in health care contexts. Our finding that having a college or postgraduate degree is associated with greater disability bias, for example, stands in contrast to a body of work suggesting the opposite with respect to racial and anti-immigrant prejudice.<sup>33</sup> It is unclear, however, whether greater disability bias is an unfortunate outcome of increasing education or whether people from backgrounds with lower levels of disability bias, perhaps due to greater personal or family experience with disability, are less likely to enter or complete

higher education. The evidence from previous research about other forms of discrimination is mixed, with recent quasi-experimental studies reflecting contradictory findings on whether education causes an increase in prejudice.<sup>33,34</sup> Future research could employ panel data to test stronger causal claims. Adding questions measuring disability bias to longitudinal studies of public opinion could also lay the groundwork for more meaningful quasi-experimental work about strategies for mitigating negative attitudes toward people with disabilities.

Regardless of causal origin, the presence of greater disability bias in college-educated populations should serve as a source of concern for civil rights policy makers. In the area of health care, policy makers often delegate to expert opinion, particularly on complex technical questions relating to clinical care. In the realm of bioethics, a long-standing body of work documents substantive disagreements between disability activists and bioethicists, with activists arguing that many bioethicists harbor troubling ideas about people with disabilities.<sup>13,35</sup> Our results reinforce this concern, showing that completing higher education does not prevent disability bias and may instead be associated with it.

Our finding that younger age cohorts were less likely to deprioritize people with disabilities represents a promising sign for the future. We believe that this result is most likely a cohort rather than an aging effect, as older adults are more likely to have disabilities themselves. Insofar as personal experience with disability mitigates disability bias, the effect of population aging would predict the opposite result from the one we found.

We think that it is more likely that younger age cohorts have a different orientation toward people with disabilities than older cohorts and that this difference will persist over time. If so, this would suggest a future with less disability bias and greater equality of opportunity for people with disabilities. The inclusion of questions on disability bias in future public opinion surveys will help further validate our findings over time.

**ROLE OF POLITICAL IDEOLOGY** Our findings show dramatically different responses to patient race and gender according to respondents' political ideology. Deprioritization of transgender patients, for example, was found primarily among conservative respondents. Finding substantial bias against transgender people among political conservatives may reflect long-standing bias against transgender people, exacerbated by increasing attacks on transgender rights by conservative politicians and media.<sup>36,37</sup>

In contrast, the prioritization of Black and Asian patients was driven entirely by liberal and

## Our findings provide support for long-standing concerns regarding disability bias in health care resource allocation.

moderate respondents, whereas conservative respondents had no statistically significant preference. These results echo the ideologically divided debate surrounding state proposals to use race as a factor in the allocation of other COVID-19 resources, such as monoclonal antibodies.<sup>38</sup>

Arguments for taking race into account emerged in part because existing allocation protocols in crisis standards of care have well-documented racial biases.<sup>38</sup> Even after long-term life expectancy is removed as an allocation criterion (which disadvantages Black Americans because of their higher rates of life-limiting comorbidities), racial biases in many of the prognostic scoring tools (such as the Sequential Organ Failure Assessment Score) used for assessing short-term mortality risk remain.<sup>38,39</sup> For policy makers who have legal, ethical, or political concerns with using race as a factor, prior work suggests that prioritizing neighborhoods with greater social disadvantage can accomplish some of the same goals.<sup>40</sup> However, some argue that use of place-based approaches alone is insufficient for allocation decisions, as such frameworks do not capture forms of disadvantage that are not geographically clustered (such as disability).<sup>13</sup> Policy makers are still searching for tools to enhance equity that can garner legitimacy from public support across ideological divides.

### Conclusion

Our findings provide support for long-standing concerns regarding disability bias in health care resource allocation. The bias we found against people with disabilities, older patients, and transgender patients provides empirical evidence to inform civil rights enforcement efforts and highlights the importance of expanding bias mitigation efforts in health policy making, especially in conditions of scarcity. Our investigation into public opinion helps identify the nature and



intensity of disability bias in different portions of the public during COVID-19, but this research design could also be used as a blueprint for examining bias among clinicians and policy makers. Our research suggests that the fight for protecting the rights of people with disabilities

is far from over and that policy makers and advocates should be particularly sensitive to potential biases against people with disabilities during public health crises such as the COVID-19 pandemic. ■

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## NOTES

- 1 Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health*. 2015;105(Suppl 2):S198–206.
- 2 Jezzoni LI, Rao SR, Resselam J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, et al. Physicians' perceptions of people with disability and their health care. *Health Aff (Millwood)*. 2021;40(2):297–306.
- 3 National Council on Disability. Medical futility and disability bias [Internet]. Washington (DC): NCD; 2019 Nov 20 [cited 2022 Jun 29]. Available from: [https://ncd.gov/sites/default/files/NCD\\_Medical\\_Futility\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf)
- 4 Schneider AL, Ingram HM. Social constructions, anticipatory feedback strategies, and deceptive public policy. *Policy Stud J*. 2019;47(2):206–36.
- 5 Bell E, Ter Mkrtychyan A, Wehde W, Smith K. Just or unjust? How ideological beliefs shape street level bureaucrats' perceptions of administrative burden. *Public Adm Rev*. 2021;81(4):610–24.
- 6 Naughton K, Schmid C, Yackee SW, Zhan X. Understanding commenter influence during agency rule development. *J Policy Anal Manage*. 2009;28(2):258–77.
- 7 van Oorschot W. Making the difference in social Europe: deservingness perceptions among citizens of European welfare states. *J Eur Soc Policy*. 2006;16(1):23–42.
- 8 Schneider A, Ingram H. Social construction of target populations: implications for politics and policy. *Am Polit Sci Rev*. 1993;87(2):334–47.
- 9 Cansunar A. Who is high income, anyway? Social comparison, subjective group identification, and preferences over progressive taxation. *J Polit*. 2021;83(4):1292–306.
- 10 Gething L. The Interaction with Disabled Persons Scale. *Soc Behav Personal*. 1994;9(5):23.
- 11 Cottrell CA, Neuberg SL. Different emotional reactions to different groups: a sociofunctional threat-based approach to “prejudice.” *J Pers Soc Psychol*. 2005;88(5):770–89.
- 12 Dorfman D. Fear of the disability con: perceptions of fraud and special rights discourse. *Law Soc Rev*. 2019;53(4):1051–91.
- 13 Ne'eman A, Stein MA, Berger ZD, Dorfman D. The treatment of disability under crisis standards of care: an empirical and normative analysis of change over time during COVID-19. *J Health Polit Policy Law*. 2021;46(5):831–60.
- 14 Office of Sen. Kirsten Gillibrand. Gillibrand successfully leads bipartisan, bicameral call to protect civil rights for people with disabilities amidst COVID-19 pandemic; HHS issues new guidance to health care providers to enhance protections for those with disabilities [Internet]. New York (NY): Office of Sen. Kirsten Gillibrand; 2022 Feb 14 [cited 2022 Jun 29]. Available from: <https://www.gillibrand.senate.gov/news/press/release/gillibrand-successfully-leads-bipartisan-bicameral-call-to-protect-civil-rights-for-people-with-disabilities-amidst-covid-19-pandemic-hhs-issues-new-guidance-to-health-care-providers-to-enhance-protections-for-those-with-disabilities->
- 15 Office of Rep. Ayanna Pressley. Rep. Pressley calls on Governor Baker to rescind crisis of care standards that disproportionately harm communities of color & disability community [Internet]. Hyde Park (MA): Office of Rep. Ayanna Pressley; 2020 Apr 13 [cited 2022 Jun 29]. Available from: <https://pressley.house.gov/media/press-releases/rep-pressley-calls-governor-baker-rescind-crisis-care-standards>
- 16 Department of Health and Human Services, Office for Civil Rights. FAQs for healthcare providers during the COVID-19 public health emergency: federal civil rights protections for individuals with disabilities under Section 504 and Section 1557 [Internet]. Washington (DC): HHS; 2022 Feb [cited 2022 Jun 6]. Available from: <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/disability-faqs/index.html>
- 17 *Social desirability bias* is defined as “the tendency of some respondents to report an answer in a way they deem to be more socially acceptable than would be their ‘true’ answer... The outcome of the strategy is overreporting of socially desirable behaviors or attitudes and underreporting of socially undesirable behaviors or attitudes.” Lavrakas PJ. *Encyclopedia of survey research methods*. London: SAGE Publications, Inc.; 2008. Vol 1, Social desirability; p. 826.
- 18 Buckwalter W, Peterson A. Public attitudes toward allocating scarce resources in the COVID-19 pandem-

- ic. *PLoS One*. 2020;15(11):e0240651.
- 19 Reeskens T, Roosma F, Wanders E. The perceived deservingness of COVID-19 healthcare in the Netherlands: a conjoint experiment on priority access to intensive care and vaccination. *BMC Public Health*. 2021;21(1):447.
  - 20 Knotz CM, Gandenberger MK, Fossati F, Bonoli G. Public attitudes toward pandemic triage: evidence from conjoint survey experiments in Switzerland. *Soc Sci Med*. 2021;285:114238.
  - 21 De la Cuesta B, Egami N, Imai K. Improving the external validity of conjoint analysis: the essential role of profile distribution. *Polit Anal*. 2022;30(1):19–45.
  - 22 Horiuchi Y, Markovich ZD, Yamamoto T. Does conjoint analysis mitigate social desirability bias? *Polit Anal*. 2021 Sep 15. [Epub ahead of print].
  - 23 Hainmueller J, Hopkins DJ. The hidden American immigration consensus: a conjoint analysis of attitudes toward immigrants. *Am J Pol Sci*. 2015;59(3):529–48.
  - 24 Hainmueller J, Hangartner D, Yamamoto T. Validating vignette and conjoint survey experiments against real-world behavior. *Proc Natl Acad Sci U S A*. 2015;112(8):2395–400.
  - 25 To access the appendix, click on the Details tab of the article online.
  - 26 Centers for Disease Control and Prevention [Internet]. Atlanta (GA): CDC. Press release, CDC updates “How COVID is Spread” webpage; 2020 Oct 5 [cited 2022 Aug 23]. Available from: <https://www.cdc.gov/media/releases/2020/s1005-how-spread-covid.html>
  - 27 de Bekker-Grob EW, Donkers B, Jonker MF, Stolk EA. Sample size requirements for discrete-choice experiments in healthcare: a practical guide. *Patient*. 2015;8(5):373–84.
  - 28 Crenshaw K. Demarginalizing the intersection of race and sex: a Black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *U Chi Legal F*. 1989;1:139–67.
  - 29 Schneider M, Bell E, Ne’eman A, Strolovitch D. Who gets the last ventilator or compensatory school resources? Disability & deservingness during COVID-19 [Internet]. Charlottesville (VA): Center for Open Science; [cited 2022 Aug 23]. Available from: <https://osf.io/j34mt>
  - 30 Department of Health and Human Services, Office for Civil Rights. Bulletin: civil rights, HIPAA, and the coronavirus disease 2019 (COVID-19) [Internet]. Washington (DC): HHS; 2020 Mar [cited 2022 Jun 6]. Available at: <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>
  - 31 Rajczi A, Daar J, Kheriaty A, Dastur C. The University of California crisis standards of care: public reasoning for socially responsible medicine. *Hastings Cent Rep*. 2021;51(5):30–41.
  - 32 Department of Health and Human Services, Administration for Community Living. Protecting rights and preventing abuse of people with disabilities [Internet]. Washington (DC): HHS; 2022 May [cited 2022 Aug 10]. Available from: <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>
  - 33 Lancee B, Sarrasin O. Educated preferences or selection effects? A longitudinal analysis of the impact of educational attainment on attitudes towards immigrants. *Eur Sociol Rev*. 2015;31(4):490–501.
  - 34 Cavaille C, Marshall J. Education and anti-immigration attitudes: evidence from compulsory schooling reforms across Western Europe. *Am Polit Sci Rev*. 2019;113(1):254–63.
  - 35 Stramondo JA. Bioethics, adaptive preferences, and judging the quality of a life with disability. *Soc Theory Pract*. 2021;47(1):199–220.
  - 36 Kreitzer RJ, Smith CW. Reproducible and replicable: an empirical assessment of the social construction of politically relevant target groups. *PS Polit Sci Polit*. 2018;51(4):768–74.
  - 37 Drabish K, Theeke LA. Health impact of stigma, discrimination, prejudice, and bias experienced by transgender people: a systematic review of quantitative studies. *Issues Ment Health Nurs*. 2022;43(2):111–8.
  - 38 Schmidt H, Roberts DE, Eneanya ND. Rationing, racism, and justice: advancing the debate around “colourblind” COVID-19 ventilator allocation. *J Med Ethics*. 2022;48(2):126–30.35.
  - 39 Miller WD, Han X, Peek ME, CharanAshana D, Parker WF. Accuracy of the Sequential Organ Failure Assessment Score for in-hospital mortality by race and relevance to crisis standards of care. *JAMA Netw Open*. 2021;4(6):e2113891.
  - 40 Schmidt H, Shaikh SJ, Sadecki E, Gollust S. US adults’ preferences for race-based and place-based prioritisation for COVID-19 vaccines. *J Med Ethics*. 2022;48(7):497–500.

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# FAQs for Healthcare Providers during the COVID-19 Public Health Emergency: Federal Civil Rights Protections for Individuals with Disabilities under Section 504 and Section 1557

The U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) has made clear that [civil rights protections remain in full force and effect during disasters or emergencies, including the COVID-19 pandemic - PDF](#) (<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>). These laws include Section 504 of the Rehabilitation Act (Section 504) and Section 1557 of the Affordable Care Act (Section 1557) which prohibit discrimination on the basis of disability. <sup>1</sup> ([#footnote1\\_5t37csm](#)). OCR is providing this FAQ guidance <sup>2</sup> ([#footnote2\\_2g0kttq](#)) on Federal civil rights obligations under Section 504 and Section 1557 in light of the [continuing public health and national emergency](#) (<https://www.phe.gov/emergency/news/healthactions/phe/Pages/COVID-19July2021.aspx>) concerning the [Coronavirus Disease 2019 \(COVID-19\)](#) (<https://www.cdc.gov/coronavirus/2019-nCoV/index.html>).

To further help covered entities comply with civil rights laws and advise patients and consumers of their rights, OCR issued a series of guidance documents, <sup>3</sup> ([#footnote3\\_9gr02x0](#)) provided technical assistance, and worked with covered entities to resolve complaints alleging discrimination on the basis of [disability](#), (<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/index.html>) [race, color, national origin - PDF](#) (<https://www.hhs.gov/sites/default/files/title-vi-bulletin.pdf>), [sex](#) (<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/index.html>), and [age - PDF](#) (<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>).

In a public health emergency, when resources can be scarce, individuals with disabilities may be subjected to stereotypes, bias, and other obstacles that may impede their access to healthcare. It is vital that individuals with disabilities are not prevented from receiving needed healthcare or health services because of discrimination in violation of Section 504 and Section 1557. Accordingly, OCR offers the following guidance.

## Federal Civil Rights during the COVID-19 Public Health Emergency

**1. What Federal civil rights laws prohibiting discrimination on the basis of disability apply to healthcare providers during a public health emergency and to whom do they apply?**

Federal civil rights laws continue to apply during any public health emergency, including COVID-19, and OCR continues to enforce laws prohibiting discrimination on the basis of disability. [4 \(#footnote4\\_m43xfmw\)](#). Recipients of HHS funds are subject to Section 504 of the Rehabilitation Act (504). [5 \(#footnote5\\_b1refuk\)](#). In addition, Section 1557 of the Affordable Care Act (1557) applies to any health program or activity, any part of which is receiving federal financial assistance from HHS. [6 \(#footnote6\\_tgrbbud\)](#)

## **2. To what healthcare and health services do Section 504 and Section 1557 apply during the COVID-19 public health emergency?**

Where one or both of these disability rights laws apply, they apply to all healthcare and health services, regardless of the patient population served or type of service provided. This includes provision of medical supplies, administration of medication, hospitalization, long-term care, and intensive treatments and critical care, such as oxygen therapy and mechanical ventilators. When these laws apply, they also apply to state Crisis Standards of Care plans and procedures for triaging scarce resources that hospitals are required to follow, and to hospitals adopting and implementing standards, whether by choice or because they are required.

## **3. Who is a qualified individual with a disability who is protected under Section 504 and Section 1557?**

Under Section 504 and Section 1557, a covered entity may not deny or limit, on the basis of disability, the participation of a qualified individual with a disability in its health programs and services. [7 \(#footnote7\\_s100rim\)](#)

These laws require the definition of “disability” to be construed broadly, in favor of expansive coverage. [8 \(#footnote8\\_7nxwi5r\)](#). These statutes and the regulations implementing Section 504 and Section 1557 define a “disability” with respect to an individual as a physical or mental impairment that substantially limits one or more of the major life activities of such an individual, a record of such an impairment, or being regarded as having such an impairment. [9 \(#footnote9\\_10t64o3\)](#). An individual with a disability is “qualified” if that person meets the essential eligibility requirements for receipt of services or participation in the program or activity with or without reasonable modification to rules, policies or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services. [10 \(#footnote10\\_osjpoj\)](#). However, the fact that an individual with a disability is qualified to receive health care from a provider does not necessarily mean that the individual has a right to any particular health care service.

## **Application of Section 504 and Section 1557 to Crisis Standards of Care**

## **4. How does the prohibition against discrimination apply to the provision of healthcare to individuals with disabilities during a public health emergency?**

In general, Section 504 and Section 1557 ensure that individuals with disabilities are not excluded from participation in, or denied the benefits of, services, programs, or activities, or otherwise subjected to discrimination, on the basis of disability <sup>11</sup> and have an opportunity to participate in, or benefit from, services equal to that afforded others. <sup>12</sup> Programs must be accessible to and usable by individuals with disabilities. <sup>13</sup>

### *Stereotypes, bias and quality of life judgments*

When allocating scarce resources or care in a public health emergency, covered entities must analyze the specific patient's ability to benefit from the treatment sought, free from stereotypes and bias about disability, including prejudicial preconceptions and assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities. <sup>14</sup>

By 'bias,' OCR is referring to an unfavorable perception based on prejudice, assumptions, conclusions or beliefs about an individual or group of individuals with a specific disability or any disability that is not supported by current medical knowledge or the best available objective evidence. Use of assessment tools or factors for making resource allocation decisions that screen out or tend to screen out individuals with disabilities or any class of individuals with disabilities from fully and equally enjoying any healthcare service, program, or activity being offered, unless such criteria can be shown to be necessary for the provision of the service, program or activity being offered, would violate nondiscrimination laws. <sup>15</sup>

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### *Categorical exclusions on the basis of disability*

Categorical exclusions in Crisis Standards of Care that deny critical healthcare services to individuals based solely on the type of disability an individual has, when treatment would not be futile for individuals with that type of disability, violate disability rights laws. For example, a hospital is prohibited from having a categorical exclusion denying life-saving care to individuals with Down syndrome based on a judgment that people without Down syndrome would be a greater benefit to society or would experience a richer or fuller life than those with Down syndrome.

### *Resource allocation decisions*

While covered entities may rely upon applicable Crisis Standards of Care in making resource allocation decisions that affect individuals with disabilities, those standards should be based on current medical knowledge or the best available objective evidence regarding effectiveness of treatment. To avoid disability discrimination, Crisis Standards of Care should be applied in a way that assesses whether the treatment sought is likely to be effective for each individual patient. Hospitals may, however, deny care during a public health emergency on the basis that such care is unlikely to be effective for a particular



patient, after analyzing that patient's ability to respond to the treatment being sought. The patient's pre-existing disability or diagnosis should not form the basis for decisions regarding the allocation of scarce treatment, unless that underlying condition is so severe that it would prevent the treatment sought from being effective or would prevent the patient from surviving until discharge from the hospital or shortly thereafter. Further, when mortality predictions are based on a patient's underlying disability, and not the condition for which they need immediate care, the less grounded in objective medical evidence they are likely to be, as critical care providers are not likely to have expertise concerning the life expectancy of every underlying condition patients have.

### *Reasonable modifications for individuals with disabilities*

In addition, Section 504 and Section 1557 require covered entities to make reasonable modifications to policies, practices and procedures where necessary to provide individuals with disabilities an equal opportunity to participate in covered health programs and activities, unless the modifications would work a fundamental alteration in the nature of the health program or activity or impose an undue financial and administrative burden. <sup>16</sup> (#footnote16\_2srnqfm). If, as part of its Crisis Standards of Care, a hospital is using an assessment tool that unnecessarily screens out or tends to screen out individuals with disabilities from the opportunity to benefit from an aid, benefit, or service, and alternative tools are not available, a hospital may need to make a reasonable modification in its use of the assessment tool unless doing so would cause a fundamental alteration or impose an undue financial and administrative burden. For example, the Glasgow Coma Scale considers whether a person's speech is comprehensible and whether they obey commands for movement. Someone with cerebral palsy may have difficulty speaking or moving as part of their underlying disability, which is not the condition that caused them to seek treatment at a hospital. Adjustments must be made to ensure that such a person's pre-existing condition, and the symptoms of that condition, are not considered when using the Glasgow Coma Scale to evaluate whether they qualify for treatment. Similarly, a covered entity may need to make reasonable modifications for individuals with disabilities when evaluating the effectiveness of a treatment. For example, in evaluating the effectiveness of ventilator treatment, a covered entity may need to allow an individual with a disability some additional time on a ventilator to assess likely clinical improvement, unless doing so would constitute a fundamental alteration of the ventilator trial or impose an undue burden.

**5. I am a health provider and am concerned that an individual with a disability or an individual who is likely to have a disability after treatment will have lower quality of life or relative worth to society than an individual without a disability who also requires treatment. May I take this into account in prioritizing what healthcare or services to provide to an individual with a disability?**

No. Under Section 504 and Section 1557, the decision to allocate scarce medical resources during a public health emergency, including pursuant to Crisis Standards of Care, may not be based on stereotypes, pre-conceptions, prejudice, or generalizations about the relative worth or quality of life or value to society of the individual based on his or her disability, pre-or post-treatment.

**6. I am a health provider and am concerned that treating an individual with a disability who has COVID-19 may require more of a particular resource than treating individuals without disabilities for COVID-19. Can I make decisions about whether to provide healthcare or deny the resource to an individual with a disability altogether based on these concerns?**

No. Individuals with disabilities may not be denied an equal opportunity to participate in and benefit from healthcare programs and services. During the COVID-19 public health emergency, a provider may not refuse to admit for COVID-19 treatment a patient with a disability who may require more services or resources than other patients with COVID-19, as such a denial would prevent the patient with a disability from having an opportunity to benefit from care that is equal to the opportunity provided to others, on the basis of a disability.

In some circumstances, covered entities may be required as a reasonable modification to provide more resources to individuals with disabilities than they provide to others. For example, a hospital may need to make reasonable modifications to a trial assessing whether ventilator treatment is effective for a patient to accurately assess its effectiveness for individuals with disabilities. In evaluating the effectiveness of mechanical ventilation, the hospital may need to provide some additional time to an individual with a disability, unless doing so would constitute a fundamental alteration or undue burden.

**7. I am a health provider operating in the COVID-19 public health emergency and am concerned that an individual with a disability may not live as long as an individual without a disability after treatment. May I use this information when deciding whether and to what extent to provide healthcare or services to an individual with a disability?**

No. Disability nondiscrimination laws and their implementing regulations prohibit covered entities, including those implementing Crisis Standards of Care, from imposing or applying eligibility criteria that screen out or tend to screen out individuals with disabilities, or any class of individuals with disabilities, from fully and equally enjoying a service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered. [17. \(#footnote17\\_5m3jqne\)](#) In the context of Crisis Standards of Care implementation, which is designed to address resource shortages in a temporary emergency, a patient's likelihood of survival long after hospital discharge, which may depend upon many factors and may be difficult to predict, is unlikely to be related to the need to make allocation decisions about scarce resources on a temporary basis. It is also unlikely to be related to the effectiveness of the medical interventions being allocated. The further in the future a provider forecasts,

the less likely survival has to do with the effectiveness of the medical intervention in the context of the public health emergency necessitating Crisis Standards of Care. Judgments about long-term life expectancy are inherently uncertain and may screen out or tend to screen out individuals with disabilities from access to care without being necessary for the safe provision of the healthcare being offered.

In contrast, a criterion based on a patient's medical condition having a high likelihood of death in the short term, even with aggressive treatment, would be an acceptable basis for giving an individual lower priority for care under disability rights law, so long as the lower priority is applied to both patients with and without disabilities. For example, a patient experiencing multiple organ failure and who is not anticipated to survive to hospital discharge even with aggressive treatment could be given lower priority for access to critical care.

## Application of Section 504 and Section 1557 to Visitation Policies

### **8. Many acute care and long-term care settings have restrictions on visitors, limiting entrance to patients, residents, and personnel with limited exceptions for end-of-life situations. How do Section 504 and Section 1557 apply to such restrictions?**

During the COVID-19 public health emergency, some hospitals developed stricter visitation policies or started to enforce existing visitation policies they had not earlier enforced, because of a concern that anyone visiting the hospital could pose an additional risk of COVID-19 to patients and staff. In general, such restrictions are permissible under Section 504 and Section 1557 if those restrictions are in place for safety reasons based on objective risks. However, where these policies do not account for the needs of people with disabilities, they may result in unequal care and violate Section 504 and Section 1557. For example, when a patient's disability prevents them from providing their medical history or understanding medical decisions or directions, the medical provider should explore whether a modification to its visitor policy may be safely carried out.

#### *Reasonable modifications to visitation policies*

Some people have disabilities that prevent them from providing their medical history or understanding medical decisions or directions. Permitting a patient or resident with a disability to use a support person when necessary to have an equal opportunity to obtain and benefit from healthcare services is a reasonable modification that generally must be provided unless it would fundamentally alter the nature of the service, program, or activity or impose an undue financial and administrative burden. For example, a hospital may be required to allow a support person to participate in a consultation so the support person can explain the information exchange in simple, understandable language to the patient, and ensure that the provider has the information necessary to treat the patient. Whether a covered entity must allow the support person to be physically present as a reasonable modification depends on a number of factors, including safety issues and whether remote participation would be effective.

In some situations, a covered entity will be able to meet its obligation to provide a reasonable modification by enabling a support person to communicate remotely with a patient (by voice or video phone calls) when needed by the individual with a disability. In others, the support person will not be effective unless present in person, because of the nature of the individual's disability or the type of service provided by the support person, or for other reasons. Where the individual is entitled to an in-person support person, covered entities should take necessary steps to allow the support person to be present when needed. Such steps may include modifying visiting hours and visitation restriction policies. [18 \(#footnote18\\_5rrek1n\)](#)

### *Legitimate safety requirements*

Section 504 and Section 1557 allow covered entities to have legitimate requirements necessary for the safe operation of their services, programs, or activities. However, covered entities must ensure that their safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about individuals with disabilities. [19 \(#footnote19\\_64siyyw\)](#). Covered entities can therefore require support persons and interpreters to comply with safety requirements, such as requiring them to participate in temperature checks and other screening measures and to use Personal Protective Equipment (PPE), and can refuse entry to individuals who refuse or fail to meet these requirements.

In addition, the use of a designated support person by an individual with a disability for decision-making and tasks other than effective communication does not eliminate the responsibility of the setting to ensure effective communication and provide appropriate auxiliary aids and services to individuals with disabilities when necessary to provide effective communication. Covered entities are required to take steps to ensure that their communications with people with disabilities are as effective as communications with others, except where a covered entity can show that providing effective communication would fundamentally alter the nature of the program or activity in question or would result in an undue financial or administrative burden on the covered entity. [20 \(#footnote20\\_jasqz9w\)](#). Covered entities must provide appropriate auxiliary aids and services, such as alternative formats and sign language interpreters, where necessary for effective communication. [21 \(#footnote21\\_g12sl01\)](#)

## Application of Section 504 and Section 1557 to Vaccination, Testing and Contact Tracing Programs

### **9. I am part of a covered entity managing a vaccination, testing, or contact tracing program for COVID-19. What should I keep in mind in order to comply with Section 504 and Section 1557 in undertaking these activities?**

OCR has issued guidance outlining legal standards under Section 504 and Section 1557 and providing concrete examples of the application of the legal standards in the context of COVID-19 vaccine programs. [22 \(#footnote22\\_txzi0dx\)](#). OCR also issued a Fact Sheet setting out key actions to provide access to

vaccination programs for people with disabilities. [23 \(#footnote23\\_y3oomz3\)](#). This information, in addition to other guidance about civil rights protections during the COVID-19 public health emergency, is available at <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/index.html> (<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/index.html>).

Civil rights obligations when administering a testing or contact tracing program are similar to civil rights obligations when operating a vaccination program.

Covered entities must take appropriate steps to ensure that communications with members of the public with disabilities are as effective as communications with others. [24 \(#footnote24\\_d1s400t\)](#). This includes providing appropriate auxiliary aids and services [25 \(#footnote25\\_zo226b7\)](#) where necessary to provide qualified individuals with disabilities an equal opportunity to participate in, and benefit from, COVID-19 vaccination, testing and contact tracing-related communications. [26 \(#footnote26\\_ssjk84p\)](#). This includes making information available through means accessible to individuals with disabilities, such as accessible information technology, braille, large print materials, audio description, sign language interpreters, Telecommunications Relay Service (TRS), a Video Relay Service (VRS), Video Remote Interpreting (VRI), and other tools to facilitate effective communication for individuals with disabilities at vaccination and testing site locations, through the testing and vaccination appointment registration process, and during testing and vaccination outreach activities. [27 \(#footnote27\\_rjmg9\)](#).

Similarly, covered entities must ensure that programs are accessible to and usable by individuals with disabilities and must comply with applicable accessibility standards. Covered entities may not deny individuals with disabilities an equal opportunity to participate in and benefit from the testing or vaccination program as a result of accessibility barriers at testing or vaccination sites. For example, where an indoor testing site is not accessible, the covered entity should consider offering mobile testing services for individuals with disabilities who are not otherwise able to obtain testing. Where necessary to allow individuals to safely access testing, covered entities must make modifications to policies, practices, and procedures where necessary to permit people with disabilities at a higher risk of contracting COVID-19 or at increased risk for severe illness or death from COVID-19 to safely access these services, so long as such modifications would not constitute a fundamental alteration of the testing program or service or impose an undue financial or administrative burden. This might include allowing such individuals to enter a facility at a time or through an entrance that will reduce their contact with others.

*DISCLAIMER: This guidance document is not a final agency action and may be rescinded or modified in the Department's discretion. Noncompliance with any voluntary standards or suggested practices contained in guidance documents not required by law will not, in itself, result in any enforcement action.*

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## Footnotes



1. [↩ \(#footnoteref1\\_5t37csm\)](#). Other Federal civil rights laws, such as Titles II and III of the Americans with Disabilities Act (ADA) also protect individuals with disabilities and continue to apply during public health emergencies. While this document does not provide guidance on the ADA, it does include footnote citations to the ADA and its implementing regulations, where relevant. In interpreting Section 504, courts look to the ADA where that statute provides more specific guidance.
2. [↩ \(#footnoteref2\\_2g0kttq\)](#). The contents of this document do not have the force and effect of law and are not meant to bind the public in any way, unless specifically incorporated into a contract. This document is intended only to provide clarity to the public regarding existing requirements under the law.
3. [↩ \(#footnoteref3\\_9gr02x0\)](#). Guidance documents include U.S. Dep't of Health & Human Servs., BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) (Mar. 28, 2020), <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf> - PDF (<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>) and U.S. Dep't of Health & Human Servs., BULLETIN: Ensuring the Rights of Persons with Limited English Proficiency in Health Care During COVID-19 (May 15, 2020), <https://www.hhs.gov/sites/default/files/lep-bulletin-5-15-2020-english.pdf> - PDF (<https://www.hhs.gov/sites/default/files/lep-bulletin-5-15-2020-english.pdf>).
4. [↩ \(#footnoteref4\\_m43xfmw\)](#). U.S. Dep't of Health & Human Servs., BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) (Mar. 28, 2020), <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf> - PDF (<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>). Among other Federal civil rights laws, OCR enforces Federal civil rights laws that prohibit discrimination on the basis of disability, including: Section 504, Section 1557, and Title II of the ADA. More information on the laws and regulations OCR enforces and their applicability is available at <https://www.hhs.gov/civil-rights/for-providers/laws-regulations-guidance/laws/index.html> (<https://www.hhs.gov/civil-rights/for-providers/laws-regulations-guidance/laws/index.html>). The ADA, which protects individuals with disabilities from discrimination by state and local governments (Title II) and public accommodations (Title III), is outside of the scope of this guidance. The U.S. Department of Justice is charged with implementing Titles II and III of the ADA. For more information on the ADA's protections, including its application during COVID-19, see [www.ada.gov](http://www.ada.gov).
5. [↩ \(#footnoteref5\\_b1refuk\)](#). 29 U.S.C. § 794(a).
6. [↩ \(#footnoteref6\\_tgrbbud\)](#). 42 U.S.C. § 18116(a).
7. [↩ \(#footnoteref7\\_s100rim\)](#). 29 U.S.C. § 794(a); 42 U.S.C. § 18116(a).
8. [↩ \(#footnoteref8\\_7nxwi5r\)](#). 29 U.S.C. § 705(9)(B) (incorporating ADA definition); 42 U.S.C. § 12102(4)(A); 45 C.F.R. § 92.102(c) (incorporating ADA and Section 504 definition). Long **COVID can be a disability under these laws; see** U.S. Dep't of Health & Human Servs. & U.S. Dep't. of Justice, **"Guidance on 'Long COVID' as a Disability Under the ADA, Section 504, and Section 1557" (July 26, 2021)**, <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>. (<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>)
9. [↩ \(#footnoteref9\\_l0t64o3\)](#). 29 U.S.C. § 705(9)(B); 42 U.S.C. § 12102(1); 45 C.F.R. § 84.3(j); 45 C.F.R. § 85.3; 45 C.F.R. § 92.102(c). Note that the Section 504 regulations use the term "handicap" instead of "disability."
10. [↩ \(#footnoteref10\\_osjpoj\)](#). 42 U.S.C. § 12131(2); 45 C.F.R. 84.3(l)(4) (using the term "qualified handicapped person").
11. [↩ \(#footnoteref11\\_w1m3nsg\)](#). 29 U.S.C. § 794(a); 42 U.S.C. § 18116(a).
12. [↩ \(#footnoteref12\\_mx97gws\)](#). 45 C.F.R. § 84.4(b)(1)(ii).
13. [↩ \(#footnoteref13\\_f4d8odu\)](#). 45 C.F.R. 84.22.
14. [↩ \(#footnoteref14\\_7sktr3n\)](#). See U.S. Dep't of Health & Human Servs., BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) (Mar. 28, 2020), <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf> - PDF (<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>).
15. [↩ \(#footnoteref15\\_pxix1y5\)](#). 28 C.F.R. § 35.130(b)(8).
16. [↩ \(#footnoteref16\\_2srnqfm\)](#). See *Alexander v. Choate*, 469 U.S. 287, 301 (1985); *Southeastern Community College v. Davis*, 442 U.S. 397, 413 (1979); 45 C.F.R. § 92.105.
17. [↩ \(#footnoteref17\\_5m3jqne\)](#). 28 C.F.R. § 35.130(b)(8).
18. [↩ \(#footnoteref18\\_5rrek1n\)](#). The National Center on Advancing Person-Centered Practices and Systems offers some potentially useful resources for developing a Health Care Person Centered Profile as part of the response to visitor restrictions due to COVID. The Profile is designed to communicate a person's wants and needs if they are hospitalized without the direct support of their caregivers, family, neighbors, or friends. The Profile is available at [https://ncapps.acl.gov/docs/COVID-19/Resources/Health%20Care%20Person%20Centered%20Profile\\_2021\\_FINAL.pdf](https://ncapps.acl.gov/docs/COVID-19/Resources/Health%20Care%20Person%20Centered%20Profile_2021_FINAL.pdf) - PDF ([https://ncapps.acl.gov/docs/COVID-19/Resources/Health%20Care%20Person%20Centered%20Profile\\_2021\\_FINAL.pdf](https://ncapps.acl.gov/docs/COVID-19/Resources/Health%20Care%20Person%20Centered%20Profile_2021_FINAL.pdf)), and instructions are available at [https://ncapps.acl.gov/docs/COVID-](https://ncapps.acl.gov/docs/COVID-19/Resources/Health%20Care%20Person%20Centered%20Profile_2021_FINAL.pdf)

[19/Resources/Instructions%20for%20Health%20Care%20PC%20Profile.pdf - PDF \(https://ncapps.acl.gov/docs/COVID-19/Resources/Instructions%20for%20Health%20Care%20PC%20Profile.pdf\)](#).

19. ↩ (#footnoteref19\_64siyyw). 28 C.F.R. § 35.130(h).

20. ↩ (#footnoteref20\_jasqz9w). U.S. Dep't of Health & Human Servs., Office for Civil Rights, HHS Office for Civil Rights Guidance on Federal Legal Standards Prohibiting Disability Discrimination in COVID-19 Vaccination Programs (Apr. 12, 2021), <https://www.hhs.gov/sites/default/files/federal-legal-standards-prohibiting-disability-discrimination-covid-19-vaccination.pdf> - PDF (<https://www.hhs.gov/sites/default/files/federal-legal-standards-prohibiting-disability-discrimination-covid-19-vaccination.pdf>).

21. ↩ (#footnoteref21\_g12sl01). U.S. Dep't of Health & Human Servs., Office for Civil Rights, HHS Office for Civil Rights Guidance on Federal Legal Standards Prohibiting Disability Discrimination in COVID-19 Vaccination Programs (Apr. 12, 2021), <https://www.hhs.gov/sites/default/files/federal-legal-standards-prohibiting-disability-discrimination-covid-19-vaccination.pdf> - PDF (<https://www.hhs.gov/sites/default/files/federal-legal-standards-prohibiting-disability-discrimination-covid-19-vaccination.pdf>).

22. ↩ (#footnoteref22\_txzi0dx). U.S. Dep't of Health & Human Servs., Office for Civil Rights, HHS Office for Civil Rights Guidance on Federal Legal Standards Prohibiting Disability Discrimination in COVID-19 Vaccination Programs (Apr. 12, 2021), <https://www.hhs.gov/sites/default/files/federal-legal-standards-prohibiting-disability-discrimination-covid-19-vaccination.pdf> - PDF (<https://www.hhs.gov/sites/default/files/federal-legal-standards-prohibiting-disability-discrimination-covid-19-vaccination.pdf>).

23. ↩ (#footnoteref23\_y3oomz3). U.S. Dep't of Health & Human Servs., Office for Civil Rights, Disability Access in Vaccine Distribution (Apr. 12, 2021), <https://www.hhs.gov/sites/default/files/disability-access-vaccine-distribution.pdf> - PDF (<https://www.hhs.gov/sites/default/files/disability-access-vaccine-distribution.pdf>).

24. ↩ (#footnoteref24\_d1s400t). 45 C.F.R. 92.102(a); *see also* 45 C.F.R. §§ 84.4(b)(4), 84.52(a), 85.21 & 85.51.

25. ↩ (#footnoteref25\_zo226b7). 45 C.F.R. § 92.102(b); *see also* 45 C.F.R. § 84.52(d).

26. ↩ (#footnoteref26\_ssjk84p). 45 C.F.R. § 84.4(b)(1)(ii); 45 C.F.R. § 85.21(b)(1)(ii).

27. ↩ (#footnoteref27\_rjmg9). 45 C.F.R. § 92.102(b)(1); for additional information on effective communication requirements, please see DOJ, "Effective Communication," <https://www.ada.gov/effective-comm.htm> (<https://www.ada.gov/effective-comm.htm>).

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