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Rationing and Disability: The Civil Rights and Wrongs of State Triage Protocols

Deborah Hellman[*] and Kate M. Nicholson[**]

Abstract

The COVID-19 pandemic and the unprecedented natural disasters of 2020 remind us of the importance of emergency preparedness. This Article contributes to our legal and ethical readiness by examining state "Crisis Standards of Care," which are the standards that determine how medical resources are allocated in times of scarcity. The Article identifies a flaw in the policy choice at the heart of the standards: the standards focus on saving as many lives as possible but, in so doing, will predictably disadvantage the ability of people with disabilities and racial minorities to access life-saving care.

To date, scholarly attention has focused on explicit exclusions of people with particular medical conditions or the standards' failure to be sufficiently individualized. Amending the protocols to address these concerns, while important, will simply tinker at the margins. The more consequential and

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harder question is how states should balance the demand to save as many lives as possible while also ensuring that people with disabilities and other vulnerable groups are treated fairly.

To answer that question, this Article distills and analyzes four rationing principles that animate the state standards and contends that none ultimately balances these two important aims in a manner consistent with the Americans with Disabilities Act (ADA) and the moral commitments on which it rests. It thus provides a moral and legal framework to guide the ongoing revision of the standards. The Article concludes by proposing a novel, alternative rationing system that reserves resources to accommodate both efficiency and equity, thereby better instantiating the balance that undergirds the ADA.

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INTRODUCTION

The COVID-19 pandemic has underscored the importance of emergency preparedness. As we have learned, being prepared means having adequate supplies of medical resources, sufficient medical personnel, and ample space in hospitals. In addition, to address both the current pandemic and the next emergency, we need up-to-date systems for tracking disease, analyzing data, and distributing goods and services. But emergency preparedness is more than an issue of supplies, personnel, and systems; it also requires that the legal and ethical tools we bring to bear to address crises are justified and consistent with relevant law.

Among such tools are the state "Crisis Standards of Care" that direct how scarce medical resources should be allocated when supply is insufficient to meet the need. Many of these Crisis Standards were written well in advance of the current pandemic. New York, for example, drafted its comprehensive

"Ventilator Allocation Guidelines" in 2015.[1] However, since the pandemic's onset, a large number of states have modified their protocols[2] or adopted new ones entirely.[3] In this domain as in others, we were not fully ready.

A central feature of the Crisis Standards of Care that were in place when the pandemic hit was a near singular focus on saving the most lives possible.[4] While this goal seems reasonable, in practice, the rationing principles needed to achieve it will negatively and disproportionately affect the ability of people with disabilities[5] to get access to life-saving care.[6] This problem is not merely hypothetical. As of this writing, at least four states—Arizona, New Mexico, Alaska, and Idaho—in addition to Washington, D.C. have activated their crisis standards.[7] Moreover, even if, or when, the crisis is not

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[1] N.Y. STATE TASK FORCE ON LIFE & LAW, N.Y. STATE DEP'T OF HEALTH, VENTILATOR ALLOCATION GUIDELINES (2015) [hereinafter N.Y. VENTILATOR GUIDELINES], https://perma.cc/248A-KABV (PDF).

[2] *See, e.g.*, MINN. DEP'T OF HEALTH, PATIENT CARE STRATEGIES FOR SCARCE RESOURCE OPERATIONS (2020) [hereinafter MINNESOTA GUIDELINES], https://perma.cc/2RYD-6Z24 (PDF) (revising the State of Minnesota's Crisis Standards of Care in response to the COVID-19 pandemic); UTAH DEP'T OF HEALTH ET AL., UTAH CRISIS STANDARDS OF CARE GUIDELINES (2020) [hereinafter UTAH GUIDELINES], https://perma.cc/UH3Z-NKHR (PDF) (updating the previous Crisis Standards of Care from 2010).

[3] *See, e.g.*, IDAHO DEP'T OF HEALTH & WELFARE, PATIENT CARE: STRATEGIES FOR SCARCE RESOURCE SITUATIONS (2020) [hereinafter IDAHO GUIDELINES], https://perma.cc/5WXT-BJL8 (PDF); MASS. EXEC. OFF. OF HEALTH & HUM. SERVS.: DEP'T OF PUB. HEALTH, CRISIS STANDARDS OF CARE, PLANNING GUIDANCE FOR THE COVID-19 PANDEMIC (Oct. 2020) [hereinafter MASSACHUSETTS GUIDELINES], https://perma.cc/3XX2-7SYG (PDF).

[4] *See* N.Y. VENTILATOR GUIDELINES, *supra* note 1, at 4 ("The primary goal of the Guidelines is to save the most lives in an influenza pandemic where there are a limited number of available ventilators.").

[5] We refer generically to individuals with disabilities throughout this Article, by which we mean any individual with a pre-existing condition that would be considered a disability within the meaning of the ADA. Of course, many people may become disabled from the coronavirus disease or its consequences, but where rationing decisions are made at the onset, it is existing disabilities that inform our inquiry.

[6] As we discuss in Part II, the ADA and the related civil rights laws prohibit facially-neutral policies that have the effect of discriminating on the basis of disability. *See infra* notes 107 and 109 and accompanying text.

[7] *See* ARIZ. DEP'T OF HEALTH SERVS., COVID-19 PANDEMIC: CRISIS STANDARDS OF CARE ACTIVATION RECOMMENDATION FROM STATE DISASTER MEDICAL ADVISORY COMMITTEE (SDMAC) AND ADHS FINAL DETERMINATION 4 (2020), https://perma.cc/DN63-L4UB (PDF) (recommending that Arizona

acute, the prospect of the implementation of these standards means that people from vulnerable groups are left to grapple with the anxiety that, should they require hospitalization, they may be denied access to life-saving care.

The Crisis Standards of Care thus raise significant legal and moral issues. In particular, many may violate the Americans with Disabilities Act (ADA)[8] and related civil rights laws,[9] and the moral commitment to equal worth on which those laws rest. Unsurprisingly, in the early days of the pandemic, disability rights advocates raised challenges to these protocols in complaints to the Office for Civil Rights (OCR) at the Department of Health and Human Services.[10] And OCR quickly

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hospitals implement the state's Crisis Standards of Care policy); N.M. DEP'T OF HEALTH, PUBLIC HEALTH EMERGENCY ORDER RECOGNIZING THE ACTIVATION OF CRISIS CARE STANDARDS 2 (2020), https://perma.cc/BE3T-ASMZ (PDF) (ordering that certain healthcare professionals be credentialed under procedures outlined in the Crisis Standards of Care during the COVID-19 pandemic); D.C. DEP'T OF HEALTH, AUTHORIZATION OF USE OF CRISIS STANDARDS OF CARE BY HEALTHCARE FACILITIES DURING THE COVID-19 DECLARED EMERGENCY 1–2 (2020), https://perma.cc/R2GM-23VQ (PDF) (authorizing the implementation of D.C.'s Crisis Standards of Care based on findings that the COVID-19 pandemic is overwhelming healthcare providers); *see also* ALASKA DEP'T OF HEALTH & SOC. SERVS., ACTIVATION OF STATE PATIENT CARE STRATEGIES FOR SCARCE RESOURCE SITUATIONS (2021), https://perma.cc/L25L-BBVU (PDF); IDAHO DEP'T OF HEALTH & WELFARE, DECLARATION OF CRISIS STANDARDS OF CARE (2021), https://perma.cc/7ABU-5ACU (PDF).

[8] Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified as amended in scattered sections of 42 and 47 U.S.C.).

[9] Almost all healthcare decision-makers are covered by: the ADA; § 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; and/or § 1557 of the Patient Protection and Affordable Care Act (ACA), 42 U.S.C. § 18116. These laws contain analogous general prohibitions against discrimination on the basis of disability, but § 504 and the ADA are much more detailed. Section 504 is the precursor to the ADA, which applies to those receiving federal financial assistance and federal contractors. The ADA provides that nothing is to apply a lesser standard than the standards articulated under § 504. *See* 28 C.F.R. pt. 35 (2019) (articulating the specific prohibitions provided under § 504).

[10] For complaints against Washington, Alabama, Tennessee, Utah, Oklahoma, North Carolina, Oregon, Arizona, Nebraska, and North Texas protocols, see *HHS-OCR Complaints Re COVID-19 Medical Discrimination*, ARC (Mar. 23, 2020), https://perma.cc/S4W6-66V7. OCR has already resolved complaints against Alabama, Tennessee, and Utah. *See* Press Release, OCR, U.S. Dep't of Health & Hum. Servs., OCR Reaches Early Case Resolution with Alabama After It Removes Discriminatory Ventilator Triaging Guidelines (Apr. 8, 2020) [hereinafter OCR HHS Press Release Alabama], https://perma.cc/T7CK-2VJB (PDF) (announcing the end of a compliance review of the State of Alabama in response to claims that Alabama's Crisis

responded with a statement reaffirming that any rationing must be undertaken in a way that protects the basic civil rights of people with disabilities.[11] More recently, a small number of the states that have revised or adopted new protocols have recognized, at least in principle, that the goal of saving the most lives possible must be modified to take account of how that aim impacts vulnerable groups.[12] Oregon, which is perhaps at the forefront of this shift in perspective, even goes so far as to suggest that the traditional focus in triage standards on saving the most lives possible is flawed because it "may lead to further

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Standards of Care impermissibility discriminated on the basis of age and disability status); Press Release, OCR, U.S. Dep't of Health & Hum. Servs., OCR Resolves Complaint with Tennessee After It Revises Its Triage Plans to Protect Against Disability Discrimination (June 26, 2020) [hereinafter OCR HHS Press Release Tennessee], https://perma.cc/U65S-GARV (PDF) (documenting the various changes Tennessee made to its crisis standards of care, including eliminating life expectancy as a factor in allocating scarce medical resources); Sheri Fink, *Who Gets Lifesaving Care? Tennessee Changes Rules After Federal Complaint*, N.Y. TIMES (June 26, 2020), https://perma.cc/CCM8-K6W6; Press Release, OCR, U.S. Dep't of Health & Hum. Servs., OCR Resolves Complaint Against Utah After It Revised Crisis Standards of Care to Protect Against Age and Disability Discrimination (Aug. 20, 2020) [hereinafter OCR HHS Press Release Utah], https://perma.cc/7FEX-7ZSJ. As discussed in Part III, the complaint lodged in Utah focused not only on explicit discrimination but also on assessment tools that deprioritize people with disabilities, or the sort of disparate impact discrimination we address in this Article.

[11] *See* OCR, U.S. DEP'T OF HEALTH & HUM. SERVS., BULLETIN: CIVIL RIGHTS, HIPAA, AND THE CORONAVIRUS DISEASE 2019 (COVID-19) (2020) [hereinafter OCR HHS Bulletin], https://perma.cc/XXU5-T4QZ (PDF) ("In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws."); Press Release, OCR, U.S. Dep't of Health & Hum. Servs., OCR Issues Bulletin on Civil Rights Laws and HIPAA Flexibilities That Apply During the COVID-19 Emergency (Mar. 28, 2020), https://perma.cc/FQ3J-K9S3 (announcing the release of the OCR HHS Bulletin, which reaffirms healthcare providers' legal and regulatory obligations not to discriminate on the basis of disability during the COVID-19 pandemic); Sheri Fink, *U.S. Civil Rights Office Rejects Rationing Medical Care Based on Disability, Age*, N.Y. TIMES (Mar. 28, 2020), https://perma.cc/E66G-3B7R (last updated Mar. 30, 2020) (documenting the various civil rights complaints filed by the Department of Health and Human Services to ensure that healthcare providers are not violating individual civil rights when providing services).

[12] *See, e.g.*, OR. HEALTH AUTH., PRINCIPLES IN PROMOTING HEALTH EQUITY DURING RESOURCE CONSTRAINED EVENTS 3 (Dec. 7, 2020) [hereinafter OREGON PRINCIPLES], https://perma.cc/24VY-GQ3A (PDF).

inequitable access to life-saving resources and health inequalities."[13]

While it is not yet clear whether these developments augur a trend away from the singular focus on saving the most lives possible, they demonstrate a renewed interest in the important and pressing question of how to allocate scarce medical resources in times of emergency. Should the focus be exclusively on saving the most lives possible? Or should that laudable and important aim be balanced with the goal of ensuring access for people with disabilities and other vulnerable groups? This Article takes up that question.

The complaints already lodged[14] and the legal scholarship to date[15] focus chiefly on a narrow problem with the state protocols: some expressly exclude people with particular disabilities from treatment.[16] While we agree that protocols which expressly single out specific disabilities as a basis for denying care are inherently problematic, our focus is elsewhere. We address the more difficult question raised by facially neutral rationing policies that will save lives but, at the same time, will disproportionately exclude people with disabilities from care.

The resolution of this dilemma is likely to be extremely consequential.[17] While a relatively small number of people are left out by the explicit exclusions that have now been removed from some state protocols, the policy choice to aim exclusively at saving the most lives will deprioritize large numbers of people

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[13] *Id.*

[14] *See supra* note 10 and accompanying text.

[15] *See, e.g.*, Samuel R. Bagenstos, *May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing*, 130 YALE L.J. F. 1, 3–4 (2020) [hereinafter Bagenstos, *May Hospitals Withhold Ventilators*] (arguing that disability discrimination present in Crisis Standards of Care protocols is a violation of the law); *see also* Govind Persad, *Disability Law and the Case for Evidence-Based Triage in a Pandemic*, 130 YALE L.J.F. 26, 34–35 (2020) ("It is plausible—though contestable—that decisions about which patients will receive scarce medical treatments are governed by disability discrimination law.").

[16] *See* Bagenstos, *May Hospitals Withhold Ventilators*, *supra* note 15, at 2 (discussing the disability-based distinctions that Crisis Standards of Care make when determining who receives live-saving treatments during a period of increased demand).

[17] *See infra* Part II.

whose prior health status augurs a poor prognosis.[18] This Article thus addresses the central moral and legal choice that lies at the heart of the rationing protocols.

Importantly, there is a significant overlap between the groups defined as people with disabilities and racial minority groups.[19] Indeed, COVID-19 has had such a significant disparate impact on African-American, Native American, and Latinx people at least in part because individuals within these groups have health conditions, including conditions that are disabilities under the law, that make them more vulnerable to bad outcomes from this disease.[20] So while we focus on the common ground of disability, and evaluate whether the fact that these protocols negatively affect access to health care for people with existing disabilities violates current law, it is important to note that this negative effect will also fall especially heavily on racial minorities.[21]

Even in cases where no rationing occurs, the choices reflected in emergency preparedness protocols matter. The existence and endorsement of these policies sends a message to

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[18] *See infra* Part III.C.

[19] *See* Rashmi Goyat et al., *Racial/Ethnic Disparities in Disability Prevalence*, 3 J. RACIAL & ETHNIC HEALTH DISPARITIES 635, 641 (2016) ("A significantly higher percentage of non-Hispanic African Americans (14.8%) than non-Hispanic Whites (10.2%) had severe disability; the rates for Latinos were 8.1%."); Martha Ross & Nicole Bateman, *Disability Rates Among Working-Age Adults Are Shaped by Race, Place, and Education*, BROOKINGS (May 15, 2018), https://perma.cc/5THG-X995 ("At the national level, Native Americans have the highest disability rate among working-age adults (16 percent), followed by blacks (11 percent), whites (9 percent), Hispanics (7 percent), and Asians (4 percent).").

[20] *See* Kamyar Arasteh, *Prevalence of Comorbidities and Risks Associated with COVID-19 Among Black and Hispanic Populations in New York City: An Examination of the 2018 New York City Community Health Survey*, 8 J. RACIAL & ETHNIC HEALTH DISPARITIES 863, 863 (2020) (concluding that "[t]he greater prevalence of the factors associated with COVID-19 infection and adverse outcomes puts Black and Hispanic populations in NYC at a greater risk. These factors are also related to poverty and should be mitigated together with reducing racial/ethnic inequities").

[21] For a brief history of intersectionality and disability, see Rabia Belt & Doron Dorfman, *Disability, Law, and the Humanities: The Rise of Disability Legal Studies*, *in* OXFORD HANDBOOK OF L. & HUMAN. 145 (Simon Stern et al., eds., 2019). See NATALIE M. CHIN ET AL., EXAMINING HOW CRISIS STANDARDS OF CARE MAY LEAD TO INTERSECTIONAL MEDICAL DISCRIMINATION AGAINST COVID-19 PATIENTS, https://perma.cc/V3MW-XKUA (PDF), for more on the intersectional problem of medical discrimination in the COVID-19 pandemic.

people with disabilities and other vulnerable groups that their lives are less important than others or that the hard-won achievement of legal protections that ensure that they are treated equally is fragile and easily overridden in difficult times.[22]

To be sure, the decisions required in times of scarcity are not simple. We appreciate the "hard choices" these protocols require. Our aim is to illustrate in an accessible manner exactly what principles state crisis standards embody, and to examine these principles, both legally and morally. This is especially important because these protocols are in flux, as modifications are emerging in real time[23] and states have announced intentions to revisit these questions while they continue to plan for this pandemic and future crises.[24] In this potentially transitional moment, the singular focus on saving the most lives possible is starting to be reexamined and contested.

In the end, we argue that the best understanding of existing law, as well as the most morally defensible option, would require modification of most state protocols.[25] In our view, the traditional prioritization of saving the most lives is flawed, and the experience of the current pandemic demonstrates the need to revise the protocols so that this goal is pursued within a framework that also ensures that people with disabilities and members of other vulnerable groups are not left out.[26] We conclude by offering those involved in future emergency planning a novel, systemic solution for balancing both goals.[27]

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[22] *See infra* Part II.E.3.

[23] *See* N.J. DEP'T OF HEALTH, ALLOCATION OF CRITICAL CARE RESOURCES DURING A PUBLIC HEALTH EMERGENCY 1 (2020) [hereinafter N.J. GUIDELINES], https://perma.cc/DBH7-WCVB (PDF) (revising the previous Crisis Standards of Care with the understanding that they are subject to change at any time); OREGON PRINCIPLES, *supra* note 12, at 1 (issuing an interim statement following the Oregon Health Authority's September 2020 "decision to no longer reference or depend on previously established guidance, due to its potential for perpetuating discrimination and health inequities").

[24] *See* OREGON PRINCIPLES, *supra* note 12, at 1 (stating that the Oregon Health Authority "has begun meetings with community partners and health care experts in order to co-create a new and inclusive process with the goal of developing revised crisis care guidance centered on health equity").

[25] *See infra* Part IV.B.

[26] *See infra* Part III.

[27] *See infra* Part IV.A.

The Article proceeds as follows. In Part I, we lay out four hypothetical principles for rationing scarce medical resources and describe the ways in which the current state protocols rest on these rationing principles. Part II provides the legal background for our discussion. It addresses how the ADA and other discrimination laws bear on the legal permissibility of the state standards. Part III contains the heart of our analysis. There, we examine the permissibility of each of the four rationing principles and conclude that all are problematic and thus in need of revision. Finally, Part IV offers a novel proposal for how state protocols should be amended to take account of both the understandable desire to save as many people as possible and the imperative to ensure that in doing so people with disabilities and other vulnerable groups have a fair chance to access life-saving care. A conclusion follows.

I. RATIONING PRINCIPLES

A. *In Theory*

Imagine that medical resources are scarce. How *should* a state or hospital determine who gets access to these resources? Which aims or principles ought to inform their decisions? In any rationing situation, there will be many possibilities.[28] For example, the familiar (if outdated), "women and children first" principle that guided who got the limited lifeboat spots on the Titanic rests on the combination of two rationing principles: (1) women should be preferred to men; and (2) children should be preferred over adults. Today, sex-based rationing is unlikely to be adopted but age-based rationing—especially when it provides a preference for children—is one possible approach.[29]

To make concrete and accessible the choices that policymakers face in designing protocols to guide the rationing of scarce medical resources, we offer four hypothetical principles illustrated in the stylized scenarios below. In these scenarios, we focus on a generic "scarce medical resource" or SMR, because

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[28] *See generally* Saul Smilansky, *A Hostage Situation*, 116 J. PHIL. 447 (2019) (cataloging the many principles that could plausibly apply to rationing of a scarce life-saving resource and arguing that several among them are morally permissible).

[29] *See infra* Part III.B.

which resource or resources will become scarce in any crisis is difficult to predict in advance. In the spring of 2020, ventilators were scarce.[30] As we write, scarcity of hospital beds and trained medical personnel is limiting care.[31] In the future, the scarce resource might be a medicine, a device, or something else that we cannot now imagine. But what we can imagine, and prepare for, are the principles that could be brought to bear in determining how society addresses this scarcity. Four possible rationing principles follow:

<u>Scenario One</u>: Probability of Survival

Suppose that Patient A has an X probability of surviving after treatment with the SMR while Patient B has a .5X probability of survival after treatment.

<u>Principle One</u>: A rationing principle based on *Probability of Survival* would prioritize A over B because A has a greater likelihood of surviving treatment.

<u>Scenario Two</u>: Level of Resource Commitment

Suppose that Patient C requires Y units of time with the SMR to recover while Patient D requires four times that amount to achieve the same result.

<u>Principle Two</u>: A rationing principle based on *Level of Resource Commitment* would prioritize C over D because C will use the resource for less time than would D.

<u>Scenario Three</u>: Life Expectancy

Suppose that Patient E and Patient F have the same probability of survival after treatment for the same amount of time, but that Patient E has a life expectancy of twenty years after treatment while Patient F has a life expectancy of five years after treatment.

<u>Principle Three</u>: A rationing principle based on *Life Expectancy* would prioritize E over F because E has a longer life expectancy after treatment.

<u>Scenario Four</u>: Quality of Life

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[30] *See* Sarah Kliff et al., *There Aren't Enough Ventilators to Cope with the Coronavirus*, N.Y. TIMES (Mar. 18, 2020), https://perma.cc/7W97-L38U (last updated Mar. 26, 2020) (discussing the worldwide shortage of ventilators during the COVID-19 pandemic).

[31] *See* Reed Abelson, *Covid Overload: U.S. Hospitals Are Running Out of Beds for Patients*, N.Y. TIMES (Nov. 27, 2020), https://perma.cc/CK3U-DE6Q (documenting various consequences of a nationwide shortage of healthcare personnel and the shortage's effect on non-COVID-19 patients).

Suppose that Patient G and Patient H have the same likelihood of survival after treatment with the SMR for the same amount of time and are likely to survive for the same number of years after treatment. However, G will have "a higher quality of life" than will H.

<u>Principle Four</u>: A rationing principle based on perceived *Quality of Life* would prioritize G over H because G is perceived to have a better quality of life.

These examples, while stripped down and stylized, employ factors that are commonly used in the state protocols.[32] The factors could easily be combined. We present them separately to explore whether each principle is morally and legally permissible and if not, why not. In the next section we show how each of these principles operates in state protocols.

B. *In Practice*

In this section, we provide an overview of key aspects of the state "Crisis Standards of Care." The overarching aim of the state protocols is to save the most lives.[33] For example, the University of Washington, which drafted a new document specifically focused on allocating scarce resources in light of COVID-19 in the early days of the pandemic, provides that "the standard construct for medical resource allocation in time of scarcity is based upon a utilitarian framework, often stated as making decisions that provide the greatest good for the greatest number."[34] Similarly, New York's "Ventilator Allocation Guidelines," which were issued in 2015 in anticipation of a possible influenza pandemic, provide that "[t]he primary goal . . . is to save the most lives in an influenza pandemic where there are a limited number of available ventilators."[35] Today,

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[32] *See infra* Part II.

[33] *See* Katie Savin & Laura Guidry-Grimes, *Confronting Disability Discrimination During the Pandemic*, HASTINGS CTR. (Apr. 2, 2020), https://perma.cc/6E3L-7HRY (advancing recommendations to change crisis triage protocols to minimize structural disability discrimination).

[34] UNIV. WASH. MED. CTR., MATERIAL RESOURCE ALLOCATION PRINCIPLES AND GUIDELINES: COVID-19 OUTBREAK 1 [hereinafter U. WASH. ALLOCATION PRINCIPLES], https://perma.cc/HC4N-3LMY (PDF).

[35] N.Y. VENTILATOR GUIDELINES, *supra* note 1, at 4; *see* MASSACHUSETTS GUIDELINES, *supra* note 3, at 12 (articulating the general understanding that the purpose of the Guidelines is to save the most lives as possible); KY. PUB.

the picture is somewhat murkier, as a few states have updated their protocols to articulate, at least in principle, a desire for greater balancing of the goals of saving lives and ensuring inclusion.[36]

The approach of saving the most lives is described in the Crisis Standards of Care as "utilitarian" in orientation.[37] However, several different ethical theories could, and do, support the importance of saving as many lives as possible.[38] We use the term "utility" as shorthand because it is the term used by the protocols, but our intention is simply to ask whether the exclusive aim of maximizing the number of lives saved comports with ethical norms and existing law.

To get a handle on precisely how the state crisis standards of care implement this maximizing-lives-saved approach and to

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HEALTH, CRISIS STANDARDS OF CARE: GUIDANCE FOR THE ETHICAL ALLOCATION OF SCARCE RESOURCES DURING A COMMUNITY-WIDE PUBLIC HEALTH EMERGENCY 35 (2020) [hereinafter KENTUCKY GUIDELINES], https://perma.cc/PJH5-GXDX (PDF) (describing the Kentucky Department of Public Health's duty as a "charge to do the best for the most, saving as many lives as possible with a marked scarcity of resources").

[36] As we observed in the Introduction, most notable in this regard is an action taken by the Oregon Health Authority to rescind its previous crisis standards. *See* OREGON PRINCIPLES, *supra* note 12, at 3 (issuing a statement of principles and announcing the intention to revise its standards going forward, while noting that "[t]he primary goal of crisis care guidance has traditionally been to save the most lives" with insufficient consideration of health equity and nondiscrimination). Similarly, New Jersey, which revised its protocol in December 2020, reframes its animating principle as one obtaining "maximum benefit for populations of patients, often expressed as doing the greatest good for the greatest number, while promoting just distribution of benefits, burdens, and costs." N.J. GUIDELINES, *supra* note 23, at 3. The protocol that operationalizes this principle, however, continues to ration on the basis of principles which we would reject as giving insufficient credence to inclusivity and distributive concerns.

[37] *See* N.J. GUIDELINES, *supra* note 23, at 4 ("Any allocation system should be equitable (fair) and serve to maximize lives and life-years saved (utility)."); R.I. DEP'T OF HEALTH, CRISIS STANDARDS OF CARE GUIDELINES 5–6 (2020) [hereinafter R.I. GUIDELINES], https://perma.cc/CKR9-LT7X (PDF) (noting that healthcare institutions' duty to steward resources reflects "the utilitarian goal of saving the greatest possible number of lives"); U. WASH. ALLOCATION PRINCIPLES, *supra* note 34, at 1 (stating that scarce medical resource allocation typically "is based upon a utilitarian framework, often stated as making decisions that provide the greatest good for the greatest number," while "[g]reatest good . . . is generally considered maximizing survival of patients").

[38] *See generally* Smilansky, *supra* note 28.

generate the ethical questions our scenarios explore, we describe how each of these "hypothetical" rationing principles are instantiated in the state protocols.

1. Principle One: Probability of Survival

State standards operationalize the goal of saving the most lives by prioritizing people who can derive the most benefit from scarce medical resources. For example, New Jersey's standards provide that "[p]atients who are more likely to survive with intensive/critical care are prioritized over patients who are less likely to survive with intensive care/critical care."[39] In practice, this means that patients are ranked in terms of their likelihood of survival with treatment and the patients in need of treatment who are most likely to benefit from it are offered treatment first. In Pennsylvania, patients are divided into color coded categories and the protocol directs that "individuals in the red group have the best chance to benefit from critical care interventions and should therefore receive priority over all other groups in the face of scarcity."[40] This approach rations scarce medical resources based on *Probability of Survival*, Principle One in our scenarios.[41]

Most states measure probability of survival using a metric called a "SOFA" score, which many jurisdictions see as a proxy

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[39] N.J. GUIDELINES, *supra* note 23, at 8.

[40] *See* PA. DEP'T OF HEALTH, INTERIM PENNSYLVANIA CRISIS STANDARDS OF CARE FOR PANDEMIC GUIDELINES 31 (2020) [hereinafter PENNSYLVANIA GUIDELINES], https://perma.cc/TD2N-HP5T (PDF)

> [I]ndividuals in the red group have the best chance to benefit from critical care interventions and should therefore receive priority over all other groups in the face of scarcity. The orange group has intermediate priority and should receive critical care resources if there are available resources after all patients in the red group have been allocated critical care resources. The yellow group has lowest priority and should receive critical care resources if there are available resources after all patients in the red and orange groups have been allocated critical care resources.

Accord N.Y. VENTILATOR GUIDELINES, *supra* note 1, at 6–7 (assigning patients color codes to determine the level of access to a ventilator with blue-code patients representing the lowest access and red-code patients representing the highest access).

[41] *See supra* Part I.A.

for mortality risk.[42] SOFA is an acronym for "Sequential Organ Failure Assessment" and works as follows:

> The SOFA score adds points based on clinical measures of function in six key organs and systems: lungs, liver, brain, kidneys, blood clotting, and blood pressure. For each variable, dysfunction is measured on a zero to four scale, with four being the worst score. A perfect SOFA score, indicating normal function in all six categories, is 0; the worst possible score is 24 and indicates life-threatening abnormalities in all six systems.[43]

The value of SOFA scores is consistency.[44] Rather than relying on subjective judgments of prognosis, clinicians must assess each organ or system and tally points in a standard way.[45] Some states, like Vermont, use a Modified Sequential Organ Failure Assessment (mSOFA).[46] Other states, like Tennessee, provide for use of either SOFA or mSOFA assessments.[47] Both tests operate in a similar manner.[48]

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[42] *See, e.g.*, KENTUCKY GUIDELINES, *supra* note 35, at 35 (using patients' SOFA scores to determine "those who are too ill to likely survive"); N.J. GUIDELINES, *supra* note 23, at 7 ("[T]he Sequential Organ Failure Assessment (SOFA) score . . . is used to determine patients' prognoses for hospital survival."); R.I. GUIDELINES, *supra* note 37, at 17–18 ("The most common triage tool of survivability for adults is the Sequential Organ Failure Assessment (SOFA) tool.").

[43] N.Y. VENTILATOR GUIDELINES, *supra* note 1, at 49–50.

[44] *See, e.g.*, *id.* at 52 (rationalizing the use of SOFA scores for clinical ventilator allocation protocol because "clinical criteria to support triage decisions promote fairness and consistency, as well as provide clinicians with guidance to follow when they are faced with this difficult situation").

[45] *See, e.g.*, *id.* at 14 ("A SOFA score adds points based on clinical measures of function in six key organs and systems: lungs, liver, brain, kidneys, blood clotting, and blood pressure.").

[46] *See* VT. DEP'T OF HEALTH, VERMONT CRISIS STANDARDS OF CARE PLAN 47–48 (2020), https://perma.cc/RR3N-JYRU (PDF) (describing the mSOFA Scores as a "quantitative and qualitative decision-making" guideline for the "Ethical Allocation of Scarce Mechanical Ventilators").

[47] *See* TENN. DEP'T OF HEALTH, GUIDANCE FOR THE ETHICAL ALLOCATION OF SCARCE RESOURCES DURING A COMMUNITY-WIDE PUBLIC HEALTH EMERGENCY AS DECLARED BY THE GOVERNOR OF TENNESSEE B-3 (2020) [hereinafter TENNESSEE GUIDELINES], https://perma.cc/S5LF-VQKV (PDF) (allowing hospitals to use "the Sequential Organ Failure Assessment (SOFA) Score or the Modified-SOFA (MSOFA)" to determine patients' likelihood of survival).

[48] *See, e.g.*, *id.* (explaining that the use of SOFA requires additional blood tests while the mSOFA only requires creatine measurement, but that

In some states, evaluation using a SOFA-type scale is only the first step, and additional factors, such as whether the patient presents with an underlying co-morbid condition, or disability, is used as a proxy for probability of survival.[49] Still other state protocols use general descriptions of likelihood to benefit from treatment as a factor for prioritizing access to life-saving care.[50] All of these considerations relate to *Probability of Survival.*

2. Principle Two: Level of Resource Commitment

Some states expressly use *Level of Resource Commitment* as a prioritization factor when deciding whether to allocate a scarce medical resource.[51] In Alaska, for example, those patients likely to use a resource for fewer than three days and those likely to improve with access to the resource are assigned a higher priority than those likely to use it for more than seven days.[52]

"[t]he cutoffs remain the same using either score, and the prediction for both is essentially the same").

[49] *See, e.g.*, MINNESOTA GUIDELINES, *supra* note 2, at 6-2 ("SOFA scores should never be used to deny a ventilator to a patient but should be used in combination with other factors to compare patients needing the resource."); OKLA. STATE DEP'T OF HEALTH, HOSPITAL CRISIS STANDARDS OF CARE 14 (2020) [hereinafter OKLAHOMA GUIDELINES], https://perma.cc/PS3M-R5CS (PDF) (combining a patient's SOFA score, their "prognosis for short-term survival," and their "[p]rognosis for long-term survival" to assign a level of priority for allocation of scarce resources).

[50] *See, e.g.*, ILL. DEP'T OF PUB. HEALTH, GUIDELINES ON EMERGENCY PREPAREDNESS FOR HOSPITALS DURING COVID-19 7 [hereinafter ILLINOIS GUIDELINES], https://perma.cc/QBN3-STXB (PDF) (allowing "de-prioritization of patients who are unlikely to benefit from the scarce resource or treatment").

[51] *See, e.g.*, ALASKA DEP'T OF HEALTH & SOC. SERVS., PATIENT CARE STRATEGIES FOR SCARCE RESOURCE SITUATIONS 6-2 (2020) [hereinafter ALASKA GUIDELINES], https://perma.cc/XCJ3-GZWG (PDF) ("Re-allocate ventilator/resource only if patient presenting with respiratory failure has significantly better chance of survival/benefit as compared to patient currently receiving ventilation."); GOVERNOR'S EXPERT EMERGENCY EPIDEMIC RESPONSE COMM. MED. ADVISORY GRP., RECOMMENDATIONS FOR CRISIS STANDARDS OF CARE FOR HOSPITALS FOR THE COVID-19 PANDEMIC 12 (2020) [hereinafter COLORADO GUIDELINES], https://perma.cc/8AKM-4XPJ (PDF) (listing "[d]uration of mechanical ventilation," "[t]rajectory of illness," and "[i]ntensity of Resource Utilization" as the primary considerations for re-allocation decisions).

[52] ALASKA GUIDELINES, *supra* note 51, at 6-2. Some states apply this principle more generally but without rigid cutoffs. *See* MINN. DEP'T OF HEALTH, ALLOCATION OF VENTILATORS & RELATED SCARCE CRITICAL CARE RESOURCES

Other states, such as Kentucky, go so far as to use an anticipated level of resource intensity as a basis to exclude patients from life-saving care.[53]

A more common way in which the state protocols ration by *Level of Resource Commitment* is with policies that set standard times by which a patient must show improvement to continue to use a scarce medical resource. For example, an early version of the Massachusetts rationing protocol provided that "[p]atients showing improvement will continue with critical care/ventilation until the next assessment."[54] If there are patients waiting for a scarce medical resource, some states allow a resource that is currently in use to be withdrawn from a patient who has deteriorated or has not improved by the time of reassessment.[55] Most jurisdictions re-evaluate on a regular basis, but states use different standards of measurement, often by assigning preset amounts of time (improvement within a certain number of days) with the allotted time varying depending upon the priority group the patient is assigned to.[56]

DURING THE COVID-19 PANDEMIC 6 (2020) [hereinafter MINNESOTA ALLOCATION OF VENTILATORS], https://perma.cc/EC69-UX53 (PDF) ("Patients who are reliably predicted to need a resource for a substantially greater amount of time than other patients currently needing the resource may be deprioritized to allow more patients to have access.").

[53] *See* KENTUCKY GUIDELINES, *supra* note 35, at 35 (expressly excluding from hospital and ICU care those patients whose existing chronic condition, or disability, may cause them to "require a larger-than-normal number of resources").

[54] MASS. EXEC. OFF. OF HEALTH & HUM. SERVS.: DEP'T OF PUB. HEALTH, CRISIS STANDARDS OF CARE, PLANNING GUIDANCE FOR THE COVID-19 PANDEMIC 23 (Apr. 2020), https://perma.cc/MEG5-WBUG.

[55] *See, e.g.*, CAL. DEP'T OF PUB. HEALTH, LETTER TO HEALTH CARE DELIVERY LEADERS AND COUNTY HEALTH ENTITIES 28–29 (2020) [hereinafter CALIFORNIA GUIDANCE], https://perma.cc/8A9W-CH69 (PDF) ("[T]he goal of maximizing the benefit for communities of patients would be jeopardized if patients who were determined to be unlikely to survive hospitalization were allowed indefinite use of scarce critical care services."); MASSACHUSETTS GUIDELINES, *supra* note 3, at 25–26 ("[T]herapeutic trials may be shorter if the ability of the hospital to reallocate the ordinary course of critical care is overwhelmed by the demand for such resources."); N.J. GUIDELINES, *supra* note 23, at 2 ("The triage team will conduct periodic reassessments of all patients receiving ICU/critical care services during times of crises.").

[56] *See, e.g.*, N.Y. VENTILATOR GUIDELINES, *supra* note 1, at 63–67 (criteria for reevaluating patients with different priority levels at 48-hour and 120-hour assessments); S.C. PANDEMIC INFLUENZA ETHICS TASK FORCE, SOUTH CAROLINA PREPARES FOR PANDEMIC INFLUENZA: AN ETHICAL PERSPECTIVE 66–69

We envision two rationales for this policy. First, a patient who has not improved by the check-in point may be unlikely to improve at all. If so, continued allocation of the scarce resource to this patient provides little benefit. While this threshold for lack of benefit is likely far less demanding than the "futility" threshold that is used in normal circumstances,[57] the basic idea is similar. Yet, some patients may require longer times with the resource to achieve the same level of improvement that another person might achieve with fewer days or hours. In that case it is not a question of futility, or near futility. Rather, the reassessment and reallocation approach in the state protocols is likely grounded by a different and more ethically controversial rationale. By standardizing the time within which a patient must improve to continue to have access to the scarce medical resource, a state is prioritizing those patients who need less time with scarce medical resources over those who need more.[58]

We label both types of policies—those governing initial decision-making and those used for reassessment—as using the rationing principle of *Level of Resource Commitment*.[59]

3. Principle Three: Life Expectancy

The state approaches differ with regard to whether and how they consider life expectancy. Some states that previously rationed on the basis of life expectancy, like Oregon, have now

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(2009) [hereinafter SOUTH CAROLINA GUIDELINES], https://perma.cc/JWT7-RGXQ (PDF) (criteria for reevaluating patients with different priority levels at 48-hour and 96-hour assessments).

[57] *See infra* Part II.E.1.

[58] South Carolina takes just this approach. *See* SOUTH CAROLINA GUIDELINES, *supra* note 56, at 68–69 (using the absence of change in SOFA score as a criterion for assigning a lower triage priority). When considering reallocation of a scarce medical resource, some states will reallocate only if a patient presenting has a "significantly better chance of survival benefit" as compared with the patient currently receiving ventilation. ALASKA GUIDELINES, *supra* note 51, at 6-2. These include Alaska and Minnesota. *See id.* (allowing re-allocation only when the patient using the ventilator has a "significant difference in prognosis . . . [c]ompared to other patient(s) requiring and awaiting external ventilation"); MINNESOTA GUIDELINES, *supra* note 2, at 6-2 (allowing reallocation "only if [the] patient presenting with respiratory failure has significantly better chance of survival/benefit as compared to [the] patient currently receiving ventilation").

[59] *See supra* Part I.A.

rejected this principle.[60] Other states continue to use life expectancy as a rationing principle in the way they prioritize care,[61] or as a tie-breaking criterion.[62]

Rationing by life expectancy should not, however, be confused with age-based rationing, which several states adopt.[63] New York, for example, rations based on age by giving priority

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[60] *See* OREGON PRINCIPLES, *supra* note 12, at 6

> [U]se of life expectancy criterion in assessing prognosis or in scoring (e.g., "life years" or "1 or 5-year mortality assessments") will also perpetuate inequities . . . . For this reason, life expectancy as a criterion in scoring should not be used in decision-making about the allocation of scarce resources during a public health crisis.

Tennessee and Utah, which were the subject of complaints by disability advocates about their protocols, also rationed on the basis of *Life Expectancy*. *Cf.* OCR HHS Press Release Tennessee, *supra* note 10 (providing for all such policies to be removed); OCR HHS Press Release Utah, *supra* note 10 (same).

[61] Alaska, for example, assigns people with conditions that are likely to result in death within one to two years a lower priority for care. *See* ALASKA GUIDELINES, *supra* note 51, at 6-2 (recommending resource re-allocation when the patient has a "[h]igh potential for death (SOFA score ≥ 12)"). Some states, like Oklahoma, consider much longer time frames, such as malignancy in which death is anticipated in less than ten years. *See* OKLAHOMA GUIDELINES, *supra* note 49, at 13–15 (labeling "[m]alignancy with a <10 year expected survival" as a "Major Comorbidit[y]," adding two points to Oklahoma's multi-principle scoring system).

[62] *See* CALIFORNIA GUIDANCE, *supra* note 55, at 27–28 (resolving "ties" by giving "[p]atients who do not have a severely limited near-term prognosis for survival . . . priority over those who are likely to die in the near-term, even if they survive the acute critical illness"); FLA. BIOETHICS NETWORK, ETHICS GUIDELINES FOR CRISIS STANDARDS OF CARE IN PUBLIC HEALTH EMERGENCIES 14 (2020) [hereinafter FLORIDA GUIDANCE], https://perma.cc/69K5-265K (PDF) ("Ties within Priorities Groups are adjudicated using individualized assessment of, first, co-morbidities associated with short-term survival; second, life cycle; third, healthcare workers and staff.").

[63] *See* UNIV. OF MD., MARYLAND FRAMEWORK FOR THE ALLOCATION OF SCARCE LIFE-SUSTAINING MEDICAL RESOURCES IN A CATASTROPHIC PUBLIC HEALTH EMERGENCY 13 (2017) [hereinafter MARYLAND GUIDELINES], https://perma.cc/4ELB-AY45 (PDF) (prioritizing allocation of resources by age where the "highest priority in this scoring system is given to children"). For states which consider age in a tie situation, see, for example, N.J. GUIDELINES, *supra* note 23, at 10–11 ("[L]ife-cycle considerations should be used as a tiebreaker if there are not enough resources to provide to all patients within a priority group."); PENNSYLVANIA GUIDELINES, *supra* note 40, at 34 ("In the event that there are 'ties' . . . younger individuals receive priority because they have had the least opportunity to live through life's stages."); SOUTH CAROLINA GUIDELINES, *supra* note 56, at 30, 71–72 (breaking ties "between patients with equal SOFA scores" by "prioritizing younger patients").

to patients seventeen-years-old or younger over anyone over seventeen, so long as both patients are in the same category with regard to their probability of benefit.[64] Despite its reference to age, New York rejects consideration of life expectancy and expressly considers only "short-term likelihood of survival of the acute medical episode and is not focused on whether a patient may survive a given illness or disease in the long-term."[65] The N.Y. Ventilator Guidelines thus ration based on age but not on life expectancy. In sum, while prioritizing the young could be based on a principle of life-expectancy, it need not be as the young could be prioritized over the old for other reasons.

4. Principle Four: Quality of Life

None of the state protocols explicitly endorse rationing based on perceptions of the quality of life of a person with a disability. Many explicitly reject it.[66] For example, the California Plan cautions that "[t]o ensure non-discrimination against individuals with disabilities, triage protocols must either not score individuals based on their quality of life after treatment, or assess at most how far treatment will return the patient to their own baseline quality of life."[67] Similarly, the Illinois Plan states that "an ethical framework does not permit withholding treatment or prioritizing resources based on one factor, judgments that some individuals have a higher quality or value of life than others, or judgments about greater 'social value' in comparison to others."[68] We nevertheless include this principle in our discussion because considerations regarding the

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[64] *See* N.Y. VENTILATOR GUIDELINES, *supra* note 1, at 88–89 ("[W]hen the patients all have equal (or near equal) likelihoods of survival, . . . young age [may] play a tie-breaking role in determining whether a patient receives/continues with ventilator therapy.").

[65] *Id.* at 34.

[66] *See, e.g.*, ILLINOIS GUIDELINES, *supra* note 50, at 6; R.I. GUIDELINES, *supra* note 37, at 16 ("[D]isability, . . . perceived social worth, [or] perceived quality of life . . . must not be considered in making priority determinations."); TENNESSEE GUIDELINES, *supra* note 47, at 12 (reiterating that all federal laws protecting patients with disabilities "remain in effect during an emergency").

[67] CALIFORNIA GUIDANCE, *supra* note 55, at 17.

[68] ILLINOIS GUIDELINES, *supra* note 50, at 6.

Quality of Life of individuals with disabilities may inadvertently affect how the protocols are actually applied.[69]

In this section, we outlined how state rationing protocols employ the four rationing principles we distilled. Before addressing how the law and ethics might treat each principle, we provide a brief overview of the legal protections against discrimination on the basis of disability that governs these questions.

II. THE ADA & DISCRIMINATION ON THE BASIS OF DISABILITY

In this Part, we address the primary law that protects the rights of individuals with disabilities, the Americans with Disabilities Act (ADA).[70] We begin by setting up the conceptual distinction between disparate treatment discrimination and disparate impact discrimination that is relevant in both this law and in discrimination law more generally.[71] While some of the state protocols explicitly exclude people with particular

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[69] One issue that is beyond the scope of our analysis but critically important to the life and safety of a subset of people with disabilities is the danger that individuals who use ventilators regularly for a pre-existing condition may have their personal ventilators reallocated to others when they enter the triage process. Increasingly, states that are revising their protocols are including explicit protections for chronic ventilation users. *See, e.g.*, OREGON PRINCIPLES, *supra* note 12, at 6 ("Patients who are chronically ventilator-dependent outside of the critical care context should not have their ventilators withdrawn."); MINNESOTA ALLOCATION OF VENTILATORS, *supra* note 52, at 5, https://perma.cc/S6QU-MA8B (PDF) ("Patients who are chronically ventilator dependent outside of the critical care context will not have their ventilators withdrawn in order to extend supplies."). We believe that an explicit prohibition should be a part of all rationing protocols. People should not live in fear of having their personal ventilation device taken away, typically at the expense of their lives, simply because they seek access to medical care. Fortunately, the OCR resolutions in Tennessee and Utah expressly prohibit re-allocating the personal ventilation devices away from chronic ventilation users. *See, e.g.*, OCR HHS Press Release Utah, *supra* note 10 (incorporating "language stating that hospitals should not re-allocate personal ventilators brought by a patient to an acute care facility").

[70] *See supra* note 9 and accompanying text. As previously noted, the ADA does not apply a lesser standard than required by Section 504. *See* 42 U.S.C. § 12201(a) ("[N]othing in this Act shall be construed to apply a lesser standard than the standards applied under title V of the Rehabilitation Act of 1973."). We focus on the ADA as the most fundamental and far-reaching of these laws.

[71] *See infra* Part II.A.

disabilities from care (disparate treatment), the harder cases are the disparate impact cases we address in this Article, in which facially neutral policies have a disproportionate negative impact on a protected group.[72] As we explain in Part II.A, each of the rationing principles is likely to do just this. This section thus sets up the legal question that must be addressed by reference to the ADA.

In Part II.B, we provide relevant background on the social history of discrimination against persons with disabilities that the ADA seeks to remedy. Part II.C outlines the ADA's basic nondiscrimination provisions, paying particular attention to the way the ADA treats policies and actions that have a disparate impact on disabled persons, and Part II.D outlines how the ADA balances considerations of utility and inclusion. In Part II.E, we turn to case law and administrative agency determinations addressing scarcity, including the recent OCR resolutions of complaints lodged by disability rights advocates against the rationing protocols, themselves. Finally, in Part II.F, we call attention to the focus in the doctrine on the contrast between stereotyping and individualized inquiry because this contrast, while useful, has been over-emphasized in our view, distorting the picture of what is needed to comply with the ADA's insistence on the genuine inclusion of people with disabilities.

A. *Disparate Treatment Versus Disparate Impact*

U.S. discrimination law is organized around two distinct concepts of "discrimination": disparate treatment and disparate impact. In disparate treatment cases, the law or policy explicitly distinguishes between people on the basis of a legally protected trait and treats people with and without the trait differently. For example, some state protocols have explicitly excluded people with specific disabilities from care.[73] Disparate impact, by contrast, addresses laws and policies that do not target people with a particular trait for different treatment, but

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[72] *See infra* notes 80–81 and accompanying text.

[73] *See, e.g.*, TENN. 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, attach. C at 5 (2016), https://perma.cc/RAY8-YCP9 (PDF) (listing exclusion criteria for hospital admission, including, e.g., "[a]dvanced untreatable neuromuscular disease").

nonetheless affect people differently. In particular, people with the legally protected trait fare worse under the facially neutral law than do those without the trait. In such cases, discrimination statutes, including the ADA, require that this "disparate impact" be justified.[74]

Disparate treatment cases are the easy cases. As a result, it is unsurprising that complaints against such exclusions in state protocols have already been addressed.[75] The disparate impact cases present the harder cases. The principles with which we began this Article all reflect policy choices that will, if applied, have a disparate impact on people with disabilities. None of these principles explicitly exclude people with disabilities, yet as we describe below, each is likely to have a significant adverse impact on the ability of disabled people to access life-saving treatment.

If people with disabilities have health conditions or impairments that make them less likely to survive with the scarce medical resource than non-disabled people, then *Probability of Survival* will disfavor the disabled. If people with disabilities are likely to use a scarce resource for a longer period than are non-disabled people, then *Level of Resource Commitment* will disfavor the disabled. If people with disabilities are more likely to have lower life-expectancy than people without disabilities, then *Life Expectancy* will disfavor the disabled. Finally, if *Quality of Life* measures are used to ration resources, they will disfavor the disabled to the extent that a life with disability is judged to be of lower quality than one without a disability.

When we consider all the rationing decisions that health care providers may face, the net effect is that individuals with disabilities and members of racial minorities with comorbid conditions are more likely to be denied access to life-saving care. Of course, none of these policies will negatively affect all disabled people. A blind person, for example, may well have the same probability of survival (all else equal) as a sighted

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[74] 42 U.S.C. § 12132; 28 C.F.R. § 35.130(b)(3).

[75] *See* OCR HHS Press Release Alabama, *supra* note 10 (challenging exclusionary criteria in Alabama); OCR HHS Press Release Tennessee, *supra* note 10 (challenging exclusionary criteria in Tennessee); OCR HHS Press Release Utah, *supra* note 10 (challenging exclusionary criteria in Utah).

person.[76] Nevertheless, such a policy will likely have a disparate negative impact on people with disabilities because the group of people harmed by the policy is likely to contain a disproportionate number of disabled people.

Some scholars argue that this is not the relevant measure to assess whether a policy produces a disparate impact. For example, Govind Persad argues that we should focus instead on whether people with disabilities will benefit from policies that maximize lives saved.[77] If more disabled people have disabilities

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[76] Despite the intuitive appeal of this example, evidence from one of the largest mortality studies of COVID-19 shows that people who are blind are actually at higher risk of mortality from this disease. *See* Greg Laub, *Largest to Date COVID Mortality Study Released*, MEDPAGE TODAY (Nov. 11, 2020), https://perma.cc/3V28-NMLL ("We found that blindness, for example, was an independent risk factor."). This finding may result from blind people living disproportionately in congregate care settings, a known high-risk environment. *See, e.g.*, Scott D. Landes et al., *COVID-19 Case-Fatality Disparities Among People with Intellectual and Developmental Disabilities: Evidence from 12 US Jurisdictions*, 14 DISABILITY & HEALTH J. 1, 1–2 (2021) (determining that the COVID-19 case-fatality and case-mortality rates were higher for individuals with intellectual and developmental disabilities [IDD] living in shared residential spaces, as opposed to individuals with IDD living on their own or in a family home). Scott Landes and his colleagues' work on the disparate impact of COVID-19 on people with developmental and intellectual disabilities suggests that living in congregate care settings or receiving 24/7 nursing care likely plays a role. *See id.* ("[C]ase-fatality rate[s] remained higher for people with IDD living in residential group homes.").

But with visual impairments, as with other disabilities, the reasons may also be more complex. Bodies are integrated wholes and impairments are not often so segregable. Visual impairments, for example, may stem from or be exacerbated by co-morbid conditions. *See* Maria D. Pinazo-Durán et al., *Ocular Comorbidities and the Relationship Between Eye Diseases and Systemic Disorders*, 2016 BIOMED RSCH. INT'L (SPECIAL ISSUE) 1, 1 (2016) (noting concomitant systemic diseases common with visual impairments). The same is true of many disabilities that initially appear not to involve co-morbidities, such as autism. *See* Finale Doshi-Velez et al., *Comorbidity Clusters in Autism Spectrum Disorders: An Electronic Health Record Time-Series Analysis*, 133 PEDIATRICS e54, e56 (2014) (outlining common concurrent conditions with autism). Other disabilities like spinal cord injuries often involve complicating concurrent health conditions. *See* Travis E. Marion et al., *Previously Identified Common Post-Injury Adverse Events in Traumatic Spinal Cord Injury—Validation of Existing Literature and Relation to Selected Potentially Modifiable Comorbidities: A Prospective Canadian Cohort Study*, 34 J. NEUROTRAUMA 2883, 2883 (2017) (listing comorbidities and complications that often accompany spinal cord injuries).

[77] *See* Persad, *supra* note 15, at 41–48 (arguing that this approach "likely saves more lives among patients with disabilities," rather than

that are unlikely to affect their survival than have disabilities that do diminish their likelihood of survival, then people with disabilities as a group may be benefited, rather than harmed, by the policies that aim to maximize lives saved. Persad asserts that this is the case (or at least that it is plausible) and so policies that favor saving the most lives will in fact benefit people with disabilities.[78]

Persad focuses on a different comparative question than we do. We ask whether the rationing protocols produce a disparate negative impact on people with disabilities. When we look at who benefits and who does not from the adoption of a policy, we ask whether the percentage of disabled people in the harmed group is greater than in the population of people seeking care. Persad focuses on a different question. He asks instead whether more disabled people are in the group helped by a policy than the group harmed by the same policy.[79]

Which is the relevant comparison, legally and morally? The answer to the legal question is clear. Discrimination law directs that we focus on whether the group of people negatively affected by a law or policy contains a disproportionate number of people from the protected group.[80] To see why, consider the following example. Suppose an employer were considering a policy which excludes job applicants with a criminal record. If such a policy produces a disparate impact on racial minorities, it will require justification under current law.[81] While this justification may be available, that issue isn't reached unless there is, in fact, a disparate impact on the basis of race. How should such a question be addressed? Courts will look at whether applicants

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"primarily burdening people with disabilities while primarily benefiting people without disabilities").

[78] *See id.* at 17 (finding it "plausible that the people with disabilities who would be saved only by evidence-based triage outnumber the people with disabilities in the . . . group who would fare better under random selection or minimal triage").

[79] *Id.*

[80] *See* Griggs v. Duke Power Co., 401 U.S. 424, 429 (1971) (finding that the employer's testing and educational requirements, which "operated to render ineligible a markedly disproportionate number" of Black workers, were "unlawful under Title VII unless shown to be job related").

[81] *See id.* at 429–31 (establishing that employment policies that are "discriminatory in operation" must be "shown to be related to job performance," otherwise "the practice is prohibited").

excluded by the policy are disproportionately racial minorities.[82] What Persad's approach suggests instead is that a court should assess whether this policy helps more Black individuals (because they do not have a criminal record) than it hurts (because they do).[83] This is not what the law requires.

Disparate impact analysis under the ADA is no different. The relevant standard to state a prima facie case is to allege a disparate impact on individuals with disabilities as compared with non-disabled persons.[84] From a legal perspective, then, Persad's focus is on the wrong comparison. Morally, the question is more complex. Both comparisons matter. The fact that a policy that saves more lives may also save more disabled lives is relevant, as is the fact that people with disabilities are likely to

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[82] *See, e.g.*, *id.* at 426 (examining whether a policy requiring applicants to pass a general intelligence test that "operate[s] to disqualify Negroes at a substantially higher rate than white applicants" is prohibited under the Civil Rights Act of 1964, Title VII).

[83] *See* Persad, *supra* note 15, at 29 (arguing that evidence-based triage is ethical because it "not only saves more lives overall, but it likely saves more lives among patients with disabilities").

[84] *See* Femino v. NFA Corp., 274 F. App'x 8, 10 (1st Cir. 2008) (requiring the plaintiff to demonstrate "a disparate impact on a group characteristic . . . that falls within the protective ambit of [the ADA]" and then present evidence showing that similarly-situated individuals with disabilities are disproportionately affected by the policy in question). Indeed, although the federal circuits differ in regard to what type or level of evidence is required to survive under a disparate impact theory, all concur that the relevant measure is whether the policy disparately affects disabled as compared with non-disabled persons. *See* Roberts v. City of Chicago, 817 F.3d 561, 566 (7th Cir. 2016) (requiring evidence of a "significant disparity between disabled and non-disabled applicants"); B.C. v. Mount Vernon Sch. Dist., 837 F.3d 152, 162 (2d Cir. 2016) (requiring "significantly adverse or disproportionate impact on persons of a particular type produced by the defendant's facially neutral acts or policies" and measuring disparity in outcome as between persons of that type and those falling outside the group (internal quotation omitted)). One wrinkle worth noting however is that, while the comparison we emphasize is the relevant one to determine whether the plaintiff has set out a prima facie case of disparate impact discrimination, courts may consider how many disabled people are served when determining whether the access provided is "meaningful" under the standard articulated in *Alexander v. Choate*, 469 U.S. 287, 297 (1985). There, the court determined access was meaningful where nearly all disabled persons (from the record, more than 95 percent) would be served. *Id.* at 303. It did not, however, simply consider that more disabled benefited than were excluded. *Id.* at 302–04 (focusing on the number of disabled individuals that would be served by the program and whether the "criteria [has] a particular exclusionary effect on the handicapped").

comprise a disproportionate share of the group of people harmed by such a policy. Where we disagree with Persad as a moral matter is with regard to his contention that the first fact negates the significance of the second.[85] Rather, as we argue below, both measures matter.[86] Lastly, we should note that the factual premise on which Persad's argument is based—that more disabled people will be helped than harmed by prioritizing saving the most lives—is speculative and difficult to verify.

The disparate impact that each of the rationing principles generates leads to a question: Are the significant negative effects on the ability of people with disabilities to access life-saving treatment likely to outweigh the purported benefit of each of these rationing principles in the view of the ADA? To inform our answer to that question, we now turn to the statute itself, beginning with the history that informed its passage.

B. *Disability Discrimination that Informed the ADA*

The ADA's robust protections of disabled persons respond to a history of social treatment that ranges from pernicious to neglectful.[87] The specter of eugenics, for example, hovers in especially unsettling ways over any discussion of medical rationing and disability.[88] Forced sterilization of disabled

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[85] In Persad's view, "[a] greater but unequal chance of survival seems ethically preferable to a smaller but more equal chance." Persad, *supra* note 15, at 45. It is precisely this claim that we argue is debatable in Part IV.

[86] *See infra* Part III.

[87] Our society has confined individuals with disabilities to institutions, many of which were and are operated in egregiously substandard conditions. *See generally* Emily Johnson, *Letter from the Editor: Disability, Medicine, and Ethics*, 18 AMA J. ETHICS 355 (2016). So-called "ugly laws" on the books in American cities in the nineteenth and twentieth centuries expressly prohibited people with disabilities (those deemed to be "diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person") from appearing in public spaces. *See generally* Adrienne Phelps Coco, *Diseased, Maimed, Mutilated: Categorizations of Disability and An Ugly Law in Late Nineteenth-Century Chicago*, 44 J. SOC. HIST. 23 (2010) (discussing Chicago law specifically). For the broader history of ugly laws, see SUSAN SCHWEIK, THE UGLY LAWS: DISABILITY IN PUBLIC 63–84 (2009) (explaining "unsightly beggar ordinances"—laws often used to arrest disabled people on the street—within the context of disability history).

[88] *See, e.g.*, Buck v. Bell, 274 U.S. 200, 208 (1927) (upholding the compulsory sterilization of Carrie Buck under a law permitting forced

persons by healthcare providers was upheld by the highest court in the land with Justice Oliver Wendell Holmes's haunting determination that "three generations of imbeciles are enough."[89]

In its findings underlying the ADA, Congress recounted the degree to which disabled individuals have been excluded from society, often not because of anything inherent to their conditions, but because of choices society has made about whom to include or exclude.[90] This discrimination was so wide-reaching as to affect every aspect of life, including—significantly—discrimination in health services.[91] The ADA's legislative history is replete with testimony about the barriers people with disabilities face in the healthcare setting.[92]

There is also ample evidence that health care providers possess conscious and unconscious biases related to disability, and that these biases create barriers to care, contribute to the provision of substandard services, and lead to poorer health

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sterilization for those diagnosed as incompetent and deemed likely to transmit disability to offspring).

[89] *Id.* at 207.

[90] *See* 42 U.S.C. § 12101(a)(1) ("[P]hysical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination.").

[91] *See* 42 U.S.C. § 12101(a)(3) ("[D]iscrimination against individuals with disabilities persists in such critical areas as . . . health services.").

[92] *See, e.g.*, 136 CONG. REC. E1839–40 (daily ed. June 7, 1990) (statement of Rep. Steny H. Hoyer) (explaining that under the ADA, doctors' offices and other healthcare providers cannot discriminate on the basis of disability and must ensure full and equal enjoyment of services, facilities, privileges, and accommodations); *Americans with Disabilities Act of 1988: J. Hearing on S. 2345 Before the Subcomm. on the Handicapped of the S. Comm. on Lab. & Hum. Res. and the Subcomm. on Select Educ. of the H. Comm. on Educ. & Lab.*, 100th Cong. 39–56 (1988) (focusing on discrimination against individuals with HIV/AIDs); *Americans with Disabilities Act of 1989: J. Hearing on H.R. 2273 Before the Subcomm. on Select Educ. & Emp. Opportunities of the H. Comm. on Educ. & Lab.*, 101st Cong. 63 (1989) (citing testimony that found that hearing impaired individuals are "admitted to hospitals, undergo surgery, and are released without the benefit of a sign language interpreter to receive information critical to their health"); *Americans with Disabilities Act of 1989: Hearings on H.R. 2273 Before the Subcomm. on Civ. & Const. Rts. of the H. Comm. on the Judiciary*, 101st Cong. 264 (1989) (citing consumer surveys on issues with health care affordability and availability for people with disabilities).

outcomes.[93] Also important, studies have found that few healthcare professionals understand their legal obligations to individuals with disabilities.[94]

Finally, disability scholars have written about the degree to which both technocratic and democratic processes have largely omitted disabled persons, such that views "about them" and the policies which govern their lives, are largely informed "without them."[95] One implication of this history is that assessments of the consequences of disability, including those about the quality of life people with disabilities enjoy, emerge largely from nondisabled people.[96] Against this background, we should be especially attentive in assessing whether state rationing protocols impermissibly discriminate against people with disabilities.

C. *The ADA's Non-Discrimination Provisions*

The ADA is Congress's most extensive civil rights legislation since the Civil Rights Act of 1964. The ADA's purpose is "to provide a clear and comprehensive national mandate for the elimination of discrimination" on the basis of disability.[97] Disability, which is to be construed broadly in favor of expansive

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[93] *See* Silvia Yee et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*, DISABILITY RTS. EDUC. & DEF. FUND 1, 39–47 (2016), https://perma.cc/2F5Q-DUEA (PDF).

[94] *See* Nicole D. Agaronnik et al., *Knowledge of Practicing Physicians About Their Legal Obligations when Caring for Patients with Disability*, 38 HEALTH AFFS. 545, 550 (2019) ("[M]ost physician participants exhibited a superficial or incorrect understanding of their legal responsibilities to patients with disabilities.").

[95] *See* Samuel R. Bagenstos, *The Americans with Disabilities Act as Risk Regulation*, 101 COLUM. L. REV. 1479, 1507–09 (2001) (discussing the Oregon Health Services Commission "expert" decision to rank "quality of life" measures that disfavor people with disabilities above public concerns from community meetings); JAMES CHARLTON, NOTHING ABOUT US WITHOUT US 3 (1998) (discussing how the phrase "Nothing about us without us" was re-coined in the early 1990s as a central expression of the disability rights movement). For a critique from the community of the ways in which the field of bioethics specifically has neglected the disability analysis, see this series of government reports from the National Council on Disability on Bioethics: *Bioethics and Disability Report Series*, NAT'L COUNCIL ON DISABILITY, https://perma.cc/Y758-FEQ4.

[96] *See infra* note 144 and accompanying text.

[97] 42 U.S.C. § 12101(b)(1).

coverage,[98] is defined functionally "as a physical or mental impairment that substantially limits one or more major life activities." [99] This breadth of coverage means that individuals with a considerable range of health conditions are entitled to the ADA's protections.[100]

Virtually all decisionmakers involved in medical rationing are covered by the ADA. The state and local government actors that issue, activate, and apply the protocols are covered by Title II of the ADA.[101] Private health care providers who effectuate rationing are covered as places of public accommodation by Title III of the ADA.[102] Obligations extend to actions taken directly or through contractual arrangements, so the law also reaches the actions of corporate health care systems.[103]

The primary nondiscrimination provision in Title II provides that "no qualified individual with a disability shall, by

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[98] 42 U.S.C. § 12102(4); *see* ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553 (amending the ADA to include a definition of disability that "shall be construed in favor of broad coverage of individuals under this Act, to the maximum extent permitted by the terms of this Act").

[99] 42 U.S.C. § 12102(1)(A). The law also covers those having a history of such an impairment, or who are perceived as having such an impairment. 42 U.S.C. §§ 12102(1)(B)–(C).

[100] *See* 28 C.F.R. §§ 35.101(b), 36.101(b) (2020) ("[T]he definition of disability in this part shall be construed broadly in favor of expansive coverage to the maximum extent permitted by the terms of the ADA." (internal quotation marks omitted)); 154 CONG. REC. S7957 (daily ed. July 31, 2008) (statement of Sen. Thomas Harkin) ("This bill will make it easier for people with disabilities to be covered by the ADA because it effectively expands the definition of disability to include many more major life activities, as well as a new category of major bodily functions.").

[101] 42 U.S.C. §§ 12131–12165; 28 C.F.R. pt. 35 (2020). Title II, which covers state and local government entities, is most closely modeled on Section 504. *Cf.* 29 U.S.C. § 794. Like Section 504, minimal non-discrimination language is laid out in the statute with the bulk of the specific provisions in its implementing regulation at 28 C.F.R. pt. 35.

[102] 42 U.S.C. §§ 12182–12189; 28 C.F.R. pt. 36 (2020). Although we analyze the state protocols, we are conscious that many decisions will be made by private actors, who are covered by Title III.

[103] *See* 42 U.S.C. § 12112(b)(2) (including "participating in a contractual or other arrangement or relationship that has the effect of subjecting a covered entity's qualified applicant or employee with a disability to the discrimination prohibited by this subchapter" as prohibited discrimination under the ADA); *see also* 28 C.F.R. §§ 35.130(b)(1), 35.130(b)(3) (2020) (defining specific instances in which a public entity may not contractually deny benefits, aid, or service to individuals with disabilities).

reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[104] Title III's chief mandate requires that people with disabilities have full and equal enjoyment of an entity's services,[105] or "an equal opportunity to obtain the same results as others."[106]

Both the ADA and its implementing regulations go on to define "discrimination on the basis of disability" to include various acts and omissions:[107] those that explicitly discriminate on the basis of disability, i.e., disparate treatment; and those disadvantage individuals with disabilities, i.e., disparate impact discrimination.[108] Among the prohibited facially-neutral actions resulting in disparate impact discrimination are those that "impose eligibility criteria that screen out or tend to screen out" individuals with disabilities,[109] or that use "standards, criteria, or methods of administration" which produce a disparate impact on people with disabilities.[110]

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[104] 42 U.S.C. § 12132. A primary difference between Title II and Section 504, on the one hand, and Title III, on the other, is the requirement in Title II and Section 504 that the individual be a "qualified" person with a disability. *Id.*; *see* 29 U.S.C. § 794(a). That is, a qualified individual is an individual "who, with or without reasonable modifications to rules, policies, or practices," meets "the essential eligibility requirements" for participation or the receipt of services. 42 U.S.C. § 12131(2). For a compelling treatment of the question of whether someone is qualified in the context of rationing, see Bagenstos, *May Hospitals Withhold Ventilators*, *supra* note 15.

[105] 42 U.S.C. § 12182(a).

[106] H.R. REP. NO. 101-485, pt. 3, at 55 (1990), *as reprinted in* 1990 U.S.C.C.A.N. 445, 478.

[107] For example, the ADA prohibits: denying individuals with disabilities opportunities to participate, allowing them to benefit on an unequal basis, or offering opportunities that are separate or different from those offered to others (unless doing so is necessary to ensure equal treatment). 42 U.S.C. §§ 12182(b)(1)(A)(i)–(iv), 12182(b)(1)(C); *see also* 28 C.F.R. §§ 35.130, 36.201–204 (listing instances where an act or omission can be considered discrimination on the basis of disability).

[108] *See* 28 C.F.R. §§ 35.130, 36.201–04 (including specific instances when acts or omissions are considered discriminatory on the basis of disability); 28 C.F.R. pt. 36, app. C, § 36.204 (2020) (stating that § 36.204 incorporates "a disparate impact standard to ensure the effectiveness of the legislative mandate to end discrimination").

[109] 42 U.S.C. § 12182(b)(2)(A)(i); *see also* 28 C.F.R. § 35.130(b)(8) (2020).

[110] 42 U.S.C. § 12182(b)(1)(D); *see also* 28 C.F.R. § 36.204 (2020) ("A public accommodation shall not, directly or through contractual or other

Importantly, facially-neutral policies that negatively affect people with disabilities have been invalidated by the courts when and because disabled people were unable to get "meaningful access" to health care services.[111] For example, in *Alexander v. Choate*,[112] a case decided under Section 504, the Court held that disabled people cannot be denied "meaningful access" to health benefits, noting that Congress's intentions would "ring hollow if the resulting legislation could not rectify the harms resulting from action that discriminated by effect as well as by design."[113] Courts have applied this same "meaningful access" standard to healthcare cases under the ADA,[114] as in *Rodde v. Bonta*,[115] where the Court of Appeals for the Ninth Circuit considered a county's decision to close the one healthcare facility in the area that provided rehabilitative services.[116] The *Rodde* court concluded that while "*Alexander* may allow the [c]ounty to step down services equally for *all* who rely on it for their healthcare needs," it does not sanction eliminating services relied on disproportionately by the disabled.[117]

To recap, the express language of the ADA, its implementing regulations, and court decisions all forbid discrimination based on facially-neutral policies or practices that have a disparate impact on individuals with disabilities without adequate justification. These protections apply to

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arrangements, utilize standards or criteria or methods of administration that have the effect of discriminating on the basis of disability, or that perpetuate the discrimination of others who are subject to common administrative control."); 28 C.F.R. pt. 36, app. C, § 36.204 (incorporating the disparate impact standard).

[111] *See, e.g.*, Alexander v. Choate, 469 U.S. 287, 297, 302 (1985); Rodde v. Bonta, 357 F.3d 988, 998 (9th Cir. 2004).

[112] 469 U.S. 287 (1985).

[113] *Id.* at 297.

[114] *See, e.g.*, Crowder v. Kitagawa, 81 F.3d 1480, 1484–85 (9th Cir. 1996) (finding that quarantine procedures that applied equally disproportionately burdened those visually-impaired persons dependent on guide dogs, thereby denying them "meaningful access" to state services, programs, and activities).

[115] 357 F.3d 988 (9th Cir. 2004).

[116] *See id.* at 998 ("While the disabled could theoretically seek service from the remaining facilities . . . the services designed for the general population would not adequately serve the unique needs of the disabled, who therefore would be effectively denied services that the non-disabled continued to receive.").

[117] *Id.* at 997.

healthcare, and disabled persons are entitled to meaningful access to health services.

D. *The ADA's Balancing Calculus*

A central tenet of the ADA is that people do not start on an equal footing in their ability to benefit from services and that this inequality is caused, at least in part, by choices society has made.[118] To address these choices—choices which reflect biases so entrenched in the fabric of our social structure as to be built into the very physical structures in which we operate—the ADA imposes a number of remedial duties, or specific affirmative steps, that covered entities must undertake, ranging from things like making architectural changes to their facilities[119] to furnishing sign language interpreters.[120] The affirmative duty most relevant to the rationing discussion is a provision similar to the more familiar "reasonable accommodation" mandate in employment, which requires entities to make "reasonable modifications" to their policies, practices, and procedures where necessary to ensure that their services are accessible.[121]

These obligations are not absolute. For example, covered entities are not required to provide sign language interpreters if doing so would constitute an undue financial or administrative burden.[122] In this sense, the ADA strikes a balance between the

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[118] *See* 42 U.S.C. § 12101(a) (stating that society has isolated and segregated individuals with disabilities, leading to discrimination in health services, and that discrimination "denies people with disabilities the opportunity to compete on an equal basis").

[119] 42 U.S.C. §§ 12182 (b)(2)(A)(iv), 12183; *see also* 28 C.F.R. §§ 35.150–51 (2020) (stating that public entities must ensure, through facility construction or redesign if necessary, that their services are readily accessible to and usable by people with disabilities).

[120] 42 U.S.C. § 12182(b)(2)(A)(iii); *see also* 28 C.F.R. §§ 35.160(b), 36.303 (2020) (requiring public entities and places of public accommodation to provide auxiliary aids and services such as interpreters to facilitate communication).

[121] 42 U.S.C. § 12182(b)(2)(A)(ii); *see also* 28 C.F.R. § 36.302(a) (2020) ("A public accommodation shall make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities").

[122] 42 U.S.C. § 12182(b)(2)(A)(iii); *see also* 28 C.F.R. §§ 35.164, 36.303(a) (2020) (providing that a public entity or accommodation is not required to provide auxiliary aids or services when they would result in an undue burden).

values of inclusion and efficiency. But the ADA tilts toward inclusion. The appropriate measure of undue burden in that instance is not the cost of providing an interpreter for a medical appointment versus the amount of money that appointment generates; rather this cost is measured against the total financial resources of the entity.[123] Similarly, entities are required to take affirmative steps to ensure equal access for individuals with disabilities and are excused from doing so only if they meet a very high bar—if the action would "fundamentally alter" the services the entity provides.[124] In sum, the ADA imposes affirmative obligations on covered entities to ensure equal access to health services. In so doing, it balances the interests of inclusion with efficiency, but places greater weight on inclusion.

E. *ADA Cases on Healthcare, Scarcity, and Rationing*

To assess how courts might approach rationing on the basis of disability in a time of crisis, in this section we examine near analogs. But because courts are sometimes reluctant to get into the details of medical decision-making, we first address the question of whether rationing decisions are medical judgments.[125] We conclude that they are not. While clinicians

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[123] *See* JONATHAN R. MOOK, AMERICANS WITH DISABILITIES ACT: PUBLIC ACCOMMODATIONS & COMMERCIAL FACILITIES § 3.02 (45th ed. 2021) (stating that to determine "whether providing a sign language interpreter . . . would constitute an undue burden" the court must compare "the cost of the interpretive services and the overall financial resources . . . not the revenue that may be generated by the patient's visit alone"); 28 C.F.R. § 36.104 (2020) (providing factors to measure what constitutes an undue burden, including overall financial resources of entity and nature and cost of action needed).

[124] 42 U.S.C. § 12182(b)(2)(A)(ii). For another example, eligibility criteria that discriminate may be used if such criteria are deemed necessary to the services an entity provides. *Id.* at § 12182(b)(2)(A)(i); 28 C.F.R. §§ 35.130(b)(8), 36.301(a). The classic example of such an eligibility requirement is the ability of states to screen for vision impairment in issuing driver's licenses. *See* 28 C.F.R. pt. 35, app. B, § 35.130 (2020).

[125] The reluctance of courts to get involved in medical decision-making stems largely from so-called "Baby Doe" cases decided under Section 504. The most significant of these cases is *United States v. University Hospital*, 729 F.2d 144 (2d Cir. 1984). *See id.* at 156 (expressing concern about applying Section 504 to the "fluid context" of medical treatment decisions); *see also* Bowen v. Am. Hosp. Ass'n, 476 U.S. 610, 624–25 (1986) (declining to apply *University Hospital*'s reasoning regarding medical judgments in a Baby Doe case).

apply the protocols using medical criteria, the choices embedded in those protocols—both the principles informing them and the algorithms that operationalize them—are policy decisions. In fact, the state protocols go to great lengths to distance clinicians from decision-making.[126] The application of these protocols is thus unlikely to be considered an exercise in medical judgment. Even if a rationing determination was considered medical judgment, a court is unlikely to defer to that judgment where, as here, it results in a denial of access to care. In *Bragdon v. Abbott*,[127] for example, the Supreme Court decisively applied the ADA to the context of medical judgment,[128] rejecting Dr. Bragdon's medical determination that an individual with HIV required treatment in a hospital setting after he declined to treat her in his office.[129] In finding that Dr. Bragdon had violated the ADA, the court treated his medical judgment as tantamount to an outright denial of care.[130] In sum, rationing judgments are primarily policy-based and thus subject to scrutiny under the ADA. Even if they are considered medical judgments, they are unlikely to receive deference and will instead be assessed for compliance with the ADA because they will result in a denial of care.

To assess how a court might approach the protocols under the ADA, we consider: the reluctance of courts to terminate or limit use of medical resources by disabled persons when scarcity is not paramount; the reluctance of administrative agencies to permit rationing in a non-crisis situation; and the

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[126] States such as California, Colorado, and Kentucky rely on SOFA scores to determine resource allocation. *See* CALIFORNIA GUIDANCE, *supra* note 55, at 25–26; COLORADO GUIDELINES, *supra* note 51, at 6–7; KENTUCKY GUIDELINES, *supra* note 35, at 35.

[127] 524 U.S. 624 (1998).

[128] The Court also applied Title II of the ADA to medical decision-making in the context of a public entity's decisions regarding provision of mental health services in *Olmstead v. L.C.*, 527 U.S. 581 (1999).

[129] *See Bragdon*, 524 U.S. at 651 ("Petitioner failed to present any objective, medical evidence showing that treating respondent in a hospital would be safer or more efficient in preventing HIV transmission than treatment in a well-equipped dental office.").

[130] *See id.* at 649–50 (concluding that courts should assess the objective reasonableness of the views of healthcare professionals without deferring to their individual judgments).

administrative resolutions of complaints by disability rights activists regarding the current triage protocols thus far reached.

1. Limiting Resources Without Scarcity

Courts and administrative agencies have previously considered the allocation and limitation of critical medical resources in non-crisis settings.[131] Two features of the law in this area are potentially relevant. First, while futile care can generally be denied, decisions regarding futility must be applied in a similar fashion to disabled and nondisabled patients.[132] Indeed, courts have demonstrated reluctance to withdraw critical, lifesaving resources where disability is a factor.[133] Second, the fact that a disabled patient will require more medical resources is not a legitimate reason to deny them care.[134]

Generally, medical resources may be denied when providing them would be futile, often defined as situations in which the likelihood of success of a medical intervention is exceedingly poor.[135] Yet, even in cases of extreme futility, courts may be reluctant to deny life-sustaining treatment like ventilators. In *In re Baby K,*[136] for example, the court held that a hospital could

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[131] *See, e.g.*, *In re* Baby K, 832 F. Supp. 1022, 1029 (E.D. Va. 1993) (denying an hospital's request to withhold ventilator treatment from an anencephalic child); 45 C.F.R. § 84.555(f)(1)(ii)(B) (determining futility is appropriate to consider in the denial of medical care for Section 504 purposes).

[132] *See, e.g.*, *Baby K*, 832 F. Supp. at 1028–29 (determining that the denial of "futile" medical care to an anencephalic baby would result in denial of medical care on the basis of disability and therefore violate the ADA).

[133] *See id.*

[134] *See* Wagner *ex rel.* Wagner v. Fair Acres Geriatric Ctr., 49 F.3d 1002, 1017 (3d Cir. 1995) (finding summary judgment improper because a state-run intermediate care nursing facility could have cared for the plaintiff, who was "otherwise qualified" for admission, had it made reasonable accommodations).

[135] *See, e.g.*, Barber v. Super. Ct., 195 Cal. Rptr. 484, 491 (Ct. App. 1983)

> A physician has no duty to continue treatment, once it has proved to be ineffective. Although there may be a duty to provide life-sustaining machinery in the immediate aftermath of a cardio-respiratory arrest, there is no duty to continue its use once it has become futile in the opinion of qualified medical personnel.

See generally 3 ALEXANDER M. CAPRON & IRWIN M. BIRNBAUM, TREATISE ON HEALTH CARE LAW § 18.04(5)(b) (Hooper, Lundy & Bookman, Inc., et al. eds., 2021).

[136] 832 F. Supp. 1022 (E.D. Va. 1993).

not deny ventilator services that the hospital deemed had no therapeutic or palliative purpose to an anencephalic baby,[137] when those services would otherwise be provided to a baby without disabilities.[138]

Section 504 of the Rehabilitation Act of 1973 has been interpreted to require access to care in situations in which a person's pre-existing condition will demand an increased commitment of resources. For example, in *Wagner v. Fair Acres Geriatric Center*,[139] the Court of Appeals for the Third Circuit determined that denying someone with Alzheimer's disease access to a skilled nursing facility on the basis that she would require a heightened level of care and resources violated the law's basic non-discrimination provisions, which are analogous to those of the ADA.[140] In normal times, courts have been reluctant to withdraw lifesaving care, even cases of futility where disability is a factor, and have prohibited consideration of a person's likely greater need for resources.

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[137] *See id.* at 1038.

[138] The case arose under the ADA, Section 504, and the Emergency Medical Treatment and Active Labor Act (EMTALA), which requires hospitals to stabilize patients in emergency circumstances which likely also influenced the outcome. *See* 42 U.S.C. § 1395dd (stating that a hospital must either provide medical treatment to stabilize a patient in emergency condition or transfer the patient to another medical facility).

Generally, tort principles suggest that there is no duty to help someone, although, in the case of hospitals, EMTALA somewhat alters the equation. *See* RESTATEMENT (THIRD) OF TORTS § 37 (AM. L. INST. 2012) (stating that generally, unless an actor shares a special relationship to the harmed party or the party creating harm to another, the actor has no general duty of care to rescue or render aid). Under common law it is clear that once one is providing help, a higher duty accrues. *See* RESTATEMENT (SECOND) OF TORTS § 324 (AM. L. INST. 1965) (stating that once an actor comes to the aid of another, the actor assumes liability for any bodily harm caused by the actor's withdrawal of aid if the discontinuation leaves the helpless party in a worse position than when the actor initially intervened). Considerations involving withdrawal of treatment once a patient is stabilized may be informed by that duty.

[139] 49 F.3d 1002 (3d Cir. 1995).

[140] *See id.* at 1009–11 (finding that while a nursing facility may have been required to make "reasonable accommodations" to care for a patient with Alzheimer's, the patient was "otherwise qualified" for admission, making her denial on such grounds violative of Section 504 of the Rehabilitation Act). As noted in *supra* note 9, the ADA provides that nothing is to apply a lesser standard than the standards articulated under § 504. *See* 28 C.F.R. pt. 35 (2019) (articulating the specific prohibitions provided under § 504).

2. Scarcity Without Crisis

In situations involving scarcity outside of a state of crisis, administrative agencies have acted to protect the right of individuals with disabilities to access medical resources and care. The rationing of organs for transplants provides an apt example. While courts have not ruled on how the ADA applies to organ allocation specifically, the reigning assumption from administrative agency determinations is that the ADA protects disabled patients from rationing decisions that limit their access to organs on the basis of their disabilities.[141]

Administrative agencies have also considered the matter of healthcare rationing in the context of assessing the level of health benefits provided by public programs. An example that has received a good deal of scholarly attention arose in the early 1990s when the State of Oregon applied to the Secretary of the Department of Health and Human Services for a Medicaid Waiver under Section 1115 of the Social Security Act.[142] At issue was a novel program to substantially expand the number of people covered by Medicaid by limiting the services provided.[143]

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[141] *See, e.g.*, Press Release, OCR, U.S. Dep't of Health & Hum. Servs., OCR Resolves Disability Complaint of Individual Who Was Denied the Opportunity for Heart Transplant List Placement (Feb. 12, 2019), https://perma.cc/54XB-8HJZ (resolving a complaint against the University of North Carolina Health Care System for denying a person with an intellectual disability the opportunity to be placed on the United Network for Organ Sharing); David A. Sylvester, *About Face on Organ Transplant*, S.F. CHRON., Jan. 13, 1996, at F16 (reporting on the case of Sandra Jensen, a woman with Down Syndrome who was originally denied a transplant, but became the first woman with Down Syndrome to receive an organ transplant after the Justice Department involvement). *But see* McElroy v. Patient Selection Comm., No. 4:06CV3162, 2007 WL 4180695, at *5 (D. Neb. Nov. 21, 2007), *aff'd*, No. 07-3877, 2009 WL 50176, at *1 (8th Cir. Jan. 9, 2009) (deferring to defendant's medical judgment in a pro se case brought by an individual with paranoid schizophrenia and delusional disorder where the individual was denied an organ transplant for "legitimate medical reasons").

[142] *See, e.g.*, Arti K. Rai, *Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care*, 72 IND. L.J. 1015, 1052–58 (1997) (examining Oregon's attempt to incorporate quality of life and life expectancy metrics into its Medicaid expansion proposal).

[143] *See* OFF. OF TECH. ASSESSMENT, EVALUATION OF THE OREGON MEDICAID PROPOSAL 3 (1992), https://perma.cc/H8QL-SS6D (PDF) ("[T]he Medicaid eligible population would be expanded to include all legal State residents with incomes below the FPL [Federal Poverty Line]. In contrast, at present, most

In order to determine which services were covered, Oregon created a ranked scale prioritizing health care procedures.[144] In effect, this ranking disproportionately excluded people with disabilities from care due to the way that benefit was assessed.

Then-Secretary Sullivan rejected the Oregon proposal on the basis that it discriminated against disabled individuals and thus would violate the ADA.[145] His denial was partially based on evidence in the record that the system was based "in substantial part on the premise that the value of a life of a person with a disability is less than the value of a life of a person without a disability"; a premise which is "inconsistent with the Americans with Disabilities Act."[146] The Secretary went on to outline what might be permissible actions under the statute, such as content neutral factors that do not take disability into account or—significantly—that do not have "exclusionary effect[s]."[147]

To recap, where rationing occurs in the context of scarcity, administrative agencies appear willing to intervene to protect individuals with disabilities from discrimination that is explicit, as well as that which has a disparate impact or exclusionary effects.

3. Scarcity in Times of Crisis

The discussion thus far has focused on how courts and agencies have addressed situations that are analogous to the issues presented in the crisis standards of care. We now turn to the resolution of complaints about the current triage protocols by the Office for Civil Rights at the Department of Health and

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people in Oregon must fall into a federally specified need category . . . to qualify for Medicaid.").

[144] *See* Letter from Louis W. Sullivan, Secretary, U.S. Dep't of Health & Hum. Servs., to Barbara Roberts, Governor of Oregon (Aug. 3, 1992), *in ADA Analyses of the Oregon Health Care Plan*, 9 ISSUES L. & MED. 397, 409, 411–12 (1994) [hereinafter HHS Analysis of Oregon Health Plan] (discussing Oregon's proposed quality-adjustment rating system, which would determine which treatments Medicaid would cover).

[145] *See id.* at 409.

[146] *Id.* at 410. Sullivan also rejected quality of life data on the grounds that it was based on stereotypic assumptions. *See id.*

[147] *Id.* at 411.

Human Services (OCR),[148] which has enforcement responsibilities under the ADA, Section 504, and the nondiscrimination provisions of the Affordable Care Act.[149] At the time of our writing, OCR had resolved three complaints involving rationing protocols—in Alabama, Tennessee, and Utah.[150] The resolutions are part of a process known as Early Complaint Resolution, in which OCR provides technical assistance, but makes no legal finding of liability.[151]

While they are not legally binding, these resolutions nevertheless provide a road map for how agencies, and perhaps future courts, may treat claims of discrimination involving medical triage in a time of crisis. Each successive OCR resolution has been more demanding and broader in reach, with the resolutions in Tennessee and Utah not only addressing explicit categorical exclusions, but also policies that disadvantage people with disabilities.[152]

OCR issued its first resolution on April 8, 2020 in which Alabama agreed to withdraw its 2010 criteria entirely and, going forward, not to include provisions that single out people

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[148] See *supra* note 10 for a list of complaints lodged during the COVID-19 crisis.

[149] *See* OCR, *Laws and Regulations Enforced by OCR*, U.S. DEP'T OF HEALTH & HUM. SERVS., https://perma.cc/A46Y-EZNM (listing the nondiscrimination regulations and laws that the OCR oversees and enforces).

[150] *See* OCR HHS Press Release Alabama, *supra* note 10 (stating that OCR resolved its Alabama compliance review "after the state removed its ventilator rationing guidelines that allegedly discriminated on the basis of disability and age"); OCR HHS Press Release Tennessee, *supra* note 10 (explaining that OCR resolved its Tennessee compliance complaint after Tennessee revised the criteria in its crisis standards of care plan to prevent age or disability discrimination); OCR HHS Press Release Utah, *supra* note 10 (announcing that the OCR resolved its case with Utah after the state amended its crisis standards of care instructions and protocols).

[151] *See* OCR HHS Press Release Utah, *supra* note 10 ("ECR [Early Complaint Resolution] is a voluntary, forward-looking, process where OCR mediates quick, efficient, and effective resolutions of disputes to the satisfaction of all the parties without determining legal liability.").

[152] *See id.* ("[P]roviders may not impose blanket 'Do Not Resuscitate' policies for reasons of resource constraint, or require patients to consent to a particular advanced care planning decision in order to continue to receive services from a facility."); OCR HHS Press Release Tennessee, *supra* note 10 (stating that Tennessee "[c]larified that resource-intensity and duration of need on the basis of age or disability should not be used as criteria for the allocation or re-allocation of scarce medical resources.").

with certain disabilities for unfavorable treatment in future Crisis Standards of Care.[153] This resolution is a strong indication that explicit exclusions on the basis of disability that deny individuals with specified conditions any possibility of receiving life-saving care are likely to be rejected.

The OCR resolutions reached on June 26, 2020 with Tennessee and August 20, 2020 with Utah similarly address explicit exclusions by eliminating them. But they also address the predictable disparate impact these standards have on the ability of people with disabilities to gain access to life-saving care.[154] Indeed, both resolutions consider each of the four rationing principles. They flatly reject rationing based on *Quality of Life* and *Life Expectancy*.[155] Both also forbid consideration of concerns about a person's likely greater need for resources or greater duration of need—the principle we call *Level of Resource Commitment*—from *automatically* placing such individuals at a lower priority for receipt of care and require that assessments based on *Probability of Survival* be accurate and individualized.[156] While these OCR resolutions thus take a strong stand against the first two principles, their approach to the latter two, and in particular to *Probability of Survival,* is more equivocal.

For reasons we address in Part III, these resolutions do not go as far as they should. These actions depict an agency wrestling with the precise dilemma we identify. On the one hand, the agency recognizes that current law forbids policies that unfairly exclude people with disabilities and, at the same time, it is loath to force states to forgo policies that will save more lives.

What is significant is that the OCR resolutions signal that laws which govern the rights of protected groups remain in full force even in times of emergency. Indeed, the resolutions

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[153] *See* OCR HHS Press Release Alabama, *supra* note 10.

[154] *See* OCR HHS Press Release Tennessee, *supra* note 10; OCR HHS Press Release Utah, *supra* note 10.

[155] *See* OCR HHS Press Release Utah, *supra* note 10 (requiring the removal of life expectancy as a factor in resource allocation, even where scarce); OCR HHS Press Release Tennessee, *supra* note 10 (stating that providers must only factor "imminent mortality" rather than long-term health and life expectancy when reallocating scarce resources).

[156] *See, e.g.*, OCR HHS Press Release Utah, *supra* note 10.

suggest that the law will be applied in much the same way during times of crisis as in ordinary times.[157] The proscription of reliance on a person's likely need for more resources, for example, recalls the decision during ordinary times in *Wagner*, where denying a woman placement in a skilled nursing facility because of her likely heightened need for resources violated section 504 of the Rehabilitation Act.[158] In addition, like the Court in *Bragdon*,[159] the OCR resolutions require that medical determinations be based on "the best available, objective medical evidence" using an individualized assessment, a key legal concept which we address in the next section.[160]

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[157] In suggesting that the law during times of crisis applies with the same force as in ordinary times, the OCR resolutions, like the earlier Bulletin OCR issued, are not unlike decisions by courts. *See* OCR HHS Bulletin, *supra* note 11, at 1 ("In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws."). Indeed, this same reasoning informed the U.S. Supreme Court's per curiam decision in *Roman Catholic Diocese of Brooklyn v. Cuomo*, 141 S. Ct. 63 (2020), a case challenging COVID-19 restrictions on attendance at religious services as violating first amendment rights. *Id.* at 66. The Court noted that "even in a pandemic, the Constitution cannot be put away and forgotten." *Id.* at 68. Justice Gorsuch's concurring opinion took this position even more forcefully, beginning by stating, "Government is not free to disregard the First Amendment in times of crisis." *Id.* at 69 (Gorsuch, J., concurring). The protocols themselves explicitly state that they displace some existing law. *See* OCR HHS Bulletin, *supra* note 11, at 2 ("Some actions or accommodations may not be required on the basis that they may fundamentally alter the nature of a program, pose an undue financial and administrative burden, or pose a direct threat."). However, what they endeavor to displace is legal liability for healthcare providers. *See id.* (explaining that the Public Readiness and Emergency Preparedness (PREP) Act may provide healthcare providers with some immunity from liability with respect to private claims). They do not, and indeed cannot, displace their own obligation to comply with federal law. *See id.* at 1 ("The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect.").

[158] *See* Wagner *ex rel.* Wagner v. Fair Acres Geriatric Ctr., 49 F.3d 1002, 1014–16 (3d Cir. 1995) (holding that a woman's status as a "challenging and demanding patient" could not alone justify her exclusion from a nursing home).

[159] *See* Bragdon v. Abbott, 524 U.S. 624, 649–50 (1998) (holding that courts should examine the medical evidence available and assess the "objective reasonableness of the views of health care professionals without deferring to their individual judgments").

[160] OCR HHS Bulletin, *supra* note 11, at 1.

F. *Stereotyping and Individualized Inquiry*

To round off the legal background, we end this section by looking at the law from a slightly different angle. Rather than focusing on the statute or analogous case law, we turn to two important conceptual frames within discrimination law which play a significant role in ADA cases.

Two concepts animate discrimination law in the United States: (1) a prohibition on "stereotyping"; and (2) a preference for "individualized inquiry."[161] The ADA is no exception.[162] Each of these concepts is somewhat elusive and courts are often unclear about what each prohibits or requires. A stereotype is a type of generalization.[163] But not all generalizations are stereotypes. For example, some scholars argue that only false generalizations are stereotypes.[164] Others disagree.[165] The concept of "individualized inquiry" is similarly ambiguous.[166]

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[161] For a discussion of the way these ideas animate the constitutional law of sex discrimination, see Deborah Hellman, *Sex, Causation, and Algorithms: Equal Protection in the Age of Machine Learning*, 98 WASH. U. L. REV. 481 (2020).

[162] The ADA's direct threat provision, interpreted by the Court in *Bragdon*, is instructive. Both the statute and regulation provide for a careful, individualized assessment, which is a case-by-case inquiry that relies on objective evidence. *See Bragdon*, 524 U.S. at 649 (explaining that under the ADA's direct threat provision, a health care provider "had the duty to assess the risk of infection based on the objective, scientific information available to him and others in his profession").

[163] *See Stereotype*, MERRIAM-WEBSTER DICTIONARY (2020) (defining a stereotype as something "conforming to a fixed or general pattern").

[164] *See* Lawrence Blum, *Stereotypes and Stereotyping: A Moral Analysis*, 33 PHIL. PAPERS 251, 251 (2004) (arguing that "[s]tereotypes are false or misleading generalizations about groups held in a manner than that renders them largely, though not entirely, immune to counterevidence," and finding stereotypes morally problematic for this reason).

[165] *See* Erin Beeghly, *What is a Stereotype? What is Stereotyping?*, 30 HYPATIA 675, 675 (2015) (advocating a non-moralized account of stereotyping according to which not all stereotyping is wrong); Erin Beeghly, *What's Wrong with Stereotypes? The Falsity Hypothesis*, 47 SOC. THEORY & PRAC. 33, 33 (2021) (arguing against the view that stereotypes are false generalizations).

[166] For an excellent treatment of what individualized inquiry might mean in equal protection doctrine, see Benjamin Eidelson, *Respect, Individualism, and Colorblindness*, 129 YALE L.J. 1600, 1600 (2020) (arguing that individualized inquiry is best understood not as a prohibition on all reliance on group-based generalizations, but instead as a requirement that

For the purposes of this analysis, we put aside the nuances and complexities, fascinating though they are, and instead stipulate a definition of each that coheres reasonably well with the way these concepts are used within the ADA and the cases interpreting it.

In disability discrimination law, the prohibition on "stereotyping" does two things. First, it operates to challenge false generalizations. The classic case that relies on this concept of a stereotype, *School Board of Nassau County v. Arline*,[167] involved a teacher who had recovered from tuberculosis but was terminated due to the school board's fear of the disease.[168] There, the Court observed that disability laws are designed to avoid denials of benefits or services that are rooted in the "prejudiced attitudes or ignorance of others."[169] Second, and importantly, the concept of a stereotype is also used to contest perceptions about disability grounded exclusively in the perspectives of nondisabled people. In other words, this notion of a stereotype calls attention to instances where the perspective of the people without disabilities is used to assess the experience of living with disabilities, rather than relying on or incorporating the perspective of people with disabilities themselves.[170] We will use the concept of a "stereotype" to refer to each of these ideas: a false generalization and a generalization built around the perspective of the nondisabled which excludes the perspective of persons with disabilities.

By contrast, the concept of "individualized inquiry" is invoked to require that a decision-maker refrain from generalizations about the limitations that a particular disability might impose when making judgments about the actual abilities of a person with that disability.[171] Instead, the decision-maker

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actors respond to members of groups in ways that respect how they have and continue to exercise their autonomy).

[167] 480 U.S. 273 (1987).

[168] *Id.* at 276.

[169] *Id.* at 284.

[170] *See* CHARLTON, *supra* note 95, at 3–21 (discussing the slogan "nothing about us without us").

[171] *See Arline*, 480 U.S. at 287 (concluding that Section 504 of the Rehabilitation Act requires an individualized inquiry to protect disabled individuals from "deprivations based on prejudice, stereotypes, or unfounded fear, while giving appropriate weight to such legitimate concerns of grantees as avoiding exposing others to significant health and safety risks").

(an employer, service provider, etc.) must assess the needs and abilities of the individual at issue in the context of their ability to use or participate in the relevant service or program.[172]

One of the named complainants in the OCR complaint against the rationing protocol adopted in Washington State provides an apt example of the doctrine of individualized inquiry.[173] Rose was twenty-eight and had cystic fibrosis.[174] According to the complaint, a clinician might assume that a person with cystic fibrosis is likely to have diminished lung capacity, experience frequent hospitalization and IV antibiotic use, and have a life expectancy of thirty years.[175] Preliminary data suggest that people with chronic lung disease are at a higher risk of developing severe illness from COVID-19,[176] and at twenty-eight, Rose may appear to be near the end of her life, and at heightened risk.[177] Yet Rose herself has never been hospitalized or required use of IV antibiotics and her actual breathing capacity is greater than that of 70 percent of the general population.[178] Were a hospital to consider Rose's actual capacity rather than relying on a generalization about the

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[172] *See, e.g.*, Holiday v. City of Chattanooga, 206 F.3d 637, 643 (6th Cir. 2000) ("In order to properly evaluate a job applicant on the basis of his personal characteristics, the employer must conduct an individualized inquiry into the individual's actual medical condition, and the impact, if any, the condition might have on that individual's ability to perform the job in question.").

[173] Letter from Disability Rights Washington, Self Advocates in Leadership, The Arc of the United States, and Ivanova Smith to Roger Severino, Director, OCR, U.S. Dep't of Health & Hum. Servs. 2 (Mar. 23, 2020), https://perma.cc/Z5U3-CB3N (PDF) [hereinafter Letter from Disability Rights Washington].

[174] *Id.* at 2.

[175] *See id.* at 13 ("Cystic fibrosis is typically perceived as a severe condition. If a clinician knows only that an adult patient has a diagnosis of cystic fibrosis, they are likely to make certain assumptions in the absence of a more detailed medical history.").

[176] CDC COVID-19 Response Team, *Preliminary Estimates of the Prevalence of Selected Underlying Health Conditions Among Patients with Coronavirus Disease 2019—United States, February 12–March 28, 2020*, 69 MORBIDITY & MORTALITY WKLY. REP. 382, 385 (Apr. 3, 2020), https://perma.cc/PBC7-X72S (PDF) ("Based on preliminary U.S. data, persons with underlying health conditions such as diabetes mellitus, chronic lung disease, and cardiovascular disease, appear to be at higher risk for severe COVID-19-associated disease than persons without these conditions.").

[177] *See* Letter from Disability Rights Washington, *supra* note 173, at 13.

[178] *Id.* at 13–14.

breathing capacity of people with cystic fibrosis, Rose would be more likely to be offered treatment with a scarce medical resource like a ventilator.[179]

The prohibition on stereotyping and mandate of individualized inquiry will have implications for the permissibility of the state protocols. The prohibition on stereotyping prohibits reliance on myths or unsubstantiated information and instead directs that care should be based on objective evidence.[180] This directive from discrimination law emphasizes the importance of looking to evidence rather than anecdote whenever possible, which is an especially important consideration when information about new diseases is provisional and evolving. In addition, the prohibition on stereotyping insists including the perspective of people with disabilities and is skeptical of judgments about life with disability that exclude their perspective. This dimension of the prohibition on stereotyping is likely to be especially relevant when evaluating rationing principles based on "quality of life."

The individualized inquiry requirement is also relevant and beneficial to ensuring access to treatment for people with disabilities. However, while important, the ameliorative aspects of individualized inquiry are likely to be modest.[181] For this reason, if courts and others focus only on ensuring individualized assessment, they risk abandoning the deeper commitments that underlie the ADA—its insistence on access to health care for people with disabilities and on a fair balance between the needs of the community and those of the individual person with a disability.

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[179] *See id.* at 13–14 ("The UWMC's 'Material Resource Allocation Principles and Guidelines' emphasize maximizing survival. They further qualify 'overall survival' as 'healthy, long-term survival, recognizing that this represents weighting the survival of young otherwise healthy patients more heavily than that of older, chronically debilitated patients.'").

[180] *See Sch. Bd. of Nassau Cnty. v. Arline*, 480 U.S. 273, 284–86 (1987) (holding that broadly defined disabilities subject to generalizations and myths leave a person with a disability vulnerable to discrimination without individualized, objective review).

[181] *See, e.g.*, Letter from Disability Rights Washington, *supra* note 173, at 13–14 (emphasizing that Rose would be one of few patients with cystic fibrosis likely to gain access to lifesaving treatment upon individualized assessment because she is an outlier patient, experiencing mild symptoms atypical of an average patient).

The requirement of individualized inquiry stands to benefit someone like Rose, the woman described in the OCR complaint from Washington, who is unlike others with the same disease.[182] It is for this reason that disability rights advocates assert that "[t]o avoid discrimination, doctors or triage teams must perform a thorough individualized review of each patient and not assume that any specific diagnosis is determinative of prognosis or near-term survival without an analysis of current and best available objective medical evidence and the individual's ability to respond to treatment."[183] Note that the complaint is not that the generalizations about cystic fibrosis (the disease Rose has) are false; only that they do not apply in her case. For this reason, individualized inquiry in this context and many others is only helpful for outliers.

By contrast, people who do fit the generalizations applicable to their disease or disability will not be helped by individualized inquiry. The fact that the law requires individualized assessment does not mean that individualized assessment is sufficient to meet the requirements of the ADA. Individualized inquiry is a floor, to be sure, but not a ceiling.

The more difficult question to answer is where that sufficiency line is. Facially-neutral policies aimed at saving the most lives will disproportionately disadvantage the ability of people with disabilities to access life-saving care.[184] A prohibition on stereotyping will weed out inaccurate generalizations and so will help ensure access when protocols rely on mistaken views. A demand for individualized inquiry will ensure that the small number of disabled people who are unlike others with their disabilities are able to get care. But the most consequential issues will not be addressed by either of these demands. In the next section, we turn to each of the four rationing principles and assess their permissibility, drawing on all the law canvassed in this section, as well as the moral principles on which it rests.

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[182] *See id.*

[183] BAZELON CTR. FOR MENTAL HEALTH L. ET AL., APPLYING HHS'S GUIDANCE FOR STATES AND HEALTH CARE PROVIDERS ON AVOIDING DISABILITY-BASED DISCRIMINATION IN TREATMENT RATIONING 1 (2020), https://perma.cc/7UCT-MJW3 (PDF).

[184] *See supra* Part II.A.

III. EVALUATING THE RATIONING PRINCIPLES

In this Part, we address the four rationing principles outlined in the scenarios with which we began this Article and analyze whether each is legally and morally permissible. Parts III.A and III.B discuss the easier cases, the rationing principles based on *Quality of Life* and *Life Expectancy*, and argue that both are inconsistent with the demands of discrimination law and the moral foundations underlying it. Part III.C turns to the hard cases, rationing based on *Probability of Survival* and *Level of Resource Commitment*, and argues that an approach that favors either or both principles without also mitigating the disparate impact on people with disabilities is unfaithful to the ADA and not morally justified. The bulk of our discussion focuses on *Probability of Survival* and *Level of Resource Commitment*, which raise the thorniest legal and moral issues and thus will benefit most from significant attention. These principles have attracted less criticism from disability advocates and scholars than the explicit exclusions and quality of life measures.[185] They also have some ardent and well-regarded defenders.[186]

A. *Undervaluing Life with Disability: Quality-of-Life Considerations*

First, we consider a rationing principle based on "quality of life." This principle is well-studied and has long been the subject of controversy.[187] In brief, the idea underlying rationing based on quality of life is that if the same scarce resource can be used to provide one year of good quality of life versus one year of poor quality of life, we should use it for the high quality of life rather than the low quality of life. While this idea may seem plausible at first blush, it has troubling implications morally and legally.

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[185] *See supra* note 15.

[186] *See, e.g.*, Persad, *supra* note 15, at 26 (arguing that COVID-19 policies were implemented to manage healthcare resource constraints and, in turn, support that the "two core goals—saving more lives and saving more years of life—are compatible and consonant with disability law").

[187] *See* Bagenstos, *May Hospitals Withhold Ventilators*, *supra* note 15 (discussing the argument that disability-based criteria likely rest on potentially erroneous judgments about the life prospects of individuals with disabilities).

Because life years without disability are often judged as more valuable than life years with disability, the health needs of people with disabilities typically get lower priority in any rationing scheme based on quality of life.[188]

Quality-of-life judgments are flawed and undervalue the lives of people with disabilities because they rely on stereotypes and because they are often operationalized in ways that exclude the input of people with disabilities themselves. A large body of scholarship demonstrates that life with a disability is not qualitatively worse than life without a disability.[189] Thus, a quality-of-life-based approach is likely to judge life with disability as worse due to the misperceptions of nondisabled people about life with disabilities. In addition, quality-of-life judgments are often flawed because they rely on the assessments of nondisabled people and exclude the perspectives of people with disabilities. To that extent, they are epistemically partial. Our first objection to this form of rationing is that it relies on the sort of impermissible stereotypes that the ADA was designed to redress.[190]

A second consideration also argues against rationing based on quality of life. Suppose, for the sake of argument, we determined that life with disability was qualitatively worse than life without, and the choice is whether to favor a person with greater quality of life over a person with a less quality of life. Suppose also that the reason for this lower quality of life is social conditions. If life with disability is worse because people

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[188] *See, e.g.*, John Harris, *QALYfying the Value of Life*, 13 J. MED. 117, 117 (1987) (arguing that using quality adjusted life years fails to treat people as equals because it disadvantages people whose underlying health conditions yield a lower quality of life than will a someone with better health and so the former will lose access to health resources, a form of double jeopardy); *see also supra* Part II.E.3 (explaining that Oregon's Medicare rationing plan disproportionately excluded individuals with disabilities from care).

[189] *See, e.g.*, ELIZABETH BARNES, THE MINORITY BODY: A THEORY OF DISABILITY 71 (2016) (explaining that "there is a vast body of evidence that suggests that non-disabled people are extraordinarily bad at predicting the effects of disability on *perceived* well-being"); Samuel Bagenstos & Margo Schlanger, *Hedonic Damages, Hedonic Adaptation, and Disability*, 60 VAND. L. REV. 745, 749 (2007) ("[P]eople who experience disabling injuries tend to adapt to their disabilities. To the extent that they experience continuing hedonic loss, it is physical pain and loss of societal opportunities—not anything inherent in the disability—that is the major contributor.").

[190] *See supra* Part II.F.

with disabilities are treated unjustly, then an approach that considers quality of life would compound or augment the disadvantage of the already-disadvantaged person. Individuals and institutions may have a moral obligation not to compound prior injustice.[191] If the lower quality of life that some disabled people experience results from societal injustice, then refusing them life-saving treatment because life with disability yields fewer quality life years compounds this injustice.

Even if life with disability was worse for reasons unrelated to unjust social factors, there are still problems with rationing based on quality of life. Limiting access to care for a person with a disability because her quality of life from a pre-existing disability is lower than that of a person without a disability is cruel. In his influential critique of the use of "quality adjusted life years," known as QALYs, John Harris labels that approach a form of "double jeopardy":

> QALYs dictate that because an individual is unfortunate, because she has once become a victim of disaster, we are required to visit upon her a second and perhaps graver misfortune. The first disaster leaves her with a poor quality of life and QALYs then require that in virtue of this she be ruled out as a candidate for life-saving treatment, or at best, that she be given little or no chance of benefiting from what little amelioration her condition admits of. Her first disaster leaves her with a poor quality of life and when she presents herself for help, along come QALYs and finish her off![192]

The use of quality-of-life judgments is most compelling when an individual person is deciding between two treatments, each of which offers different quality of life. When the same approach is used to decide which of two people to treat, however, then important distributional concerns arise.

To recap, rationing based on quality of life is problematic because: it typically relies on inaccurate stereotypes; it often lacks the perspective of disabled people; to the extent poorer quality of life results from social injustice, it compounds this

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[191] *See* Deborah Hellman, *Indirect Discrimination and the Duty to Avoid Compounding Injustice*, *in* FOUNDATIONS OF INDIRECT DISCRIMINATION LAW 105, 107–09 (Hugh Collins & Tarunabh Khaitan eds., 2018) (arguing that disparate impact liability may be grounded in a duty to avoid compounding injustice).

[192] Harris, *supra* note 188, at 120.

injustice; and it conflicts with moral theories that direct that inequality is most justified when it benefits the worst off.[193] For all of these reasons, this rationing principle is the most clearly prohibited by both the ADA and widely-shared moral principles.[194]

Perhaps for these reasons, none of the state protocols expressly ration based on quality-of-life measures. But quality-of-life considerations are still important in a discussion of rationing because perceptions about the quality of life of a person with a disability may inform decisions in invisible or invidious ways, especially if they stem from unconscious bias on the part of decisionmakers.[195] Reports in the press have highlighted instances in which professionals appear to have rationed care due a perception of the poor quality of life of a person with a pre-existing disability.[196] As discussed in Part II, there is considerable evidence of conscious and unconscious bias

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[193] *See, e.g.*, Matthew D. Adler & Nils Holtug, *Prioritarianism: A Response to Critics*, 18 POL. PHIL. & ECON. 101, 124 (2019) (defending the view that the worst-off ought to get priority in the distribution of scarce resources).

[194] Other scholars argue that rejecting quality of life measures has several problems including that "it would sometimes rank one treatment higher than another, though this would be worse for someone and better for no one," but that fixing this problem creates others that are equally bad such that the task is "like trying to get bubbles out from behind the wallpaper; pushing down in one place simply moves the bubble elsewhere." Nick Beckstead & Toby Ord, *Bubbles Under the Wallpaper: Healthcare Rationing and Discrimination*, *in* BIOETHICS: AN ANTHOLOGY 406, 407 (Helga Kuhse et al. eds., 3d ed. 2015).

[195] *See* Yee et al., *supra* note 93, at 138 (concluding that biases and stereotypes from health care providers concerning people with disabilities directly contribute to observable differences in health care treatments, thereby resulting in adverse health outcome for individuals in that group).

[196] *See* Joel Shapiro, *As Hospitals Fear Being Overwhelmed by COVID-19, Do the Disabled Get the Same Access?*, NPR (Dec. 14, 2020 3:47 PM) [hereinafter Joel Shapiro], https://perma.cc/JH8L-F2JV (telling the story of the death of Sarah Sweeney, and alluding to dozens of additional complaints of discrimination in rationing in Oregon); Kim Roberts, *Austin Hospital Withheld Treatment from Disabled Man Who Contracted Coronavirus*, TEXAN (June 29, 2020), https://perma.cc/DJJ3-8Q7W (detailing the death of Michael Hickson, a disabled man who was withheld medical treatment from St. David's South Austin Medical Center); Ariana Eunjung Cha, *Quadriplegic Man's Death from Covid-19 Spotlights Questions of Disability, Race and Family*, WASH. POST (July 5, 2020), https://perma.cc/8WAG-UB42 (highlighting Michael Hickson's experience).

on the part of healthcare professionals related to disability.[197] To mitigate against the operation of such biases regarding decisions with life-or-death consequences—decisions which are often made "behind closed doors"[198]—we endorse those protocols which explicitly reject medical rationing based on quality of life.[199] Strong, prohibitory language is necessary to provide some prophylactic against decisions that may, in fact, be based on stereotypic assumptions about the value or quality of life of disabled people: decisions, in other words, that are forbidden by the ADA.[200] Indeed, following the OCR resolutions discussed in Part II, the revised standards in both Tennessee and Utah both contain language prohibiting rationing determinations based on *Quality of Life*.[201]

Even prohibitory language, however, may ultimately prove ineffective in mitigating against biases, especially where those biases are unconscious or implicit. Additional remedial action may be required. In Part IV, we recommend an alternative rationing system that would more effectively mitigate concerns regarding the role that perceptions of a person's quality of life may play in their ability to receive meaningful access to care.

B. *A Fair Share of Life: The Relevance and Irrelevance of Life Expectancy*

The rationing principle we label *Life Expectancy* would allocate scarce medical resources based on an assessment of the number of years a person is expected to live after treatment.[202]

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[197] *See supra* Part II.B.

[198] *See* Joel Shapiro, *supra* note 196 (analyzing the stories of individuals who were refused treatment due to their disabilities and subsequently died).

[199] *See, e.g.*, ILLINOIS GUIDELINES, *supra* note 50, at 6 (rejecting rationing based on quality of life); R.I. GUIDELINES, *supra* note 37, at 16 (same); TENNESSEE GUIDELINES, *supra* note 47, at 12 (same).

[200] *See supra* Part II.

[201] *See* TENNESSEE GUIDELINES, *supra* note 47, at 12 ("[P]ersons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age."); UTAH GUIDELINES, *supra* note 2, at 3 ("[P]ersons with disabilities should not be denied medical care based on stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age.").

[202] *See supra* Part I.B.

For this reason, it would generally favor giving resources to the young over the old.[203] However, depending on how it is employed, it also would disadvantage people with disabilities if the disability at issue is one for which life expectancy is generally lower than for the average person.[204] This rationing principle is likely to discriminate not only on the basis of disability but also on the basis of age. Whether such age-based discrimination is permissible legally (or morally) raises issues distinct from those that are our focus and so we note them here only to draw out the way in which the claims of age-based and disability-based discrimination differ.[205]

If age discrimination is morally permissible in the context of rationing scarce medical resources, the reason is likely to be that older people have already lived a long life. This fact matters both because they have at least experienced the good fortune of long life,[206] and have likely already used their fair share of social resources. For these reasons, it may make sense to favor someone who has not enjoyed this good fortune (yet) or has not already consumed their fair share of resources. If the rationale for favoring the young over the old is something along these lines, then it would not extend to a young person with a disability that shortens her life expectancy, as compared with the average non-disabled person. What matters on this rationale is age, or perhaps only advanced age, not life expectancy itself. We stress this point not to argue that favoring children over

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[203] *See supra* Part I.B.

[204] *See supra* Part I.B.

[205] The bulletin issued by OCR at the start of the current pandemic underscores that laws prohibiting discrimination on the basis of age, which are of more limited scope that those to disability, continue to be in effect even during a crisis. *See* OCR HHS Bulletin, *supra* note 11, at 1 (affirming that, during the COVID-19, discrimination on the basis of age in health services is prohibited). For an interesting treatment of the varied approaches to age discrimination in both statutory and constitutional law and an account of when they are justified, see Alexander A. Boni-Saenz, *Age, Time, and Discrimination*, 53 GA. L. REV. 845 (2019) (arguing that age discrimination does not violate norms of equality in most instances because the fact that people age means that each person has an equal opportunity of benefit and harm from age-based restrictions but that age discrimination may violate non-comparative liberty-based rights).

[206] Of course, not all older people have experienced good fortune more generally. In saying this, we mean only that older people have experienced good fortune in this domain.

older people is morally and legally justified. Rather, our point is that *if* this is the reason for such a preference, it would not extend to disfavoring non-elderly people with disabilities who have shortened life expectancy.

Rationing based on life-expectancy itself is much more difficult to defend for two reasons. First, this rationing principle is likely to negatively affect people with disabilities whose disability suggests that they are likely to have shorter-than-average lives. Second, life-expectancy-based rationing is problematic because it does not attend to the distribution of the life-years saved. For example, it may be morally preferable to give two more years to a young person with a short life expectancy than ten years to an older person.[207]

We conclude that life expectancy should not be used as a rationing principle unless the person is very close to death. In this view, we are not alone.[208] According to the American College of Physicians: "Allocation of treatments must maximize *the number of patients who will recover,* not the number of 'life-years,' which is inherently biased."[209]

However, whenever even near-term life expectancy is used, the ADA's focus on individualized inquiry would require that the life expectancy of each person be assessed directly rather than relying on generalizations about the life expectancy of people with particular diseases or disabilities.[210] This individualized assessment will mitigate the disparate impact somewhat. But, as we argued earlier, if people with particular disabilities really

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[207] Prioritarian moral theory, which favors prioritizing the least well-off, would favor such an approach. *See, e.g.*, Adler & Holtug, *supra* note 193.

[208] *See Non-Discrimination in the Stewardship and Allocation of Resources During Health System Catastrophes Including COVID-19*, AM. COLL. OF PHYSICIANS (Mar. 26, 2020), https://perma.cc/Y5TW-QMPM (PDF) (arguing that, in times of medical catastrophe, patient need, effectiveness, and prognosis must be examined to maximize the number of patients with the potential to recover).

[209] *Id.*; *see* Thomas A. Bledsoe et al., *Universal Do-Not-Resuscitate Orders, Social Worth, and Life-Years: Opposing Discriminatory Approaches to the Allocation of Resources During the COVID-19 Pandemic and Other Health System Catastrophes*, 173 ANNALS INTERNAL MED. 230, 230–31 (2020) (arguing that state guidelines about crisis standards of care and journal articles promoting a "life-years" approach to rationing, also called a life cycle or fair innings approach, is unfair because it systematically disfavors older patients, disabled persons, and potentially other groups).

[210] *See supra* notes 161–172 and accompanying text.

do have lower life expectancy than people without such disabilities, reliance on individualized inquiry is unlikely to do much to cure the serious disparate impact problems that reliance on life expectancy will produce.[211]

Perhaps this is the reason that, per the OCR resolutions, the revised protocols in both Utah and Tennessee have removed language that previously permitted use of the rationing principle we call *Life Expectancy* in the allocation of scarce medical resources.[212]

C. *The Hard Cases: Probability of Survival and Level of Resource Commitment*

The *Probability of Survival* and *Level of Resource Commitment* principles present the most difficult cases, and thus bring the tradeoff we highlight between saving the most lives and ensuring a fair distribution of harm into the clearest focus. Each principle will save lives. *Probability of Survival* will save lives because it requires that each scarce medical resource be used on the patients most likely to survive. *Level of Resource Commitment* will save lives because more people can be saved with each resource if the person using it does so for a shorter period of time. At the same time, both principles will have a significant disparate impact on the access that people with disabilities have to life-saving medical treatment.[213] As such, each principle is potentially problematic under the ADA. Both principles force us to grapple with the difficult question of where

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[211] *See supra* notes 181–187 and accompanying text.

[212] *See* Pam Katz, *Resolution of Federal Civil Rights Complaint Raises the Bar in Prohibiting Medical Discrimination Against People with Disabilities During COVID-19 Pandemic*, ARC (June 26, 2020), https://perma.cc/RHM2-HKHR (noting that, due to the complaint's resolution, "Tennessee is now the first state to explicitly eliminate longer-term survivability as a consideration in treatment decisions, changing its Guidance to allow medical personnel to consider only 'imminence of mortality'"); OCR HHS Press Release Utah, *supra* note 10 (noting the removal of "prior language permitting the use of a patient's long-term life expectancy as a factor in the allocation and re-allocation of scarce medical resources"); UTAH GUIDELINES, *supra* note 2, at 4, 6 (referring to "short-term outcomes" and "short-term mortality" risk). Depending upon how "short-term" is employed in practice, these modifications may comport with our belief that Life Expectancy should be considered only when death is very near. *See supra* notes 208–209 and accompanying text.

[213] *See supra* Part I.B.1–2.

precisely the ADA draws the line between acceptable and unacceptable disparate impact.

At the most abstract level, the ADA rests on the bedrock moral principle that people matter equally and thus are entitled to be treated in a manner that accords them equal concern and respect.[214] But as we saw in Part II, the ADA instantiates that principle by adopting a balance between the twin aims of efficiency and inclusion.[215] In order to be true to this pluralist vision, state rationing protocols should reject a singular focus on saving the most lives, as some have begun to do, and instead adopt an approach that balances the pressing need to save the most lives possible with an equally important focus on how the benefits and burdens of such an approach will fall.

The first reason that the Crisis Standards of Care should instantiate a balance between utility and equity, then, is that the law requires it. From a moral perspective, reasonable people might disagree about whether policymakers should focus exclusively on saving the most lives possible or instead should provide each person with an equal chance of getting access to life saving treatment, or whether they should adopt some other plausible rationing principle like prioritizing health care workers, children, people who have been disadvantaged in some other domain or something else. That said, the fact that the law adopts a balance between utility and equity matters morally because the fact that this is the choice made by democratically accountable decisionmakers has moral weight.

The balance the ADA strikes between utility and equity is a compromise between two familiar philosophical views about when and whether "numbers count."[216] On one view, all else equal, it is better that to sabe more people than fewer.[217] On the other view, the value of people's lives cannot be aggregated in this way.[218] Rather, each person's life has value because of its value to the person whose life it is. In other words, "[F]ive individuals each losing his life does not add up to anyone's

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[214] *See, e.g.*, RONALD DWORKIN, JUSTICE FOR HEDGEHOGS 379–99 (2011) (articulating a theory of political equality).

[215] *See supra* Part II.D.

[216] John M. Taurek, *Should the Numbers Count?*, 6 PHIL. & PUB. AFFS. 293, 293 (1977).

[217] *See id.* at 294.

[218] *See id.* at 300.

experiencing a loss five times greater than the loss suffered by any one of the five."[219] For this reason, each person should be given an equal chance to survive. This discussion is all very abstract, so let us illustrate it with an example first proposed by John Taurek: *Island Rescue*.

> *Island Rescue*: Your boat is approaching an island on which there are several people desperately in need of rescue. On the north side, there are ten people; on the south side there are five. You only have enough time to go to one side. Should you go north, because you will save more people; or should you flip a coin because each of the people matters equally and by flipping a coin you give each person an equal chance of being rescued? [220]

Both views have something going for them, or at least we believe so.

Island Rescue is similar in some respects to the famous *Trolley Problem*, in which you must decide whether or not to divert a train heading for a track on which there are five people to another track on which there is only one person.[221] But the *Trolley Problem*, about which people also disagree, is complicated by differences about the moral relevance of doing something versus allowing it to happen. Island Rescue strips out this complication and therefore cleanly poses the question of whether saving more people *is* clearly better, other things being equal, than saving fewer.[222]

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[219] *Id.* at 307.

[220] *Id.* at 310–11 (paraphrased from original).

[221] The trolley problem was first proposed by Philippa Foot and later elaborated by Judith Jarvis Thomson. *See* Philippa Foot, *The Problem of Abortion and the Doctrine of the Double Effect*, 5 OXFORD REV. 5, 6 (1967); Judith Jarvis Thomson, *Killing, Letting Die, and the Trolley Problem*, 59 MONIST 204, 206–08 (1976).

[222] There is a robust literature on this topic. *See, e.g.*, Taurek, *supra* note 216, at 310 (arguing that the numbers do not matter and so members of the larger group and the smaller group have an equal claim on the rescuer to be saved); T. M. SCANLON, WHAT WE OWE TO EACH OTHER 234–38 (2000) (offering a resolution of the dilemma that justifies saving the larger group without aggregating the interests of each person); Jens Timmermann, *The Individualist Lottery: How People Count But Not Their Numbers*, 64 ANALYSIS 106, 111 (2004) (presenting a resolution that values saving more lives and is modified by a principle that affords members of the smaller group a proportionate opportunity to be saved); Katharina Berndt Rasmussen, *Should the Probabilities Count?*, 159 PHIL. STUD. 205, 214 (2011) (complicating the

The philosopher Jens Timmermann offers an answer to the question posed by *Island Rescue*. He provides a compromise between the view, on the one hand, that saving more people is always better and the view, on the other hand, that each person should have an equal chance of rescue in an approach to the problem he calls an "individualist lottery."[223] The basic idea is this. Imagine a wheel divided into fifteen equal segments representing each person in need of rescue with a space that accords with her equal worth. Five of these segments represent the people on the south side, ten represent the people on the north. You spin the wheel and if it lands on a person on the north side, you go north. If it lands on a person on the south side, you go south. The upshot of this approach is that the people on the north have a two-thirds likelihood of being saved and the people on the south have a one-third likelihood of rescue.[224] This method thus gives some weight to the fact that more people are on the north, as they are twice as likely to be saved. But the people on the south have some chance of survival as well. As Timmermann explains, "it is rational for the members of a society not to choose to maximize the probability of being saved" because "[a] somewhat lower overall probability is the price they would be willing to pay for their claims never being discounted right at the beginning."[225] Timmermann justifies this approach on contractualist grounds[226] and also believes that it makes sense of our "conflicting common-sense intuitions" that numbers do matter but that individuals matter too.[227]

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analysis by considering the probability of rescue as well as the number of people to be saved); Gerard Vong, *Weighing Up Weighted Lotteries: Scarcity, Overlap Cases, and Fair Inequalities of Chance*, 130 ETHICS 320, 324 (2020) (discussing how unweighted lotteries cannot handle so-called "overlap cases" and proposing a novel weighted lottery that can).

[223] *See* Timmermann, *supra* note 222, at 110.

[224] *See id.* at 110–11 (explaining the *Island Rescue* hypothetical).

[225] *Id.* at 112.

[226] A contractualist moral theory asks, in some form, what policies could be justified to other people. *See* SCANLON, *supra* note 222, at 5 (explaining the author's view that "thinking about right and wrong is, at the most basic level, thinking about what could be justified to others on grounds that they, if appropriately motivated, could not reasonably reject"). *See generally* JOHN RAWLS, A THEORY OF JUSTICE (rev. ed. 1999).

[227] Timmermann, *supra* note 222, at 112.

We offer Timmermann's individualist lottery to show the moral appeal of the balance that the ADA strikes between efficiency and equity, in the abstract. We recognize that not all readers will share his intuitions or be as drawn to it as we are. For our purposes, here, it is sufficient that it is a plausible position with philosophical defenders[228] and is the one adopted by the ADA.[229]

The argument in favor of balancing saving lives with ensuring equitable access to care is stronger still when we move from the world of abstract hypothetical thought experiments to the real world. The ADA was written, after all, for the world in which we live.

Rather than ask how one should weigh saving ten people as compared to saving five, where nothing distinguishes the ten from the five, the Crisis Standards of Care establish rationing policies in the actual world in which the people likely to be disadvantaged are a distinct social group, people with disabilities, and one that overlaps with other vulnerable groups like racial minorities.[230] In addition, this is a group (like the groups it overlaps with) that has been disadvantaged in the past.[231] As a result, policymakers should worry that their willingness to accept negative impacts on disabled people in the name of saving the most lives possible both is, and will be perceived to be, infected by a differential sympathy toward those who are disadvantaged by this policy.[232]

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[228] According to Lara Buchak's "risk-weighted expected utility maximization,"

> there are actually three psychological components in preference formation and decision making: how much an individual values outcomes (utilities), how likely an individual thinks various states of the world are to obtain (probabilities), and the extent to which an individual is willing to trade off value in worse scenarios against value in better scenarios (the risk function).

Lara Buchak, *Taking Risks Behind the Veil of Ignorance*, 127 ETHICS 610, 616 (2017).

[229] *See supra* Part II.D.

[230] *See supra* Part I.B.

[231] *See supra* Part II.B.

[232] A concern for such differential sympathy is precisely what led John Hart Ely to suggest that courts should review legislation that affects discrete and insular minorities especially closely. *See* JOHN HART ELY, DEMOCRACY AND DISTRUST 77–88 (1980) (explaining that prejudice can disrupt the ability of

This discussion suggests that while rationing based on either *Probability of Survival* or *Level of Resource Commitment* has something important to be said for it—each principle will save lives—this benefit must be balanced by another important aim: ensuring that people with disabilities have equitable access to care. The ADA itself rests on a balance between two goals, efficiency and equity, and that commitment survives even in an emergency.[233] As a result, state rationing protocols must forego a singular focus on saving the most lives and instead adopt a pluralist approach,[234] one which respects both the important aim of saving as many lives as possible and the equally important goal of including people with disabilities in a manner that treats them as equals.

Before we go on to describe how that might be done, we examine two arguments against the position just advanced. First, we consider the claim that the *Probability of Survival* principle avoids waste and so is more defensible than *Level of Resource Commitment*. Second, we consider the claim that the *Level of Resource Commitment* principle is not denigrating to the people it disadvantages and so it is more defensible than *Probability of Survival*. Both these arguments attempt to distinguish between these two rationing principles and thereby to say that saving the most lives in that way is acceptable while doing so via the other principle is not. Ultimately, we reject both arguments and conclude that the two principles are morally equivalent and thus should be treated similarly.

1. Avoiding Waste

Perhaps *Probability of Survival* has a virtue that we haven't yet considered: it avoids wasting scarce medical resources. Waste, in this argument, is defined as a situation in which the scarce medical resource saves no life.[235] Joseph Stramondo offers

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majority members to empathize with minority group members and so fail to represent them).

[233] *See supra* note 157 and accompanying text.

[234] See Smilansky, *supra* note 28, for a defense of pluralism in cases of scarcity and rationing, emphasizing that in these circumstances there are "no unique, morally best options, although there are wrong ones." *Id.* at 460.

[235] *See* Joseph Stramondo, *Disability, Likelihood of Survival, and Inefficiency Amidst Pandemic*, BIOETHICS.NET (Apr. 6, 2020, 12:10 PM),

an argument along these lines. Here's how that argument goes. Suppose that we are deciding whether to give the resource to person A or person B, each of whom is predicted to use the resource for the same amount of time, but person A is more likely to survive than person B. If we choose to give the resource to A (as *Probability of Survival* dictates), there is less likelihood that the resource will save no one and thus be wasted.[236] This is a virtue. In Stramondo's view, this virtue differentiates the *Probability of Survival* principle from *Level of Resource Commitment*, even though both are similar in prioritizing saving the most lives possible. To see why, compare that example to the following one. Suppose we are deciding whether to give the resource to person C or person D, each of whom has the same likelihood of survival but one of whom will need to use the resource for longer. While giving the resource to the person who will use it for less time could save another life by freeing up the resource earlier, the chance that the resource will be wasted by saving no one's life is the same whichever option we choose because C and D have the same likelihood of survival. For this reason, Stramondo favors *Probability of Survival* as a rationing principle over *Level of Resource Commitment*.[237]

Avoiding waste is surely important and prioritizing patients with a greater likelihood of survival will ensure that fewer resources are wasted than if the principle were not employed. But doing so will not ensure that the particular resource at issue is not wasted. If patient A has a 30 percent chance of survival and patient B has a 60 percent chance of survival, for example, there is a significant chance the resource will save no one regardless of which patient gets the resource.

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https://perma.cc/YWF5-RZEC (explaining that a scenario in which medical resources are used to save someone's life is not a "waste" of resources).

[236] *See id.* (explaining the argument that *Probability of Survival* avoids medical resource waste); Ari Ne'eman et al., *The Treatment of Disability under Crisis Standards of Care: An Empirical and Normative Analysis,* 46 J. HEALTH, POL., POL'Y & L. 831, 838 (2021) (adopting our schema delineating the four relevant rationing principles and endorsing Stramondo's argument that rationing based on probability of survival is permissible while rationing based on resource intensity is not).

[237] *See Stramondo*, *supra* note 235 ("I think we can actually accept the likelihood of survival criterion while rejecting the level of resource commitment criterion, even if both aim at maximizing the number of lives saved.").

Moreover, the fact that this principle wastes fewer resources overall may just be a way of saying that more lives will be saved. If so, the argument from avoiding waste does not provide a reason to favor this principle over *Level of Resource Commitment* because implementing that principle will also save lives and thereby avoid waste.[238] Thus, this argument does not in fact add anything new to the equation. If waste consists in the fact that use of scarce resources does not yield a life saved, then avoiding waste is simply another way of describing principles that save the most lives in the aggregate. For this reason, avoiding "waste" does not differentiate the *Probability of Survival* principle from rationing based on *Level of Resource Commitment*.

2. Avoiding Denigration

Perhaps *Level of Resource Commitment* is a more attractive rationing principle than we have thus far recognized because it does a good job of expressing the equal moral worth of all potential patients. To see why, consider how the rationale that underlies each principle might be expressed to the person who is denied the resource as a result.[239] First, *Level of Resource Commitment*: We are not giving you this resource because if we give it to you, you will likely need it for so long that we can save only one person, but if we give it to someone else who will use it for less time, we could save four people. Second, *Probability of Survival*: We are not giving you this resource because you are only 30 percent likely to survive and we can give it to another

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[238] Others share this view, but for different reasons. *See, e.g.*, Eduardo Rivera-López, *Probabilities in Tragic Choices*, 20 UTILITAS 323, 331 (2008) (arguing that choices between saving more people versus fewer people and between people with higher probabilities of survival versus lesser probabilities of survival are "at a fundamental level, sufficiently similar," such that the same approach should apply to both, which, in the author's view, is consequentialist).

[239] The idea that we should test principles considering whether they could be justified to those whom they negatively affect draws on the work of Tim Scanlon, who describes moral justification as a matter of whether a person could "reasonably reject" a principle. *See* SCANLON, *supra* note 222, at 192 ("In the contractualist analysis of right and wrong, what is presupposed first and foremost is the aim of finding principles that others who share this aim could not reasonably reject.").

who is 60 percent likely to survive and thus have a better chance of saving someone with it.

While in both cases lives will be saved overall by deploying the principle at issue, *Level of Resource Commitment* may be able to express that rationale more directly and so to communicate that the person denied the resource is denied care because *numbers* matter rather than because *she* doesn't matter (or doesn't matter equally). She is denied access to the scarce medical resource in order to save more people with that resource than would be saved if it were allocated to her. In the case of *Probability of Survival*, by contrast, the justification of the principle seems to suggest that one person is less worth saving than the other. Society says to that person: you are denied care because giving the resource to another is more likely to save her life than giving it to you is to save yours. This justification may seem to suggest that because the other person is more likely to survive, she is more valuable or more worth saving.

While this argument has some initial appeal and thus seems to provide an additional reason to favor the *Level of Resource Commitment* principle, this seeming reason is evanescent. While *Probability of Survival* may initially seem to value the lives of some more than others, in fact, it values saving more lives over fewer just as does *Level of Resource Commitment*. The person with the greater likelihood of survival is prioritized not because she matters more but because by giving the resource to her, more lives will be saved. Both policies save lives in the aggregate. The similarities between these principles thus overshadow their differences.

D. *Reasonable Modification: The Law's Compromise*

As detailed in Part II.B, the ADA itself includes a doctrine that explicitly directs how to balance efficiency and inclusion: the reasonable modification provision.[240] When a policy or practice of a covered entity would exclude people with disabilities, the law demands that the entity make "reasonable

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[240] *See* 42 U.S.C. § 12182(b)(2)(A)(ii) (balancing efficiency and inclusion implicitly by defining discrimination as "a failure to make *reasonable modifications* in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities").

modifications."[241] The term itself contains a nod to each of these values. Modifications are required to accommodate the needs of people with disabilities, but only when these modifications are reasonable, thereby also taking some account of the needs of the entity and the purpose it serves.[242]

In what follows, we examine the ways in which this doctrine has been used thus far in the context of the state rationing protocols. To preview our evaluation, reasonable modification doctrine's prior use has helped to invalidate the clearest exclusions of people with disabilities and to require some important changes, but does not yet appear to fully effectuate the genuine balance of these two important values in the manner that the ADA requires.

In its resolution of disputes involving state rationing standards in both Tennessee and Utah, OCR has required reasonable policy modifications that limit policies grounded in the rationing principles *Level of Resource Commitment* and *Probability of Survival*.[243] From our reading of the press releases and the revised protocols from both states, the required modifications are ameliorative, but do not go far enough.

Consider the OCR resolution of a complaint by disability rights advocates against the protocol in Tennessee.[244] At first blush, the government appears to reject rationing on the basis of *Level of Resource Commitment* altogether, asserting in comprehensive language that "resource-intensity and duration of need on the basis of age or disability should not be used as criteria for the allocation or re-allocation of scarce medical resources."[245] Yet in the next sentence, OCR backs off this strong

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[241] *See id.*; *see also* 28 C.F.R. § 36.302(a) (2019) ("A public accommodation shall make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities.").

[242] *See* 42 U.S.C. § 12182(b)(2)(A)(ii) (requiring only "reasonable" modifications, and not requiring such modifications if they would "fundamentally alter" the nature of the practice).

[243] *See, e.g.*, OCR HHS Press Release Tennessee, *supra* note 10 (explaining that after receiving technical assistance from OCR, Tennessee updated its plan to clarify that the amount of resources needed or duration of need should not be considered when allocating resources); OCR HHS Press Release Utah, *supra* note 10 (same).

[244] *See* OCR HHS Press Release Tennessee, *supra* note 10.

[245] *Id.*

claim with the statement that the goal is to protect people who "require additional treatment resources due to their age or disability from automatically being given a lower priority to receive life-saving care."[246] Taken together, the OCR statements may only prohibit the reliance on generalizations about the amount of resources people with particular disabilities will require and to mandate individualized assessment regarding whether a patient really will need a high level of resources. If this reading is correct, the resolution of the Tennessee complaint represents a modest limitation on this rationing principle. For people with disabilities in Tennessee who are likely to use a scarce medical resource for more time than the average non-disabled person, this modification is unlikely to help.[247]

On the other hand, OCR's broad statement rejecting *Level of Resource Commitment* as a rationing principle suggests that a more meaningful application of the reasonable modification mandate is possible.[248] The "reasonable modification" required by OCR to the protocols in Tennessee and Utah regarding *Probability of Survival* as a rationing principle is more clearly of modest import. OCR stated in a press release that its goal was to "ensure that people with disabilities are evaluated based on their actual mortality risk, not disability-related characteristics unrelated to their likelihood of survival."[249] In other words, OCR does not appear to object to actual probability of survival after treatment being used to ration resources; it objects to the reliance on generalizations about the likelihood of survival of individual people with disabilities.[250] In addition, all assessments using the SOFA and MSOFA scales are required to

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[246] *Id.*

[247] *See id.*

[248] Indeed, that the OCR HHS Press Release in Utah omits the word "automatically" suggests that this more meaningful reading may ultimately prevail. *See* OCR HHS Press Release Utah, *supra* note 10 ("This protects patients who require additional treatment resources due to their age or disability from being given a lower priority to receive life-saving care due to such need."). Part of the problem of parsing meaning from these documents is that they are quite brief and exist at a level of generality that obscures a clear reading of their intention. *See id.* (providing only an overview of the changes made in the Revised Guidance).

[249] OCR HHS Press Release Utah, *supra* note 10.

[250] *See id.* (requiring individualized assessment in lieu of "categorical exclusion").

be individualized, but, again, such individualization will primarily only help people who do not fit these generalizations.[251]

We do not want to be overly critical here, nor to dismiss the importance of this reasonable modification, which will surely help two groups of people. First, the modifications will help outliers, those whose experience of a particular disability is unlike that of many or most people with the same condition. Second, the modifications will help by prohibiting screening tools that are unrelated to the aim of saving lives.[252] For example, if the screening tool requires the patient being able to offer a verbal response, it may be an inaccurate indicator of survivability for patients who are unable to communicate verbally.[253] But for people with disabilities who really do have a lower probability of survival than the average non-disabled person, these modifications are unlikely to be of help.

It is interesting that OCR's application of the reasonable modification mandate appears to go further in protecting against decisions based on *Level of Resource Commitment* than in rationing based on *Probability of Survival*.[254] The reason for this difference may be practical rather than normative.[255] The

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[251] *See supra* notes 173–184 and accompanying text.

[252] *See, e.g.*, UTAH GUIDELINES, *supra* note 2, at 4 (noting that modifications are meant to "ensure that disability-related characteristics unrelated to short-term mortality risk do not worsen the patient's score").

[253] The revised guidance in Tennessee notes that modifications may be necessary for people with deafness, or cognitive or mobility impairments, and elaborates where the SOFA and MSOFA algorithms are described. *See* TENNESSEE GUIDELINES, *supra* note 47, at 8, B-5. The guidance offers the example of the Glasgow Coma Scale, a tool for measuring acute brain injury, which requires patients to respond verbally and move limbs: "For patients with pre-existing speech disabilities or disabilities that effect motor movement, this may result in a higher SOFA score even in instances where the patient's disability is not relevant to short-term mortality risk." *Id.* at B-5.

[254] *See, e.g.*, OCR HHS Press Release Tennessee, *supra* note 10 (highlighting that a key change in the state guidance "[c]larified that resource-intensity and duration of need on the basis of age or disability should not be used as criteria for the allocation or re-allocation of scarce medical resources").

[255] There is a normative reason that may explain the stronger stance on *Level of Resource Commitment*. Because reassessment to decide whether to withdraw use of the resource from one individual in order to give it to another is a key aspect of how that rationing principle operates in the protocols, the stronger stance on *Level of Resource Commitment* may reflect the difference

question of how best to remediate the principles that have a disproportionate impact is, after all, a distinct consideration from whether the principles are valid.

For example, the revised Utah guidelines call for additional protections for individuals with disabilities, including "reasonable modification" to the assessment process for reallocation.[256] It is impossible to know if the reasonable modification envisioned by Utah is like that in Tennessee, which serves only to ensure that the SOFA-type tests are applied in a way that results in an accurate finding of the person's actual mortality risk.[257] But a more meaningful reading is possible. If the reasonable modification instead requires that a person with a pre-existing disability be given more time with a resource in order to show the same degree of improvement as a similarly-situated person without a disability, then it would effectively place the individual with a pre-existing disability on an equal footing. Such a modification would provide that person with "an equal opportunity to achieve the same result" as the ADA requires, and thus alleviate our concern with the *Level of Resource Commitment* principle.[258] This use of the reasonable modification provision is familiar because it has been required by the ADA in other contexts, such as accommodations in testing that afford extra time to an individual with an intellectual disability.[259]

By contrast, it may be more difficult as a practical matter to envision how to reasonably modify rationing schemes grounded in *Probability of Survival* without abandoning the importance of saving lives. In our view, a reasonable

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between withholding care on the one hand, and withdrawing care that is likely to result in terminating life on the other.

[256] *See* UTAH GUIDELINES, *supra* note 2, at 5, 7 (reasoning that certain "disability-related characteristics" may be "unrelated to short-term mortality risk").

[257] *Compare* UTAH GUIDELINES, *supra* note 2, at 5–7 (specifying reasonable modifications to be made during assessments), *with* TENNESSEE GUIDELINES, *supra* note 47, at 2, 8 (noting that "a reasonable modification of SOFA may be a necessary accommodation").

[258] H.R. REP. NO. 101-485, at 55 (1990); *see supra* Part II.C.

[259] *See, e.g.*, Betts v. Rector & Visitors of Univ. of Va., No. 97-1850, 1999 WL 739415, at *4 (4th Cir. Sept. 22, 1999) (noting that both parties agreed, pursuant to the ADA, that "allowing [a student] double time on his exams was a reasonable accommodation").

modification of that principle requires balancing saving the most lives possible with the importance of treating individuals with disabilities fairly. In Part IV, we offer a remedial solution to precisely this problem.

IV. A PLURALIST APPROACH

In this Part, we provide a reasonable modification of the *Probability of Survival Principle*. This modification allows both goals—saving the most lives and ensuring that people with disabilities get reasonable access to care—to operate. In so doing, this proposal replaces the singular focus on saving the most lives possible that currently animates the state protocols and moves toward a more pluralistic vision.

In the debate about how to ration scarce resources, the choice is often presented as between saving the most lives possible or rationing based on a lottery or *first-come, first-served* (FC-FS).[260] Scholars who favor rationing based on the principle of FC-FS and lotteries defend these approaches on the grounds that they accord equal value to each person.[261]

However, FC-FS and lotteries have drawbacks. Prioritizing those who arrive at hospitals first risks prioritizing wealthier or more privileged patients who are more comfortable seeking medical care or simply have easier access to it.[262] And, while we

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[260] *See* Mildred Z. Solomon et al., *Covid-19 Crisis Triage—Optimizing Health Outcomes and Disability Rights*, 383 NEW ENG. J. MED. e27(1), e27(1) (2020) (arguing that a first-come, first-served approach "would leave many people with disabilities worse off"). *Compare* Persad, *Evidence-Based Triage in a Pandemic*, *supra* note 15, at 26 (discussing how it is permissible within disability law to consider patients' probability of survival and the quantity of resources required), *with* Bagenstos, *May Hospitals Withhold Ventilators*, *supra* note 15, at 4 (suggesting the consideration of various factors or a lottery system in lieu of a first come-first served system).

[261] *See* Bagenstos, *May Hospitals Withhold Ventilators*, *supra* note 15, at 4 (noting that "[e]ven a lottery would be fairer" than the current rationing protocols); Ari Ne'eman, *'I Will Not Apologize for My Needs'*, N.Y. TIMES (Mar. 23, 2020), https://perma.cc/KAF7-T2UN ("[W]e should maintain a broad approach of 'first come first served' when it comes to lifesaving care, even scarce medical resources like ventilators.").

[262] *See* Govind Persad et al., *Principles for Allocation of Scarce Medical Interventions*, 373 LANCET 423, 424 (2009) (arguing that first-come, first-served "favours people who are well-off, who become informed, and travel more quickly, and can queue for interventions without competing for employment or child-care concerns").

appreciate the ways in which a lottery instantiates the equal worth of all, adoption of this principles goes too far in abandoning the importance of saving the most lives.

What is missing from the debate, to date, is a proposal that incorporates *both* the value of saving the most lives and the value of inclusion, and explicitly offers an approach that obviates the need to choose one or the other. Prioritizing saving the most lives is akin to always going north in the *Island Rescue* hypothetical.[263] Using a lottery is like flipping a coin. What we need instead is an approach that approximates the individualist lottery Timmermann describes: one that accords weight to saving more lives, while not discounting the claims of the disabled "right at the beginning."[264]

In this Part, we draw upon an innovative approach proposed by a group of economists that appears to do this. We offer this approach as a reasonable modification to the *Probability of Survival* principle. It will also mitigate concerns about rationing on the basis of *Quality of Life* that may occur in the application of the protocols. This proposal accommodates the pluralist vision that animates the ADA by allowing both the goal of saving the most lives and that of ensuring that people with disabilities get reasonable access to care to operate.

A. *Reserving Resources for Both Efficiency and Equity*

A pluralist approach which incorporates both the principle of saving the most lives (efficiency) and ensuring fair access to disabled people (equity or inclusion) is most faithful to the demands of discrimination law and the ADA.[265] The technical challenge is how to accommodate more than one value in a rationing scheme and to do so in a way that gives each value its due.

Theoretically, there are several possible methods of accommodating multiple rationing principles. One way of doing so would be to adopt a weighted lottery method, which would assign members of priority groups a higher likelihood of being selected. As this method seems to mirror Timmermann's approach to the *Island Rescue* problem, it seems initially

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[263] *See supra* notes 223–224 and accompanying text.

[264] Timmerman, *supra* note 222, at 111–12.

[265] *See supra* Part II.D.

appealing.[266] While a weighted lottery offers a way to ensure that disabled people get access, it fails to promote the twin aims of the pluralist approach in the best manner possible.[267] This is because the method still utilizes a lottery. If people with disabilities and people with a high likelihood of survival are both weighted more heavily than people who are not in either of these categories and then a lottery is used to determine to whom the resources are allocated, there remains some chance that resources will be allocated to people in neither category. If so, this method does not do the best job of achieving the aim of allocating resources in a manner that advances the values of saving the most lives possible while ensuring access to people with disabilities.

A more promising way to operationalize the pluralistic approach would be to reserve resources for people with disabilities, while allowing the remainder to be allocated in line with the principle of saving the most lives possible.[268] Specifically, this approach would allocate a percentage of the scarce resource to the saving lives principle and "reserve" a percentage for allocation to any other principle or principles considered relevant, such as ensuring a fair distribution of benefit and harm.[269] A significant advantage of this approach is its prospective and systemic application. In that sense, it instantiates the approach taken by the current protocols,

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[266] *See, e.g.*, Douglas B. White et al., *Who Should Receive Life Support During a Public Health Emergency? Using Ethical Principles to Improve Allocation Decisions*, 150 ANNALS INTERNAL MED. 132, 135 (2009) (proposing that several principles be combined, including "saving the most lives, saving the most life-years, and giving individuals equal opportunity to live through life's stages").

[267] *See* Joseph Millum, *Against Weighted Lotteries for Scarce COVID-19 Treatments*, HEALTH AFFS. (Oct. 26, 2020), https://perma.cc/278V-B4ZM (arguing that although weighted lotteries have the appearance of fairness, they still "lead to unjust outcomes").

[268] *See* PARAG A. PATHAK ET AL., FAIR ALLOCATION OF VACCINES, VENTILATORS, AND ANTIVIRAL TREATMENTS: LEAVING NO ETHICAL VALUE BEHIND IN HEALTH CARE RATIONING 37 (2021), perma.cc/T4UE-5VDF (PDF) (promoting a reserve system because it "offers additional flexibility to balance competing objectives").

[269] *See id.* at 12 (outlining a proposed structure of reserve systems with no structure for priority orders).

something especially important when one of the scarce medical resources is likely to be limited clinician time.[270]

So how might such an approach work? Economists Pathak, Sönmez, Ünver, and Yemez illustrate such a reserve system with an example in which the goal is to save the most lives possible, while at the same time reserving some scarce resources (in this case, ventilators) for health care workers.[271] They imagine that this reserve for health care workers can be justified on the basis of either reciprocity (because health care workers have sacrificed for others, they have earned some preference) or incentives (if these workers know that they'll get priority, more of them will be willing to risk their own health to care for patients).[272] Suppose that a state or society were to endorse either of these justifications and thus wish to allocate some priority to health care workers. Without a system like that proposed by these authors, problems might arise. In particular, the number of health care workers (especially if that category is understood expansively, as it frequently is) may exceed the supply of the scarce resource. As a result, prioritizing health care workers would require abandoning the goal of saving the most lives altogether.

Indeed, New York explicitly considered and rejected just such a priority for health care workers in its rationing protocol for exactly this reason.[273] The committee that drafted the N.Y. Ventilator Guidelines rejected prioritizing health care workers, despite their conviction that health care workers should get some priority, because including that priority would too dramatically undercut the goal of saving as many lives as

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[270] *See, e.g.*, Ezekiel J. Emanuel et al., *Fair Allocation of Scarce Medical Resources in the Time of Covid-19*, 382 NEW ENG. J. MED. 2049, 2050 ("[I]n the Covid-19 pandemic, the limiting factor for ventilator use will most likely not be ventilators but healthy respiratory therapists and trained critical care staff to operate them safely over three shifts every day.").

[271] *See* PATHAK ET AL., *supra* note 268, at 12 (proposing a reserve system that allows for certain groups, such as healthcare workers, to have heightened priority for treatment). Whether the two principles we discuss should be supplemented by others, such as privileging health care workers, for example, is a compelling question. For now, it is worthwhile to highlight that this system can accommodate a pluralist vision, and one which may incorporate many principles.

[272] *Id.* at 9.

[273] *See* N.Y. VENTILATOR GUIDELINES, *supra* note 1, at 44–45.

possible.[274] What they lacked, and what is needed, is a technological solution that allows policymakers to more easily balance multiple principles, which is something that Pathak et al. provide.[275]

The solution is a method that allocates a percentage of the scarce resource to each of the principles that society determines should be included.[276] As applied to the example above, it provides a way for a state to limit *ex ante* the degree to which the priority for health care workers encroaches on the saving the most lives principle. If, for example, 80 percent of the scarce medical resources are allocated toward the saving the most lives principle, and 20 percent are reserved for health care workers, the choice to prioritize healthcare workers can only ever affect 20 percent of the scarce medical resources. Simple enough. The complication arises when members of the groups represented by different policy choices overlap, with some people being present in more than one group.[277] A central insight of Pathak et al. is that the order in which the reserves are processed matters, as we explain below.

The reserve can be operationalized in either of two ways. It can provide a "boost" for a group, giving it extra resources, as might be justified in the case for health care workers.[278] Or it can function as a "protective measure" to ensure that members of a group are not left out altogether.[279] The order in which the reserve category is processed determines whether it functions as

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[274] *See id.* at 4 ("The primary goal of the Guidelines is to save the most lives in an influenza pandemic where there are a limited number of ventilators. To accomplish this goal, patients for whom ventilator therapy would most likely be lifesaving are prioritized.").

[275] *See* Parag A. Pathak et al., *Leaving No Ethical Value Behind: Triage Protocol Design for Pandemic Rationing* 1–2 (Nat'l Bureau of Econ. Rsch., Working Paper No. 26951) (advocating for a reserve design system to distribute scarce medical resources during a crisis).

[276] *See id.* at 6–7 (discussing the popularity of the priority system of allocating resources, where the rank of the principle must be determined).

[277] *See* PATHAK ET AL., *supra* note 268, at 28 (providing the example of an individual falling into two priority categories by being considered both essential personnel and disadvantaged).

[278] *See, e.g.*, Pathak et al., *supra* note 275, at 10 (explaining that "the later a reserve category is processed the better for its beneficiaries").

[279] *See id.* (explaining that "if a reserve category is intended as a 'protective measure' for a group of participants, then the category should be processed after more inclusive categories open to all").

a boost or a protective measure.[280] If the reserve category is processed first, it functions as a protective measure; if it is processed second, it functions as a boost. In our view and consistent with the ADA's emphasis on equal rather than superior opportunity, and in the view of Pathak et al.,[281] the reserve for disability should function not as a boost but as a protective measure.

While a discussion of the mathematics of the reserve system is beyond the scope of this Article, what is important to understand is that this model provides an algorithm that enables policymakers to allocate resources according to multiple principles—one that can be fashioned in advance and applied much like the algorithms in SOFA-type scoring.[282] For our purposes, this method provides a middle road between the goals of saving the most lives and ensuring that benefits and harms are distributed fairly.

B. *What Legal Issues Does the Reserve Approach Give Rise To?*

One might wonder whether the reserve system we suggest, in which scarce medical resources are reserved for people with disabilities, would raise other legal issues. In particular, is such an approach similar enough to a racial quota to be legally impermissible?[283] After all, the racial quotas that have been struck down by the Supreme Court involve situations in which states reserve other scarce resources, like places at colleges or universities, for members of racial minority groups.[284] In this Section we analyze this legal question and conclude that a reserve for people with disabilities is likely to be legally permissible. That said, any uncertainty in this regard can be avoided by pursuing the goal of ensuring access to individuals

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[280] *Id.*

[281] *See id.* at 12 (explaining that "a *disabled protective category* can be established for disabled patients reserving some of the units for these groups").

[282] *See id.* at 12–22 (offering various algorithms with modifiable components to simulate different reserve possibilities).

[283] *See* Regents of Univ. of Cal. v. Bakke, 438 U.S. 265, 307 (1978) (holding that the Constitution forbids admitting "specified percentage[s] of a particular group merely because of its race or ethnic origin" in higher education contexts).

[284] *See id.* at 272–73.

with disabilities or other vulnerable groups with a facially-neutral policy that focuses more generally on disadvantage.

A state could adopt the reserve approach we propose in two different ways. The state protocol might specify that a percentage of the resources is allocated to saving the most lives possible and the remainder reserved for people with disabilities. Alternatively, the protocol might specify that a percentage of scarce medical resources be reserved for patients who are disadvantaged, as determined by a recognized index of disadvantage. We might call the first approach a *disability-based reserve* and the second approach a *disadvantage-based reserve*.

What legal issues does the *disability-based reserve* give rise to? Critics might object that it amounts to a "quota" for people with disabilities—a word that has come to have strong negative connotations in the United States.[285] That said, thus far only racial quotas are clearly impermissible under existing constitutional law.[286] By contrast, the Supreme Court treats disability classifications as non-suspect and thus formally subject only to rationality review, although the type of rationality review applied to disability is more searching than rationality review for economic classifications.[287] The rationality review applied to disability is somewhat harder to pass.[288] Still, even under this more searching standard, a court is likely to find that a state has a rational interest in reserving resources for people with disabilities who are otherwise denied a fair shot at life-saving care. Thus, were a state to allocate X percent of a

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[285] *See, e.g.*, Louis Menand, *The Changing Meaning of Affirmative Action*, NEW YORKER (Jan. 13, 2020), (arguing that people who disapprove of affirmative action use "the dreaded Q-word, 'quota,'" thereby supporting our contention that the word "quota" carries a negative connotation with the general public).

[286] See *Bakke*, 438 U.S. at 319–20 (engaging in no discussion on how the Court's opinion would impact quotas based on characteristics other than race, and only ruling that the "explicit racial classification" failed to "promote a substantial state interest").

[287] *See* City of Cleburne v. Cleburne Living Ctr., 473 U.S. 432, 442–43 (1985).

[288] *See id.* at 440 (indicating a lower type of rational review for "social or economic legislation" as opposed to disability laws and assessing the fit between the alleged purposes of the statute and its means with some rigor).

scarce medical resource for people most likely to survive, in accord with the save the most lives principle, and reserve Y percent of the resources for people with disabilities, in accordance with the inclusion principle, the policy will likely be constitutional.

Alternatively, a state could adopt a *disadvantage-based reserve*. This approach would allocate X percent of a scarce medical resource to people most likely to survive, in accord with the save the most lives principle, and reserve Y percent for people who qualify as disadvantaged. For example, if 75 percent of scarce medical resources are allocated based on *Probability of Survival*, 25 percent could be reserved for people who are disadvantaged. This facially-neutral approach is also unlikely to have any legal liabilities.[289]

If both the *disability-based reserve* and the *disadvantage-based reserve* are legally permissible, which should be preferred? There are several practical considerations that bear on the choice between the *disability-based reserve* and the *disadvantage-based reserve*. The *disability-based reserve* may be more straightforward to apply and will more clearly express that people with disabilities are valued and included in the distribution of health care in times of emergency. The *disadvantage-based* approach, by contrast, has the benefit of overlap with other disadvantaged groups, especially racial minorities and the poor.[290] Nevertheless, given the breadth of the definition of disability under the ADA, and the fact that social and economic disadvantage and poor health often coexist, there may not be a significant difference between these two

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[289] *See* Washington v. Davis, 426 U.S. 229, 242 (1976) (discussing race, but noting that a facially neutral law that served goals within the government's power would not be invalidated "simply because it may affect a greater proportion of one [group] than of another").

[290] *See, e.g.*, Andrew Peterson et al., *Ethics of Reallocating Ventilators in the Covid-19 Pandemic*, 369 BRIT. MED. J. 1, 2 (2020) (explaining that "[i]n the US, people of colour have a higher burden of disease ([e.g.], hypertension and diabetes) than other populations" and that "[s]uch comorbidities can contribute to poor prognoses in covid-19"). The disadvantage-based reserve would include those whose underlying medical conditions do not meet the definition of disability in the ADA.

approaches in practice.[291] If so, the substantial practical advantage of using disability to define the reserve suggests that it is preferable.

C. *Reasonable Modification Redux*

Earlier we considered whether and how the ADA's reasonable modification mandate might help to achieve a balance between the twin aims of saving the most lives and ensuring fair treatment to people with disabilities.[292] At the moment, state protocols pursue the goal of saving the most lives through the rationing principles *Level of Resource Commitment* and *Probability of Survival*.[293] We noted that in the most generous reading of the OCR resolutions, the reasonable modification doctrine is able to strike a balance between these two aims when applied to the *Level of Resource Commitment* rationing principle.[294] State protocols can specify, for example, that people with disabilities should be afforded more time to show improvement or greater intensity of resource use before a resource is reallocated.[295] If states employ reasonable modification in this way to guard against rationing on the basis of *Level of Resource Commitment* when allocating and reallocating resources, the doctrine would go a long way toward addressing our concerns on this rationing principle.

A reasonable modification of the *Probability of Survival* principle requires a more holistic change. Rather than tinkering with how the principle is applied, the reserve approach requires that states implement a system that explicitly and at the outset balances saving the most lives and including people with disabilities.[296] Because the state protocols are all policies covered by Title II of the ADA, a reasonable modification to

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[291] *See* 42 U.S.C. § 12102(1)(A) (defining disability generally as "a physical or mental impairment that substantially limits one or more major life activities").

[292] *See supra* Part II.D.

[293] *See supra* Part I.B.1–2.

[294] *See supra* Part III.C–D.

[295] *See, e.g.*, *supra* note 157 and accompanying text.

[296] *See* PATHAK ET AL., *supra* note 268, at 3 (indicating that in the proposed reserve system "units are divided into multiple categories" at the beginning of the divvying up process).

incorporate a reserve system is a legally viable application of that doctrine.[297]

If the reserve approach is to constitute a reasonable modification of the *Probability of Survival Principle*, how large should the *disability-based reserve* be to be reasonable? We answer that question in two ways. First, we offer a theoretical answer. The idea is to balance the twin aims of saving the most lives and ensuring equal access to people with disabilities. In a sense, we are looking for a reserve size that is somewhere in between these poles. It might be helpful then to think about where these two poles are. On one side is an approach that endeavors to save the most lives but that uses an approach that is likely to screen out people with disabilities (full efficiency). On the other side is an approach that allocates resources to people with disabilities that is equivalent to their proportion in the population seeking care (full inclusion). In the latter case, if people with disabilities, hypothetically, were to make up 25 percent of the population needing the scarce medical resource, then they would get 25 percent of the available resource. In theory, a balance between these two principles would reserve between 0 and 25 percent of the scarce medical resource for people with disabilities.[298]

Second, we offer a procedural answer to the question of what size reserve is reasonable. The ADA sets the basic parameters, but it does not determine exactly how large the reserve should be.[299] Determining exactly where the balance between these two aims lies requires a moral assessment that society as a whole must provide. For that reason, we recommend that the percentage of the scarce resource to be reserved for people with disabilities should be determined via a process involving community members or by democratically-accountable decisionmakers or both. In either

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[297] In the sense that it is a global modification of the protocol, this reasonable modification would operate more like OCR modifications of the principle of *Life Expectancy,* in which the covered jurisdictions removed all provisions that rationed care on that basis from their protocols. *See supra* note 212 and accompanying text. Of course, the remedy for *Life Expectancy* was more straightforward and easier to effectuate.

[298] The 25 percent number was entirely hypothetical and should not be taken as signifying anything.

[299] *See supra* Part III.D.

case, people with disabilities and their advocates should be included in the process.

Finally, the reserve approach will also mitigate against rationing based on *Quality of Life* inadvertently affecting outcomes. The protocols that expressly prohibit rationing on that basis are helpful, but if the real problem is the implicit biases of healthcare professionals regarding disability, a sentence in the protocol stating that decisions should not be made on this basis is unlikely do much.[300] On the other hand, if professionals applying rationing protocols know that society has reserved a set of resources for people with disabilities—if disability is already built into the algorithm that helps determine who does and does not receive scarce medical resources—people with disabilities are more assured of access to care.

In sum, because the reserve approach will mitigate the disparate impact of explicit rationing based on *Probability of Survival* and implicit rationing based on *Quality of Life*, it provides an appropriate and ameliorative reasonable modification of current Crisis Standards of Care.

CONCLUSION

In this Article, we evaluated the state protocols that govern how medical care should be rationed in times of crisis when there are insufficient medical resources to meet the need. We began by articulating a problem that lies at the heart of the current state rationing protocols: their near singular focus on saving the most lives possible. This important goal, we argued, must be balanced by the goal of ensuring that harms do not fall disproportionately on disadvantaged groups like people with disabilities.

In order to evaluate how the state protocols will result in the sort of disparate impact on individuals with disabilities that is forbidden by the ADA and related anti-discrimination laws, we identified four key rationing principles. Three of the rationing principles—*Life Expectancy*, *Level of Resource Commitment*, and *Probability of Survival*—are expressly reflected in the state Crisis Standards of Care. A fourth

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[300] *See supra* notes 195–201 and accompanying text.

rationing principle, *Quality of Life*, remains relevant because it may inadvertently affect the application of the protocols. The first contribution of the Article is to articulate the principles that undergird the state standards in a simple and straightforward way so that it is easy to evaluate them. The decision about which principles ought to guide medical rationing is, after all, one for policymakers and citizens to make, not scholars.

The second contribution of this Article is to provide a comprehensive and detailed discussion of the legal and ethical issues implicated by each principle. While recent resolutions of complaints about these state protocols by an administrative agency with responsibility for enforcement of the ADA and related laws have found these standards deficient, these resolutions exist at a level of generality that offers little clear guidance. We hope that this Article's more detailed exploration will provide future decisionmakers, be they courts or emergency preparedness planners and policymakers, with a more refined understanding of the key moral and legal issues.

In our view, medical providers and policymakers should be resistant to policies—sensible as saving the most lives may sound at first blush—that in practice will mean that people with disabilities will be unable to access life-saving medical care. Policies that explicitly exclude people with disabilities are easy to spot and are clearly both legally and morally problematic. More consequential will be those policies that allocate care based on *Quality of Life*, *Life Expectancy*, *Level of Resource Commitment*, and *Probability of Survival* principles. Each of these rationing principles will disparately disadvantage people with disabilities in ways forbidden by the ADA and related antidiscrimination laws.

We argued that rationing based on *Quality of Life* and *Life Expectancy* are both clearly impermissible. The state protocols should specifically abjure quality of life judgments and take steps to guard against such judgments implicitly affecting rationing determinations. The protocols should also reject rationing based on life expectancy. While there may be valid arguments for preferring the young over the old, age-based preferences should not be operationalized in terms of life expectancy.

By contrast, rationing based on *Level of Resource Commitment* and *Probability of Survival* present more difficult issues. On the one hand, reliance on each of these two principles will save lives. On the other hand, their use will have a significant negative impact on the ability of people with disabilities to access life-saving care. We argued that the ADA requires a balance between these two values, something that is missing in most of the state protocols.

We then turned to the separate question of how this deficit should be remedied, drawing upon the reasonable modification doctrine in the ADA. We found that policies that rely on *Level of Resource Commitment* can be modified by forgoing uniform benchmarks for determining how long a patient may use a resource before it is reallocated or how much of the resource she may use. While many state Crisis Standards of Care still ration based on *Level of Resource Commitment* without modifying that principle to accommodate the needs of patients with disabilities, some revised state protocols have adopted this change, which we endorse and commend.[301]

Modifying rationing protocols based on *Probability of Survival* will require more comprehensive change. To appropriately balance the importance of both saving lives *and* of ensuring fair access of people with disabilities to scarce medical resources, we propose that states specify a percentage of the scarce resources that is to be allocated in accordance with each of these principles, as the reserve system we describe permits. This remedy also helps guard against rationing based on *Quality of Life*. The remedy is practical, morally justified, and most importantly, consistent with existing law.

The COVID-19 pandemic has revealed many vulnerabilities in our planning—gaps in the supply chain, inadequate tracking systems, and faulty channels of distribution—as crises are bound to do.[302] When the rubber met the road, the vulnerabilities in our ethical and legal preparedness also became evident. The Crisis Standards of Care traditionally focus solely on saving the most lives possible. Amidst the COVID-19 pandemic, the moral and legal vulnerabilities of that approach have become clearer. As a result, some states have

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[301] *See supra* note 212 and accompanying text.

[302] *See, e.g.*, Hans Thalbauer, *How COVID-19 Exposed Weaknesses in the Global Supply Chain*, FORBES (Apr. 20, 2020), https://perma.cc/D82T-XRDA (detailing the global supply chain's reaction to COVID-19 and noting that "companies and the supply chains were not prepared for a pandemic").

modified their plans. While these changes do not go far enough, they demonstrate that the question of how best to balance the twin aims of efficiency and equity is important and is one that policymakers have an appetite to address. It is our hope that the analysis presented in this Article will inform and affect those discussions.