

Understanding the Distributive Equity Framework for Allocating Scarce Medical Resources in Times of Crisis

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The goal of this Note is to examine the moral and legal questions raised by scarcity of life-saving medical resources from a distributive justice perspective. This Note argues that the traditional antidiscrimination framework cannot resolve questions of resource allocation because antidiscrimination laws focus on eliminating barriers to access without addressing issues of substantive equity. Because a solution requires prioritizing across similarly legitimate claims to healthcare to ensure equitable access to health for all, resource allocation is a substantive concern better suited for analysis under a distributive equity framework. This Note identifies the proper space—or good—of distribution as the basic human capability of health and the appropriate metric for distribution within that space as a structured balance of utilitarian and prioritarian principles called the Principle of Proportionate Priority (PPP), a new principle of distributive justice developed by Professor Talha Syed of Berkeley Law. This Note contributes to its relevant field of scholarship by applying this novel principle in the context of medical-resource allocation and proposing it as a useful tool for states to improve resource-allocation protocols like the Crisis Standards of Care developed in response to COVID-19.

Under the proper distributive equity framework, the Principle of Proportionate Priority appropriately affords priority as a matter of degree based on how much worse off a patient is relative to others and how much they stand to benefit from treatment. In practical terms, this means a patient's claim for priority is strongest when they have both the greatest need, because of their young age or poor lifetime levels of health, and the greatest potential for benefit, because of their chance of survival or the effectiveness of treatment. This comparative priority approach is preferable to a strictly utilitarian principle that ignores the plight of the worst off or a strictly need-based prioritarian principle that disregards the importance of efficiently stewarding resources, particularly in times of scarcity. When developing protocols for the allocation of scarce medical resources, states can fairly consider the rationing factors of age, severity of condition, probability of survival, and life expectancy after treatment

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to determine whether a patient suffers from greater need or stands to reap greater benefits from treatment.

Introduction

In late February and early March 2020, the United States watched in horror as Italy, the new European epicenter of the coronavirus epidemic, faced dramatic shortages of ICU beds, medical staff, and ventilators.¹ At the time, the United States federal government had no official national criteria for rationing scarce medical resources like ICU beds and mechanical ventilators in an emergency.² With the Centers for Disease Control and Prevention (CDC) predicting that between 2.4 million and 21 million Americans would require hospitalization during the pandemic and Italian hospitals reporting that between 10% and 25% of hospitalized patients required ventilation,³ officials from state governments, medical associations, and hospitals began to look for guidance to develop their own rationing plans.⁴

Despite the absence of readily available federal guidelines in 2020, the COVID-19 pandemic was not the first crisis to raise the issue of rationing scarce medical resources like ventilators during a pandemic. In 2011, the Ethics Subcommittee of the Advisory Committee to the Director of the CDC supplemented its 2007 document addressing ethical considerations in vaccine distribution prioritization.⁵ The focus of the supplemental document was to address “ethical issues for allocation of mechanical ventilators” during a severe influenza pandemic.⁶ The document aimed to provide decision-makers at the federal, state, territorial, tribal, and local levels “with an overview of the complex ethical landscape associated with decision making

1. Lucia Craxì, Marco Vergano, Julian Savulescu & Dominic Wilkinson, *Rationing in a Pandemic: Lessons from Italy*, 12 *ASIAN BIOETHICS REV.* 325, 325–26 (2020).

2. Alice Park & Jeffrey Kluger, *The Coronavirus Pandemic Is Forcing U.S. Doctors to Ration Care for All Patients*, *TIME* (Apr. 22, 2020, 8:00 AM), <https://time.com/5825145/coronavirus-rationing-health-care/> [<https://perma.cc/Q7TB-AMFB>].

3. Robert D. Truog, Christine Mitchell & George Q. Daley, *The Toughest Triage—Allocating Ventilators in a Pandemic*, 382 *NEW ENG. J. MED.* 1973, 1973–74 (2020).

4. See, e.g., Martha Debinger, *Thinking Through the Unthinkable: How Mass. Hospitals May Decide Who Gets a Ventilator in the COVID-19 Surge*, *WBUR* (Apr. 6, 2020), <https://www.wbur.org/news/2020/04/07/icu-ventilator-triage-massachusetts-covid-19-coronavirus> [<https://perma.cc/7ZXX-QJCP>] (discussing collaboration between the Massachusetts Department of Health, doctors, and hospitals to create resource rationing guidelines during the COVID crisis).

5. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM. OF THE ADVISORY COMM. TO THE DIR., CTRS. FOR DISEASE CONTROL & PREVENTION, *ETHICAL CONSIDERATIONS FOR DECISION MAKING REGARDING ALLOCATION OF MECHANICAL VENTILATORS DURING A SEVERE INFLUENZA PANDEMIC OR OTHER PUBLIC HEALTH EMERGENCY 3* (2011) [hereinafter *VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM.*].

6. *Id.* at 3.

about allocation of scarce life-sustaining healthcare resources.”⁷ It also acknowledged that ethical priorities in the practice of medicine may change during a pandemic from requiring “undivided loyalty to the health interests” of an individual patient to maximizing “the health of the public.”⁸ This change in framework for ethical decision-making was repeated in comments by medical ethicist Dr. Douglas White at the start of the pandemic: “[A] public health emergency triggers a change in the ethical principles that we use to make care decisions” by “shift[ing] focus from individual patients and trying to maximize their well-being, to looking at outcomes for an entire population.”⁹ The shift should only occur, however, “when there is a substantial extreme mismatch between patient need and available resources, that is, when the numbers of critically ill patients surpass the capability of traditional critical care capacity.”¹⁰

Though the presence of a public health emergency is generally understood to require some change in resource-allocation decisions from normal standards of care, there has been much discussion and debate over the right goals and criteria for scarce, life-saving-resource allocation.¹¹ Some state allocation protocols have come under scrutiny for singling out specific disabilities as a basis for denying care.¹² In April 2020, the Office for Civil

7. *Id.* The document was meant to serve “as a conceptual framework to assist the planning process,” not “as detailed guidance about allocation decisions.” *Id.*

8. *Id.* at 6.

9. Park & Kluger, *supra* note 2.

10. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 7.

11. See, e.g., Ezekiel J. Emanuel, Govind Persad, Ross Upshur, Beatriz Thome, Michael Parker, Aaron Glickman, Cathy Zhang, Connor Boyle, Maxwell Smith & James P. Phillips, *Fair Allocation of Scarce Medical Resources in the Time of Covid-19*, 382 NEW ENG. J. MED. 2049, 2051 (2020) (“The question is not whether to set priorities, but how to do so ethically and consistently, rather than basing decisions on individual institutions’ approaches or a clinician’s intuition in the heat of the moment.”).

12. See Press Release, 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), <https://www.hhs.gov/about/news/2020/06/26/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against-disability.html> [<https://perma.cc/U4FZ-3M3R>] (removing categorical exclusion criteria that disqualified people with “advanced neuromuscular disease, metastatic cancer, traumatic brain injury, dementia, and other disabilities” from receiving a ventilator); Press Release, U.S. Dep’t of Health & Hum. Servs., OCR Resolves Civil Rights Complaint Against Pennsylvania After It Revises Its Pandemic Health Care Triage Policies to Protect Against Disability Discrimination (Apr. 16, 2020), <https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html> [<https://perma.cc/L7R4-L4R6>] (removing criteria that “automatically deprioritized persons on the basis of particular disabilities” without requiring an individualized assessment based on objective medical evidence first); Douglas B. White & Bernard Lo, *A Framework for Rationing Ventilators and Critical Care Beds During the COVID-19 Pandemic*, 323 J. AM. MED. ASS’N 1773, E1 (2020) (criticizing as ethically flawed professional guidelines and state recommendations that exclude patients based on “certain comorbid conditions, such as class III or IV heart failure, severe chronic lung disease, end-stage renal disease, and severe cognitive impairment”).

Rights (OCR) at the U.S. Department of Health and Human Services (HHS) resolved a compliance review initiated by a complaint from the Alabama Disabilities Advocacy Program, which alleged that Alabama's Crisis Standards of Care "allowed for denying ventilator services to individuals based on the presence of intellectual disabilities, including 'profound mental retardation' and 'moderate to severe dementia.'"¹³ In its April press release, OCR revealed its concern that Alabama's protocols as written could have resulted in discrimination against disabled individuals and the elderly.¹⁴ Because Alabama promised to discontinue the use of "provisions singling out certain disabilities for unfavorable treatment [and] categorical age cutoffs," OCR closed its compliance review and complaint investigation "as satisfactorily resolved without a finding of liability."¹⁵

In December 2020, the Office for Civil Rights collaborated with the National Academy of Medicine (NAM) to advise on the development of a joint statement with nine other national organizations¹⁶ calling for best practices in the implementation of Crisis Standards of Care during the COVID-19 winter surge.¹⁷ The HHS-endorsed statement called for "governors, health departments, hospitals, and other health care sector partners" to take immediate action to "save lives and fairly allocate limited resources" with the goal of "do[ing] the most good possible for the largest number of people."¹⁸ The ethical implications of adopting this outwardly utilitarian goal of doing "the greatest good for the greatest number" are

13. Press Release, U.S. Dep't Health & Hum. Servs., OCR Reaches Early Case Resolution with Alabama After It Removes Discriminatory Ventilator Triaging Guidelines (Apr. 8, 2020), <https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html> [<https://perma.cc/4YLA-NZCJ>].

14. *Id.* (expressing concern that Alabama's standards could "result in discrimination against persons with disabilities by denying or stopping ventilator services simply because an individual has an intellectual disability" or that they might "be used to impose blunt age categorizations, such that older persons might automatically be deemed ineligible for life-saving care without any individualized assessment or examination").

15. *Id.*

16. The nine organizations that signed the joint statement with NAM are Johns Hopkins Center for Health Security; Association of American Medical Colleges; American Association of Colleges of Nursing; American Medical Association; American Nurses Association; National Council of State Boards of Nursing; National League for Nursing; National Medical Association; and American Academy of Developmental Medicine & Dentistry. *National Organizations Call for Action to Implement Crisis Standards of Care During COVID-19 Surge*, NAT'L ACAD. OF MED. (Dec. 18, 2020), <https://nam.edu/national-organizations-call-for-action-to-implement-crisis-standards-of-care-during-covid-19-surge/> [<https://perma.cc/N9AC-KP3C>].

17. Press Release, U.S. Dep't Health & Hum. Servs., OCR Provides Technical Assistance to Ensure Crisis Standards of Care Protect Against Age and Disability Discrimination (Jan. 14, 2021), <https://www.hhs.gov/about/news/2021/01/14/ocr-provides-technical-assistance-ensure-crisis-standards-of-care-protect-against-age-disability-discrimination.html> [<https://perma.cc/SE49-Y87Z>].

18. *National Organizations Call for Action to Implement Crisis Standards of Care During COVID-19 Surge*, *supra* note 16.

complex, and the limits outlined provide little help in narrowing down which considerations are appropriate and which are not. The statement recommends that hospitals and healthcare systems “[m]ake resource allocation decisions based on individualized assessments of each patient, using the best available objective medical evidence concerning likelihood of death prior to or imminently after hospital discharge, including clinical factors relevant and available to such determinations, which may include age under limited circumstances.”¹⁹ However, the guidance forbids using disability-based or age-based categorical exclusion criteria and incorporating judgments on long-term life expectancy and quality of life when making these individualized assessments.²⁰ It further specifies that these assessments “should NOT deprioritize persons on the basis of disability or age because they may consume more treatment resources or require auxiliary aids or supports.”²¹

In short, the threat of scarcities of lifesaving resources during the COVID-19 pandemic required states and hospitals to prepare, revise, and, in some cases, enact Crisis Standards of Care for allocating medical resources if supply failed to meet demand during the pandemic. These circumstances raised a difficult question and provided no national consensus on an answer: What framework and criteria should guide scarce-resource-allocation decisions?

Part I of this Note will attempt to decipher the meanings of the allocation principles hinted at in the limited guidance issued by the U.S. Department of Health and Human Services regarding allocation protocols. It will then identify alternative principles, or metrics, of distribution that are further explored in Part III. Part II will describe the issues and the debate surrounding the legality of proposed allocation criteria. It will also explain why antidiscrimination law sets only a minimum standard for societal behavior that is insufficient to devise an equitable plan for the allocation of scarce resources. The proper framework must weigh the similarly legitimate claims of different patients against each other to provide fair access to the good of positive health outcomes. Thus, it is a framework sounding in distributive justice, a necessarily relational approach requiring comparative judgments within and across patients’ health statuses. Part III identifies the space of distribution and the competing metrics for distribution within that space. Because neither utilitarianism nor need-based prioritarianism encompasses all the relevant moral considerations for justly allocating scarce resources, a hybrid principle is needed. Professor Talha Syed’s Principle of Proportionate Priority (PPP) is introduced to fill that need. Part IV further expands on PPP

19. *Id.* (emphasis omitted).

20. *Id.*

21. *Id.* (emphasis omitted).

and discusses the relevant considerations that crisis protocols must be prepared to address. Finally, Part V evaluates a model rationing policy in light of PPP and distills some general principles for allocation guidelines.

I. Decoding the Call to Do the “Greatest Good for the Greatest Number”

The maxim of doing “the greatest good for the greatest number” reflects the principle of maximizing net benefits, which can take several different forms. First, it can take the form of maximizing the number of lives saved and minimizing resource waste “by allocating to those most likely to survive to hospital discharge.”²² This approach rejects the triage principle of attending to the “sickest first”—under which patients in the worst condition are prioritized to receive resources—in favor of an approach that is less likely to “waste” resources on those who are too sick to survive even with those resources.²³ This version of the “greatest good” approach appears consistent with the NAM guidance, which allows for allocation decisions to consider “likelihood of death prior to or imminently after hospital discharge.”²⁴ It is the most commonly recommended approach for allocating scarce ventilators but is widely criticized for ignoring other ethically relevant considerations, like the number of life years saved.²⁵

Second, the “greatest good” principle can take the form of maximizing net benefits by considering differences in life conditions between patients.²⁶ Under this approach, allocation rules may seek to maximize years of life saved by giving preference based on age or based on differences in underlying health conditions. Assuming probability of near-term survival remains equal, this approach would endorse a twenty-year-old receiving preference over a sixty-year-old.²⁷ Likewise, it would endorse a sixty-year-old who is otherwise healthy receiving preference over a sixty-year-old with an underlying health problem that limits her life expectancy.²⁸ Guidelines for lung transplant allocation, which incorporate patients’ expected duration of survival after transplantation, provide a precedent for the use of this

22. Wendy F. Hensel & Leslie E. Wolf, *Playing God: The Legality of Plans Denying Scarce Resources to People with Disabilities in Public Health Emergencies*, 63 FLA. L. REV. 719, 726 (2011).

23. *Id.*

24. *National Organizations Call for Action to Implement Crisis Standards of Care During COVID-19 Surge*, *supra* note 16.

25. White & Lo, *supra* note 12, at E1 (“The moral intuition of many people would support prioritizing a patient who stands to otherwise lose 40 years of life, compared with one with a chronic illness that will in all likelihood result in death within a few years.”).

26. Hensel & Wolf, *supra* note 22, at 724–26.

27. *Id.* at 726.

28. *Id.* See also VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 13 (considering years of life saved in addition to the number of lives saved).

criterion.²⁹ Under an even purer utilitarian approach, allocation rules may seek to maximize quality of life years saved, expressing a preference for life years without disease or disability.³⁰ The NAM guidance is arguably ambiguous regarding whether quality of life judgments may *never* be used as a criterion to deprioritize an individual for care or whether they may simply not be used as a categorical exclusion criterion.³¹ But additional HHS guidance appears to foreclose any consideration of quality of life judgments.³² In addition, many bioethicists and scholars reject the use of quality-adjusted life years (QALYs) because of their “potential to create invidious distinctions between people based on arbitrary judgments regarding quality of life.”³³

Maximizing net benefits, though an important public health consideration under circumstances where disease poses a threat to overall population health, is not the only ethical principle to consider when allocating scarce resources during a pandemic. Another principle worthy of consideration is the “life-cycle” principle. Under the life-cycle principle, each individual deserves an “equal opportunity to live through the various phases of life.”³⁴ Thus, younger individuals are given relative priority over older individuals because they are worse off by reason of having had the least opportunity to live through life’s stages, including childhood, young adulthood, middle age, and old age.³⁵ Proponents defend the life-cycle principle as inherently egalitarian because it “applies the notion of equality to individuals’ *whole lifetime experiences*” and because “everyone faces the prospect of aging.”³⁶ The principle is limited in usefulness, however, to situations where competing patients exhibit “significant age differences

29. White & Lo, *supra* note 12, at E1.

30. Hensel & Wolf, *supra* note 22, at 726–27.

31. *See supra* note 21 and accompanying text.

32. *See* U.S. DEP’T HEALTH & HUM. SERVS., OFFICE FOR CIV. RIGHTS, BULLETIN: CIVIL RIGHTS, HIPAA, AND THE CORONAVIRUS DISEASE 2019 (COVID-19) 1 (2020) [hereinafter HHS OCR BULLETIN], <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf> [<https://perma.cc/268M-QZRP>] (“[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.”); Office for Civil Rights, *Interim Guidance on Critical Care Resources Allocation for Direct-Service IHS Hospitals*, U.S. DEP’T HEALTH & HUM. SERVS. (Jan. 6, 2021), <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/ihs-interim-guidance/index.html> [<https://perma.cc/46LK-ZHG8>] (“[A]ssessments of quality of life (both pre- and post-treatment) [and] judgments about a person’s relative ‘worth’ . . . should not be used as criteria in making resource-allocation decisions.”).

33. *E.g.*, VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 13; *see also* Emanuel, *supra* note 11, at 2052 (“Limited time and information during an emergency also counsel against incorporating patients’ future quality of life, and quality-adjusted life-years, into benefit maximization.”).

34. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 15.

35. *Id.*

36. *Id.*

rather than small differences of a few years.”³⁷ So, the life-cycle principle will not be of much help in resolving allocation decisions between a thirty-five-year-old patient and a forty-year-old patient.

Some scholars reject the goal of maximizing population health in favor of a “fair chances” principle, on the grounds that it is unfair to ask individuals with a smaller—but still significant—chance of survival to give up all chance of survival for the “greater good.”³⁸ Those who advocate for the fair chances principle may endorse rules based on a first-come, first-served basis, random selection (by lottery or coin-flip, for instance), or weighted lottery (wherein those with a higher probability of survival have a greater chance of being chosen, but those with a lower probability of survival are not completely out of the running).³⁹ These methods are criticized for inefficient stewarding of scarce resources (when those who receive them are unlikely to survive)⁴⁰ and for the “practical limitations [of] applying a complex, weighted lottery in an emergency setting.”⁴¹

Many state Crisis Standards of Care have indeed focused on the goal of saving the most lives possible⁴²—a sensible goal on its face, considering the purpose of public health efforts to maximize the health of the population.⁴³ But a small number of states, like Oregon, have recognized that protocols aimed at “saving the most lives or life-years systematically disadvantage[] . . . communities of color, tribal communities and people with disabilities” because they fail to consider historical and current health inequities.⁴⁴ The Oregon Health Authority recommends against including underlying conditions or disability, life expectancy, resource utilization, quality of life, or baseline need for ventilation in a scoring rubric or similar triage framework for allocating scarce healthcare resources.⁴⁵ Considering such health inequities raises the question: What is the proper—or at least legal and ethical—goal for resource-allocation frameworks?

II. Antidiscrimination and Allocating Scarce Medical Resources

This section will frame the scholarly discussion of antidiscrimination law as it relates to the allocation of scarce medical resources in times of crisis.

37. *Id.*

38. *Id.* at 15–16.

39. Hensel & Wolf, *supra* note 22, at 727.

40. *Id.*

41. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM, *supra* note 5, at 16.

42. Deborah Hellman & Kate M. Nicholson, *Rationing and Disability: The Civil Rights and Wrongs of State Triage Protocols*, 78 WASH. & LEE L. REV. 1207, 1210 (2021).

43. Hensel & Wolf, *supra* note 22, at 724.

44. OR. HEALTH AUTH., PRINCIPLES IN PROMOTING HEALTH EQUITY DURING RESOURCE CONSTRAINED EVENTS 3 (2020), <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le3513.pdf> [<https://perma.cc/Z69A-664W>].

45. *Id.* at 5–6.

The Americans with Disabilities Act (ADA) protects “qualified individuals” with a disability from discrimination in employment, public services, public accommodations, and services operated by private entities and in the areas of transportation and telecommunications.⁴⁶ The stated purpose of the ADA is “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”⁴⁷

A. *Surveying the Legal Landscape and Scholarly Debate*

Through the ADA, Congress sought to ban not only obvious forms of discrimination based on open prejudice⁴⁸ but also facially neutral policies and practices that have the effect of discriminating based on disability.⁴⁹ It sought to achieve this purpose through the enactment of the following provisions: Title II prohibits state and local governments from discriminating against a “qualified individual” based on their disability by excluding them from participation in or denying them the benefits of the “services, programs, or activities of a public entity.”⁵⁰ According to language in the preamble to the regulations implementing Title II, “services, programs, and activities” of a public entity should be construed broadly to include “anything [that] a public entity does.”⁵¹ Title III prohibits private entities operating any “place of public accommodation” from discriminating “on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of [that] place of public accommodation.”⁵² Title III classifies the professional offices of private healthcare providers and private hospitals as “public accommodations,” thus bringing them within the statute’s reach.⁵³ To the extent it affects employee compensation in the form of employer-sponsored health insurance, Title I’s prohibition on discrimination in employment *is* relevant to an analysis of discrimination in

46. 42 U.S.C. §§ 12101–12213; 47 U.S.C. § 255.

47. 42 U.S.C. § 12101(b)(1).

48. 42 U.S.C. § 12101(a)(5); *see also* Mary R. Anderlik & Wendy J. Wilkinson, *The Americans with Disabilities Act and Managed Care*, 37 HOUS. L. REV. 1163, 1182 (2000) (explaining that the statute and regulations make clear that the ADA’s mandate reaches discrimination in the form of “the effects of neglect and indifference”).

49. *See, e.g.*, 28 C.F.R. § 35.130(b)(3)(i) (2020) (prohibiting public entities from using criteria or methods of administration “[t]hat have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability”); *see also* Alexander v. Choate, 469 U.S. 287, 299 (1985) (assuming without deciding that “§ 504 [of the Rehabilitation Act of 1974] reaches at least some conduct that has an unjustifiable disparate impact upon the handicapped”). The legislative history of Title II of the ADA adopts *Choate* as the standard. Hensel & Wolf, *supra* note 22, at 744 n.155.

50. 42 U.S.C. § 12132.

51. 28 C.F.R. § 35, app. B (2016).

52. 42 U.S.C. § 12182.

53. 42 U.S.C. § 12181(7).

the healthcare context⁵⁴—but that is not a focus of this Note. And Title IV, which contains miscellaneous provisions,⁵⁵ is simply not relevant to the healthcare discussion at all.⁵⁶

By prohibiting discrimination in state and local governments and in the private sector, the ADA both incorporated and expanded the antidiscrimination provision of Section 504 of the Rehabilitation Act of 1973.⁵⁷ Section 504 prohibits disability-based discrimination by executive agencies, programs, and activities receiving federal financial assistance.⁵⁸ The Rehabilitation Act remains in effect today, but when it comes to policies like the Crisis Standards of Care implemented by states and municipalities during the COVID-19 pandemic, it is Title II that is likely to control.⁵⁹ Under Title II, a state or locality’s policies may not discriminate against a “qualified individual with a disability.”⁶⁰ The statute defines this term as “an individual with a disability who, with or without reasonable modifications to rules, policies, or practices . . . or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.”⁶¹ Much of the discussion surrounding the ADA’s applicability to medical decision-making stems from the interpretation of this phrase—“qualified individual”—which can be likened to “another variation of the reasonableness test.”⁶²

Title II regulations specify a public entity must make “reasonable modifications” when necessary to avoid discrimination on the basis of disability, unless doing so “would fundamentally alter the nature of the service, program, or activity” being offered.⁶³ What constitutes a reasonable

54. Sara Rosenbaum, *The Americans with Disabilities Act in a Health Care Context*, in *THE FUTURE OF DISABILITY IN AMERICA* 426, 429 (Marilyn J. Field & Alan M. Jette eds., 2007), <https://www.ncbi.nlm.nih.gov/books/NBK11429/> [<https://perma.cc/DX4Y-LSVK>]; 42 U.S.C. § 12112(a).

55. 42 U.S.C. §§ 12201–12213.

56. Rosenbaum, *supra* note 54, at 429.

57. *Id.* at 429–30.

58. 29 U.S.C. § 794.

59. NANCY LEE JONES, CONG. RSCH. SERV., RL33381, *THE AMERICANS WITH DISABILITIES ACT (ADA): ALLOCATION OF SCARCE MEDICAL RESOURCES DURING A PANDEMIC* 15 (2008), <https://www.everycrsreport.com/reports/RL33381.html#ifn47> [<https://perma.cc/35Z7-LWZR>].

60. 42 U.S.C. § 12132.

61. *Id.* § 12131(2).

62. *See* Anderlik & Wilkinson, *supra* note 48, at 1194 (“[D]ifferential treatment of a person with a disability is not discrimination if the nature of the disability is such that no reasonable modification would reconcile the abilities, or needs, of the person with . . . the capacities of the program or good or service, as applicable.”). *But cf.* Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, 130 *YALE L.J.F.* 1, 7 (2020) (arguing that precedent “recognize[s] that states could not permissibly evade the bar on disability discrimination simply by turning the absence of a disability into a qualification for a job or benefit”).

63. 28 C.F.R. § 35.130(b)(7)(i) (2020).

modification is highly fact specific and beyond the scope of this Note, but the Supreme Court has held that the cost of providing the service, in light of the resources available, is one relevant factor to consider.⁶⁴ The regulations specify that, in addition to setting a nondiscrimination standard, Title II requires that public entities provide qualified individuals with “an opportunity to participate in or benefit from” their programs and services that is equal to that afforded others;⁶⁵ it also forbids public entities from denying, on the basis of disability, the “equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others” and from “apply[ing] eligibility criteria that screen out or tend to screen out an individual with a disability . . . from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.”⁶⁶ Thus, Title II requires *equal opportunity*—it does not require equal results.⁶⁷ In many situations, modifications that are needed to create equal opportunity will be viewed as reasonable while modifications needed to create equal results may not be.⁶⁸

Although the ADA does not explicitly provide for its application in circumstances of emergency or disaster, its broad provisions and stated goal of “assur[ing] equality of opportunity, full participation, independent living, and economic self-sufficiency for [disabled] individuals”⁶⁹ imply that its protections do apply in emergency situations. This assumption is supported by statements from the agencies responsible for enforcing the ADA and other similar civil rights statutes.⁷⁰ Recently, the HHS Office for Civil Rights

64. See *Olmstead v. L.C.*, 527 U.S. 581, 597 (1999) (“In evaluating a State’s fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities . . .”); Cary LaCheen, *Using Title II of the Americans with Disabilities Act on Behalf of Clients in TANF Programs*, 8 GEO. J. ON POVERTY L. & POL’Y 1, 132–33 (2001) (pointing out that “cost should not be the only consideration in reasonable modification determinations”).

65. 28 C.F.R. § 35.130(b)(1)(ii) (2020).

66. 28 C.F.R. §§ 35.130(b)(1)(iii), (b)(8) (2020).

67. U.S. DEP’T OF JUST., THE AMERICANS WITH DISABILITIES ACT TITLE II TECHNICAL ASSISTANCE MANUAL § II-3.3000, <https://www.ada.gov/taman2.html> [<https://perma.cc/MBK3-JT5D>]. See also *Alexander v. Choate*, 469 U.S. 287, 304 (1985) (“The [Rehabilitation] Act does not, however, guarantee the handicapped equal results from the provision of state Medicaid . . .”).

68. LaCheen, *supra* note 64, at 129.

69. 42 U.S.C. § 12101(a)(7).

70. For example, in a 2008 guide relating to local government emergency preparedness released by the Department of Justice, the Department observed the “important role[] of local government [in] protect[ing] their citizenry from harm, including helping people prepare for and respond to emergencies. Making local government emergency preparedness and response programs accessible to people with disabilities is a critical part of this responsibility . . . [and] is also required by the Americans with Disabilities Act . . .” U.S. DEP’T OF JUST., AN ADA GUIDE FOR LOCAL GOVERNMENTS: MAKING COMMUNITY EMERGENCY PREPAREDNESS AND RESPONSE PROGRAMS

released a statement emphasizing that Section 1557 of the Affordable Care Act⁷¹ and Section 504 of the Rehabilitation Act, “like other civil rights statutes OCR enforces, remain in effect” during the COVID-19 pandemic.⁷²

To summarize, the ADA and Section 504 of the Rehabilitation Act, “reflect[] the government’s commitment to equality of opportunity for people with disabilities in even the most demanding of circumstances.”⁷³ Though it is clear that antidiscrimination protections continue to apply in times of emergency, “there is little precedent applying disability law to the allocation of scarce, lifesaving treatments.”⁷⁴ And despite the outwardly broad language of the ADA, precedent indicates that healthcare providers may not be found to have illegally discriminated when their medical treatment decisions are grounded in objective factual predictions.⁷⁵ An early case arising from the passage of Section 504 of the Rehabilitation Act found that the statute’s “otherwise qualified” language, later incorporated into Title II of the ADA, “is geared toward relatively static programs or activities such as education . . . and transportation systems,” and therefore “cannot be applied in the comparatively fluid context of medical treatment decisions.”⁷⁶ On the other hand, as some scholars have pointed out, the ADA provides no “safe harbor” provision for medical decision-making like it does for insurance.⁷⁷ How courts will review discrimination in the context of medical treatment decisions is a related, but ultimately separate, inquiry to how courts will apply federal antidiscrimination laws to challenged protocols prospectively allocating scarce medical resources during a pandemic.⁷⁸

It seems obvious that a state policy that categorically excludes individuals with specific disabilities from accessing medical resources, even

ACCESSIBLE TO PEOPLE WITH DISABILITIES (2008), <https://www.ada.gov/emergencyprepguide.htm> [<https://perma.cc/U9X3-P3DX>].

71. Section 1557, incorporating by reference the discrimination prohibition in Section 504 of the Rehabilitation Act, prohibits disability-based discrimination by health programs that receive financial assistance or are operated under a federal program or activity. Patient Protection and Affordable Care Act, Pub. L. No. 111–148, § 1557(a), 124 Stat. 119, 260 (2010) (codified at 42 U.S.C. § 18116(a)).

72. HHS OCR BULLETIN, *supra* note 32, at 1.

73. Hensel & Wolf, *supra* note 22, at 741.

74. Govind Persad, *Disability Law and the Case for Evidence-Based Triage in a Pandemic*, 130 YALE L.J.F. 26, 31 (2020); *see also* JONES, *supra* note 59, at 12 (“There has been no situation directly analogous to one that might be posed by allocation issues regarding medical resources during an influenza pandemic . . .”).

75. Persad, *supra* note 74, at 34.

76. *United States v. Univ. Hosp., State Univ. of N.Y.*, 729 F.2d 144, 156 (2d Cir. 1984).

77. *Anderlik & Wilkinson*, *supra* note 48, at 1190, 1194.

78. *Compare* *Burger v. Bloomberg*, 418 F.3d 882, 883 (8th Cir. 2005) (“[A] lawsuit under the Rehab Act or the Americans with Disabilities Act (ADA) cannot be based on medical treatment decisions . . .”), *with* *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 624 (1986) (“[A] hospital rule or state policy denying or limiting [meaningful] access [to medical services] would be subject to challenge under § 504.”).

in times of scarcity and crisis, would violate the ADA's prohibition on discrimination based on disability.⁷⁹ Such policies, whether based on animus, a belief of inferiority, or another illegitimate or irrational belief, preclude all access as a matter of course and therefore violate the ADA's requirement to provide the same opportunity to benefit from services that is afforded to non-disabled individuals. The more difficult question is whether a state's policy prioritizing treatment in a more general way—to those for whom treatment will be most medically effective, for example—will be actionable under the ADA.⁸⁰ Many scholars defend the use of certain rationing criteria in allocating scarce treatments so long as they are based on objective medical evidence in the context of individualized assessments.⁸¹

Professor Samuel R. Bagenstos, however, argues that “[disability] law, best understood, rules out a protocol that puts disabled people at the back of the line because they have pre-existing medical conditions that do not make them unable to benefit from the treatment they seek.”⁸² In arguing that the law does not allow a pre-existing disability to render an individual “unqualified” to receive treatment for a new condition (except in the narrow circumstance where treatment will be futile), Bagenstos seems to suggest that there are no legitimate reasons to treat disabled people differently in the medical context.⁸³ In other words, any disparate impact on disabled individuals must be covertly driven by nefarious intentions or uninformed decision-makers. But Bagenstos also stresses that the ADA's purpose is “to bar the use of disability, *standing alone*, as a (dis)qualification for the receipt of needed benefits,”⁸⁴ implying that his real concern is with policies that discriminate outright by excluding individuals *because of* their disabilities. He acknowledges that resource-allocation decisions rest on a series of value judgments about what we should seek to maximize, yet inexplicably denies that those value judgments play any role in understanding disability law's role in the process.⁸⁵

Some scholars argue that policies which allocate care based on quality of life, level of resource commitment, life expectancy, or probability of survival violate antidiscrimination laws because of the disparate impact these

79. Hensel & Wolf, *supra* note 22, at 744; Bagenstos, *supra* note 62, at 4 (demonstrating that policies “that expressly use disability as a factor in denying life-saving treatment discriminate *because of* a disability”) (emphasis added).

80. Hensel & Wolf, *supra* note 22, at 758.

81. Persad, *supra* note 74, at 29–31.

82. Bagenstos, *supra* note 62, at 4.

83. *Id.* at 7–8.

84. *Id.* at 10 (emphasis added).

85. *Id.* at 9–10 (“Philosophers could debate how we should answer these questions. . . . Wherever we might come down on the philosophical debate, the disability discrimination statutes resolve them for purposes of the law. . .”).

rationing factors have on individuals with disabilities.⁸⁶ In their article, Professor Deborah Hellman of the University of Virginia School of Law and civil rights attorney Kate M. Nicholson address the problems posed by facially neutral policies that have a disproportionate negative impact on the disabled community.⁸⁷ Delving into the history of the social treatment and types of disability discrimination that informed the ADA, the authors craft the argument that the language of the ADA, its 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.”⁸⁸ But there is a problem with the disparate impact analysis undertaken by these authors with respect to allocation protocols. As further explained below, disparate impact captures only those cases where there is no legitimate reason for the distinction except to treat the disabled group worse. That some adequate justifications exist to treat disabled individuals differently betrays the authors’ argument that any rationing factors having a disproportionate negative impact on the disabled community violate antidiscrimination laws. What constitutes an adequate justification is not explored in depth. The authors include a cursory mention of the Supreme Court’s language in *Alexander v. Choate*,⁸⁹ holding that disabled individuals cannot be denied “meaningful access” to health benefits.⁹⁰ But the meaningful access standard articulated by the Court is unclear, especially in the context of scarce resources.⁹¹ Will access be meaningful if any access is provided? Or will access be meaningful only if it is theoretically available on the same basis as afforded to able-bodied individuals? Or does some other standard apply? And what constitutes an adequate justification to deny meaningful access?

The authors conclude that quality of life judgments constitute disparate impact, because these judgments rely on inaccurate stereotypes,⁹² and that life expectancy should not be considered unless a person is very close to death, because of the negative effect on those whose “disability suggests that they are likely to have shorter-than-average lives.”⁹³ They also deem the level

86. Hellman & Nicholson, *supra* note 42, at 1229.

87. *See id.* at 1233 (questioning whether “the significant negative effects on the ability of people with disabilities to access life-saving treatment [are] likely to outweigh the purported benefit of” the above-mentioned rationing factors).

88. *Id.* at 29.

89. 469 U.S. 287 (1985).

90. Hellman & Nicholson, *supra* note 42, at 1238. By contrast, another scholar believes that “*Choate’s* reasoning suggests that neutral durational limits on resources in times of crisis may be upheld in some circumstances *even if they disproportionately affect people with disabilities.*” Hensel & Wolf, *supra* note 22, at 750 (emphasis added).

91. Hensel & Wolf, *supra* note 22, at 750–51.

92. Hellman & Nicholson, *supra* note 42, at 1256.

93. *Id.* at 1260.

of resource commitment and probability of survival problematic because of the “significant negative impact on the ability of people with disabilities to access life-saving care.”⁹⁴ The authors’ concern, still voiced in terms of disparate impact, is that these “principles force us to grapple with the difficult question of where precisely the ADA draws the line between acceptable and unacceptable disparate impact.”⁹⁵ Unfortunately, this is a confused way to think about it. The ADA prohibits disparate impact that results from an intent to treat a certain group as inferior or unequal, but it permits certain groups to be treated differently when there is a legitimate reason for doing so. Unable to break out of this overly broad disparate impact view, the authors conclude that the ADA requires balancing both inclusion and efficiency (i.e., saving the most lives), with greater weight placed on the interest of inclusion.⁹⁶ The result is a proposal to reserve some percentage of “resources for people with disabilities, while allowing the remainder to be allocated in line with the principle of saving the most lives possible.”⁹⁷ If interpreted as requiring a “quota” for individuals with disabilities, such a policy could run into problems under constitutional law, which bars the use of quotas at least in the racial context.⁹⁸

In a paper published last June, Professor Govind Persad of the University of Denver Sturm College of Law argued that policies that allocate scarce medical resources based on probability of survival and quantity of resource usage, with the goals of saving more lives or more years of life, are compatible with disability law as long as they are based on medical evidence and not inaccurate stereotypes.⁹⁹ Of the surveyed works, Persad’s is the only one that crosses the threshold from disparate impact under the discrimination view into the realm of distributive equity. In defense of his theory—what he calls “evidence-based triage”—Persad points to guidance from HHS released March 28, 2020:

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. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a

94. *Id.* at 1285–86.

95. *Id.* at 1261–62.

96. *Id.* at 1239–40.

97. *Id.* at 1276.

98. *Id.* at 1279–80.

99. Persad, *supra* note 74, at 26–29, 35 (“[T]he cases finding that providers have illegally discriminated involve groundless judgments or invidious stereotypes, not factually grounded prediction.”).

person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.¹⁰⁰

So long as policy goals "can be pursued without reliance on unfair classifications," the argument goes, they can "continue to incorporate assessments of patients' prospect of benefit with the aim of saving more lives and years of life."¹⁰¹ Persad draws analogies to legal precedent recognizing probability of survival as a legitimate factor in organ allocation¹⁰² to support his contention that disability law permits triage guidelines that deny treatment to individuals with disabilities in situations where treatment would not be futile but where there are large differences in the probability of benefit.¹⁰³ He also points to the Supreme Court's *Choate*¹⁰⁴ and *Olmstead*¹⁰⁵ decisions as proof that considering the quantity of resource usage is consistent with disability law when the quantity of resources a patient is likely to require risks depriving other patients of needed resources.¹⁰⁶ These examples, along with the distinction he draws between "groundless judgments or invidious stereotypes" and "factually grounded prediction" of consequences (in the context of effectiveness of treatment),¹⁰⁷ indicate that Persad recognizes legitimate reasons for treating differently situated people differently. Persad acknowledges that rationing policies must be evaluated under a distributive equity framework: "A triage policy that is worse for individuals with specific

100. HHS OCR BULLETIN, *supra* note 32, at 1; *see* Persad, *supra* note 74, at 29 (quoting the March 28, 2020 HHS guidance).

101. Persad, *supra* note 74, at 30–31.

102. *Id.* at 31–32 (citing *Barnett v. Kaiser Found. Health Plan, Inc.*, 32 F.3d 413, 417 (9th Cir. 1994)). The *Barnett* court concluded that, in the context of a liver shortage, "[p]oor survival rate is an acceptable medical criterion" and that "doctors are justifiably concerned with allocation to patients with increased chances of survival." *Barnett v. Kaiser. Found. Health Plan, Inc.*, 32 F.3d at 417.

103. Persad, *supra* note 74, at 31–34.

104. *Alexander v. Choate*, 469 U.S. 287, 302–03 (1985) (rejecting the argument that a fourteen-day annual limit on Medicaid-covered hospitalization for all patients violated Section 504 due to its disparate impact on disabled individuals with greater healthcare needs because Section 504's guarantee of "meaningful access" does not "guarantee that each recipient will receive that level of health care precisely tailored to his or her particular needs").

105. *Olmstead v. L.C.*, 527 U.S. 581, 604 (1999) (plurality opinion) (finding that, "in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities").

106. *See* Persad, *supra* note 74, at 36 (relying on these precedents for the propositions that disability law "permits the provision of an equal quantum of resources to all patients, even if this produces unequal outcomes for patients with specific disabilities" and that "limited resources can justify refusing to maximally accommodate people with specific disabilities when doing so would deprive others . . . whom the state is also bound to protect").

107. *Id.* at 35.

disabilities cannot be dismissed as unjust discrimination on that basis, but must be analyzed against a broader backdrop of normative analysis that considers the claims of different individuals and social groups.”¹⁰⁸

B. *The Insufficiency of Antidiscrimination Law*

To what extent do or don’t the limits of the ADA help us resolve the problem of distributing scarce lifesaving resources in an ethical way? This subpart will explain why antidiscrimination law is a necessary but insufficient guiding principle for designing fair healthcare protocols for the allocation of scarce medical resources in times of crisis.

There are three levels of analysis for understanding resource-allocation arguments: discrimination (i.e., disparate treatment), disparate impact, and substantive distributive justice. Discrimination encompasses treating an individual or a category of individuals differently based on animus or an irrational or illegitimate belief.¹⁰⁹ In the context of disability, this means treating disabled people in a worse way because of some preconceived notion that they are bad, unworthy, or incapable or because of unfounded stereotypes or generalizations about them *because of* their disability. Disparate impact, on the other hand, does not facially tie access to an individual’s status as a member of a particular group.¹¹⁰ Instead, these facially neutral measures both negatively affect a particular group *and* serve no legitimate purpose other than treating that group in a worse way. Finally, substantive distributive justice may counsel measures that negatively affect a certain group but only when a legitimate justification exists for doing so.¹¹¹ Thus, factors like quality of life, duration of need, duration of benefit, and medical effectiveness are not discriminatory when there are legitimate reasons for using them.

What many sides of the debate surveyed above seem to miss is this third level of analysis, substantive distributive justice. Antidiscrimination law in general is designed to prevent society and its machinery from treating individuals, or some category of individuals, differently based on an improper purpose or reason.¹¹² An improper purpose or reason is best grouped into one of three forms: The first form is animosity or hatred of a

108. *Id.* at 46.

109. *Disparate Treatment*, MERRIAM-WEBSTER.COM, <https://www.merriam-webster.com/legal/disparate%20treatment> [<https://perma.cc/XW68-2K2A>].

110. *Disparate Impact*, MERRIAM-WEBSTER.COM, <https://www.merriam-webster.com/legal/disparate%20impact> [<https://perma.cc/FSA4-3CD3>].

111. See Talha Syed, *Educational Accommodation and Distributive Equity: The Principle of Proportionate Progress*, 50 CONN. L. REV. 485, 489–90 (2018) (remarking that a socially just distribution of resources does not involve “decreas[ing] inequality for its own sake”).

112. See *id.* at 507 (noting that the Rehabilitation Act and Americans with Disabilities Act are “widely understood to extend to disability the reach of traditional civil-rights concerns with combating invidious discrimination”).

particular group, often because of their race, sex, or religion. The second form is an irrational or unfounded belief about people or the group they belong to, such as the unfounded belief that deaf persons are incapable of pursuing an education. And the third form is an illegitimate belief, like the belief that childhood disability is the result of a curse from God. Treating someone differently based on an improper purpose does not show equal concern and respect for them as a fellow being, which is an evil that antidiscrimination law seeks to remedy. But outside of these improper reasons, can we really say there are *no* acceptable reasons for treating people differently? This is a key distinction between an antidiscrimination framework and a distributive equity framework.

Antidiscrimination law is not a sufficient framework through which to tackle problems of resource allocation because eliminating facial discrimination and discriminatory disparate impact won't resolve the question of who gets life-saving resources.¹¹³ Because of antidiscrimination law's focus on equal opportunity—rather than equal outcomes—laws like the ADA pursue only *procedural* fairness by eliminating illegitimate barriers to access.¹¹⁴ Moreover, standards like meaningful access and reasonable modification are both textually vague and substantively unclear in the context of allocating scarce medical resources; neither sheds any light on the underlying goal we should try to achieve in these circumstances.¹¹⁵

In the healthcare-equity context, there are legitimate reasons to treat people differently because different people have different health needs.¹¹⁶ Where a policy is not facially discriminatory but leads to different outcomes for disabled individuals, there are two distinct inquiries. First, we must ask: “Is the only probable reason behind this policy to treat this class of people as inferior based on animus or an irrational or illegitimate belief?” If so, the treatment is based on an improper purpose, constituting impermissible and discriminatory disparate impact; this kind of treatment should be remedied under antidiscrimination law. A clear example of discriminatory disparate impact can be seen in the poll taxes used to prevent black Americans from voting—an area where equality in the form of one person, one vote is not only desirable but also achievable.

113. See Talha Syed, Rethinking Educational Equity: Opportunity to Compete or Develop? 6 n.16 (unpublished manuscript) (on file with author) (discussing how antidiscrimination law is not well-suited to deal with allocation of scarce educational resources).

114. Syed, *supra* note 111, at 507.

115. Cf. *id.* at 505, 509 (pointing to the lack of a clear guiding aim as one source of difficulty for deciphering the meaning of adequate benefits in the educational context).

116. See Betsy Q. Cliff, Michael Rozier & A. Mark Fendrick, *Health Insurance Benefits Should Be Equitable, Not Necessarily Equal*, HEALTH AFFAIRS BLOG (May 22, 2017) (promoting the view that differentiating based on the likelihood of clinical benefit is sensible because people have different health needs and respond differently to medical treatment), <https://www.healthaffairs.org/doi/10.1377/hblog20170522.060211/full/> [<https://perma.cc/N57B-525F>].

If the answer to the first question is “no,” however, the inquiry continues. Next, we must ask: “If the policy results in individuals with disabilities being worse off than others in society, even if this effect is the result of entirely legitimate considerations and therefore not ‘discriminatory,’ is that nevertheless impermissible?”¹¹⁷ The second inquiry shifts our concern from the fairness of the process to the fairness of the result—a distributive justice concern. Distributive equity assumes that, as different people require different levels of care, some differentiation between groups is both good and necessary.¹¹⁸ In the healthcare and disability context, our aim should be to “secure effective access to a substantive good of fundamental importance”—the good of positive health outcomes.¹¹⁹ And achieving this goal requires acknowledging that some individuals with disabilities are “differentially situated in respect of that aim” because they face a “conversion deficit[] in translating a given bundle of means (healthcare) into valuable ends (positive health outcomes).”¹²⁰

To illustrate a colorable consideration in substantive fairness decisions, imagine that doctors must choose between saving an eighty-year-old who has lived a full life and an eighteen-year-old whose life in many ways has just begun. Many people plausibly feel that doctors should focus their efforts on saving the younger person.¹²¹ Many people also plausibly feel that we should steward resources in such a way as to make their use most effective. “[R]educed capacities arising from disability”—like those arising from advanced age—“may indicate a reduced probability of benefitting from intensive care treatment, because of a reduced probability of survival and life expectancy.”¹²² Thus, there exist important cases where considering an individual’s disability is neither disparate treatment nor discriminatory disparate impact but rather a legitimate consideration in making distributive justice decisions, where the aim should be to strike a fair balance between the competing interests of the individual and the rest of society.¹²³ For example, how do we allocate resources between an individual with cystic fibrosis who

117. See Syed, *supra* note 111, at 508 (suggesting that a commitment to discriminatory disparate impact analysis may require conceding that uneven effects are only impermissible “when they likely reflect some illegitimate consideration” and “thus become permissible when a legitimate or ‘rational’ basis for them can be adduced”).

118. Cliff, *supra* note 116.

119. Syed, *supra* note 111, at 556–57.

120. *Id.*

121. For example, in Italy during the beginning of the COVID-19 outbreak, protocols denied patients over the age of eighty access to intensive care as hospitals reached capacity. Erica Di Blasi, *Italians over 80 “Will Be Left to Die” as Country Overwhelmed by Coronavirus*, THE TELEGRAPH (Mar. 14, 2020, 4:38 PM), <https://www.telegraph.co.uk/news/2020/03/14/italians-80-will-left-die-country-overwhelmed-coronavirus/> [<https://perma.cc/99HC-PX5N>].

122. Julian Savulescu, James Cameron & Dominic Wilkinson, *Equality or Utility? Ethics and Law of Rationing Ventilators*, 125 BRIT. J. ANAESTHESIA 10, 12 (2020).

123. *Id.* at 11.

has a 5% chance of survival after treatment and another individual with a 90% chance of survival, all else being equal? Or between a person with terminal cancer who is likely to live only 6 months after treatment and another individual who is likely to live 40 years or more? What distinctions are fair to draw between people and what trade-offs are we ethically permitted to make? In situations where multiple legitimate claims are competing for the same resource, the ADA and other formal equality provisions stop short of even attempting to answer these questions.¹²⁴

III. Distributive Equity: The Framework for Allocating Scarce Medical Resources

How should we, as a society, weigh the similarly legitimate, competing claims of all individuals for limited critical care resources in times of crisis? This is not a question with an easy—or even correct—answer. In attempting to respond to it, we must decide whether disability is a legitimate consideration at all. If it is, in what context is it relevant? These are the questions we must address before we can design allocation protocols that appropriately prioritize the claims to scarce resources of patients with disabilities against the similarly legitimate claims of other patients.

A. *The Space of Distribution*

Crisis conditions demand that we set limits on access to treatment, denying some individuals the resources they might have otherwise received under normal circumstances. Doctors and ethicists agree that developing a triage plan for how to prioritize patients ethically and consistently is crucial to “maintain[ing] the function of the healthcare system and prevent[ing] random or otherwise inequitable distribution of scarce resources.”¹²⁵ So to what good or “space” should we strive to provide access?¹²⁶ And how should we measure an egalitarian distribution of that good?¹²⁷ First, we must identify the space of equity that we should be concerned with—that is, what it is that

124. The inadequacy of applying the ADA to issues of distributive equity is reflected in the *Choate* decision, where the Court rejected the argument that the ADA’s predecessor, Section 504 of the Rehabilitation Act, reached “all action disparately affecting the handicapped” and instead held only that it reached “some conduct that has an unjustifiable disparate impact” on the disabled. *Alexander v. Choate*, 469 U.S. 287, 298–99 (1985).

125. Ryan C. Maves, James Downar, Jeffrey R. Dichter, John L. Hick, Asha Devereaux, James A. Geiling, Niranjana Kissoon, Nathaniel Hupert, Alexander S. Niven, Mary A. King, Lewis L. Rubinson, Dan Hanfling, James G. Hodge, Jr., Mary Faith Marshall, Katherine Fischkoff, Laura E. Evans, Mark R. Tonelli, Randy S. Wax, Gilbert Seda, John S. Parrish, Robert D. Truog, Charles L. Sprung & Michael D. Christian, *Triage of Scarce Critical Care Resources in COVID-19: An Implementation Guide for Regional Allocation*, 158 CHEST 212, 216 (2020).

126. Syed, *supra* note 111, at 541.

127. William W. Fisher & Talha Syed, *Global Justice in Healthcare: Developing Drugs for the Developing World*, 40 U.C. DAVIS L. REV. 581, 633 n.115 (2007).

we are trying to distribute when critical care resources are limited. Only then can we begin to address fair ways to measure distribution of that space.

The philosophical debates about disadvantages from disability and distributive justice center around three main candidates for the space of distribution: welfare (or utility), resources, and capabilities.¹²⁸ Proponents of all three camps agree that fairness requires that individuals be held reasonably responsible for their developed talents, expensive tastes, and management of their affairs, but not for “unchosen or ‘involuntary’ sources of advantage or disadvantage.”¹²⁹

The first possible space for consideration is welfare or utility, for which “the only sensible ultimate aim is to enable people to realize happiness according to their own” subjective preferences.¹³⁰ The utilitarian space is not concerned about the amount of resource *per se* but rather how much pleasure or advantage each individual person derives from the resource. A common measure of distribution in the utilitarian space is maximization, discussed in the healthcare context as “maximizing net benefit.”¹³¹ This measure advises prioritizing those who gain the most benefit from a good or that action which does the greatest good for the greatest number.

A second space for consideration is “resources”—that is, some “general, all-purpose means valuable for the pursuit of any of a wide array of diverse life plans.”¹³² But a focus on resources—even on primary goods like rights, liberties, income, and wealth—pulls too far in the opposite direction of utility’s aim to provide access to end-states of happiness. The resources space treats objects in the world as if they are intrinsically valuable to people, ignoring the relationship between the individual and the good. Especially in the case of scarce medical resources, we should be concerned with how patients derive or fail to derive advantage from those resources.

Between the overly subjective welfare/utility space and the overly fetishist resources space falls a third space for consideration—basic capabilities. This space is promising because it “shift[s] attention from goods to what goods do to human beings.”¹³³ The capabilities framework centers around the idea that the freedom of each person to choose and to act, thereby

128. Syed, *supra* note 111, at 543.

129. *Id.* at 543–44.

130. *Id.* at 544.

131. For a discussion about maximizing net benefit, see *supra* Part I.

132. Syed, *supra* note 111, at 545; see also Ronald Dworkin, *What Is Equality? Part 2: Equality of Resources*, 10 PHIL. & PUB. AFF. 283, 307 (1981) (“[T]he point of equality of resources is . . . that people should have the same external resources at their command to make of them what, given these various features and talents, they can.”).

133. Amartya Sen, *Equality of What?*, Address at The Tanner Lecture on Human Values 218–19 (May 22, 1979).

achieving states of valuable “functioning,” is of great moral importance.¹³⁴ This freedom is a combination of a person’s internal abilities and their political, social, and economic environment, including external sets of resources.¹³⁵ The capabilities approach focuses on each individual person as an end, rather than measuring capabilities at the group level (whether that be family, ethnic group, or society as a whole)¹³⁶ because “the conversion of goods to capabilities varies from person to person substantially.”¹³⁷ Even though two people are given the same good, they may nevertheless differ in their capability levels resulting from the use of that good.¹³⁸ When involuntary differential needs from disability hamper an individual’s access to health capabilities, it is cause for distributive concern.¹³⁹

If we find the capabilities space attractive for the distribution problem posed by scarce healthcare treatments—which I admittedly do—there remains “the problem of indexing the basic capability bundles.”¹⁴⁰ The internal capability of “health” is a good starting point; people ought to be capable, to the fullest extent possible considering their existing levels of health, of achieving good health. Under a democratic view, health care is intrinsically good for an individual because it gives the recipient the capability of health—and life. But when resources are scarce, we must value one individual’s health capability against the social opportunity costs for others trying to access their own good health outcomes. When making these social trade-offs, however, it would be unfair to trade across areas of cognitive health and physical health.¹⁴¹ These areas of potential disadvantage

134. See Syed, *supra* note 111, at 546 (“The right locus of concern, on [the capabilities] view, lies midway between external means and subjective end-states: states of valuable ‘functioning’—of ‘being’ (e.g., well-fed) and ‘doing’ (e.g., reading, mobility)—that are tailored to individual persons and yet externally measurable and not reducible to their subjective satisfaction or enjoyment.”); see also MARTHA C. NUSSBAUM, CREATING CAPABILITIES: THE HUMAN DEVELOPMENT APPROACH 20 (2011) (offering Sen’s standard definition of a capability as “the alternative combinations of functionings that are feasible for [a person] to achieve”).

135. NUSSBAUM, *supra* note 134, at 20.

136. *Id.* at 35.

137. Sen, *supra* note 133, at 219.

138. This reflects the conversion difference between disabled patients and non-disabled patients that commonly occurs in the healthcare context. The conversion deficit is accounted for in the rationing factor called “Level of Resource Commitment” and can be thought of as a contributing factor to severity of condition. Though the Department of Health and Human Services has issued guidance that this factor cannot be used to *automatically* give someone lower priority for receiving a scarce life-saving treatment, it hasn’t been entirely prohibited. For an explanation of “Level of Resource Commitment,” see Hellman & Nicholson, *supra* note 42, at 1222–24.

139. Syed, *supra* note 111, at 547–48.

140. Sen, *supra* note 133, at 219.

141. For example, it would be unfair to weigh one person’s cognitive disability against their receiving treatment for a physical ailment simply because a competing candidate for treatment lacked a cognitive disability. Thus, before making allocation decisions, it will be necessary to narrow the relevant but broad category of “health” into reasonable subdomains.

belong to different capability subdomains, having “independent qualitative value that is not sensibly compared or traded off against the other[.]”¹⁴² While decisions must still be made about how to allocate resources within each subdomain, there should be no trade-offs between the different subdomains of people’s lives.¹⁴³

In the allocation context, focusing on the space of capabilities over utility or welfare avoids the problems of subjective preferences. For example, it makes irrelevant the fact that a rich person may derive more pleasure or satisfaction from an additional five years of life than a poorer person might. It also renders irrelevant the fact that lengthening the life of a non-disabled individual by ten years may provide more “utility” than lengthening the life of an individual with a cognitive disability by the same number of years. Concentrating on the subdomain of physical health capabilities also helps identify what types of benefits and needs to consider when making trade-offs of tangible medical resources. A continuing lower quality of life due to cognitive disability cannot discount a patient’s potential benefit from a physical health treatment. But a pre-existing physical condition could fairly discount a patient’s potential benefit from treatment if such discounting is based on an assessment that another patient would receive greater physical improvement from treatment and would consequently have a higher quality of life. On the other side of the equation, we can say that a patient’s worse physical condition may give her a claim to higher priority for treatment because of her greater need. But we cannot say that a patient’s cognitive disability gives him priority for physical health treatments because his disability is in a totally separate subdomain of capabilities.

B. Competing Metrics for Distribution

What should be the measure of an equitable distribution of access to the capability of health? And more specific to the context of scarce resources, what types of individual differences or other grounds justify deviations from an equal distribution? As discussed in Part II, disability and antidiscrimination laws are insufficient for determining equitable distribution, so substantive distribution principles are necessary to resolve these questions.

If what we mean by equitable is ensuring equal opportunity to receive health care, we are concerned with purely procedural justice or ensuring a fair process.¹⁴⁴ In the context of non-granular, or indivisible, goods, “benefitting people equally entails providing equal chances at the scarce

142. Syed, *supra* note 111, at 551.

143. For an example of splitting capabilities into subdomains to prevent improper trade-offs in the educational development context, see *id.* at 551–52.

144. See *supra* note 114 and accompanying text.

intervention.”¹⁴⁵ From a procedural-justice perspective, the fact “[t]hat a patient’s odds [of survival] are lower . . . in no way reflects that patient’s virtue, merit, worth, or any other similarly relevant basis for treating people differently.”¹⁴⁶ Thus, treating people equally demands only equality of opportunity and ignores other seemingly relevant factors; even probability of benefit would not be a morally relevant basis for treating similarly situated patients differently from one another.

Equality of opportunity can be achieved in the scarce-resource context through the principles of lottery or first come, first served. The lottery principle supports “[r]andom decisions between someone who can gain 40 years and someone who can gain only 4 months, or someone who has already lived for 80 years and someone who has lived only 20 years.”¹⁴⁷ Lotteries provide the procedural advantages of assigning equal value and respect to each person’s desire to live, requiring little information about recipients, and being easy to administer and resistant to corruption.¹⁴⁸ While surveys of physicians, citizens, and economists show that many people have “strong moral intuitions toward egalitarian allocation” principles, they nevertheless reveal a moral tension between the desire to “maximize usefulness and to rescue those in need.”¹⁴⁹ Ignoring differences in intuitively important factors such as patient need and probability of benefit dodges the substantive distribution problem in favor of pure procedural justice.

The second principle that supports equal opportunity is first come, first served. Defenders of this principle tout it as “a natural lottery” and see as a feature—not a bug—the fact that it “allows physicians to avoid discontinuing interventions, such as respirators, even when other criteria support moving those interventions to new arrivals.”¹⁵⁰ First come, first served is more problematic than random lottery. Both ignore relevant differences between people, but first come, first served also fails to treat people equally in practice because it favors the wealthy, those who are more informed, those who can travel quickly, and those who are well-connected or powerful.¹⁵¹ Thus, first come, first served is a flawed principle for achieving even procedural justice.

If what we mean by equitable is instead finding a fair distribution of resources, we are concerned with substantive distributive equity. The main

145. Govind Persad, Alan Wertheimer & Ezekiel J. Emanuel, *Principles for Allocation of Scarce Medical Interventions*, 373 THE LANCET 423, 423 (2009).

146. Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491, 515 (1995).

147. Persad, *supra* note 145, at 423.

148. *Id.*

149. Leslie P. Scheunemann & Douglas B. White, *The Ethics and Reality of Rationing in Medicine*, 140 CHEST 1625, 1628–29 (2011).

150. Persad, *supra* note 145, at 424.

151. *Id.*

criteria for consideration are telic equality, utilitarianism, and pure need-based priority. Telic equality—based on the principle that “[i]t is in itself bad if some people are worse off than others”—treats equality as inherently, instead of instrumentally, good.¹⁵² Equalizing health outcomes across patient populations would require equalizing the distribution of scarce, non-granular resources that cannot be split up evenly among people. Thus, an equal distribution would require leveling down to zero because the only way to treat everyone the same would be to give everyone nothing. Telic equality is thus not a desirable criterion in the scarce-medical-resource context; it is better to save some lives than none.

The utilitarian criterion seeks to maximize total benefits by prioritizing those who are most likely to benefit in certain ways. A strictly utilitarian approach counsels consideration of the probability of benefit, life expectancy, and quality of life.¹⁵³ But as previously discussed, maximizing benefits can be understood in different ways in the context of scarce medical resources.¹⁵⁴ Saving the most lives is a commonly lauded principle in medical-resource allocation because it recognizes the value in each individual life and avoids comparisons between different life conditions (e.g., quality of life). Most people agree that probability of survival is relevant to determining whether treatment should be provided and that, all else equal, it is better to save five lives than one. But because patient conditions are rarely equal, “saving the most individual lives” ignores other morally relevant principles: some lives have been shorter than others and some lives could be extended longer than others.¹⁵⁵ Alternatively, the utilitarian criterion of maximizing benefits could be achieved through the principle of saving the most life years. The life years principle gives priority to patients likely to survive the longest after treatment.¹⁵⁶ It is a persuasive argument that, all else equal, an intervention should go to Patient A, who will receive twenty additional life years, over Patient B, who will receive only ten additional life years. But the life years principle also advocates that an intervention should go to Patient A over Patient C, who will receive nineteen life years after treatment, even if Patient C has a slightly higher probability of survival. Furthermore, the life years principle fails to consider how “[m]aking a well-off person slightly better off rather than slightly improving a worse-off person’s life would be unjust.”¹⁵⁷

152. Derek Parfit, *Equality and Priority*, 10 *RATIO* 204, 206 (1997).

153. Savulescu, *supra* note 122, at 11.

154. For a discussion of the principles of saving the most lives and life years in the context of maximizing net benefits, see *supra* notes 22–33 and accompanying text.

155. Persad, *supra* note 145, at 425.

156. Emanuel, *supra* note 11, at 2051.

157. Persad, *supra* note 145, at 425.

The third substantive distribution criterion, need-based prioritarianism, attempts to help those who are considered “worse off” by giving them priority when life-saving treatments are scarce. There are at least two ways of understanding pure, need-based priority: (1) giving absolute priority to the worst off (maximin) and (2) giving priority to the worst off until their needs have been catered to, and then giving priority to the next-worst-off (leximin).¹⁵⁸ In the context of health, fairness requires that those who are worse off through no fault of their own be given special concern because improvements in health have greater moral significance the lower a patient’s starting health levels are compared to others.¹⁵⁹ According to at least one scholar’s theory, it is reasonable to ask healthier people to accept that less healthy people get priority for scarce resources or treatment, as long as the priority given is a matter of degree based on how much worse off a patient is relative to others.¹⁶⁰ The criterion of need-based priority is reflected in the allocation principles of “sickest first” and “youngest first.” Sickest first, though a commonly used triage principle under normal conditions, is not an ideal principle for Crisis Standards of Care allocation. Though it considers a patient’s prognosis if left untreated to determine how much worse off they are, it ignores post-treatment prognosis.¹⁶¹ Because many treatments are less effective for the sickest people, applying the sickest-first principle may achieve only minor improvements at high costs to others¹⁶²—a weakness of maximin. Sickest first receives further criticism for “myopically bas[ing] allocation on how sick someone is at the current time,” ignoring a currently healthier person with a progressive illness who could benefit from treatment and will be worse off later when they succumb to their illness.¹⁶³

By contrast, the principle of “youngest first” prioritizes “those who would otherwise die having had the fewest life-years”—a different idea of who is the worst off.¹⁶⁴ Prioritizing the young does not rely on valuations of their intrinsic worth or social usefulness but on giving all individuals an equal chance to live a normal life span.¹⁶⁵ Giving absolute priority to the youngest first can be criticized for ignoring differences in prognosis between patients and for ignoring future life expectancy. It can also be criticized for showing extreme preference for infants, if one adopts the view that the “death of a

158. See generally JOHN RAWLS, A THEORY OF JUSTICE (Rev. ed. 1999) (discussing the “difference principle” (maximin) and “lexical difference principle” (leximin)).

159. See Syed, *supra* note 113, at 9–11 (discussing the comparative priority view).

160. See *id.* at 9 (advocating for the same framework of distribution in the context of educational resources).

161. Persad, *supra* note 145, at 424.

162. *Id.*

163. *Id.* at 425.

164. *Id.*

165. *Id.* For a discussion of the life-cycle principle, see *supra* notes 34–37 and accompanying text.

[twenty]-year-old young woman is intuitively worse than that of a [two]-month-old girl” because the young woman has a more developed personality and “has drawn upon the investment of others to begin as-yet-unfulfilled projects.”¹⁶⁶

The utilitarian and need-based priority criteria have strengths and weaknesses, but neither fully incorporates all relevant moral considerations for allocating scarce resources. A relatively new criterion, Professor Talha Syed’s Principle of Proportionate Priority (PPP), combines in a principled and structured way the utilitarian value placed on benefit derived with the prioritarian value placed on greater need. Under PPP, patients with health issues are to receive priority if (and only if) they are worse off than others and to the extent that they are worse off than others.¹⁶⁷ This principle recognizes that different starting levels of health matter because they indicate greater need. Those in greater need are given greater priority because fairness requires improving conditions for the suffering, but such priority is given to the extent of their comparative potential for improvement or benefit.¹⁶⁸

A major draw of PPP is that it recognizes that maximizing net benefits for health outcomes across the population is not inherently valuable. If it were, maximization would require having more and more people receive incrementally smaller health improvements—because of the sheer number of people with imperfect health, health improvements in the aggregate would increase.¹⁶⁹ Instead, PPP recognizes—all else being equal—two utilitarian principles as true: First, that it is better to help two people achieve a benefit instead of just one person.¹⁷⁰ Second, that marginal improvements are relevant considerations in interpersonal fairness.¹⁷¹ All else equal, the patient who receives even one extra year of life should receive treatment before others. But PPP also recognizes prioritarian principles regarding fairness with respect to overall levels: That, all else being equal, fairness demands priority to the worst off.¹⁷² PPP is a course-correct for both the utilitarian criterion’s oversight of the morally relevant factor of need and the absolute priority criterion’s danger of allowing a bottomless pit. It is therefore the best available criterion under which to allocate scarce resources.

166. Persad, *supra* note 145, at 425.

167. See Syed, *supra* note 111, at 527–28 (discussing the concept of comparative priority in an educational context and explaining that “students with disability are given priority *because* they are worse off . . . *to the extent that* they are worse off.”).

168. *Id.* at 526–28.

169. Video: Talha Syed, *Rights Versus Distributive Approaches to Allocating Healthcare*, TULSA L. REV. SYMP. (2013), <https://digitalcommons.law.utulsa.edu/symposia/elhauge/2013/elhauge/3/> [<https://perma.cc/4R2S-M2WW>].

170. *Id.*

171. *Id.*

172. *Id.*

IV. Applying the Principle of Proportionate Priority

The Principle of Proportionate Priority is not a detailed proposal for allocating scarce medical resources. Rather, it provides guidance for developing resource-allocation policies like the state Crisis Standards of Care. Applying PPP in the context of scarce medical resources requires states to choose which factors are appropriate and fair to consider when identifying whether a patient has a greater need or how much a patient stands to improve or benefit from a treatment. I propose that states should consider age or “life years lived,” severity of condition, probability of survival, and life expectancy after treatment. In the following analysis, we should assume that each patient has the same social usefulness and that no patient bears responsibility or desert for their condition. We should also remember that by narrowing the space of distribution to physical health capabilities, we have eliminated potential for some of the more problematic trade-offs.¹⁷³

Identifying greater need in the space of physical health capabilities means looking at a patient’s health not only in the present but also over the course of his lifetime. Thus, a sick person who has suffered from an unrelated but debilitating condition their entire life has a claim to greater need for resources than a sick person who has enjoyed overall greater health because distributive justice understands disadvantage as a matter of lifetime deprivation.¹⁷⁴ Suppose a hospital must choose to allocate resources to either a twenty-year-old patient, who is now only moderately ill but whose condition will worsen severely without treatment, or to a seventy-five-year-old patient who is already severely ill. Severity of illness indicates greater need when it renders a patient’s starting point much lower than others because preventing suffering and the ill consequences of bad health has greater moral importance the more one is already suffering. But despite the severity of their current condition, the seventy-five-year-old “is more advantaged from a lifetime perspective.”¹⁷⁵ While the seventy-five-year-old has some claim of greater need for their higher risk of death in the present, the twenty-year-old also has a claim of greater need for their higher risk of not living a full life.

Sometimes considerations that give rise to a claim for greater need will align with considerations that give rise to a claim for greater benefit. For example, “[b]ecause younger age is typically a proxy for better prognosis, the use of age-based criteria usually both achieves better outcomes and assists

173. In other words, we won’t count someone’s *cognitive* disability against them in terms of the benefit they stand to receive from a *physical* health treatment. Nor will a cognitive disability give them a claim to greater need for physical health treatments. See *supra* subpart III(A).

174. See Govind Persad, *Evaluating the Legality of Age-Based Criteria in Health Care: From Nondiscrimination and Discretion to Distributive Justice*, 60 B.C. L. REV. 889, 927 (2019) (“[T]he lifetime justice approach understands disadvantage as a matter of lifetime deprivation.”).

175. *Id.*

the least advantaged.”¹⁷⁶ So to the extent that treating a younger person is likely to be more effective based on increased probability of survival, the younger person has a claim of both greater need and greater benefit. Similarly, a patient with a more severe condition may have a claim to higher potential benefit from treatment. In theory, the potential for benefit is greater where the risk of death is greater.

In many situations, however, a patient with a very severe condition may have a probability of survival so low that it lowers or altogether cancels out their claim for greater benefit. This reduction in benefit due to low probability of short-term survival may outweigh the patient’s increase in need from the severity of the illness. Such patients may still receive a significant benefit from less restricted resources and palliative care. Thus, it may be more appropriate for a patient with a more severe condition but low probability of survival to be given priority for resources that would alleviate their symptoms rather than resources that would (likely fail to) save their life.

Often, considerations that give rise to a claim for greater need may pull against considerations that give rise to a claim for greater benefit. Compare a sixty-year-old patient with an 85% probability of surviving their acute illness with treatment to a thirty-year-old patient with a 50% probability of survival. The sixty-year-old’s higher probability of survival gives her a claim to greater benefit because she stands a better chance of improving from treatment than the other patient. PPP recognizes that “benefits to the worse off could be morally outweighed by sufficiently great benefits to the better off [and] [i]f we ask what would be sufficient, there may not always be a precise answer.”¹⁷⁷

Because marginal improvements are relevant considerations in interpersonal fairness, merely looking at probability of survival (or lives saved) is not enough. In addition to probability of survival, “greater benefit” should encompass number of additional life years saved. Whether a patient’s life expectancy is limited because of advanced age, social inequalities, or an underlying disability, the reduction in life years saved is a relevant consideration that decreases their potential benefit from treatment. All else equal, there is greater benefit in giving one person an additional fifty years of life versus giving another person an additional five years of life. But PPP recognizes that often all else is not equal and provides a way to neutralize the troubling effects of disability and wealth inequality on life expectancy. A patient with a lower life expectancy has no claim to greater benefit, but a patient with a lower life expectancy due to no fault of their own (e.g., disability or social inequality) has a claim to greater need. The two cancel

176. *Id.*

177. Parfit, *supra* note 152, at 213.

each other out in such instances so that long-term life expectancy is not held against already disadvantaged groups.

Following the Principle of Proportionate Priority, fairness requires that Crisis Standards of Care balance the prioritization of patients with the greatest need—understood in terms of life years lived and lifetime levels of health—with those who are most likely to benefit from treatment—understood in terms of probability of survival and future life years saved. The next section will evaluate a model hospital policy for allocating scarce medical resources under PPP.

V. Evaluating a Model Hospital Allocation Policy Under PPP

In March 2020, Dr. Douglas White published a model hospital policy for allocating scarce critical care resources.¹⁷⁸ The model is based on “a decade-long research and community engagement effort” involving ethicists, disaster medicine experts, and diverse community members’ and patients’ groups.¹⁷⁹ The allocation framework is based on the aims of saving lives and saving life years while “ensuring meaningful access for all patients, ensuring individualized patient assessments, and diminishing the negative effect of social inequalities that lessen some patients’ long-term life expectancy.”¹⁸⁰ The framework is also designed to ensure that stereotypes, quality of life assessments, and judgments about a person’s “worth” play no role in allocation decisions.¹⁸¹ Soon after the model policy was made public, health authorities in several states, including Pennsylvania, Massachusetts, New Jersey, Colorado, and Oklahoma, asked their hospitals to utilize these guidelines for building their own Crisis Standards of Care protocols.¹⁸²

The model policy describes allocation criteria for the initial allocation of critical care resources as well as reassessment criteria to determine whether the continued provision of those resources is justified for individual patients.¹⁸³ It utilizes a score-based approach under which all patients are assigned a priority score on a scale of 1 to 8, with lower scores indicating higher predicted benefit from critical care. These scores are derived from a combination of “(1) patients’ likelihood of surviving to hospital discharge, assessed with an objective and validated measure of acute physiology (e.g.,

178. *Model Hospital Policy for Allocating Scarce Critical Care Resources*, UNIV. OF PITTSBURGH DEP’T OF CRITICAL CARE MED., <https://ccm.pitt.edu/node/1107> [<https://perma.cc/N8FR-JUQ2>].

179. *Id.*

180. DOUGLAS B. WHITE, ALLOCATION OF SCARCE CRITICAL CARE RESOURCES DURING A PUBLIC HEALTH EMERGENCY 1 (Apr. 15, 2020), https://ccm.pitt.edu/sites/default/files/UnivPittsburgh_ModelHospitalResourcePolicy_2020_04_15.pdf [<https://perma.cc/K6HE-WBNR>].

181. *Id.* at 2.

182. Park & Kluger, *supra* note 2.

183. WHITE, *supra* note 180, at 1.

the SOFA score);¹⁸⁴ and 2) the presence of underlying medical conditions that severely limit prognosis for near-term survival even if the patient survived the acute-critical illness.”¹⁸⁵ While all patients remain eligible to receive critical care resources,¹⁸⁶ those with the lowest priority score (and thus the highest likelihood of benefit) receive priority.

In line with the CDC Ethics Subcommittee’s conclusion that allocation protocols that only consider chances of survival to hospital discharge are insufficient,¹⁸⁷ White’s model framework “attempts to increase overall benefit by giving some priority to patients who” have a greater expected duration of near-term survival even after surviving the acute-critical illness.¹⁸⁸ According to White, the framework does not use long-term life expectancy in calculating priority scores because of the disadvantages this factor may impose on individuals with decreased long-term life expectancy from either disabilities or social inequalities.¹⁸⁹ In White’s priority–point system, a lower SOFA score—reflecting lower risk of death during hospitalization—results in fewer points awarded, and a prognosis of death within one or five years from discharge results in additional points awarded.¹⁹⁰

The problem with White’s measure of potential benefit is that it treats a patient who is expected to live five years past the acute illness the same as a patient who is expected to live fifty more years. It is logically problematic to suggest that short-term life expectancy is a morally relevant consideration, but long-term life expectancy is not. PPP recognizes the utilitarian value placed on marginal benefits in the form of additional years of life saved. Though White is correct in worrying about this factor’s effect on marginalized populations, his intuitive and ad hoc solution of excluding long-

184. Note that the use of objective measures like the Sequential Organ Failure Assessment score as mortality prediction tools during the COVID-19 pandemic has received criticism. Professors of Medicine at the Johns Hopkins School of Medicine caution that, even if the SOFA score reliably predicts outcomes, it may not be a fair tool for allocating critical resources because it “was not designed to consider or account for the complexity of historical socioeconomic marginalisation [sic] and injustice experienced by various racial, ethnic, and other marginalized groups.” See Panagis Galiatsatos, Allen Kachalia, Harolyn M.E. Belcher, Mark T. Hughes, Jeffery Kahn, Cynda H. Rushton, Jose I. Suarez, Lee Daugherty Biddison & Sherita H. Golden, *Health Equity and Distributive Justice Considerations in Critical Care Resource Allocation*, 8 LANCET 758, 758–60 (2020) (observing the limitations of SOFA scores).

185. WHITE, *supra* note 180, at 1.

186. *Id.* at 2 (describing how the model policy differs from other allocation frameworks because “it does not categorically exclude any patients who, in ordinary clinical circumstances, would be eligible for critical care resources”).

187. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 14.

188. WHITE, *supra* note 180, at 2.

189. *Id.* at 2–3; see also Galiatsatos, *supra* note 184, at 760 (“[M]any communities in the USA do not have similar lived experiences and exhibit health disparities resulting from structural racism and injustice.”).

190. WHITE, *supra* note 180, at 6 tbl.1.

term life expectancy is overbroad. PPP solves this problem because the decrease in benefit from lower long-term life expectancy is canceled out when the reason for lower long-term life expectancy comes—through no fault of the individual—from disability or wealth inequalities.¹⁹¹ When the reason for lower long-term life expectancy arises from the fact that a patient has already lived a longer life than others, however, the decrease in benefit should not be canceled out by a claim for greater need based on life years lived.

As a second step, White's model suggests grouping patients together either according to their raw scores on the 1–8 scale or by priority categories.¹⁹² All groups remain eligible to receive critical care resources, so the availability of resources on a given day determines how many patients or groups of patients will receive them.¹⁹³ The model policy leaves open the option of grouping patients by raw score or by creating priority categories: high priority for patients with raw scores 1–3, medium priority for patients with raw scores 4–5, and low priority for patients with raw scores 6–8.¹⁹⁴ Grouping based on raw priority score avoids arbitrary cut-offs, whereas using priority categories decreases the effect of marginal differences in scores, potentially alleviating some of the concerns about SOFA score accuracy and fairness.¹⁹⁵

First, assuming a theoretical world where SOFA scores are completely accurate, it's not clear why one would group based on priority categories under White's model and ignore the morally relevant marginal differences in patients' potential benefits. The second problem with White's model policy is that it fails to account for levels of need in calculating priority scores. It calculates a priority score based solely on probability of benefit and uses need only as an afterthought. Instead of accounting for need in calculating priority, White uses need-based factors as tiebreakers. When there are not enough resources to cover all patients within a given score group or priority category, White's model recommends resolving ties according to the life-cycle principle,¹⁹⁶ going so far as to recommend specific age prioritizations.¹⁹⁷ According to the model, priority should be given first to those age twelve to forty; then age forty-one to sixty; then age sixty-one to seventy-five; and

191. *See supra* Part IV.

192. WHITE, *supra* note 180, at 8.

193. *Id.*

194. *Id.* at 8–9 & tbl.2.

195. *Id.* at 8. For a criticism of the use of SOFA scores in rationing decisions, see *supra* note 184.

196. For a discussion of the life-cycle principle, see *supra* notes 34–37 and accompanying text.

197. WHITE, *supra* note 180, at 9.

finally to those older than age seventy-five.¹⁹⁸ Further ties should be broken, according to the model, based on instrumental value.¹⁹⁹

To illustrate the life-cycle tiebreaker method, under the approach that groups patients according to raw priority score, a twenty-five-year-old patient with a priority score of 2 would receive priority over a sixty-five-year-old patient with the same priority score of 2, but would not receive priority over a sixty-five-year-old patient with a better priority score of 1. Now compare how priority would be determined under PPP: the sixty-five-year-old with the priority score of 1 has a claim to resources based on greater benefit. But his claim must be weighed against the twenty-five-year-old's claim to resources based on the greater need posed by the risk of an early death. It may be the case that these factors cancel each other out and we must look elsewhere for evidence of additional need (based on overall levels of lifetime health or severity of condition) or turn to auxiliary principles (e.g., ability to save more lives through instrumental value).²⁰⁰ In cases where competing levels of need and benefit are too close to call, it may be appropriate to break a tie by lottery or another method of random allocation.²⁰¹

Finally, I offer some general principles that any model allocation policy should employ. One aspect of Dr. White's model policy is vital to any allocation policy; banning categorical exclusion criteria is ethically sound and avoids violating the procedural promise of equality of opportunity afforded by antidiscrimination laws. Public health operates under an ethical framework that requires not only that allocation decisions be necessary and effective to address the problem but also that they do so using the least restrictive measures available.²⁰² Categorically excluding certain patients from access to critical care is unnecessary when it would be "equally feasible to assign all patients a priority score" and let the availability of resources dictate who receives treatment.²⁰³ Furthermore, categorical exclusion criteria may send the message that certain groups are "not worth saving," which may be perceived as discrimination.²⁰⁴ Labeling groups as not worth saving based on a subjective assessment or stereotypes about life with a disability is unfair and antithetical to the goals of traditional medical ethics.²⁰⁵ Of course, the distributive justice framework for distributing equitable access to positive

198. *Id.*

199. *Id.* ("We also recommend that individuals who are vital to the acute care response be given priority, which could be operationalized in the form of a tiebreaker."). For a discussion of the auxiliary principle of instrumental value, see *infra* notes 208–212 and accompanying text.

200. For an argument that using instrumental value as an auxiliary principle in the context of COVID-19 is improper, see *infra* notes 211–212 and accompanying text.

201. WHITE, *supra* note 180, at 9.

202. Hensel & Wolf, *supra* note 22, at 724–25.

203. WHITE, *supra* note 180, at 7.

204. White & Lo, *supra* note 12, at E1.

205. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 13.

health outcomes permits—and often requires—trade-offs between individuals.²⁰⁶ But categorical exclusions may improperly trade across independent capability subdomains by, for example, denying ventilator access to individuals with intellectual disabilities.²⁰⁷ Decisions about how to allocate resources within a given capability subdomain, e.g., physical health, can be made effectively without resorting to categorical exclusions.

In terms of substantive distributive justice, first, it is imperative that any calculation of a priority score includes both probability of benefit and level of existing need. This systematically combines the utilitarian value placed on benefit derived with the prioritarian value placed on greater need, so that both are always factored into every case. This may pose real-world administrability problems in the form of distilling levels of need based on age, lifetime levels of health, or severity of illness into measurable units on the same scale as the tools used to measure probability of survival and life expectancy. That problem is beyond the scope of this Note, which is meant only to suggest guiding principles for resource allocation. Second, any calculation of potential benefit must include long-term life expectancy. How long an intervention can prolong an individual's life is one—though not the only—morally relevant and fair consideration for making trade-offs between people.

Finally, the auxiliary principle of recognizing the instrumental value of doctors, nurses, and other hospital staff may be appropriate for limited use in some public health emergencies, but it should not be used in allocation policies for ventilators in a pandemic. Supporters of the utilitarian criterion who aim to save the most lives argue that “prioritizing certain key individuals will achieve a ‘multiplier effect’ [because many more] lives are ultimately saved through their work.”²⁰⁸ Indeed, it takes ten years to become a critical care physician²⁰⁹—a profession undoubtedly important to achieving the aim of maximizing population health in a pandemic. However, our goal in a pandemic should not be to save the most lives but to enable each individual's life to go “as well as is possible and fair.”²¹⁰ Furthermore, the multiplier effect justification may be rendered a nullity. Patients with severe respiratory failure who require mechanical ventilation are likely to experience physical weakness and cognitive dysfunction for weeks or even months after leaving

206. See Hensel & Wolf, *supra* note 22, at 765 (acknowledging that inequitable treatment requires justification and voicing concern that categorical exclusions violate that principle of justice because such criteria “do not alleviate existing inequities, but rather disadvantage an already disadvantaged group”).

207. For a discussion of capability subdomains, see *supra* notes 141–143.

208. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 12, 14.

209. Park & Kluger, *supra* note 2.

210. See Syed, *supra* note 111, at 489 (discussing the ultimate aim of distributive justice generally) (emphasis omitted).

the hospital.²¹¹ Thus, those healthcare workers sick enough to need ventilators are unlikely to “recover in time to re-enter the work force and achieve their instrumental purposes during the pandemic wave.”²¹²

Conclusion

As states continue to revise their Crisis Standards of Care, they should replace the goal of doing “the greatest good for the greatest number” with the goals of ensuring fair access to positive health outcomes and enabling each patient’s life to go as well as is possible and fair. Doing so requires making comparisons and trade-offs between people—a task which should be done under the guidance of a structured, systematic principle that balances the relevant considerations of individual need and medical effectiveness. Antidiscrimination laws do not offer this type of structured principle because they are tools for guaranteeing procedural fairness, equipped only to eliminate illegitimate barriers to access. Only a distributive justice framework can guide fair allocation decisions where an individual’s unchosen differential needs—whether caused by disability or other factors—put them at a disadvantage compared to other competing claims for similar resources. Under this framework, a comparative priority approach appropriately affords priority as a matter of degree based on how much worse off a patient is relative to others and how much they stand to benefit from treatment. In practical terms, this means a patient’s claim for priority is strongest when they have both the greatest need, because of their young age or poor lifetime levels of health, and the greatest potential for benefit, because of their chance of survival or the effectiveness of treatment. The comparative approach is preferable to a strictly utilitarian principle that ignores the plight of the worst off or a strictly need-based prioritarian principle that disregards the importance of efficiently stewarding resources, particularly in times of scarcity. Policies that adopt this distributive equity approach will show equal concern for all individuals by recognizing that all individuals are worthy of having their needs satisfied.

211. Thomas Bice, *Life After a Ventilator*, UNC HEALTH TALK (May 11, 2020), <https://healthtalk.unchealthcare.org/life-after-a-ventilator/> [https://perma.cc/F4PH-PTHJ].

212. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM., *supra* note 5, at 15.