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Playing God: The Legality of Plans Denying Scarce Resources to People with Disabilities in Public Health Emergencies

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PLAYING GOD: THE LEGALITY OF PLANS DENYING SCARCE
RESOURCES TO PEOPLE WITH DISABILITIES IN PUBLIC
HEALTH EMERGENCIES

Wendy F. Hensel* & Leslie E. Wolf**

Abstract

Public health emergencies can arise in a number of different ways. They can follow a natural disaster, such as Hurricane Katrina, the 2004 tsunami, and the recent earthquakes in Haiti and Chile. They may be man-made, such as the September 11 attacks and the anthrax scare. They may also be infectious. While no pandemic flu has yet reached the severity of the 1918 flu, there have been several scares, including avian flu and most recently H1N1.

Few questions are more ethically or legally loaded than determining who will receive scarce medical resources in the event of a widespread public health emergency. The answer will often mean the difference between life and death for affected Americans.

Despite this reality, or perhaps because of it, there has been little guidance from the federal and state governments on how to prioritize distribution of those resources among individuals. To fill this gap, some public health and medical organizations promulgated protocols that set forth a hierarchy of resource allocation in response to the predicted H1N1 pandemic. Although these efforts at advance planning are to be lauded, they raise a number of troubling civil rights issues. Several of the protocols exclude some people with disabilities from receiving care even when their disabilities do not affect the likely success of the medical interventions at issue. Both the legality of such plans and the ethical implications of promoting the health of the community at the expense of people with disabilities are highly problematic.

This Article explores the legality of the proposed allocation protocols under the Americans with Disabilities Act (ADA) and the Rehabilitation Act. It also evaluates their compatibility with the ethical principles that guide public health decisions and discusses their implications for people with disabilities in the preplanning for public health emergencies.

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I. INTRODUCTION

It is no surprise that people with disabilities are often overlooked or given short shrift when public health emergencies arise.¹ In the best of

1. See NAT’L COUNCIL ON DISABILITY, THE IMPACT OF HURRICANES KATRINA AND RITA ON PEOPLE WITH DISABILITIES: A LOOK BACK AND REMAINING CHALLENGES 2 (2006), available at http://www.ncd.gov/newsroom/publications/2006/pdf/hurricanes_impact.pdf (“[P]eople with disabilities were disproportionately affected by the Hurricanes because their needs were often overlooked or completely disregarded.”); Sharona Hoffman, *Preparing for Disaster: Protecting the*

circumstances, challenges facing this group may be invisible because they arise out of the implicit assumptions and institutional arrangements that form the backdrop of daily life.² The particular challenges that people with disabilities face in widespread crises, however, can have deadly consequences. Because of their special needs and, in some cases, compromised health status, people with disabilities' potential for catastrophic outcomes far exceeds that of more typical Americans.³

Recognizing this, both state and federal legislation directs public health and emergency officials to take the needs of people with disabilities explicitly into account when planning for public health emergencies.⁴ In the wake of Hurricane Katrina, for example, Congress passed legislation both detailing the steps necessary to protect the disability community in times of crisis and directing FEMA to employ a disability coordinator.⁵ Such efforts demonstrate a societal commitment to ensuring equal access to services even during a crisis. They also recognize that decisionmaking is likely to be more just and better reasoned when done deliberately in anticipation of emergencies rather than in the midst of a full-blown disaster.⁶ Advance planning also provides an opportunity for public

Most Vulnerable in Emergencies, 42 U.C. DAVIS L. REV. 1491, 1491 (2009) (noting that special needs populations, including people with disabilities, are “often disregarded in [disaster readiness] initiatives”).

2. See Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L. L. REV. 141, 187 (2005).

3. Hoffman, *supra* note 1, at 1494, 1496 (noting that in the wake of Hurricane Katrina, “[t]he infirm elderly, poor, and disabled were the most likely to die” and that people with disabilities “are likely to suffer disproportionate harm in disasters”); cf. Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 53 (2000) (explaining that “legal protection against discrimination in accessing health care services can be of critical importance” because of the “ongoing and sometimes extensive health care needs” of people with disabilities).

4. See *infra* Part III.B.

5. Post-Katrina Emergency Management Reform Act of 2006, Pub. L. No. 109-295, § 513, 120 Stat. 1394, 1408 (codified at 6 U.S.C. § 321b (2006)); see also Robert T. Stafford Disaster Relief and Emergency Assistance Act, Pub. L. No. 93-288, § 311, 88 Stat. 143, 150 (1974) (codified as amended at 42 U.S.C. § 5151 (2006)) (establishing non-discrimination mandate and directing authorities to accomplish relief activities without discrimination); Pandemic and All-Hazards Preparedness Act, Pub. L. No. 109-417, § 102(d), 120 Stat. 2831, 2834–35 (2006) (codified at 42 U.S.C. § 300hh-16 (2006)) (identifying the public health needs of at-risk individuals as a national goal).

6. See, e.g., Asha V. Devereaux et al., *Definitive Care for the Critically Ill During a Disaster: A Framework for Allocation of Scarce Resources in Mass Critical Care*, 133 CHEST 51S, 52S (Supp. 2008) (“Allocation and rationing of scarce critical care resources are legally, ethically, and emotionally complex. In the event of a catastrophic event, the lack of a plan to address these issues will result in the perception of unjust allocation of resources, or actual injustice may take place.”); G. Richard Holt, *Making Difficult Ethical Decisions in Patient Care During Natural Disasters and Other Mass Casualty Events*, 139 OTOLARYNGOLOGY-HEAD & NECK SURGERY 181, 185 (2008) (arguing it is inappropriate to ask physicians to make decisions regarding triage and resource allocation during a mass disaster and calling for case-based physician education to prepare them for such decisionmaking).

consideration and input, enhancing the potential for equitable outcomes across society.

To date, however, there has been little guidance from federal and state governments on the crucial question of *how* to allocate scarce medical resources in the event of a widespread public health emergency.⁷ As one scholar has noted, this is a “substantial oversight” in national preparedness, and there is no question that medical professionals will be faced with difficult life and death decisions as resources become scarce in a pandemic.⁸ Some public health and medical organizations have begun to address these issues independently and, in some cases, to promulgate allocation protocols that explicitly articulate and defend ethical principles for resource allocation.⁹ The overarching goal of these efforts has been to develop practical, justifiable guidelines that clinicians can implement in the event of a public health emergency. Such forward-thinking efforts are, in general, to be applauded.¹⁰

Critically, however, they also raise significant concerns about the equitable treatment of people with disabilities. Value judgments about the worth and quality of human life have the potential to play prominent roles in allocation decisions. Because we are a “culture dominated by standards created by and for the nondisabled,” the potential for bias to enter into the allocation calculus is high.¹¹ Historically, even those with moderately limiting disabilities have been viewed with pity and discomfort rather than as fully functioning human beings worth “saving.”¹² If allocation protocols

7. Hillary R. Ahle, *Anticipating Pandemic Avian Influenza: Why the Federal and State Preparedness Plans Are for the Birds*, 10 DEPAUL J. HEALTH CARE L. 213, 241–42 (2007) (noting that “none of the state pandemic plans that exist nationwide discuss helping health care providers make the tough ethical decisions” about the allocation of care in a pandemic).

8. *Id.* at 248.

9. *See infra* Part II.

10. *See, e.g.*, Ahle, *supra* note 7, at 248 (“[T]he responsibility remains to have these deliberations regarding what will be ethically acceptable before the crowded emergency rooms become a reality.”); Michael D. Christian et al., *Development of a Triage Protocol for Critical Care During an Influenza Pandemic*, 175 CAN. MED. ASS’N J. 1377, 1380 (2006) (“A significant lesson learned during this exercise is that development of a triage protocol is a complex process that cannot be undertaken during a pandemic.”); Hoffman, *supra* note 1, at 1515 (“[S]ociety should focus significant attention on vulnerable populations during emergency planning processes, when planners have the leisure of acting without the pressures of time, chaotic conditions, and an extreme dearth of resources.”).

11. Harlan Hahn, *Feminist Perspectives, Disability, Sexuality and Law: New Issues and Agendas*, 4 S. CAL. REV. L. & WOMEN’S STUD. 97, 112 (1994); *see also* Richard K. Scotch, *Models of Disability and the Americans with Disabilities Act*, 21 BERKELEY J. EMP. & LAB. L. 213, 222 (2000) (“The stigma associated with disability is so embedded and reinforced within our culture and social structure that it will take tremendous efforts to root [it] out.”).

12. *See, e.g.*, Adrienne Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990s 69, 75 (Sherrill Cohen & Nadine Taub eds., 1989) (“[N]ormals’ view the stigmatized, including the disabled, as ‘not quite human . . .’” (quoting ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY 5 (1963))); Phyllis A. Gordon et al., *Attitudes Regarding Interpersonal Relationships with Persons with Mental Illness and Mental Retardation*, 70 J. REHABILITATION 50, 50 (2004) (explaining that “[a] persistent negative attitude and social

reflect this same bias, the ability of group members to secure essential health care during times of crisis may be measurably, perhaps catastrophically, impacted.

Notably, these concerns are not merely theoretical but are also evidenced in the allocation protocols promulgated in response to public health emergencies, such as the recent swine flu pandemic. In 2009, the President's Council of Advisors on Science and Technology created a possible scenario in which half of all Americans could have been infected with swine flu during the then-upcoming flu season.¹³ If such figures proved accurate, up to 1.8 million of those infected would have required hospitalization, roughly nine times the typical number of patients hospitalized with seasonal flu.¹⁴ In addition, potentially 300,000 people could require intensive care.¹⁵ These possible numbers indicate that hospitals could be overburdened and that shortages would occur, necessitating difficult decisions about who should get access to scarce medical resources such as ventilators and critical care beds.

Several of the resulting algorithms designed to allocate these resources during a potential outbreak explicitly exclude patients with particular physical or mental disabilities from treatment. In some cases, the disability in question is excluded because it negatively affects the likelihood that the medical intervention will be successful in the short-term.¹⁶ In others, however, the identified disabilities bear no discernable relationship to immediate treatment outcomes. Instead, individuals in these categories are precluded from critical care either because they will need resources for a prolonged period of use, are deemed to have a poor quality of life post-treatment, or otherwise have a limited long-term prognosis as a result of their disabilities.¹⁷

Although the threat of a swine flu epidemic appears to have diminished for the time being, there is little doubt that the United States will face similarly difficult health care allocation decisions at some point in the future. It is critical to evaluate in advance the legal parameters within which medical professionals and public health officials must operate when

rejection of people with disabilities is evident throughout history and across cultures” and that “efforts to reduce negative stereotypes . . . do not appear to have been substantially successful” in recent years). The establishment of medical protocols does not escape these concerns because, classified as scientific inquiry, history is replete with incidences of “science” disguising cultural bias and discrimination. *See, e.g.*, Edward J. Larson, *The Meaning of Human Gene Testing for Disability Rights*, 70 U. CIN. L. REV. 913, 920 (2002) (noting that the historical eugenic movement “claimed the mantle of scientific objectivity but was rife with cultural subjectivism”).

13. PRESIDENT'S COUNCIL OF ADVISORS ON SCI. & TECH., EXEC. OFFICE OF THE PRESIDENT, REPORT TO THE PRESIDENT ON U.S. PREPARATIONS FOR 2009-H1N1 INFLUENZA 17 tbl.3-1 (2009) [hereinafter PCAST], available at http://www.whitehouse.gov/assets/documents/PCAST_H1N1_Report.pdf.

14. *See* Rob Stein, *Swine Flu Could Infect Half of U.S.: Presidential Panel's Estimate Is First to Gauge Possible Impact of Pandemic*, WASH. POST, Aug. 25, 2009, at A1.

15. PCAST, *supra* note 13, at 17 tbl.3-1.

16. *See infra* Part II.B.

17. *See infra* Part II.B.

setting treatment agendas. This Article is a first step in providing guidance to these individuals as they attempt in good faith to balance the needs of their communities with the civil rights of people with disabilities in widespread public health emergencies. Part II of this Article describes the history of the recent swine flu epidemic and explores the suspect treatment protocols that have been advanced. Part III provides an overview of both existing federal antidiscrimination law and statutes relating to public health emergencies that pertain to people with disabilities, and Part IV evaluates the legality of the identified treatment protocols under these laws. Finally, Part V evaluates the ethical implications of establishing treatment protocols that use disability as a criterion for securing access to medical care. This Article concludes that the protocols promulgated to date display a troubling disregard of both the limits imposed by civil rights laws and the ethical significance of promoting the health of the community at the expense of people with disabilities.

II. EXISTING PUBLIC HEALTH ALLOCATION PROTOCOLS

“Public health” is, by definition, concerned with populations rather than individuals.¹⁸ The overarching goal of public health efforts—whether through laws, governmental or nongovernmental action—is to maximize the health of the population.¹⁹ At its most simplistic, this goal can be expressed as the “utilitarian maxim ‘[d]o the greatest good for the greatest number.’”²⁰ However, the reality is much more complex than that. Indeed, there is debate about what constitutes the “greatest good” and how to calculate the “greatest number.”

A. Ethical Framework for Public Health Decisionmaking

Although there is no single, agreed-upon ethical framework for public health, there is substantial agreement about the essential principles guiding public health decisionmaking. First, public health interventions must be both necessary and effective to address the public health issue.²¹ Naturally, public health decisions must sometimes be made before there is complete information. For example, public health authorities needed to decide whether to isolate those infected with what later was identified as H1N1 before the virus was identified as a novel flu strain or was fully understood.²² These principles recognize this uncertainty and require that

18. LAWRENCE O. GOSTIN, PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT 16–17 (rev. 2d ed. 2008).

19. *Id.* at 3–41 (defining essential characteristics of public health law, including public nature and focus on health of populations).

20. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 385 (4th ed. 1994). For a description and critique of utilitarian philosophical principles, see *id.* at 47–55.

21. See *Jacobson v. Massachusetts*, 197 U.S. 11, 27–31 (1905); see also GOSTIN, *supra* note 18, at 121–37 (analyzing constitutional principles established by *Jacobson*).

22. Cf. Ctrs. for Disease Control & Prevention, *Novel Influenza A (H1N1) Virus Infections Among Health-Care Personnel—United States, April–May 2009*, 58 MORBIDITY & MORTALITY WKLY. REP. 641, 641, 644–45 (2009) (describing CDC recommendations to health care personnel

the intervention be necessary and effective based on currently available information.

Second, public health authorities are obligated to use the least restrictive alternative intervention available.²³ For example, in the case of H1N1, a hospital may want to require hospital personnel to wear masks to limit potential flu exposure between patients and staff. However, because of how flu is transmitted, it would be reasonable to require masks only within a specified distance of patients rather than at all times.

Third, the benefits and burdens of public health decisions should be distributed equitably among society.²⁴ The challenge is to determine what distributions may be considered “equitable,” as there are several different conceptions of equitable distribution.²⁵ Some argue that benefits and burdens should be shared equally among individuals, while others argue that benefits should be distributed according to need.²⁶ These different conceptions of distributive justice will be described more fully below.

Finally, procedural ethical principles include the requirement for fair process, which may include commonly recognized due process rights when public health decisions impose on liberty or economic interests,²⁷ and the requirement for transparency in decisionmaking.²⁸ Some have argued that transparency not only requires that decisions and decisionmaking be made public, but also that public health authorities actively engage the public in decisionmaking.²⁹

to avoid H1N1 transmission during patient care early in the H1N1 epidemic).

23. See GOSTIN, *supra* note 18, at 68; Nancy E. Kass, *An Ethics Framework for Public Health*, 91 AM. J. PUB. HEALTH 1776, 1780 (2001).

24. GOSTIN, *supra* note 18, at 68–69; Kass, *supra* note 23, at 1780–81.

25. See NAT’L COMM’N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH 8–9 (1978), available at <http://ohsr.od.nih.gov/guidelines/belmont.html> (explaining that burdens and benefits can be distributed in one of five ways: “(1) to each person an equal share, (2) to each person according to individual need, (3) to each person according to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit.”).

26. See, e.g., *id.* For a more complete discussion of the ethical principle of justice, see BEAUCHAMP & CHILDRESS, *supra* note 20, at 326–94.

27. GOSTIN, *supra* note 18, at 131–35.

28. *Id.* at 70–72; see also James G. Hodge, Jr. & Evan D. Anderson, *Principles and Practice of Legal Triage During Public Health Emergencies*, 64 N.Y.U. ANN. SURV. AM. L. 249, 281–82 (2008).

29. See, e.g., KATHY KINLAW & ROBERT LEVINE, ETHICS SUBCOMM. OF THE ADVISORY COMM. TO THE DIR., CTRS. FOR DISEASE CONTROL & PREVENTION, ETHICAL GUIDELINES IN PANDEMIC INFLUENZA 3 (2007), available at http://www.cdc.gov/od/science/integrity/phethics/panFlu_Ethic_Guidelines.pdf; Douglas B. White et al., *Who Should Receive Life Support During a Public Health Emergency? Using Ethical Principles to Improve Allocation Decision*, 150 ANNALS INTERNAL MED. 132, 137 (2009). In a recent report regarding environmental assessment, the National Research Council of the National Academies of Sciences concluded, “When done well, public participation improves the quality and legitimacy of a decision and builds the capacity of all involved to engage in the policy process.” PANEL ON PUB. PARTICIPATION IN ENVTL. ASSESSMENT & DECISION MAKING, NAT’L RESEARCH COUNCIL, PUBLIC PARTICIPATION IN ENVIRONMENTAL ASSESSMENT AND DECISION

This general framework must be further specified to apply to specific public health issues, such as the allocation of scarce resources during a public health emergency. The Centers for Disease Control and Prevention (CDC) has developed guidance on this topic.³⁰ Its goal is to identify ethical points to consider when decisionmakers at all levels prepare their plans.³¹ Notably, the document does *not* advocate for a specific allocation scheme but rather describes ethical principles that are relevant to such decisionmaking.

Some principles take into account the health of the patients. For example, emergency departments commonly use the principle “sickest first” to triage patients who arrive for care. Using this principle, those who are sickest and require immediate care receive it first. Those who are less sick must wait, in part because waiting will not adversely affect them in the long run. One drawback of this approach is that resources may be allocated to those who are sick enough that they may not survive.³² In contrast, because of the public health commitment to population health, many suggest that allocation in a public health emergency should be guided by the overarching principle of maximizing net benefits and minimizing waste of resources by allocating to those most likely to survive to hospital discharge.³³ This specification of the general principle seeks to maximize the number of lives saved.

Conceptualized in a different way, the principle of maximizing net benefits can account for differences in life conditions of patients. For example, some have argued that allocations should take into account the years of life saved in addition to the number of lives saved. This may result in different allocations based on age (for example, preferring a twenty-year-old over a sixty-year-old, assuming short-term survival is the same) or based on health conditions (for example, preferring an otherwise healthy sixty-year-old over a sixty-year-old with underlying health problems).³⁴ The principle can be further specified to seek to maximize quality life years. Under this conception, life years without disease or disability would

MAKING 2 (Thomas Dietz & Paul C. Stern eds., 2008); *see also* Hodge & Anderson, *supra* note 28, 281–82 (“Effective outreach to vulnerable populations benefits the community and leads to better choices by decision makers.”).

30. The CDC’s Ethics Subcommittee to the Advisory Committee to the Director, the author of the guidance, is a committee comprised of academics and professional ethicists who provide advice to the CDC on a broad range of public health ethics issues. Drue H. Barrett et al., *Strengthening Public Health Ethics at the Centers for Disease Control and Prevention*, 14 J. PUB. HEALTH MGMT. & PRACTICE 348, 350 (2008).

31. 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 (2010), *available at* www.gha911.org/csc/docs/ethicalconsiderations.pdf.

32. *See id.*

33. *Id.* at 12.

34. *See id.* at 12–13.

be favored over those with disease or disability.³⁵ Thus, all other things being equal, those who are otherwise healthy would get preference over those who suffer from underlying disease or disability under this variation of the principle.

Yet another variation of this principle is the life cycle principle. Under this concept, “each individual [should have an] equal opportunity to live through the various phases of life.”³⁶ Accordingly, a child would get preference over a forty-year-old, all other things being equal, because the forty-year-old has already passed through some life cycles (i.e., adolescence, young adulthood) that the child has not. This principle clearly favors younger people over older people.³⁷ However, this preference is based on life stages rather than age alone and thus may not resolve allocation decisions among people who are within the same life stage (for example, a thirty-five-year-old and a forty-year-old).

Another principle commonly invoked for allocation of scarce resources is that of fair chances. There are multiple ways in which this principle can be specified. For example, resources may be distributed on a first-come, first-served basis. Using this principle, those who are in need of medical resources receive them, regardless of condition, as long as the resources are available. Accordingly, in an epidemic, those who become sick earlier will have the best chance of receiving the resources. Like the sickest-first principle, using the first-come, first-served principle may lead to resources being used by people who may not survive.³⁸ Alternatively, resources may be distributed based on random selection, for example, by lottery. Again, there are choices as to how to conceive of “fair chance.” Each person may have an equal chance or weighting can be incorporated to take into account condition (for example, everyone with a 50% chance of survival will have the same chance of receiving a ventilator, but those with a 75% chance of survival might be twice as likely to receive a ventilator than those with a 50% chance of survival).³⁹

Finally, some have argued that allocation of scarce resources should be based on some conception of social worth. One conception of social worth that has support in public health, at least in some cases, is instrumental value. This principle grants preference to those whose services are essential

35. *Id.* at 13. The quality-adjusted life year (QALY) and disability-adjusted life year (DALY) have been used as a measure of health outcome in cost effectiveness analysis for decades. Franco Sassi, *Calculating QALYs, Comparing QALY and DALY Calculations*, 21 HEALTH POL’Y & PLAN. 402, 402 (2006). Although both methods attempt to take into account disease burden, their underlying assumptions and methods are different, and thus, measurements may differ. *Id.* at 402–03, 407. Moreover, as the CDC Ethics Subcommittee noted, calculation of either measure for individual patients would be challenging in the context of a public health emergency. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM. OF THE ADVISORY COMM. TO THE DIR., *supra* note 31, at 13.

36. VENTILATOR DOCUMENT WORKGROUP FOR THE ETHICS SUBCOMM. OF THE ADVISORY COMM. TO THE DIR., *supra* note 31, at 14.

37. *Id.* at 14–15.

38. *Id.* at 8–9.

39. *Id.* at 15.

to community service and thus have a “multiplier effect.” That is, more lives are saved if these individuals remain healthy and are available to work. For example, public health and healthcare personnel may be prioritized for flu vaccines because their services are essential to responding to the public health emergency and treating patients. In contrast, the CDC Ethics Subcommittee indicated that this principle did not justify prioritizing public health and health care personnel for ventilator allocation because someone sick enough to require ventilation is unlikely to return quickly to the workforce.⁴⁰ A broader conception of social worth focuses on overall value to society rather than instrumental value. This principle was notoriously used by the Seattle Dialysis Committee in giving preference to “professionals, heads of families, and caregivers,” and has largely been rejected as a guiding principle given the inherent biases of such evaluations.⁴¹

The principles identified by the CDC Ethics Subcommittee come from philosophical discussion, but they also have intuitive moral appeal. They are consistent with decisions people make daily (for example, in shortages, parents often feed children before themselves). Despite this intuitive appeal, there is no agreement about what should be *the* governing principle. Indeed, people accept multiple principles and may give priority to different ones depending on the specific factual circumstances. Given this reality, some have argued that allocation decisionmaking ought to take into account multiple principles, although weighting those principles may be challenging.⁴²

Even if there is agreement regarding the governing principle or principles, implementing allocation decisions in accordance with those principles typically requires additional specification.

B. *Specific Allocation Proposals*

One arena in which several groups have sought to move from the general principles described above to specific articulated criteria is the allocation of critical care medicine, such as ventilators. Unlike the CDC’s guidance document, these efforts are directed at recommending specific allocation strategies in the hope they will be adopted if needed.

1. The Task Force for Mass Care

The Task Force for Mass Care of the American College of Chest Physicians published its recommendations for guiding ventilator distribution in 2008.⁴³ The Task Force was comprised primarily of medical professionals, including thirty physicians and four registered nurses. The

40. *Id.* at 13–14.

41. *Id.*

42. *Id.* at 15–16; White et al., *supra* note 29, at 134–36.

43. Devereaux et al., *supra* note 6, at 51S. In addition to the allocation system, the document addresses operational requirements for allocating “scarce critical care resources” and for the triage process itself. *Id.*

remaining members included one attorney, two members with Bachelor of Science degrees and one member with a doctorate degree. Members came primarily from the United States, with some members from Canada and the United Kingdom.⁴⁴

The triage algorithm the Task Force proposed “is designed to be objective.”⁴⁵ It is based on several underlying principles, which are generally consistent with the general principles articulated above. In particular, the Task Force assumed that (1) triage will only occur after all attempts at increasing supply (for example, canceling elective surgeries) have been undertaken; (2) limits on ventilator access will be proportional to the actual shortage of resources; (3) “rationing of critical care will occur uniformly, be transparent, and abide by objective medical criteria; (4) rationing should apply equally to withholding and withdrawing life-sustaining treatments[;] . . . and (5) patients not eligible for critical care will continue to receive supportive medical or palliative care.”⁴⁶ According to the Task Force criteria, only patients who require active critical care interventions should be eligible for critical care during a crisis.⁴⁷

The Task Force exclusion criteria are intended to preclude patients from care “when they have a very high risk of death, little likelihood of long-term survival, and a correspondingly low likelihood of benefit from critical care resources.”⁴⁸ The exclusion criteria are based on “the Sequential Organ Failure Assessment (SOFA) score” and an evaluation of “the severity of chronic illness.”⁴⁹ A patient is excluded on the basis of the SOFA score if she has a minimum of 80% risk of mortality, with the assumption that this predicted level of mortality indicates a high likelihood of imminent death even with medical care.⁵⁰ The Task Force also specifically excludes individuals with certain conditions from receiving critical care during a mass crisis, including “[s]evere baseline cognitive impairment,” “[a]dvanced untreatable neuromuscular disease,” and

44. *Id.* at 64S.

45. *Id.* at 53S.

46. *Id.*

47. *Id.* at 56S.

48. *Id.*

49. *Id.* at 56S–57S. The SOFA score is expected to be calculated daily as an assessment of acute inpatient illness severity. *Id.* at 57S. It evaluates functioning of multiple organ systems and, because most ICU patients die of multiorgan failure, is predictive of in-hospital mortality. See Flavio Lopes Ferreira et al., *Serial Evaluation of the SOFA Score to Predict Outcome in Critically Ill Patients*, 286 J. AM. MED. ASS'N 1754, 1756–58 (2001). The Task Force chose this assessment over others because “(1) it primarily assesses daily organ function; (2) the ease of obtaining physiologic parameters; (3) the ease of calculating the SOFA score; (4) simple laboratory tests are used for scoring; and (5) its validation in a wide variety of critical care conditions.” Devereaux et al., *supra* note 6, at 57S. It also has the benefit of not including potentially problematic variables, such as age, in the calculation. See White et al., *supra* note 29, at 133. Conditions that affect organ function but may also be considered disabilities under the Americans with Disabilities Act will affect the SOFA score. This may cause the disabled to have a lower chance of getting access to resources during an emergency, but it does not systematically exclude them from access.

50. Devereaux et al., *supra* note 6, at 57S.

“[a]dvanced and irreversible neurologic event or condition.”⁵¹ Notably, the Task Force neither defines these conditions nor indicates which specific conditions fall into these three categories.

2. The Hick Group

A group of physicians primarily from Minnesota (the “Hick Group”) also has proposed a protocol for allocating ventilators during a public health emergency.⁵² As with the Task Force, the Hick Group starts with fundamental ethical principles that are consistent with the general principles articulated earlier. The Hick Group defines its overarching goal as allocating “facility resources to those likeliest to benefit, taking into consideration: [m]edical prognosis[, u]nderlying disease[, e]xpected duration of resource need[, d]uration of benefit[, and] quality of life after intervention.”⁵³ The group acknowledges that quality of life considerations are “unfortunately a criteria subject to significant bias and interpretation.”⁵⁴

Within these parameters, the Hick Group focuses on three key criteria for evaluating a patient for critical care services during an emergency: “[(1) o]rgan system function (and severity of impairment)[; (2) d]uration of ventilator use and duration of benefit[,]” taking into account current and underlying disease parameters; and “[(3) r]esponse to a trial of mechanical ventilation.”⁵⁵ Unlike the Task Force criteria, which specified both SOFA scores and criteria for most of the excluding conditions, the Hick Group matrix is more qualitative than quantitative. For example, although the Group suggests that a “[h]igh potential for death” based on an organ system function core like SOFA may require ventilator reallocation, it does not define that phrase.⁵⁶ Its matrix also lists “[e]xamples of underlying diseases that predict poor short-term survival” that support ventilator reallocation, including “immunodeficiency syndromes with evidence of opportunistic . . . infection” and “acute and chronic and irreversible neurologic impairment that makes patient dependent for all personal care (for example, severe stroke, congenital syndrome, persistent vegetative state, and severe dementia).”⁵⁷

3. The Ontario Working Group

The steering committee of the Ontario Health Plan for an Influenza Pandemic requested the formation of the Ontario Working Group, which

51. *Id.* at 60S tbl.6.

52. John L. Hick et al., *Clinical Review: Allocating Ventilators During Large-Scale Disasters—Problems, Planning, and Process*, 11 CRITICAL CARE 1 (2007), <http://ccforum.com/content/pdf/cc5929.pdf>.

53. *Id.* at 2.

54. *Id.*

55. *Id.* at 4.

56. *Id.* at 6 fig.1.

57. *Id.* at 6 fig.1 n.b. HIV/AIDS is one prominent example of an immunodeficiency syndrome. *Basic Information About HIV and AIDS*, DEP’T HEALTH & HUMAN SERVS., <http://www.cdc.gov/hiv/topics/basic/index.htm> (last modified Aug. 11, 2010).

was comprised of “clinicians with expertise in critical care, infectious diseases, medical ethics, military medicine, triage, and disaster management.”⁵⁸ The Working Group conducted an extensive literature review to develop a prototype triage protocol. Critical care leaders within Ontario reviewed and commented on the Working Group’s report before it was made final.⁵⁹ Like the other groups, the Working Group relied on general ethical principles in developing its protocol with the intent of providing a “practical, user-friendly and flexible” guide to decisionmaking in a pandemic.⁶⁰

The Working Group’s protocol, like that of the Task Force, relies heavily on the SOFA score. A patient who has a SOFA score of greater than eleven *or* meets exclusion criteria is excluded from critical care.⁶¹ According to the Working Group,

[The exclusion criteria] can be broken down into [three] categories: patients who have a poor prognosis despite care in an ICU, patients who require resources that simply cannot be provided during a pandemic and patients with advanced medical illnesses whose underlying illness has a poor prognosis with a high likelihood of death, even without their current concomitant critical illness.⁶²

Like the Task Force, the Working Group specifically excluded critical care during a pandemic to people with “[s]evere baseline cognitive impairment” and “[s]evere and irreversible neurologic event or condition.”⁶³ The rationale for excluding these patients appears to take into account the resources that would be required, even though such patients might benefit from care.

4. The NY Workgroup

The New York State Department of Health and the New York State Task Force on Life and the Law established the New York State Workgroup on Ventilator Allocation in an Influenza Pandemic (NY Workgroup).⁶⁴ The NY Workgroup included experts in medicine, law, and ethics.⁶⁵ The NY Workgroup developed an ethical framework that included the following principles: “[d]uty to care[; d]uty to steward resources[; d]uty to plan[; d]istributive justice[; and t]ransparency.”⁶⁶ It proposed

58. Christian et al., *supra* note 10, at 1377.

59. *Id.* at 1378.

60. *Id.* at 1380.

61. *Id.* at 1378 fig.1.

62. *Id.* at 1378.

63. *Id.* at 1379.

64. Tia Powell et al., *Allocation of Ventilators in a Public Health Disaster*, 2 DISASTER MED. & PUB. HEALTH PREPAREDNESS 20, 20 (2008).

65. *Id.*

66. *Id.* at 21.

allocation based on medical/clinical factors alone, using a combined evaluation based on the Ontario Working Group and SOFA.⁶⁷ It also excluded those with severe irreversible neurological events or conditions if they have “high expected mortality,” although this phrase is not defined.⁶⁸

III. FEDERAL LAW AND POLICY RELATING TO PEOPLE WITH DISABILITIES

Allocation protocols promulgated by public health or medical groups are governed by and must be consistent with the U.S. Constitution, federal statutes, and state law. The following discussion identifies those federal laws that may control protocol provisions to the extent they affect people with disabilities. It concludes with a review of federal legislation relating to public health emergencies to determine whether these laws may be abridged or suspended during times of national crisis.

A. Federal Disability Laws

The Fourteenth Amendment of the United States Constitution provides that no state shall “deny to any person within its jurisdiction the equal protection of the laws,”⁶⁹ a mandate that also extends to the federal government.⁷⁰ The Supreme Court has interpreted this provision to mean that “all persons similarly situated should be treated alike.”⁷¹ In general, courts will uphold challenges to legislation under the Equal Protection Clause so long as “the classification drawn by the statute is rationally related to a legitimate state interest.”⁷² The Court has applied heightened scrutiny, however, to classifications based on race, national origin, alienage, and sex because such “factors are so seldom relevant to the achievement of any legitimate state interest,” and instead, often reflect outdated notions or discriminatory animus.⁷³

To date, the Supreme Court has declined to add people with disabilities to the list of suspect classes. In *City of Cleburne v. Cleburne Living Center*, the Court concluded that the rational basis test—not heightened scrutiny—was sufficient to protect the interests of people with mental retardation. The Court reasoned that the impairment “is a characteristic that the government may legitimately take into account in a wide range of decisions,” and that “both State and Federal Governments have recently

67. *Id.* at 22–23.

68. *Id.* at 23 tbl.1.

69. U.S. CONST. amend. XIV, § 1.

70. *See* *Bolling v. Sharpe*, 347 U.S. 497, 500 (1954) (applying the Due Process Clause to the federal government).

71. *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 439 (1985).

72. *Id.* at 440.

73. *Id.* at 440–41. Classifications based on race, national origin, or alienage are subject to strict scrutiny and are upheld only “if they are suitably tailored to serve a compelling state interest.” *Id.* at 440. Classifications based on sex are subject to intermediate scrutiny and are upheld only where they are “substantially related to a sufficiently important governmental interest.” *Id.* at 441.

committed themselves to assisting the retarded.”⁷⁴ Although the Court could conceivably extend heightened scrutiny to other disabilities,⁷⁵ few could exceed the documented history of discrimination, exclusion, and institutionalization faced by people with mental retardation.⁷⁶ As a result, it is unlikely that the Equal Protection Clause would provide meaningful protection to people with disabilities in advance planning for public health emergencies.

Instead, the primary legal protection afforded to this group arises out of federal legislation. Titles II and III of the Americans with Disabilities Act and § 504 of the Rehabilitation Act broadly preclude discrimination against people with disabilities on the basis of their impairments.⁷⁷ Congress has made clear that the ADA is intended to address continuing discrimination facing group members in the “critical area[] . . . [of] health services.”⁷⁸

All public hospitals and service providers are covered under Title II of the ADA, which precludes states, local governments, and their agents from discriminating against qualified individuals with disabilities in the provision of any service, program, or activity.⁷⁹ A “qualified individual with a disability” is one who, “with or without reasonable modifications to rules, policies, or practices, the removal of architectural barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or participation in programs or activities provided by a public entity.”⁸⁰ The reference to “any service, program or activity” of the state is generally construed broadly to include “anything [that] a public entity does.”⁸¹

The regulations define discrimination to include providing “an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level

74. *Id.* at 446.

75. Some scholars have argued that in enacting the ADA in 1990, Congress intended “to mandate a heightened level of judicial scrutiny in cases dealing with a classification based on disability” pursuant to its power under § 5 of the Fourteenth Amendment. *E.g.*, Lisa A. Montanaro, *The Americans with Disabilities Act: Will the Court Get the Hint? Congress’ Attempt to Raise the Status of Persons with Disabilities in Equal Protection Cases*, 15 PACE L. REV. 621, 623–25 (1995).

76. The Court itself suggested as much, noting that “if the large and amorphous class of the mentally retarded were deemed quasi-suspect for the reasons given by the Court of Appeals, it would be difficult to find a principled way to distinguish a variety of other groups who have perhaps immutable disabilities setting them off from others.” *Cleburne*, 432 U.S. at 445.

77. *See* 42 U.S.C. §§ 12132, 12182 (2006) (ADA Titles II and III); 29 U.S.C. § 794(a) (2006) (§ 504 of the Rehabilitation Act of 1973).

78. 42 U.S.C. § 12101(a)(3).

79. *Id.* § 12132.

80. *Id.* § 12131(2); *see also* *Se. Cmty. Coll. v. Davis*, 442 U.S. 397, 406 (1979) (“An otherwise qualified person is one who is able to meet all of a program’s requirements in spite of his handicap.”).

81. *Bay Area Addiction Research & Treatment, Inc. v. City of Antioch*, 179 F.3d 725, 732 (9th Cir. 1999) (citing 28 C.F.R. pt. 35, app. A, § 35.102 (1998)).

of achievement” as that provided to people outside of the protected class.⁸² The regulations also prohibit the imposition or application of

eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.⁸³

Although the statute permits criteria that are necessary for the “safe operation” of a program, such requirements “must be based on actual risks and not on speculation, stereotypes, or generalizations about individuals with disabilities.”⁸⁴ Providers likewise must make reasonable modifications to policies for this group unless doing so would fundamentally alter the nature of the good or service being provided.⁸⁵ This affirmative defense takes into account both “fiscal and administrative considerations that factor into program restrictions.”⁸⁶ Although individuals may sue for compensatory damages based on intentional discrimination in some circumstances,⁸⁷ there is no equivalent action for disparate impact claims.⁸⁸

Many of these same provisions are included in Title III of the ADA, which regulates all “public accommodations,”⁸⁹ including nonreligious⁹⁰ private hospitals and professional service providers.⁹¹ Public accommodations may not deny individuals with disabilities the opportunity “to participate in or benefit from the goods, services, facilities, privileges,

82. 28 C.F.R. § 35.130(b)(1)(iii) (2010).

83. *Id.* § 35.130(b)(8). Notably, even criteria that “indirectly prevent or limit” the ability of people with disabilities to participate in or benefit from a service are precluded by the regulation. 28 C.F.R. pt. 35, app. A, § 35.130 (DOJ Interpretative Guidance).

84. 28 C.F.R. pt. 35, app. A, § 35.130 (DOJ Interpretative Guidance). Unlike Title III, Title II does not statutorily recognize a “direct threat” defense. The Department of Justice, however, has interpreted “essential eligibility requirements” to incorporate this concept. *See* Preamble to Title II Rules, 28 C.F.R. pt. 35, app. A, §§ 35.104, 35.130 (2010).

85. *Id.* § 35.130(b)(8).

86. Mary R. Anderlik & Wendy J. Wilkinson, *The Americans with Disabilities Act and Managed Care*, 37 HOUS. L. REV. 1163, 1223 (2000).

87. For a discussion of the remedies available under Title II and Title III, see Michael Waterstone, *The Untold Story of the Rest of the Americans with Disabilities Act*, 58 VAND. L. REV. 1807, 1859–65 (2005).

88. *Id.* at 1824.

89. 42 U.S.C. § 12181(7) (2006).

90. Title III’s exemption of religious entities and organizations is “very broad, encompassing a wide variety of situations.” 28 C.F.R. pt. 36, app. B, § 36.104 (2010). A religious entity’s use of a lay board does not automatically remove this exemption. Instead, courts will scrutinize all facts to determine “whether the church or other religious organization controls the operations . . . of the service or whether the . . . service is itself a religious organization.” *Id.*

91. 42 U.S.C. § 12181(7)(F) (identifying the “professional office of a health care provider, hospital, or other service establishment” as public accommodations); 28 C.F.R. § 36.102(e).

advantages, or accommodations” of the entity or provide unequal benefits on the basis of disability.⁹² Like Title II, Title III specifically prohibits using “eligibility criteria that screen out or tend to screen out” individuals with disabilities from the full benefit of the entity’s services, unless such criteria are “necessary for safe operation.”⁹³ Reasonable modifications to policies and procedures again must be provided unless doing so would constitute a fundamental alteration of the entity’s goods or services.⁹⁴ Nevertheless, the statute permits public accommodations to deny or limit the participation of an individual with a disability “when that individual poses a direct threat to the health or safety of others,” defined as a significant risk that cannot be eliminated by modifying policies or providing auxiliary aids and services.⁹⁵ To secure the benefit of this exception, the provider “must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge.”⁹⁶

Notably, Title III specifically precludes administrative methods that have a disparate impact on people with disabilities.⁹⁷ Public accommodations, directly or through contractual arrangements, are prohibited from employing “standards or criteria or methods of administration that have the effect of discriminating on the basis of disability, or that perpetuate the discrimination of others who are subject to common administrative control.”⁹⁸ Nevertheless, there is no private right of action for damages under Title III, although in some circumstances, the Department of Justice may seek damages and other civil penalties.⁹⁹

The precursor to the ADA, § 504 of the Rehabilitation Act, overlaps the protection afforded by the Titles II and III to a large extent.¹⁰⁰ This statute provides that “[n]o otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability” be

92. 42 U.S.C. § 12182(b)(1)(A)(i)–(ii); 28 C.F.R. § 36.202(a)–(b). The Department of Justice has explained that:

Full and equal enjoyment means the right to participate and to have an equal opportunity to obtain the same results as others to the extent possible with such accommodations as may be required by the Act and these regulations. It does not mean that an individual with a disability must achieve an identical result or level of achievement as persons without a disability.

28 C.F.R. pt. 36, app. B, § 36.201.

93. 42 U.S.C. § 12182(b)(2)(A)(i); 28 C.F.R. § 36.301(b).

94. 42 U.S.C. § 12182(b)(2)(A)(ii).

95. 28 C.F.R. § 36.208(a)–(b).

96. 28 C.F.R. § 36.208(c).

97. See 28 C.F.R. pt. 36, app. B, § 36.204 (stating that this section “incorporate[s] a disparate impact standard to ensure the effectiveness of the legislative mandate to end discrimination” and is consistent with *Alexander v. Choate*, 469 U.S. 287 (1985), discussed *infra* Part IV.C).

98. 28 C.F.R. § 36.204; see also 42 U.S.C. § 12182(b)(1)(D).

99. 42 U.S.C. § 12188(a); see also Waterstone, *supra* note 87, at 1868, 1873.

100. See Katie Eyer, *Rehabilitation Act Redux*, 23 YALE L. & POL’Y REV. 271, 303 (2005) (“The regulations that have been promulgated to enforce the ADA in the government programs and services arena are virtually identical to the § 504 . . . regulations.”).

discriminated against in any program or activity that receives federal financial assistance.¹⁰¹ It defines “program or activity” to include all of the operations of “an entire corporation, partnership, or other private organization, or an entire sole proprietorship” that “is principally engaged in the business of providing . . . health care.”¹⁰² Because most hospitals receive federal support and federal aid is likely to be far-reaching in the event of a major pandemic, it is likely that many, if not most, health care providers would fall within the reach of this statute. Requested modifications must be reasonable and need not be provided where they would either pose a direct threat to safety or constitute an undue burden or fundamental alteration.¹⁰³ Significantly, monetary damages are available for statutory violations where the defendant has demonstrated “deliberate indifference” to the civil rights of the plaintiff.¹⁰⁴ As a result, it is likely that most litigants would include a § 504 claim when seeking relief for the denial of health care on the basis of disability.

B. Public Health Laws Relating to Disability

Public health authority traditionally is exercised by the states through their historical police powers, reserved to the states through the Tenth Amendment.¹⁰⁵ Although the federal government exerts substantial authority over public health matters, it must do so through its enumerated powers, primarily the Commerce Clause and the Taxing and Spending Clause.¹⁰⁶ Public health powers are quite broad; courts historically have upheld significant restrictions on personal liberty to further public health goals, including mandatory vaccination and involuntary hospitalizations intended to protect the public from infectious diseases.¹⁰⁷

These already expansive powers may be increased in the face of a public health emergency, which can spring from infectious diseases, natural disasters, environmental threats, or man-made threats, including bioterrorism.¹⁰⁸ Although the source of the threat varies, all of these events

101. 29 U.S.C. § 794(a) (2006).

102. *Id.* § 794(b)(3)(A)(i)–(ii).

103. 42 U.S.C. § 12182 (2006); *see* *Se. Cmty. Coll. v. Davis*, 442 U.S. 397, 410–12 (1979).

104. *See* 29 U.S.C. § 794a(a)(1); *Eyer, supra* note 100, at 291 (describing damages available under § 504); *see also* *Duvall v. Cnty. of Kitsap*, 260 F.3d 1124, 1139 (9th Cir. 2001) (discussing the “deliberate indifference” standard).

105. *See* GOSTIN, *supra* note 18, at 77–80, 91–95; Michael Greenberger & Arianne Spaccarelli, *State and Federal Emergency Powers*, in *HOMELAND SECURITY: LEGAL AND POLICY ISSUES* 21, 23 (Joe D. Whitley & Lynne K. Zusman eds., 2009).

106. *See generally* GOSTIN, *supra* note 18, at 98–106; Gene W. Matthews et al., *Legal Authorities for Interventions in Public Health Emergencies*, in *LAW IN PUBLIC HEALTH PRACTICE* 262, 263–64 (Richard A. Goodman et al. eds., 2007).

107. *See, e.g.*, *Jacobson v. Massachusetts*, 197 U.S. 11, 19 (1905) (upholding mandated smallpox vaccinations); *City of N.Y. v. Antoinette R.*, 630 N.Y.S.2d 1008 (Sup. Ct. 1995) (upholding detention order for treatment of tuberculosis); *see also* GOSTIN, *supra* note 18, at 376–95 (discussing compulsory vaccinations).

108. *See* Greenberger & Spaccarelli, *supra* note 105, at 21–41; Matthews et al., *supra* note 106, at 262–83.

present a serious health threat to a large number of people at the local, regional, or even global level.¹⁰⁹ As described more fully below, to respond to such threats, federal, state, and local governments have the power to declare a public health emergency, which gives them additional authority and allows them to suspend the operation of other laws that might interfere with an effective response to the emergency.¹¹⁰ However, as the following analysis suggests, currently no laws would suspend the requirements of the ADA or the Rehabilitation Act in a public emergency.

1. Statutes Relating to Public Health Emergencies

The Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act) authorizes the federal government to provide assistance to state and local governments during disasters.¹¹¹ For purposes of the Stafford Act, “emergency” is defined broadly to encompass:

[A]ny occasion or instance for which, in the determination of the President, Federal assistance is needed to supplement State and local efforts and capabilities to save lives and to protect property and public health and safety, or to lessen or avert the threat of a catastrophe in any part of the United States.¹¹²

Declarations of emergency under the Stafford Act generally are made only following the request of a governor of a state affected by the emergency or major disaster.¹¹³ However, the President may declare an emergency without a governor’s request when “the primary responsibility for response rests with the United States because the emergency involves a subject area for which, under the Constitution or laws of the United States, the United States exercises exclusive or preeminent responsibility and authority.”¹¹⁴

109. See Lawrence O. Gostin, *The Model State Emergency Health Powers Act: Public Health and Civil Liberties in a Time of Terrorism*, 13 HEALTH MATRIX 3, 6–8 (2003).

110. Matthews et al., *supra* note 106, at 268–69; see GOSTIN, *supra* note 18, at 9–10; see also Hodge & Anderson, *supra* note 28, at 253–71.

111. 42 U.S.C. § 5121(b) (2006); Sharona Hoffman, *Responders’ Responsibility: Liability and Immunity in Public Health Emergencies*, 96 GEO. L.J. 1913, 1921 (2008).

112. 42 U.S.C. § 5122(1).

113. 42 U.S.C. §§ 5170, 5191(a). This feature of the Act was dramatically illustrated in the Hurricane Katrina case in which there was confusion over the role of the federal government in relief efforts and what specific assistance had been requested by the Louisiana governor. Greenberger & Spaccarelli, *supra* note 105, at 23.

114. 42 U.S.C. § 5191(b). The President also has the authority to declare an emergency under the National Emergencies Act. National Emergencies Act, Pub. L. No. 94-412, 90 Stat. 1255 (1976) (codified at 50 U.S.C. § 1621 (2006)). Unlike the Stafford Act, this statute does not specify the circumstances under which an emergency can be declared or indicate any specific need to protect vulnerable persons during the emergency. This may be because it comes under the War and National Defense title of the United States Code rather than the Public Health title.

Importantly, the Stafford Act prohibits discrimination in responding to an emergency. It provides:

The President shall issue, and may alter and amend, such regulations as may be necessary for the guidance of personnel carrying out Federal assistance functions at the site of a major disaster or emergency. Such regulations *shall include* provisions for insuring that the distribution of supplies, the processing of applications, and other relief and assistance activities *shall be accomplished* in an equitable and impartial manner, *without discrimination* on the grounds of race, color, religion, nationality, sex, age, *disability*, English proficiency, or economic status.¹¹⁵

Nondiscrimination is likewise a prerequisite to participation by other governmental bodies and organizations (for example, the Red Cross) in federal relief efforts.¹¹⁶

The Secretary of the Department of Health and Human Services (HHS) may declare a public health emergency under the Public Health Threat and Emergencies Act based on “a disease or disorder” that threatens public health.¹¹⁷ The Secretary is then authorized to take “such action as may be appropriate.”¹¹⁸ Declaration of an emergency grants access to a Public Health Emergency Fund and lasts ninety days, unless the Secretary terminates it earlier or renews it. As part of the Pandemic and All-Hazards Preparedness Act, Congress also directed the Secretary to “oversee the implementation of the National Preparedness goal of taking into account the public health and medical needs of at-risk individuals in the event of a public health emergency.”¹¹⁹ Specific responsibilities include ensuring that state and local grant recipients take into account the needs of “at-risk individuals,” defined to include “children, pregnant women, senior citizens and other individuals who have special needs in the event of a public health emergency.”¹²⁰

The Public Health Security and Bioterrorism Preparedness and Response Act of 2002 authorizes “accelerated approval of priority countermeasures,” which permits a designation of a drug for fast-track status under the Food, Drug, and Cosmetic Act or a device for priority review, even without company request and even over its opposition.¹²¹ It also permits the emergency waiver of some legal requirements to facilitate

115. 42 U.S.C. § 5151(a) (emphasis added).

116. *Id.* § 5151(b).

117. Public Health Threats and Emergencies Act, Pub. L. No. 106-505, § 319, 114 Stat. 2315, 2315 (2000) (codified at 42 U.S.C. § 247d (2006)).

118. 42 U.S.C. § 247d.

119. Pandemic and All-Hazards Preparedness Act, Pub. L. No. 109-417, § 2814, 120 Stat. 2831, 2834 (2006).

120. *Id.* at 2836.

121. Public Health and Bioterrorism Preparedness and Response Act of 2002, Pub. L. No. 107-188, § 122, 116 Stat. 598, 613 (2002) (codified at 21 U.S.C. § 356-1 (2006)).

care when the President or the HHS Secretary has declared a public health emergency.¹²² These include the waiver of sanctions under the Emergency Medical Treatment and Labor Act (EMTALA), which requires hospitals with emergency departments to screen and, if needed, stabilize all patients presenting at the hospital with an emergent condition.¹²³ Waiving this requirement in a public health emergency recognizes that it may be more efficient and effective to designate certain hospitals—or even other locations—for specific responses (for example, concentrate experts in the infectious condition in a couple of locations). Similarly, the Act permits alteration of Medicare, Medicaid, and State Children’s Health Insurance Program (SCHIP) provider eligibility requirements, such as in-state licensure, to expand access to medical providers.¹²⁴

In 2004, President George W. Bush issued Executive Order 13,347 concerning individuals with disabilities in emergency preparedness.¹²⁵ The purpose of the policy is “[t]o ensure that the Federal Government appropriately supports safety and security for individuals with disabilities in situations involving disasters.”¹²⁶ As articulated by the Interagency Coordinating Council in its 2005–2006 Progress Report, the Executive Order “[recognizes] that individuals with disabilities should be as safe and secure in their communities and work environments as individuals without disabilities.”¹²⁷ It requires U.S. government departments and agencies to “consider, in their emergency preparedness planning, the unique needs of . . . individuals with disabilities whom the agency serves; . . . encourage . . . consideration” of those needs by state and local governments and private organizations; and help implement emergency preparedness plans in this regard.¹²⁸ To facilitate attention to these issues, the Order establishes the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities.¹²⁹

In sum, federal emergency preparedness and response law reflects a commitment to equal access, even in the context of an emergency. The ADA and the Rehabilitation Act do not contain exceptions for emergencies. Thus, their provisions would apply to allocation of scarce resources during a public health emergency.

122. *Id.* § 143, at 627 (codified at 42 U.S.C. § 1320b-5 (2006)) (adding a new § 1135 to the Social Security Act). These include participation requirements for individual health care providers, in-state provider licensure requirements, and some sanctions. *Id.* at 628.

123. *Id.* at 627–28; *see also* Hodge & Anderson, *supra* note 28, at 257.

124. Public Health and Bioterrorism Preparedness and Response Act of 2002, § 143, at 627; *see also* Matthews et al., *supra* note 106, at 269.

125. Exec. Order No. 13,347, 69 Fed. Reg. 44,573 (July 22, 2004).

126. *Id.*

127. INTERAGENCY COORDINATING COUNCIL ON EMERGENCY PREPAREDNESS & INDIVIDUALS WITH DISABILITIES, INDIVIDUALS WITH DISABILITIES IN EMERGENCY PREPAREDNESS EXECUTIVE ORDER 13,347 PROGRESS REPORT, JULY 2005—SEPTEMBER 2006 4 (2006), *available at* <http://www.dhs.gov/xlibrary/assets/icc-0506-progressreport.pdf>.

128. Exec. Order No. 13,347, 69 Fed. Reg. at 44,573.

129. *Id.*

2. Application to Federal Antidiscrimination Laws

There are several reasons to believe that the legal waivers permitted by the public health statutes described above do not and will not affect the ADA or the Rehabilitation Act. First, in the wake of Hurricane Katrina, the federal government has taken several steps to *strengthen* the government's response to the needs of disabled individuals in the event of a public health emergency. Executive Order 13,347 in particular requires federal agencies to consider the needs of individuals with disabilities in their emergency preparedness plans, directing both the HHS Secretary and a recently established "disability coordinator" to ensure this goal.¹³⁰ Congress's clear endorsement of antidiscrimination in public health emergencies strongly suggests that it is unlikely to waive the legal protection afforded to this group in a time of limited resources.

Second, there is no provision in the ADA or Rehabilitation Act that authorizes waiver of its requirements during a public health emergency.¹³¹ Congress's silence in this regard is instructive, given that several other federal statutes explicitly include such waiver provisions. The Social Security Act and the Food Drug and Cosmetic Act, for example, expressly authorize waiver of EMTALA, Medicare/Medicaid eligibility, and drug approval requirements in an emergency.¹³² These exemptions share a common purpose—they are directed at facilitating access to medical care in times of crises.¹³³ Had Congress desired to include a similar waiver in the ADA or the Rehabilitation Act, which clearly applies to the provision of care, it could easily have done so.¹³⁴

130. 6 U.S.C. § 321b (2006); Exec. Order No. 13,347, 69 Fed. Reg. at 44,573. The Disability Coordinator shall be appointed only "[a]fter consultation with organizations representing individuals with disabilities, the National Council on Disabilities, and the Interagency Coordinating Council on Preparedness and Individuals with Disabilities." 6 U.S.C. § 321b(a). The Disability Coordinator is "to ensure that the needs of individuals with disabilities are being properly addressed in emergency preparedness and disaster relief." *Id.*

131. See Hoffman, *supra* note 1, at 1522–26 (analyzing application of the ADA in a public health emergency).

132. Public Health and Bioterrorism Preparedness and Response Act of 2002, Pub. L. No. 107-188, § 143, 116 Stat. 594, 627 (2002) (codified at 42 U.S.C. § 1320b-5 (2006)); see also Hodge & Anderson, *supra* note 28, at 257; Matthews et al., *supra* note 106, at 269.

133. For example, the EMTALA waivers allow both concentration of expertise and separation of cases in a pandemic. See Hodge & Anderson, *supra* note 28, at 280. The waivers of FDA regulations permit access to experimental therapies. Matthews et al., *supra* note 106, at 269.

134. This is particularly true given that Congress amended the ADA as recently as 2008. For a detailed discussion of these changes, see Wendy F. Hensel, *Rights Resurgence: The Impact of the ADA Amendments on Schools and Universities*, 25 GA. ST. U. L. REV. 641, 642 (2009). For an analysis of the congressional intent in enacting the ADA, see generally Mark C. Weber, *Unreasonable Accommodation and Due Hardship*, 62 FLA. L. REV. 1119 (2010).

IV. THE LEGALITY OF USING DISABILITY AS A FACTOR IN ALLOCATING SCARCE RESOURCES

The legislation discussed above reflects the government's commitment to equality of opportunity for people with disabilities in even the most demanding of circumstances. The provision of health services is subject both to anti-discrimination laws and to judicial scrutiny even in times of public health emergencies.¹³⁵ This understanding, however, does not answer the question of *how* these laws affect specific aspects of the allocation protocols. The following discussion addresses this complex inquiry with respect to categorical preclusions of care and care limitations based on duration of need, quality of life considerations, and medical effectiveness. It concludes by evaluating the affirmative defenses that may apply under the ADA and the Rehabilitation Act.

A. The "Otherwise Qualified" Requirement

In order to contest any condition identified in the allocation protocols under § 504 or Title II of the ADA, an individual with a disability must first establish that he is "qualified" so as to fall within the protected class.¹³⁶ In contrast, Title III simply precludes discrimination against all individuals on the basis of disability.¹³⁷ The absence of the qualified requirement is misleading, however, because the antidiscrimination provisions of Title III "implicitly recognize a public accommodation's freedom to enforce eligibility requirements for its services, so long as those criteria do not screen out or tend to screen out persons with disabilities."¹³⁸ As a result, class coverage under Title III in practice is conceptually analogous to that under Title II and the Rehabilitation Act.¹³⁹ In all cases, plaintiffs will need to show that they are qualified for the service in question and meet all necessary eligibility criteria.

Although seemingly straightforward on its face, the qualified requirement has proven challenging in some cases involving the denial of medical care.¹⁴⁰ In *United States v. University Hospital*, the Second Circuit found it significant that the "otherwise qualified" element of § 504 requires eligibility for a program "in spite of" any underlying disability.¹⁴¹ From this fact, it concluded that "section 504 prohibits

135. See Anderlik & Wilkinson, *supra* note 86, at 1194, 1245 (noting that there is no "safe harbor" provision in the ADA for medical decisionmaking, unlike that provided in the statute for insurance).

136. See 29 U.S.C. § 794(a) (2006); 42 U.S.C. § 12132 (2006).

137. 42 U.S.C. § 12182(a).

138. Mary A. Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179, 246 (1995).

139. See *id.*

140. See, e.g., Daniel J. Smith, *Discrimination in Provision of Medical Services on the Basis of Disability*, 49 AM. JUR. 3D *Proof of Facts* § 5 (1998) (concluding that, "By needing medical services, a disabled person is generally qualified to receive the service of any health care provider licensed to provide those particular services.").

141. *United States v. Univ. Hosp.*, 729 F.2d 144, 156 (2d Cir. 1984) (quoting *Doe v. N.Y.*

discrimination . . . only where the individual's handicap is unrelated to, and thus improper to consideration of, the services in question."¹⁴² Reasoning that "it is typically the handicap itself that gives rise to, or at least contributes to, the need for services," the court concluded that the "otherwise qualified" requirement cannot be meaningfully applied in cases involving the denial or withholding of medical treatment.¹⁴³ As a result, if there is a relationship between the underlying disability and the treatment being sought, "it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory.'"¹⁴⁴

A number of courts since *University Hospital* have affirmed this understanding of "otherwise qualified" and refused to consider challenges to the denial of medical care.¹⁴⁵ Others, however, while acknowledging that they should normally defer to professional medical judgment in assessing the qualified requirement, nevertheless conclude that "[a] strict rule of deference would enable doctors to offer merely pretextual medical opinions to cover up discriminatory decisions."¹⁴⁶ Accordingly, if the individual's underlying disability is seemingly unrelated to the treatment being sought, these courts will evaluate the legitimacy of the denial of care pursuant to the Rehabilitation Act and the ADA.

Univ., 666 F.2d 761, 775 (2d Cir. 1981)).

142. *Id.*

143. *Id.*

144. *Id.* at 157.

145. *See, e.g., Johnson v. Thompson*, 971 F.2d 1487, 1493–94 (10th Cir. 1992) (finding that plaintiffs challenging medical team's policy of recommending the withholding of treatment from infants with more severe spina bifida were not "otherwise qualified" under § 504 because the term was inapposite to medical treatment decisions). The Tenth Circuit acknowledged, however, that the "otherwise qualified" language could be satisfied where "the treatment is completely unrelated to the . . . handicapping condition." *Id.* at 1494 n.3; *see also Fitzgerald v. Corrs. Corp. of Am.*, 403 F.3d 1134, 1144 (10th Cir. 2005) (denying treatment claim where disability was the reason for seeking medical treatment); *Grzan v. Charter Hosp.*, 104 F.3d 116, 121 (7th Cir. 1997) (finding plaintiff not "otherwise qualified" because, absent her handicap, she would not have been eligible for treatment in the first place"); *Bolmer v. Oliveira*, 570 F. Supp. 2d 301, 327 (D. Conn. 2008) (same); *Lesley v. Chie*, 81 F. Supp. 2d 217, 223 (D. Mass. 2000) (collecting cases); *cf. Cushing v. Moore*, 970 F.2d 1103, 1109 (2d Cir. 1992) ("[T]he rehabilitation act does not create a cause of action based on a handicap that is directly related to providing the very services at issue.").

146. *Glanz v. Vernick*, 756 F. Supp. 632, 638 (D. Mass. 1991); *see also Johnson*, 971 F.2d at 1494 n.3 (concluding, in dicta, that the "otherwise qualified" condition of § 504 may be satisfied where a condition has "no relation" to the medical treatment sought); *Sumes v. Andres*, 938 F. Supp. 9, 12 (D.D.C. 1996) (finding plaintiff "otherwise qualified" where she was denied prenatal care because she was deaf); *Woolfolk v. Duncan*, 872 F. Supp. 1381, 1389–90 (E.D. Pa. 1995) (holding that an individual "with a disability is 'otherwise qualified' for medical benefits if there is no factor apart from the mere existence of disability that renders the participant unqualified for the benefit"); *Glanz v. Vernick*, 750 F. Supp. 39, 46 (D. Mass. 1990) (permitting a cause of action against physician who refused to perform surgery because of patient's HIV, holding that while, "The inquiry is complicated . . . by the fact that HIV status may be relevant to a determination of whether surgery is advisable . . . the determination of such subtle questions of intent and motive is a well-traveled [judicial] road.").

If a court adopts this approach, at least some of the individuals with disabilities affected by the protocols would likely satisfy the otherwise qualified requirement. Many who seek health care during a pandemic are likely to do so for reasons relating to the pandemic generally rather than their underlying disability specifically. Individuals with “severe baseline cognitive impairments” infected with influenza, for example, may have no underlying condition that specifically relates to or affects their need for a ventilator. If a medical provider nevertheless refuses to provide this care because of the underlying disability, the otherwise qualified requirement would seem to be satisfied, enabling courts to evaluate the legitimacy of the refusal.

Some courts have gone further, moreover, to conclude that individuals with disabilities may be “otherwise qualified” even when there is a relationship between the patient’s disability and services being sought.¹⁴⁷ In the case of *In re Baby K*, for example, a hospital sought to withhold ventilator treatment from an infant with anencephaly against the mother’s wishes because of medical futility.¹⁴⁸ The hospital argued that Baby K was not “otherwise qualified” to receive the treatment because she only required ventilation because of her disability. The court rejected this position, reasoning that “[j]ust as an AIDS patient seeking ear surgery is ‘otherwise qualified’ to receive treatment despite poor long term prospects of living, Baby K is ‘otherwise qualified’ to receive ventilator treatment despite similarly dismal health prospects.”¹⁴⁹ In essence, because the ventilator would resolve the infant’s immediate breathing problems, withholding it on the basis of longer-term medical futility constituted discrimination on the basis of disability.

The Third Circuit took a similar approach in a case involving the denial of an Alzheimer’s patient’s access to a nursing home. The lower court concluded that she was not “otherwise qualified” under § 504 because she would not need access to the nursing home but for her disability.¹⁵⁰ As a result, “she sought a benefit because of her handicap and not in spite of it,” thus rendering the Rehabilitation Act inapplicable.¹⁵¹ The appellate court rejected this conclusion, reasoning that this interpretation of otherwise qualified, if “taken to its logical extreme,” would mean that “no program, service or institution designed specifically to meet the needs of the handicapped would ever have to comply with section 504 because every applicant would seek access to the program or facility *because* of a handicap, not in spite of it,” contradicting “both the statutory and regulatory framework of section 504.”¹⁵² The court concluded that the focus of § 504 should not be on why a plaintiff sought access to a program,

147. See, e.g., *In re Baby K*, 832 F. Supp. 1022, 1024–25 (E.D. Va. 1993), *aff’d on other grounds*, 16 F.3d 590, 592 (4th Cir. 1995).

148. *Id.*

149. *Id.* at 1028.

150. *Wagner v. Fair Acres Geriatric Ctr.*, 49 F.3d 1002, 1005, 1009 (3d Cir. 1995).

151. *Id.*

152. *Id.* at 1010.

but instead on why the plaintiff was denied access to it.¹⁵³ To the extent that courts agree with this more liberal interpretation, individuals with disabilities seeking health care services pursuant to the protocols should be able to easily establish that they are qualified within the meaning of the ADA and the Rehabilitation Act.

B. *Categorical Exclusion of People with Disabilities from Critical Care*

Against this background, the categorical exclusion of individuals with specific disabilities from some scarce resources during a pandemic would almost certainly qualify as discrimination on the basis of disability. Such provisions facially tie access to health care to status per se. If the individual possesses the identified condition, all avenues to securing care are completely closed, and there is no individualized inquiry made into either the severity of the underlying disability or its impact on the individual in need of care. Policies that preclude entire categories of disabilities from receiving services are among “the most transparent forms of discrimination” and violate the ADA on their face.¹⁵⁴

The case of *Alexander v. Choate* is instructive here, although involving a disparate impact claim.¹⁵⁵ The plaintiffs challenged a Medicaid plan that imposed a fourteen-day annual limit on Medicaid-covered hospitalization. The plaintiffs argued that such limitations would have a disparate impact on people with disabilities because of their greater need for health care and, as such, violated the Rehabilitation Act’s anti-discrimination provision. The Supreme Court agreed that the Rehabilitation Act requires people with disabilities to be “provided with meaningful access” to the benefits offered by the state.¹⁵⁶ It does not, however, require the state to offer substantively different benefits to individuals with disabilities simply because they have a greater need for them.¹⁵⁷ The Court upheld the restriction because the Medicaid provision did

not invoke criteria that have a particular exclusionary effect on the handicapped . . . [and did] not distinguish between those whose coverage will be reduced and those whose coverage will not on the basis of any test, judgment, or trait

153. *Id.*

154. *Anderlik & Wilkinson*, *supra* note 86, at 1223; *see also* *MX Grp., Inc. v. City of Covington*, 293 F.3d 326, 342 (6th Cir. 2002) (finding blanket prohibition in zoning ordinance constituted a per se violation of Title II of the ADA).

155. 469 U.S. 287, 290 (1985). The Supreme Court assumed, without deciding the issue, that “§ 504 reaches at least some conduct that has an unjustifiable disparate impact upon the handicapped.” *Id.* at 299. Notably, the legislative history to the ADA cited *Choate* as “the definitive interpretation of section 504 that [Congress] intended [T]itle II to copy.” Mark C. Weber, *Disability Discrimination by State and Local Government: The Relationship Between Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act*, 36 WM. & MARY L. REV. 1089, 1115 (1995).

156. *Choate*, 469 U.S. at 289–90, 301.

157. *See id.* at 303–04.

that the handicapped as a class are less capable of meeting or less likely of having.¹⁵⁸

In a footnote, the Court found it significant that the plan did not limit the number of days “to only particular handicapped conditions and takes effect regardless of the particular cause of hospitalization.”¹⁵⁹

Protocols that categorically exclude individuals with specific disabilities from receiving medical care in the event of a pandemic clearly do not meet the “meaningful access” standard articulated in *Choate*. Unlike the restrictions upheld by the Court, these provisions erect absolute barriers to health services for the individuals so identified and are not neutral on their face. By definition, there can be no meaningful access when all access is precluded as a matter of course. Because these protocols refuse treatment on the basis of disability status per se, they are unlawful under the ADA and the Rehabilitation Act in the absence of a viable defense.

Other courts have applied *Choate* to reach similar conclusions in cases involving the preclusion of specific disabilities from health care programs. In *Lovell v. Chandler*, for example, the Ninth Circuit considered whether the State of Hawaii could permissibly exclude the aged, blind, and disabled from participating in an experimental HMO program because their inclusion would result in a lack of predictability and cause health care insurers to refuse to participate in the new plan.¹⁶⁰ The court rejected the state’s argument that such restrictions were necessary to the viability of the program, reasoning that “the plain language of the regulations prohibits a state from” excluding people with disabilities from a program “unless it provides them with benefits ‘as effective as those provided to others.’”¹⁶¹ Because the state provided no benefits at all to this group, the court concluded that the plan violated Title II of the ADA.¹⁶² By the same token, the complete absence of benefits afforded to individuals with particular disabilities in the protocols suggests they likewise violate federal antidiscrimination laws on their face.

In response to such concerns, it is likely that proponents of the plans would point to precedent suggesting that medical treatment decisions are not cognizable under these statutes.¹⁶³ In some cases, this objection has

158. *Id.* at 302.

159. *Id.* at 302 n.22.

160. 303 F.3d 1039, 1045–46 (9th Cir. 2002).

161. *Id.* at 1055.

162. *Id.* at 1044, 1055; *see also* *Burns v. Chandler*, 939 F. Supp. 765, 766–67 (D. Haw. 1996) (holding that Hawaii’s pilot program changing from a fee for service to a managed care plan categorically excluded the blind and disabled because plaintiffs were not offered the option to participate in a separate, equal program but instead were categorically excluded); *Anderlik & Wilkinson*, *supra* note 86, at 1197 (suggesting that *In re Baby K* stands for the proposition that “no condition-based treatment limitation is permissible under federal anti-discrimination law unless the case is one of absolute physiological futility or the limitation is at the request of a patient or surrogate”).

163. *See, e.g.*, *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

been addressed in the context of the “otherwise qualified” debate discussed earlier.¹⁶⁴ In others, the argument is stated more categorically that the statutes simply do not apply to medical treatment decisions.¹⁶⁵ This position is not surprising in light of courts’ understandable reluctance to second-guess complicated decisions made by health professionals in their area of expertise. While cases involving a firm refusal to treat may be straightforward, claims of disparate treatment will often require inquiry into the realm of professional judgment and result in a battle of experts.¹⁶⁶ Because medical treatment decisions in most circumstances necessarily must account for the existence and effects of an individual’s disability, it is strained to conclude that such consideration constitutes unlawful discrimination “because of” disability.

The logic of these cases, however, would seem inapposite to an evaluation of the legality of protocols promulgated in advance of a pandemic, particularly those which categorically preclude access to care. Notably, the Supreme Court has recognized that “a hospital rule or state policy denying or limiting [meaningful] access [to medical services] would be subject to challenge under § 504.”¹⁶⁷ Still, other courts have reasoned

decisions.”); *Fitzgerald v. Corrs. Corp. of Am.*, 403 F.3d 1134, 1144 (10th Cir. 2005); *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289, 1294 (11th Cir. 2005); *Wilson v. Woodford*, 2006 U.S. Dist. LEXIS 12330, at *3 (E.D. Cal. Mar. 23, 2006); see also Robert J. Moosy, Jr., Comment, *Health Care Prioritization and the ADA: The Oregon Plan 1991-1993*, 31 HOUS. L. REV. 265, 322 (1994) (“[M]edical data and professional judgments based on that data are probably outside of the scope of the Title II of the ADA because they are medical treatment decisions . . .”).

164. See, e.g., *Fitzgerald*, 403 F.3d at 1144 (concluding that plaintiff was not “‘otherwise qualified’ for such treatment in the absence of his alleged disability—his alleged disability in this case was the reason why [he] was seeking medical treatment”); *Toney v. U.S. Healthcare, Inc.*, 838 F. Supp. 201, 203 (E.D. Pa. 1993) (finding plaintiff failed the “otherwise qualified” test because his “handicapping condition, HIV infection, is exactly the same condition for which he seeks medical attention”).

165. See, e.g., *Schiavo*, 403 F.3d at 1294 (“The Rehabilitation Act, like the ADA, was never intended to apply to decisions involving the termination of life support or medical treatment.”); *United States v. Univ. Hosp.*, 729 F.2d 144, 160 (2d Cir. 1984) (finding that “[i]n view of [the] consistent congressional policy against the involvement of federal personnel in medical treatment decisions, we cannot presume that congress intended to repeal its earlier announcements” through passage of § 504); *Lesley v. Chie*, 81 F. Supp. 2d 217, 224 (D. Mass. 2000) (“Section 504 is not meant to apply to medical treatment decisions.”); *Toney*, 838 F. Supp. at 203 (agreeing that “medical treatment decisions . . . are nonreviewable under § 504 of the Rehabilitation Act”). As Dean Mary Crossley has noted, “an attempt to draw clear lines around the concepts of benefit, denial based on disability, and qualification of a disabled individual is doomed to failure, or at least to severe confusion. . . . [S]ome overlap in the discussion is inevitable.” Crossley, *supra* note 138, at 214–15.

166. See, e.g., Crossley, *supra* note 3, at 63; see also *Univ. Hosp.*, 729 F.2d at 157 (finding that medical treatment decisions are entitled to deference because, “[I]t would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision . . . was based on a ‘bona fide medical judgment,’ however that phrase might be defined.”).

167. *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 624 (1986). The Supreme Court specifically declined to answer the question of “whether § 504 ever applies to individual medical treatment decisions involving handicapped infants.” *Id.*

that while courts may not overturn medical decisions, § 504 “properly permits an inquiry into whether a medical decision is ‘a *bona fide* medical judgment,’ or whether handicap has improperly been taken into account.”¹⁶⁸ As such, there would seem little basis for the sweeping conclusion that all medical treatment decisions are insulated from federal review.

Moreover, a meaningful distinction can be drawn between the cases declining judicial review and the protocol provisions at issue. The cases declining to review medical treatment decisions generally require scrutiny of professional judgment rendered to a specific individual without predetermined limitations as to what care may be provided.¹⁶⁹ Because the professional’s decision pertains to and can be evaluated in the context of a particular patient and his actual need for treatment, it is necessarily based, at least to some extent, on an individualized determination as mandated by the ADA. It may be that once this threshold is crossed, the legitimacy and reasonableness of medical decisions are most appropriately evaluated in the context of state tort law and professional standards of care, rather than in the context of antidiscrimination laws.¹⁷⁰

In contrast, sweeping policies that preclude or significantly limit entire categories of people with disabilities from receiving medical care in advance of actual need necessarily are based on generalizations concerning status. Their legitimacy depends on whether scientific evidence establishes that no individual in the excluded class could possibly qualify for or benefit from the medical treatment at issue, or whether the exclusionary criteria is actually based on prejudicial stereotypes and myths. It is precisely this type of inquiry that Congress intended to reach through the ADA and the Rehabilitation Act, and such policies should be subject to judicial review.¹⁷¹

168. *Glanz v. Vernick*, 750 F. Supp. 39, 46 (D. Mass. 1990) (citing *Univ. Hosp.*, 729 F.2d at 162 (Winters, J., dissenting)).

169. *See, e.g.*, *Burger v. Bloomberg*, 418 F.3d 882, 883 (8th Cir. 2005) (prisoner alleging inadequate medical care for his diabetes); *Fitzgerald*, 403 F.3d at 1144 (equating plaintiff’s claim for relief under the ADA and the Rehabilitation Act as one for alleged medical negligence and thus not cognizable); *Grzan v. Charter Hosp.*, 104 F.3d 116, 122–23 (7th Cir. 1997) (finding the “institutional treatment decision” in *University Hospital* “a closer case” under § 504 than the individual mistreatment by the defendant physician, which essentially “alleges malpractice”); *Lesley*, 81 F. Supp. 2d at 225 (finding no cause of action where plaintiff challenged physician’s decision to transfer plaintiff to a different facility to treat her); *Toney*, 838 F. Supp. at 204 (concluding that “a medical doctor may [not] be subject to a lawsuit under § 504 for refusing to see a regular adult patient every time he or she desires”). *But see Johnson v. Thompson*, 971 F.2d 1487, 1493–94 (10th Cir. 1992).

170. *Cf. Bryant v. Madigan*, 84 F.3d 246, 249 (7th Cir. 1996) (“[I]t would be . . . odd to suppose that disabled persons whose disability is treated negligently have a federal malpractice claim by virtue of the [ADA], whereas a sick or injured but not disabled person . . . must be content with the remedy that the state law of medical malpractice provides.”).

171. *See, e.g.*, *Anderlik & Wilkinson*, *supra* note 86, at 1240 (“Rather than exempting medical decisions . . . from review, or making medical judgments themselves, courts might scrutinize coverage distinctions for the standard forms of discrimination, asking whether . . . a distinction

The significance of the distinction between individualized and predetermined categorical limitations on medical treatment is exemplified by the treatment of a woman with Down syndrome who sought a heart and lung transplant in the 1990s.¹⁷² Physicians initially refused to place her on a waiting list for a transplant because of a general assumption that all individuals with Down syndrome “lacked the mental capacity to survive the post-transplantation regimen.”¹⁷³ They took no account of the fact that she was a disability activist who had lived independently since the age of twenty.¹⁷⁴ Upon considering the issue, the U.S. Department of Justice indicated that the physicians’ actions could have violated the ADA because the denial was based on her diagnosis rather than an individualized assessment of her actual abilities.¹⁷⁵ Once that assessment was made, the physicians ultimately placed the woman on the transplant list, and she received donor organs within days.¹⁷⁶ Although the courts never considered the case, it suggests that federal antidiscrimination laws apply to medical protocols that categorically deny treatment on the basis of disability even when disability may be relevant to the treatment decision. It also demonstrates how the deference due to medical treatment decisions is rendered less significant when categorical policy exclusions are in place. Unlike individual treatment decisions, courts will not always need to enter the world of complex medical judgments in order to render a legal decision.

The breadth of the excluded categories in the pandemic protocols supports this argument, as well as the conclusion that they implicitly are based, at least in part, on unlawful assumptions. There is no scientific precision, for example, to the term “severe baseline cognitive impairments.” Individuals with a broad range of functioning could conceivably fall within this category, ranging from those in a persistent vegetative state to those with Down syndrome, schizophrenia, or Alzheimer’s disease.¹⁷⁷ In light of this variability, any generalized conclusion about their categorical ability to qualify for or benefit from critical care would seem highly suspect. It is equally true, moreover, that there can be a great deal of diversity among individuals with even the same disability.¹⁷⁸ Although some individuals with cystic fibrosis may be

reflects myths or stereotypes about a particular disability or neglect of or indifference to the needs of individuals with a . . . disability.”).

172. Crossley, *supra* note 3, at 65 (discussing case).

173. *Id.*

174. Angela T. Whitehead, *Rejecting Organs: The Organ Allocation Process and the Americans with Disabilities Act*, 24 AM. J.L. & MED. 481, 481 (1998).

175. Crossley, *supra* note 3, at 65.

176. *Id.*

177. Notably, there is no such category identified in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders, better known as the DSM-IV. See AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (4th ed. 2000).

178. See Karen J. Merrikin & Thomas D. Overcast, *Patient Selection for Heart Transplantation: When Is a Discriminating Choice Discrimination?*, 10 J. HEALTH POL., POL’Y & L. 7, 18 (1985) (“[P]ersons sharing a particular type of handicapping condition often do not share the

unlikely to achieve a favorable outcome if ventilation is provided, for example, others may have the potential to survive for many years with additional treatment. Because the exclusions are based on a generalized diagnosis rather than the individual's potential health outcomes, they suggest an assessment of the value of the lives to be saved rather than viability of specific treatment interventions—a consideration that clearly implicates and is governed by the ADA.

Proponents are nevertheless likely to argue that no disparate treatment claim is cognizable under the ADA because some individuals with disabilities will receive medical treatment pursuant to the protocols. It would seem likely that many, if not most, individuals admitted to a hospital with life-threatening illnesses during a pandemic could qualify as “disabled” under the relaxed definition promulgated in the amended ADA.¹⁷⁹ Because the majority of people with disabilities will receive, or at least qualify for, medical treatment pursuant to the protocols, they cannot be said to discriminate on the basis of disability.¹⁸⁰

The Supreme Court in *Olmstead v. L.C. ex rel. Zimring*, however, indicated that the ADA reaches both the uneven treatment of individuals with disabilities in relation to the able-bodied and the differential treatment among class members based on the nature or severity of the disability.¹⁸¹ This is consistent with courts who have concluded that “discrimination claims [are] actionable, even if it is only between members of a protected class.”¹⁸² Given that there are clear distinctions made between disabilities

same level of debilitation.”).

179. For a detailed discussion of the changes made to the disability definition, see Hensel, *supra* note 134, at 654–58 (2009). In particular, the Equal Employment Opportunity Commission's proposed regulations providing that an impairment may be substantially limiting even if relatively short-term in nature suggests that individuals in a pandemic may, by virtue of being sufficiently ill to require a ventilator, qualify as disabled. See Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, 74 Fed. Reg. 48,440 (Sept. 23, 2009) (to be codified at 29 C.F.R. § 1630.2(j)(2)(v)) (“An impairment may substantially limit a major life activity even if it lasts, or is expected to last, for fewer than six months.”).

180. See, e.g., *Traynor v. Turnage*, 485 U.S. 535, 549–50 (1988) (finding that “nothing in the Rehabilitation Act . . . requires that any benefit extended to one category of handicapped persons also must be extended to all other categories of handicapped persons,” but acknowledging that it would “arguably” be discriminatory to differentiate between disabilities “according to generalized determinations that lack any substantial basis”); see also *Anderlik & Wilkinson*, *supra* note 86, at 1235–39 (surveying cases).

181. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 598 (1999) (finding case actionable despite the fact that the plaintiffs identified no comparison class that was afforded preferential treatment); see also *Salcido ex rel. Gilliland v. Woodbury Cnty.*, 119 F. Supp. 2d 900, 937 (N.D. Iowa 2000) (“[E]xclusion of *all* persons with a specified disability, whatever the degree, from benefits provided to other disabled persons [does not] excuse discrimination by reason of that particular disability.”); *McNally v. Prison Health Servs.*, 46 F. Supp. 2d 49, 57–59 (D. Me. 1999) (finding disparate treatment where prison system had a distinct and ineffective drug distribution program for HIV-positive prisoners).

182. *Salcido*, 119 F. Supp. 2d at 937 (discussing *Olmstead*); see also *Mark H. v. Lemahieu*, 513 F.3d 922, 938 (9th Cir. 2008) (stating that “evidence that appropriate services were provided to *some* disabled individuals does not demonstrate that others were not denied meaningful access

in the protocols that may effectively mean the difference between life and death, courts should find these claims reviewable under the ADA and the Rehabilitation Act.

C. Exclusions Based on Likely Duration of Care Needed

In addition to, or in lieu of, identifying specific disabilities to exclude from care, some protocols have used the patient's likely duration of need for the scarce resource as a factor in allocation decisions.¹⁸³ The longer the patient is likely to need the intervention, such as a ventilator, the less likely he or she is to receive it in the first instance. At least one protocol explicitly recognizes that this assessment is "likely to involve more subjective interpretation of data and [is] thus more fraught with ethical peril."¹⁸⁴ The duration of need criteria is nevertheless defended as necessary "[b]ecause the conditions under which the triage process will be triggered implies a severe limitation of resources, [and] a single patient who remains in an ICU for an extended period may use resources that could save the lives of several other patients."¹⁸⁵ Accordingly, the question becomes whether facially neutral duration of care considerations are permissible under the ADA and Rehabilitation Act.

The *Choate* opinion once again is instructive here. The Supreme Court made clear that while a disparate impact claim may be cognizable under the Rehabilitation Act, it does not obligate the government "to minimize the negative effects of its decisions on persons with disabling conditions" in every instance.¹⁸⁶ There, the record presented no evidence indicating that conditions "uniquely associated" with disabilities "or occurring with greater frequency among them [could] not be effectively treated" within the coverage limitation.¹⁸⁷ As a result, the Court upheld the limitation, concluding that it would provide those both with and without disabilities "with identical and effective hospital services fully available for their use, with both classes of users subject to the same durational limitation."¹⁸⁸

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. The critical inquiry will be whether the duration of care limitation provides an equal or meaningful

'solely on the basis of their disability'" (quoting *Lovell v. Chandler*, 303 F.3d 1039, 1053–54 (9th Cir. 2002)); cf. *Henrietta D. v. Bloomberg*, 331 F.3d 261, 273 (2d Cir. 2003) (stating that "[w]e follow our fellow circuits, and the suggestions of the *Olmstead* plurality, in concluding that" plaintiffs do not need to "identify a 'comparison class' of 'similarly situated individuals given preferential treatment'" in order to state a claim under the ADA (quoting *Olmstead*, 527 U.S. at 598)).

183. See *supra* Part II.B.

184. Hick et al., *supra* note 52, at 6.

185. Devereaux et al., *supra* note 6, at 57–58; see also Christian et al., *supra* note 10, at 1379 (establishing "a ceiling on the amount of resources that can be expended on any one person" as "the third component of the triage protocol").

186. Weber, *supra* note 155, at 1116.

187. Alexander v. Choate, 469 U.S. 287, 302 n.22 (1985).

188. *Id.* at 302.

opportunity to obtain the same benefit or results as offered to non-disabled individuals.¹⁸⁹ The concept of “meaningful access” in this context, however, is not at all clear. In some instances, courts have found access to be meaningful if any kind of access is provided¹⁹⁰ or access is at least theoretically available on the same basis to both the able-bodied and disabled.¹⁹¹ These courts do not scrutinize whether individuals with disabilities actually are able to benefit from the good or service in the form in which it is offered. Under this logic, duration of need considerations in allocation protocols would likely be permissible because they are facially neutral and do not curtail all access to care by people with disabilities. In light of the reality that courts are traditionally reluctant to intrude into medical decisionmaking, this approach may be attractive to the judiciary.

There are also courts, however, which equate “meaningful” with “adequate” in some respects and scrutinize the practical effect of the exclusionary criteria.¹⁹² Although courts have declined to “define precisely the severity of the deprivation that a plaintiff must experience . . . [in

189. See 45 C.F.R. § 84.4(b)(2) (2010) (“[A]ids, benefits, and services . . . are not required to produce the identical result or level of achievement for handicapped and nonhandicapped persons, but must afford handicapped persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement.”).

190. See Laurence Paradis, *Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act: Making Programs, Services, and Activities Accessible to All*, 14 STAN. L. & POL’Y REV. 389, 399–404 (2003) (detailing case law on this issue); Alexander Abbe, Comment, “*Meaningful Access*” to Health Care and the Remedies Available to Medicaid Managed Care Recipients Under the ADA and the Rehabilitation Act, 147 U. PA. L. REV. 1161, 1190–97 (1999) (same); see also *Hunsaker v. Contra Costa Cnty.*, 149 F.3d 1041, 1044 (9th Cir. 1998) (finding that “disparate impact discrimination is actionable only if it involved a denial of ‘meaningful access’ to public benefits”); *Liberty Res., Inc. v. Phila. Hous. Auth.*, 528 F. Supp. 2d 553, 557 (E.D. Pa. 2007) (finding that Housing Choice Voucher Program was meaningfully accessible because the “core services” were available to all participants even though program ignored reality that accessible housing was in short supply and was “less than ideal”).

191. See, e.g., *Jones v. City of Monroe*, 341 F.3d 474, 478 (6th Cir. 2003) (finding access to free parking meaningful where disabled and nondisabled had equal access to it, even though plaintiff was unlikely to benefit from such access); *Rodriguez v. City of N.Y.*, 197 F.3d 611, 618 (2d Cir. 1999) (“The ADA requires only that a particular service provided to some not be denied to disabled people.”).

192. See Abbe, *supra* note 190, at 1194; Leslie Pickering Francis & Anita Silvers, *Debilitating Alexander v. Choate: “Meaningful Access” to Health Care for People with Disabilities*, 35 FORDHAM URB. L.J. 447, 466–73 (2008); Paradis, *supra* note 190, at 400–01; see also *Am. Council of the Blind v. Paulson*, 525 F.3d 1256, 1267 (D.C. Cir. 2008) (finding that blind plaintiffs stated a claim that they lacked meaningful access to U.S. currency because it is provided “in a format readable only by the sighted”); *Henrietta D. v. Bloomberg*, 331 F.3d 261, 275 (2d Cir. 2003) (clarifying that courts’ focus should be on “whether the plaintiffs with disabilities could achieve meaningful access, and not whether the access the plaintiffs had (absent a remedy) was less meaningful than what was enjoyed by others”); *Shotz v. Cates*, 256 F.3d 1077, 1080 (11th Cir. 2001) (“A violation of Title II . . . does not occur only when a disabled person is completely prevented from enjoying a service, program, or activity.”); *Crowder v. Kitagawa*, 81 F.3d 1480, 1484 (9th Cir. 1996) (“Although Hawaii’s quarantine requirement applies equally to all persons entering the state with a dog, its enforcement burdens visually-impaired persons in a manner different and greater than it burdens others.”).

order] to demonstrate a denial of meaningful access,”¹⁹³ they will scrutinize whether the access is sufficient to address the needs in question. These courts make a careful distinction between a request for additional substantive benefits and a reasonable modification to make the provided benefit accessible.¹⁹⁴ The resolution of this distinction will often turn on the way in which the benefit is defined. While “adequate health care” is too amorphous to be actionable as per *Choate*,¹⁹⁵ the more narrowly tailored “adequate ventilator use” may prove to be acceptable.

Following this line of reasoning, the durational limits would be discriminatory to the extent that their practical effect is to erect a significant hurdle between people with disabilities and scarce resources during a health emergency. If evidence suggests that individuals in the excluded categories have the potential to benefit from ventilator use but because of their disability “cannot be effectively treated”¹⁹⁶ within the established durational limits, *Choate* would suggest such limitations are actionable under the Rehabilitation Act and Title II. Disability advocates may plausibly argue that they are not seeking additional substantive benefits, but instead a reasonable modification—an extension of time—to facilitate meaningful access to the same benefit—a ventilator. This approach is consistent with the legislative history of the ADA, which makes clear that people with disabilities are entitled to “an equal opportunity to obtain the same results as others.”¹⁹⁷ An extension of time would seem to be a reasonable modification absent a showing that it would constitute a fundamental alteration or undue hardship. Where an equal result is readily achievable but is not permitted for reasons related to the individual’s disability, it would be difficult to conclude the access is meaningful in the normal sense of that word. As one scholar aptly stated, “That a person’s disability deprives her of equal odds is tragic enough, without compounding that misfortune by denying her equal access to potentially beneficial medical care.”¹⁹⁸

Further complicating the matter, the durational limits at issue in the protocols are not fixed and thus are unlikely to be uniformly applied. Whether or not the individual’s projected duration of use will preclude her from access to care will depend on a medical provider’s assessment of her condition. Such variability permits subjective notions about the worth of life with disabilities to play a potentially significant role in allocating care.

193. *Paulson*, 525 F.3d at 1269.

194. *See* *Wright v. Giuliani*, 230 F.3d 543, 547 (2d Cir. 2000).

195. *Alexander v. Choate*, 469 U.S. 287, 303 (1985).

196. *Id.* at 302 n.22; *see also* *Rodde v. Bonta*, 357 F.3d 988, 997 (9th Cir. 2004) (citing *Choate* in support of its conclusion that the closure of the Rehabilitative Center foreclosed “meaningful access” to health care for individuals with disabilities because these services “cannot currently be provided effectively anywhere in the County system”).

197. H.R. REP. NO. 101-485(III), at 55 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 478; H.R. REP. NO. 101-485(IV), at 57, *reprinted in* 1990 U.S.C.C.A.N. 512, 546 (1990) (“[I]ndividuals with disabilities must be afforded an equal opportunity to attain substantially the same result.”).

198. *See* Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491, 516 (1995).

An otherwise healthy child's need to use a ventilator for fourteen days may seem a justified use of resources. The same duration of need in an adult with severe mental retardation may seem insupportable. Inevitably, the life-and-death decisions about who should receive care will be based in part on the characteristics of the individuals who will otherwise go without. In the absence of clear guidance as to how much time is too much time, the degree of discretion provided by vague durational considerations is highly problematic. Because it may be difficult, if not impossible, to establish static durational limits in the context of an ongoing and fluid pandemic, there may be no way to incorporate durational limits into protocols without either inadvisably restricting the discretion of medical providers or running afoul of antidiscrimination laws.

Ultimately, whichever approach is adopted by the courts, the legitimacy of durational limits will depend on the extent to which evidence supports the connection between the individual's disability and likely need for prolonged care. Where there is no meaningful connection between the two, durational limits by definition are not necessary to an effective response in a pandemic. Problematically, however, any meaningful evidence in this regard will be virtually impossible to secure in advance. The earliest responders in particular will be operating in the absence of complete information in a pandemic. As such, the potential for durational limits to be imposed in a discriminatory way is problematically high, counseling against their implementation.

D. Exclusions Based on Quality of Life Considerations

Some of the protocols allocate scarce resources among pandemic patients based on the medical professional's assessment of the individual's anticipated quality of life after treatment. Individuals with functional impairments post-treatment will be less likely to receive treatment in the first instance regardless of whether their disability preexists or is a consequence of the treatment. The question becomes whether consideration of quality of life, either as a component of identifying specific disabilities for exclusion or as a general consideration for precluding care, is consistent with the ADA and the Rehabilitation Act.

The State of Oregon similarly attempted to ration health care in the early 1990s based on quality of life considerations. The subsequent Oregon Health Care Plan, designed to provide comprehensive health care to all citizens, included both managed competition and a prioritized benefits package to limit costs.¹⁹⁹ The state identified and ranked a list of reimbursable conditions by using a complex formula based on both "the medical outcomes of treatment and the perceived quality of life related to each outcome," with emphasis given to the latter.²⁰⁰ In part, the quality of

199. See *ADA Analyses of the Oregon Health Care Plan*, 9 ISSUES L. & MED. 397, 397 (1994) (describing the Oregon Plan).

200. *Id.* at 401 (quoting Letter from Thomas J. Marzen & Daniel Avila, Nat'l Legal Ctr. for Medically Dependent & Disabled, Inc., to the Honorable Chris Smith, U.S. Representative (Dec. 5, 1991) [hereinafter Letter from Marzen & Avila, Dec. 5]).

life component was assessed through public opinion polls weighing the “acceptability or distaste for particular functional limitations.”²⁰¹

In order to implement the plan as developed, Oregon was required to first secure several Medicaid waivers from the federal government. The U.S. Department of Health and Human Services initially denied the waivers, however, because of its belief that the plan’s prioritization of treatment based on quality of life considerations violated the ADA.²⁰² HHS was particularly concerned with the state’s use of public opinion polls to rank the desirability of potential treatments. Because public opinion is very likely influenced by the myths, stereotypes, and prejudices attached to disability, such polls are likely to overemphasize the impact of functional limitations and underestimate the quality of life of individuals with such limitations.²⁰³ Empirical research confirms that people who neither are disabled nor have a disabled family member consistently overestimate the burdens of living with a disability.²⁰⁴

Oregon thereafter submitted a revised plan that omitted quality of life considerations. The altered plan prioritized treatments based in part on professional medical judgment of the patient’s likely outcome, looking to the patient’s “residual effects (symptoms) because of or in spite of treatment.”²⁰⁵ An outcome was deemed to be “favorable” if the treatment was able both to “maintain life *and* to preserve or to restore an individual to an ‘asymptomatic’ state.”²⁰⁶ Treatments that left individuals in a “symptomatic” state were less likely to be funded by the state.²⁰⁷

Oregon submitted the second plan for HHS approval, which HHS denied again.²⁰⁸ HHS was concerned that the concept of “*symptom*” was

201. *Id.* at 408 (quoting Letter from Thomas J. Marzen & Daniel Avila, Nat’l Legal Ctr. for Medically Dependent & Disabled, Inc., to the Honorable Chris Smith, U.S. Representative (Dec. 17, 1991) [hereinafter Letter from Marzen & Avila, Dec. 17]).

202. *Id.* at 405 (“By utilizing these discriminatory assessments to determine a treatment’s net benefit, the plan discriminates on the basis of disability in an inappropriate manner.” (quoting Letter from Marzen & Avila, Dec. 5, *supra* note 200)).

203. *Id.* at 403–05.

204. See Jodi Halpern & Robert M. Arnold, *Affective Forecasting: An Unrecognized Challenge in Making Serious Health Decisions*, 23 J. GEN. INTERNAL MED. 1708, 1708 (2008) (noting that the difference in quality of life ratings has been demonstrated for paraplegia, visual impairment, heart disease, asthma, dialysis, and living with a colostomy and concluding that, “The overarching conclusion is that people fail to envision their own capacities to adapt to declines in health.”); Peter A. Ubel et al., *Whose Quality of Life? A Commentary Exploring Discrepancies Between Health State Evaluations of Patients and the General Public*, 12 QUALITY LIFE RES. 599, 599–600 (2003) (noting that the “discrepancies suggest that either the public does not understand how valuable life can be for people with disabilities or that people with disabilities consciously or subconsciously overstate their” health-related quality of life).

205. *ADA Analyses of the Oregon Health Care Plan*, *supra* note 199, at 414 (quoting Letter from Thomas J. Marzen & Daniel Avila, Nat’l Legal Ctr. for Medically Dependent & Disabled, Inc., to the Honorable Chris Smith, U.S. Representative (Jan. 11, 1993)).

206. *Id.*

207. See *id.* at 414–15.

208. *Id.* at 422 (referring to Letter from Timothy B. Flanagan, Assistant Attorney Gen. to Susan K. Zagame, Acting Gen. Counsel, Dep’t of Health & Human Servs. (Jan. 13, 1993)).

another term for “*disability*,” thus again implicating the ADA and the Rehabilitation Act.²⁰⁹ HHS encouraged the state to resubmit the plan, however, explaining that consideration of ““medical effectiveness”” may be permissible where the state did not “take into account changes in individuals’ functional limitations as a result of treatment.”²¹⁰ Some scholars have concluded that this approach confirms that the state may value a treatment’s ability to prevent death but effectively cannot consider “the effectiveness of treatment for non-lethal conditions.”²¹¹

Although no court has ever considered the legitimacy of the plan, its history suggests that “any methodology that would intentionally ration health care resources by associating quality of life considerations with disabilities does not comport with the mandate of the ADA.”²¹² As HHS correctly noted, quality of life considerations are not “neutral” even when couched in mathematical terms and are very likely to be driven by prejudices and stereotypes concerning the desirability of life with disabilities. There is no question that the use of such criteria in allocation protocols will result in the systematic denial of emergent care to individuals with disabilities. Disabilities may impair current functioning, diminish lifespan, and generally create challenges that are not experienced by more typical Americans—all factors that would be evaluated in a quality of life consideration. By favoring those with no functional impairments, the protocols implicitly endorse the belief that the lives of individuals without disabilities are more valuable than that of their unfortunate counterparts. This is precisely the kind of biased judgment that is precluded by the ADA and the Rehabilitation Act, and the stakes could not be higher. Resolution of this factor will often mean the difference between life and death in a public health emergency.

Notably, the treatment of the second Oregon plan suggests that the ADA, in setting treatment priorities, does not distinguish between quality of life judgments made by the public and those made by medical professionals. Some have argued that this distinction is untenable, citing the Supreme Court’s admonition in *School Board of Nassau County v. Arline* that “courts normally should defer to the reasonable medical judgments of public health officials” when making findings of medical fact.²¹³ “Because [allocation] decisions involve the medical judgments of administrative officials in their area of expertise they should be” upheld so

209. *Id.* at 421–22. Such a concern is not unreasonable given that “[f]or medicine and public health, disease and disability is the problem to solve” and eradication is part of the “professional mission.” Adrienne Asch, *Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy*, 89 AM. J. PUB. HEALTH 1649, 1650 (1999).

210. *ADA Analyses of the Oregon Health Care Plan*, *supra* note 199, at 423 (quoting HEALTH CARE FIN. ADMIN., 11-P-90160/0-01, SPECIAL TERMS AND CONDITIONS REGARDING THE OREGON PLAN (1993)).

211. Moosy, *supra* note 163, at 310.

212. *ADA Analyses of the Oregon Health Care Plan*, *supra* note 199, at 411.

213. 480 U.S. 273, 288 (1987).

long as they are exercising their judgment in good faith in a reasonable manner.²¹⁴

As history has demonstrated, however, medical professionals are not immune to the societal bias towards life with disabilities. For example, in the 1990s, well into the AIDS epidemic, one study “found that twenty-three percent of U.S. medical residents ‘indicated that they would not care for persons with AIDS if they had a choice.’”²¹⁵ In prenatal genetic diagnosis, health care professionals focus on negative aspects, including the “burden” on the family, of having a child with Down syndrome.²¹⁶ The eugenics movement, moreover, was advocated by physicians in the name of “science” and bettering society.²¹⁷ There is significant evidence that an assessment of quality of life by any nondisabled individual will systematically undervalue the quality of life with disabilities, particularly mental disabilities, whether or not the individual in question is a medical provider.²¹⁸ As Dean Mary Crossley has explained, “a physician’s quality-of-life value judgment remains just that—a subjective value judgment that may be infected with stereotypic assumptions regarding the value of life with a severe disability.”²¹⁹

In part, the problem of bias arises because of the very dominance of the medical model of disability. If medicine can alleviate some of the symptoms of the disorder, the physician’s identification of disability is less likely to deprive a patient of intensive, life-sustaining treatment.²²⁰ The

214. Moosy, *supra* note 163, at 317.

215. Ariel R. Schwartz, Note, *Doubtful Duty: Physicians’ Legal Obligations to Treat During an Epidemic*, 60 STAN. L. REV. 657, 667 (2007) (quoting study by the American Civil Liberties Union AIDS Project). Although such results could be on account of “prejudicial attitudes towards people with HIV/AIDS,” the “fear of becoming infected with AIDS, not prejudice, was the compelling factor for physicians who wanted to deny treatment.” *Id.* However, by the 1990s, it was well-known in the medical community that HIV/AIDS was not casually transmitted and that health care workers using CDC recommended precautions with all patients were highly unlikely to be infected through their work. *Bragdon v. Abbott*, 524 U.S. 624, 650–52 (1998); *Abbott v. Bragdon*, 163 F.3d 87, 89–90 (9th Cir. 1998).

216. Jan M. Hodgson et al., “*Testing Times, Challenging Choices*”: An Australian Study of Prenatal Genetic Counseling, 19 J. GENETIC COUNSEL 22, 29 (2010) (“[T]here was no overt encouragement [in any discussion] of clients to deliberate about the possibility of having a child with a disability.”). This study is consistent with earlier research in which nurses and genetic counselors (but not parents) viewed a film about families raising children with Down syndrome and found the film “unrealistic” and “too positive.” Asch, *supra* note 209, at 1654.

217. See, e.g., Paul A. Lombardo, *Disability, Eugenics, and the Culture Wars*, 2 ST. LOUIS U.J. HEALTH L. & POL’Y 57, 58–61 (2008) (discussing history of eugenics movement).

218. See, e.g., Crossley, *supra* note 138, at 224–25 (“Particularly apparent in some of the medical commentary is the devaluation of the lives of persons whose disability affects their neurological functioning.”); see also Halpern & Arnold, *supra* note 204, at 1708.

219. Crossley, *supra* note 138, at 225; see also *Developments in the Law—Medical Technology and the Law*, 103 HARV. L. REV. 1519, 1636 (1990) (“Experience indicates that if physicians are forced to choose among people in the allocation of scarce medical resources, they will choose people most like themselves and exclude those who they deem ‘unworthy.’”).

220. This is exemplified by the tort of wrongful birth and wrongful life. See, e.g., Mary Terrell White, *Making Responsible Decisions: An Interpretive Ethic for Genetic Decisionmaking*, 29

impact of societal discrimination and external barriers to a “meaningful” life are simply not considered in this analysis.²²¹ The causal focus of this inquiry is the disability in isolation rather than in the context of family, community, and the individual as a whole person. It does not acknowledge the potential richness that life may hold for those with even the most severe defects.²²²

Notably, some would argue that a more categorical approach is appropriate in the context of a public health emergency. As one protocol explained, physicians typically weigh family wishes and subjective considerations heavily when evaluating when care is “futile.”²²³ A disaster will reverse this calculus, however, “so that the weight is on objective prognostic criteria and less on subjective and individual patient factors.”²²⁴ As some scholars have recognized, however, “[i]f the anti-disability discrimination laws mean anything, they mean that a treatment that is provided to someone who will not be disabled after treatment cannot be denied to someone who will be disabled.”²²⁵ Because quality of life determinations are inherently subjective and may be based on biased assumptions concerning life with disabilities, they are unlikely to survive a challenge under the ADA or the Rehabilitation Act.²²⁶

HASTINGS CTR. REP. 14, 15 (1999) (arguing that in constructing an ethical orientation to the use of genetic testing, scholars must recognize that “[a]dvances in the diagnosis and treatment of genetic disorders may rapidly change perceptions of what counts as a genetic disease or disability”); cf. Rosamund Scott, *The Uncertain Scope of Reproductive Autonomy in Preimplantation Genetic Diagnosis and Selective Abortion*, 13 MED. L. REV. 291, 311 (detailing a sliding scale of defects that might be considered “serious” under English abortion law, based in part on “the probability of effective treatment, either *in utero* or after birth”).

221. Cf. Hahn, *supra* note 11, at 101 (describing the “common tendency to confuse disability with impairments . . . and to concentrate on clinical examinations that tend to exclude the analysis of problems outside the boundaries of the human organism”).

222. See, e.g., *id.* at 111 (“[D]isabled persons do not experience the external environment in the same way as the nondisabled. The focus of attention is different; the concentration of energy is different; the impressions formed in personal interactions are different; and the analysis of political problems may reflect this differenced vantage point.”); see also Adrienne Asch, *Disability, Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 332 (2003) (“Life with nearly all disability potentially contains rewarding personal relationships, stimulation and discovery, self-development, and contributions to others.”).

223. Hick et al., *supra* note 52, at 2.

224. *Id.* This position ignores the well-documented challenges to defining the concept of futility, even on the basis of objective, empirically based data. Paul R. Helft et al., *The Rise and Fall of the Futility Movement*, 343 NEW ENG. J. MED. 293, 293–96 (2000).

225. Maxwell J. Mehlman et al., *When Do Health Care Decisions Discriminate Against Persons with Disabilities?*, 22 J. HEALTH POL., POL’Y & L. 1385, 1396 (1997).

226. Several disability advocacy groups have argued that “any decision not to treat based on patient quality of life violates the Americans with Disabilities Act of 1991 (ADA).” Philip G. Peters, Jr., *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. U. L. REV. 798, 806 (1997) (describing positions adopted by the director of the Center on Disability and Health and counsel for the National Legal Center for the Disabled and Dependent).

E. Exclusions Based on Medical Effectiveness

Although there is little question that precluding individuals with specific disabilities from receiving critical health care in public health emergencies raises legal concerns, it is less clear whether limiting treatment more generally to those who are most likely to benefit from it would implicate the ADA. This raises the issue not of quality of life post-treatment, but rather the response to treatment administered.

The legality of this approach is likely to lie in the definition of “effectiveness” or “medical benefit” employed in the protocols. Assessing such terms will require decisionmakers both to evaluate the potential outcomes of treatment and to place values on these outcomes.²²⁷ To the extent that this evaluation is limited to the most basic question of whether a particular patient will survive or receive a physiological benefit from implementation of the scarce resource, using medical effectiveness or benefit as allocation principles would seem consistent with the ADA.²²⁸ The Supreme Court in *Choate* required only that there be meaningful access to health care under state policies.²²⁹ If there is scientifically sound data suggesting that the individual is unlikely to survive for an appreciable period of time despite access to the scarce resource, it would be reasonable to conclude they are not “qualified” for the benefit regardless of the source of the incapacity.²³⁰ This is largely consistent with the Equal Employment Opportunity Commission approach in the context of insurance plans that deny coverage for disability-specific treatment. The Commission has stated that the insurer may demonstrate the absence of subterfuge by “prov[ing] by reliable scientific evidence that the disability-specific treatment does not cure the condition, slow the degeneration/deterioration or harm attributable to the condition, alleviate the symptoms of the condition, or maintain the current health status of individuals with the disability who receive the treatment.”²³¹ To find otherwise, moreover, would call into question a number of well-established and widely accepted medical practices in place at the time the ADA was passed, such as the prioritization of heart transplant recipients.²³²

227. Peters, *supra* note 198, at 500.

228. This type of evaluation is a strict definition of effectiveness, which has been endorsed as ethically preferable compared to looser definitions in the ongoing debates of medical “futility.” Bernard Lo, *Futile Interventions*, in *RESOLVING ETHICAL DILEMMAS: A GUIDE FOR CLINICIANS* 69, 69–71 (4th ed. 2009) (citations therein).

229. *Alexander v. Choate*, 469 U.S. 287, 303–04 (1985).

230. See Peters, *supra* note 198, at 514–15 (discussing findings by other authors).

231. EQUAL EMPLOYMENT OPPORTUNITY COMM’N, INTERIM ENFORCEMENT GUIDANCE ON THE APPLICATION OF THE AMERICANS WITH DISABILITIES ACT OF 1990 TO DISABILITY-BASED DISTINCTIONS IN EMPLOYER PROVIDED HEALTH INSURANCE 14–15 (1993), available at <http://www.eeoc.gov/policy/docs/guidance.pdf>.

232. See Peters, *supra* note 198, at 522. Individuals with underlying disabilities that are likely to reduce the recipient’s odds of survival post-transplant are given a lower priority ranking for a transplant. *Id.*; see also Merrikin & Overcast, *supra* note 178, at 15 (“[T]he Rehabilitation Act does not prohibit reasonable and necessary physiologically—or mentally—based requirements of a transplantation program, even if they result in the exclusion of some handicapped individuals.”).

There is no question that some preexisting disabilities will make it more difficult for individuals to fight and survive unrelated illnesses, and therefore, such standards will exclude some individuals with disabilities from receiving care.²³³ Nevertheless, such criteria are facially neutral and involve the individualized consideration missing from the categorical denials that run afoul of the ADA. Unlike subjective interpretations regarding quality of life, the use of medical effectiveness in this manner is not based on stereotypes, generalizations, or myths about disabilities. As HHS reasoned in assessing the Oregon Plan, it should be permissible to consider “the cost of medical procedures, the length of hospital stays, prevention of death, and prevention of contagious diseases,” as well as “any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities.”²³⁴ In the absence of a strict first-come, first-served policy, the ability of the individual to immediately gain from implementation of the intervention or, more basically, to survive its application would seem to be the most neutral criteria, although nevertheless imperfect, for distributing resources in times of crises. It also most easily tracks the logic in those cases which conclude that denial of medical treatment is not reachable by the ADA. In such circumstances, it would be strained to conclude that the medical care is denied “because of” the disability. Instead, the denial is based on the individual’s functional medical status and poor odds of surviving the immediate application of the intervention.

Under this logic, the use of SOFA scores to allocate resources would seem permissible under the ADA. There is scientific evidence to suggest that that SOFA scores are “reliable predictors of outcome throughout the ICU stay.”²³⁵ Of critical significance, this assessment allocates care based on the patient’s current functional operation rather than disability status per se. Access here is equal to the extent that anyone with a similar score would be eligible for the intervention. Although individuals with severe disabilities may ultimately be less likely to achieve an acceptable score, this would seem the quintessential case where courts should defer to the medical expertise of professionals. In a critical time of limited resources, it is unlikely that courts would require physicians to administer life-saving resources to those with no chance of recovery or risk violating the ADA. Through the use of SOFA scores, the ADA’s mandate of equal access to health care is preserved, while equal outcomes are not.

If “effectiveness” or “benefit” is defined in such a way as to prefer individuals with no preexisting medical disorders, however, it may once again run afoul of the ADA and the Rehabilitation Act. Protocols that consider duration of benefit to the patient in allocating care, for example, necessarily will exclude patients with preexisting diseases whether or not

233. See Peters, *supra* note 198, at 500 (“When a disability-related comorbidity causes poorer outcomes, reliance on outcomes to allocate medical care would disfavor care of the affected disabled patients.”).

234. ADA Analyses of the Oregon Health Care Plan, *supra* note 199, at 411.

235. See Ferreira et al., *supra* note 49, at 1757.

such diseases are related to the current medical crisis. If a preexisting disability is likely to shorten the individual's life span despite treatment, the care would be less likely to be provided whether or not the medical intervention is likely to be successful. Thus, any individual with a preexisting disability that will shorten lifespan, significantly or otherwise, is automatically disfavored from receiving treatment. Of particular concern, there is no clear line-drawing in such models between the short- and long-term.

One protocol, for example, suggests that individuals with “[s]evere underlying disease with poor short-term prognosis” would likely be denied a ventilator, while individuals with “[n]o severe underlying disease” would likely receive one.²³⁶ Falling in the indeterminate range in this plan are those with severe underlying diseases who have “poor long-term prognosis and/or ongoing resource demand.”²³⁷ This same type of assessment derailed the legitimacy of the Oregon Plan. That plan's assessment of the “net benefit” of any treatment was found to be suspect because it disvalued a “treatment whenever a patient remains disabled after treatment—even if the treatment is not intended to restore those functions, causes no burdens such as pain or disorientation, and is effective in what it is intended to do.”²³⁸ As a result, “[t]he likelihood that patient will function at a lower level of ability after treatment should be irrelevant to any measure of the treatment's effectiveness if the treatment does not itself cause the loss of ability and is not intended to restore that ability.”²³⁹ By the same token, an individual with a shortened life expectancy because of a disability should not be denied treatment that will restore functioning but have no effect on life expectancy. To conclude otherwise improperly introduces into the analysis subjective assessments about the value of life with disabilities, similar to the quality of life discussion detailed earlier.

It is possible, however, to consider duration of benefit to the patient in a more neutral and limited way. Some scholars have argued, for example, that “providers ought to be permitted to prefer the patient who is reasonably expected to obtain the same benefit as another patient for a longer duration, such as more years of life, as long as the benefit is not measured in terms of quality of life” in situations involving limited resources.²⁴⁰ The “benefit” in this model is objective to the extent that an extra day of life expectancy is weighted equally for all individuals, whether or not they have an underlying disability. On its face, this approach allows equal access to care for both individuals with disabilities and those without.

It is again debatable, however, whether a standard that functionally precludes entire categories of people with disabilities from receiving health

236. Hick et al., *supra* note 52, at 222 fig.1.

237. *Id.*

238. *ADA Analyses of the Oregon Health Care Plan*, *supra* note 199, at 404 (quoting Letter from Marzen & Avila, Dec. 5, *supra* note 200).

239. *Id.*

240. Mehlman et al., *supra* note 225, at 1402.

care in times of emergency can equate with “meaningful access” as understood in *Choate*. Anyone with a fatal disease would likely be precluded from care in times of scarcity, even if the effects of the disease are unlikely to manifest for many years. Because life expectancy calculations lack scientific precision, moreover, this method leaves the door open to discriminatory animus in allocating care. Is it likely, for example, that a mentally retarded young adult would be provided with a ventilator before an otherwise healthy older adult, provided there was some scientific evidence suggesting that the former would live for a longer time period than the latter, however brief? If the provision of a ventilator to one potentially results in death to the other, the imprecise nature of life expectancy calculations allows them to be adjusted accordingly.

F. Potential Defenses Available Under Federal Law

It is not sufficient to conclude that the ADA and the Rehabilitation Act apply to the allocation protocols or to identify the discriminatory implications of some of their provisions. The protocols may nevertheless be lawful if they are “necessary” within the meaning of the ADA, such that the modification or removal of the identified criteria would constitute a fundamental alteration to the provision of emergent care in a pandemic.²⁴¹ As other scholars have noted, these terms “are sufficiently elastic to permit judicial consideration of . . . important ethical issues” involved in rationing health care.²⁴² The necessity of an eligibility requirement will depend, in part, on its “importance to the program’s ability to meet its targeted goals.”²⁴³ Courts have found proposed modifications to fundamentally alter programs when they “would endanger a program’s viability, would cause massive financial expenditures, would jeopardize the effectiveness or involve a major restructuring of a program, or would result in the creation of a new program.”²⁴⁴

Proponents of the protocols are likely to argue that the use of disability as exclusionary criteria is necessary because protocols “must rely on a limited set of objective criteria that do not require any laboratory data or other investigations” to be effective in times of crisis.²⁴⁵ An emergency requires decisionmaking and assessment on short time frames with incomplete information. There is no question that a disability diagnosis is shorthand for myriad conditions experienced by the individual that may be relevant to treatment decisions. If the use of diagnostic categories is the only or even the best way to facilitate decisionmaking in situations

241. See *infra* Part V.B.

242. See, e.g., Peters, *supra* note 198, at 509.

243. Crossley, *supra* note 138, at 233.

244. Smith, *supra* note 140, § 6.

245. Devereaux et al., *supra* note 6, at 53S. The Task Force protocol recognizes that such is the case when triage decisions are made in the “prehospital field.” *Id.* The protocol distinguishes this scenario from “tertiary triage [that] is conducted within the hospital and deals with decisions such as disposition to the operating room in trauma scenarios or to critical care areas, as is the focus of this working group.” *Id.*

requiring immediate action, courts may logically conclude that they are necessary to the efficient distribution of resources. By the same token, it would fundamentally alter the provision of care in public health emergencies to preclude their use.²⁴⁶ Requiring an individualized determination in every case could conceivably “deny the validity of the State’s focus on the collective welfare of its citizens” in times of scarce resources.²⁴⁷ Because “a disaster will severely strain human and financial resources,” any requirement imposed by the judiciary may automatically appear proportionately more burdensome and unwieldy.²⁴⁸

Supporting this interpretation is *Choate*’s recognition of the tension between the sweeping mandate of the ADA and “the desire to keep [the statute] within manageable bounds.”²⁴⁹ Given courts’ general reluctance to intrude into the realm of medical decisionmaking, a public health crisis of widespread magnitude would seem a prime area where a “hands off” approach might be urged, at least with respect to any protocols promulgated by the state.²⁵⁰ This practical perspective is coupled with the legal reality that the ADA does not always require an individualized inquiry. Broader classifications are permitted at times by courts when “substantially all excluded persons are unqualified” for the treatment in question or when it is highly impracticable to do otherwise.²⁵¹ If there is evidence to suggest a statistically sound correlation between a disability category and the absence of patient benefit, precluding categorical exclusions based on disability could potentially both hamper the state’s ability to administer scarce resources and provide little benefit to individuals with disabilities.²⁵²

246. See, e.g., Eleanor D. Kinney et al., *Altered Standards of Care for Health Care Providers in the Pandemic Influenza*, 6 IND. HEALTH L. REV. 1, 11 (2009) (concluding that in the context of public health emergencies, “[T]he goal of providing optimal care to the population may require compromising best practices or providing less than optimal care to individual patients. This approach, ethically intolerable or legally suspect under normal conditions, may be necessary and appropriate under disaster scenarios.”).

247. Crossley, *supra* note 138, at 237. As Dean Crossley has argued, deference to private hospital or association triage rankings would be significantly less compelling than a priority list developed by the state—hospitals do not “traditionally” play the role of making value judgments in the face of scarce resources as does the state. *Id.* at 249.

248. Hoffman, *supra* note 1, at 1524.

249. *Alexander v. Choate*, 469 U.S. 287, 299 (1985).

250. See Crossley, *supra* note 138, at 240 (“From the State’s perspective, this need to keep disability discrimination laws within ‘manageable bounds’ becomes particularly acute when those laws are invoked to inhibit a state’s ability to establish priorities in allocating scarce resources.”).

251. Peters, *supra* note 198, at 508. Professor Philip G. Peters Jr. concludes that “[t]he greater the percentage of excluded persons whose outcomes are likely to be significantly better than the cut-off, the less likely it is that a disability-based criterion will survive scrutiny.” *Id.* at 532. Courts would determine whether a practice is highly impracticable based on factors “such as the availability of better predictive data, the cost of acquiring it, and the administrative difficulty of using it.” *Id.*

252. See Crossley, *supra* note 138, at 227–28. It also could conceivably open the door to the argument endorsed by the *Olmstead* plurality that modifying a program may constitute a fundamental alteration where “the allocation of available resources [suggests that] immediate relief

This approach, however, is undercut by the language of the ADA and Department of Justice (DOJ) regulations. The DOJ has explained that “neutral” eligibility criteria that screen out or tend to screen out individuals with disabilities are permissible when they “are necessary for [the] safe operation” of the program.²⁵³ From this, some courts have concluded that necessity is not a defense to “overt denials of equal treatment of individuals with disabilities.”²⁵⁴ Other courts have similarly concluded that the fundamental alteration test is inapplicable to cases alleging disparate treatment, reasoning “[p]ublic entities could evade the ADA by claiming it would fundamentally alter their program to eliminate a facially discriminatory provision of a challenged program, and Congress’s intent in enacting the ADA would be defeated.”²⁵⁵ Under this line of reasoning, there is no defense applicable that would excuse the categorical exclusion of individuals with disabilities from receiving care.

As for those protocol provisions that would more appropriately be challenged on the ground of disparate impact—quality of life, duration of need, duration of benefit, and medical effectiveness—the answer to whether they are necessary to providing health care in a public health emergency depends on whether the public health maxim of the greatest good for the greatest number is in fact a legitimate and primary goal of the state in times of crisis. Stated differently, courts must determine “whether the objective of maximizing health outcomes is an ‘essential’ program objective within the meaning of the equal opportunity laws.”²⁵⁶ A number of scholars have concluded that criteria that will maximize the effectiveness of health outcomes are both “essential” and “necessary” and thus permissible under the ADA.²⁵⁷ Still, others have concluded that “the use of effectiveness criteria is vital to the goal of maximizing health outcomes from fixed resources.”²⁵⁸

Nevertheless, it would be difficult to conclude that protocol criteria based on generalizations, stereotypes, or myths about people with

for the plaintiffs would be inequitable.” *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 604 (1999) (plurality opinion). Notably, however, an important distinction may be drawn between the allocation protocols and the integration mandate at issue in *Olmstead*. Whereas a delay in moving to an integrated setting, while harmful, may be rectified in the future, the withholding of immediate medical treatment may impose irreversible and potentially deadly consequences to people with disabilities.

253. 28 C.F.R. pt. 35, app. A, § 35.130 (2010); 28 C.F.R. pt. 36, app. B, § 36.301.

254. *Burns-Vidlak v. Chandler*, 939 F. Supp. 765, 770 (D. Haw. 1996).

255. *Lovell v. Chandler*, 303 F.3d 1039, 1054 (9th Cir. 2002); *see also* *New Directions Treatment Serv. v. City of Reading*, 490 F.3d 293, 305 (3d Cir. 2007) (“We . . . agree that it is inappropriate to apply the ‘reasonable modification’ test to facially discriminatory laws.”); *MX Grp., Inc. v. City of Covington*, 293 F.3d 326, 345 (6th Cir. 2002); *Bay Area Addiction Research & Treatment, Inc. v. City of Antioch*, 179 F.3d 725, 735 (9th Cir. 1999); *G. ex rel. K. v. Hawaii*, 676 F. Supp. 2d 1046, 1056 (D. Haw. 2009).

256. Peters, *supra* note 198, at 510.

257. *Id.* at 515 (discussing scholarly opinions on the issue and concluding that they “reflect the assumption that society can and should consider the effectiveness of a medical treatment”).

258. *Id.* at 518.

disabilities are legally necessary to the effective administration of resources. Quality of life assessments, in particular, are unlikely to meet this standard. Even if the court endorses the legitimacy of the “greatest good” approach, the answer of which treatment provides the “greatest” result depends on a value assessment of the lives to be saved. There is no way to perform this assessment without reference to generalizations about life with disabilities, particularly in times of crisis when treatment decisions are likely to be made under time pressure.

Outside of this recognition, however, it is unlikely that either existing case law or the text of the ADA will clearly answer whether such terms are necessary. In an ideal world, Congress would step in to answer the legitimacy of this approach and its consistency with the ADA. In the absence of such measures, however, courts are likely to turn to the ethical implications of adopting this approach in evaluating its legality. The next Part explores these issues in detail.

V. ETHICAL IMPLICATIONS OF ADVANCE PROTOCOLS

The foregoing analysis suggests that at least components of the existing allocation protocols violate the ADA and the Rehabilitation Act. But that analysis does not end the inquiry. Some might argue that the ADA and the Rehabilitation Act were not intended to apply to emergency circumstances. The conflict between the allocation protocols and antidiscrimination laws may not suggest that the allocation protocols are wrong, but rather that the ADA and Rehabilitation Act need to be amended to allow exceptions during public health emergencies, similar to the exceptions under Medicare, Medicaid, SCHIP, and EMTALA.²⁵⁹ Accordingly, this Part examines the underlying ethical justification for the components of the allocation protocols. In doing so, this Part seeks to elucidate ethical arguments not addressed in the preceding legal analysis of the allocation protocols under the anti-discrimination laws. Laws often reflect a floor, articulating the minimum standard of behavior to which society members must conform—whereas ethical principles are more aspirational, describing how members *ought* to behave; in some instances, however, the law and ethics are more closely aligned. That is the case here. The goal of these antidiscrimination laws was to ensure equal opportunities to persons with disabilities to remedy historic discrimination and prejudice against people with disabilities that precluded them from fully participating in society.²⁶⁰ Thus, these laws represent society’s moral commitment to treating persons with disabilities with respect and affording them justice that was previously denied, and legal analysis of these laws necessarily involves consideration of the underlying ethical principles reflected in them.

259. See *supra* Part III.B.

260. See 42 U.S.C. § 12101 (West 2010).

A. *Categorical Exclusion of People with Disabilities from Critical Care*

Categorical exclusion of people with disabilities from critical care in public health emergencies poses the clearest conflict with anti-discrimination laws and the greatest ethical concern. While the allocation protocols undeniably adhere to the public health principle of maximizing population health, this categorical exclusion violates several other ethical principles. Most clearly, it violates the principle of justice, which demands equitable distribution of goods within society. While there is disagreement about what constitutes equitable distribution, there is general agreement that inequitable treatment requires justification.²⁶¹ In public health, inequitable distribution generally is justified when such distribution is required to alleviate existing inequities.²⁶² But the categorical exclusions articulated in the allocation protocols do not alleviate existing inequities, but rather disadvantage an already disadvantaged group. Moreover, as discussed previously, the excluded categories are so broad that they cannot be interpreted as representing anything other than an exclusion based on a devalued status.²⁶³ In this regard, categorical exclusion violates other core principles that public health actions be necessary and effective and be the least restrictive alternative.²⁶⁴

That categorical exclusion violates federal antidiscrimination laws lends support to this ethical analysis. Categorically excluding the disabled from critical care is inconsistent with the moral commitment to them reflected in those laws. Moreover, as described earlier, the steps the government has taken to address the needs of the disabled during a public health emergency demonstrate its intention to meet that commitment, even in the context of an emergency.²⁶⁵ If “[a] nation’s greatness is measured by how it treats its weakest members,”²⁶⁶ then abandoning this commitment to the disabled during the time of greatest need would evidence a moral weakness.

261. See generally BEAUCHAMP & CHILDRESS, *supra* note 20, at 120–81 (discussing various theories of autonomy used in health care decisionmaking and justifying the obligation to solicit and respect patients’ decisions).

262. See Kass, *supra* note 23, at 1781; see also Hoffman, *supra* note 1, at 1511–12.

263. See *supra* Part IV.B.

264. Part of the rationale for and appeal of the categorical exclusion is the relative ease of application during a public health emergency. More nuanced evaluation may not be possible under such circumstances. However, public health ethics—and law—do not support use of such broad and unsupported categories.

265. See *supra* Part III.B.

266. Stefan Parry Carmien & Gerhard Fischer, *Design, Adoption, and Assessment of a Socio-Technical Environment Supporting Independence for Persons with Cognitive Disabilities*, CHI 2008 PROCEEDINGS—BEYOND END-USER PROGRAMMING 597 (Apr. 5–10, 2008) (quoting Mohandas Gandhi).

B. Exclusions Based on Likely Duration of Care Needed

The rationale for exclusion based on durational limits suggested by some allocation protocols, from a public health perspective, is that more people may benefit (i.e., receive care and survive) if health care providers do not commit scarce resources to those who are going to need that resource for a longer period.²⁶⁷ The justification for such limits depends on the quality of the data to support them; the public health principle of effectiveness requires scientific evidence to support the assumptions about differential survival outcomes. As discussed earlier, there are reasons to be concerned that this criterion will devolve into subjective evaluations regarding quality and value of life with a disability that will disadvantage those with disabilities in ways that are ethically suspect.²⁶⁸ In this regard, the durational limits would raise similar ethical concerns as the categorical exclusions,²⁶⁹ but with the added problem that these decisions are hidden in the mantle of medical judgment, rather than being open and transparent. Thus, consideration of duration of care may result in people with disabilities receiving less care during a pandemic, even if they would be likely to survive the pandemic were they to receive the care.

On the other hand, some allocation protocols exclude people from critical care based on the intensity of care beyond necessary ventilation. That is, people who need other resources, such as nursing supervision because of dementia or other disability, and are “hard to care for” may be prevented from receiving critical care.²⁷⁰ The underlying rationale for this policy is that personnel often are scarce during an emergency because they are sick themselves, must care for sick family members, or may be at increased risk of infection because of their own health conditions (for example, pregnancy or asthma), and that devoting personnel to one “hard to care for patient” means those personnel are not available to help others. However, in this case, the patients who are excluded from care may have medical needs and a likelihood of survival that is similar to that of other patients. Such policies devalue those who have greater needs (i.e., the disabled) and do not consider that there may be other ways for handling their care. For example, this care may be provided by non-nursing hospital staff or there may be family members or friends who could provide the supportive care so that health care providers may devote their efforts to medical care. Thus, such policies may not be necessary to achieve the stated public health goal, and it is inappropriate to deprive such individuals of care and of the chance for survival based simply on their greater care needs because of their disability.

267. See *supra* Part IV.C.

268. See *supra* Part IV.C–D; *infra* Part V.C.

269. See *supra* Part V.A (describing the ethical concerns posed by categorical exclusions).

270. Christian et al., *supra* note 10, at 1378–79.

C. Exclusions Based on Quality of Life Considerations

Even those groups that rely on the quality of life criterion in their allocation protocols recognize its inherent subjectivity and potential for abuse. That those advocating for its use feel the need to warn against the dangers of this criterion in and of itself should give us pause. Why insert a criterion that is inherently subjective into an already fraught decision under circumstances that complicate thoughtful decisionmaking? The rationale for considering quality of life in allocation decisions is to avoid using scarce medical resources to support lives thought to be “not worth living” when other lives could be saved.²⁷¹ However, there is little societal agreement regarding what is a life “not worth living,” as demonstrated by public debates on preimplantation genetic diagnosis, abortion, and withdrawal of life support.²⁷² Thus, for the reasons previously articulated, allocation of medical resources on the basis of quality of life assessments is ethically suspect.²⁷³ Allocating scarce medical resources based on quality of life considerations also violates core principles of public health ethics because it disadvantages an already vulnerable group and the decisions are unsupported (and unsupportable) by data.²⁷⁴ Indeed, such decisions are close to the rejected concept of “social worth” as an allocation principle.²⁷⁵

The biases the quality of life criterion introduces into decisionmaking warrant rejecting it as a criterion. However, involving a broader range of perspectives in the development of allocation proposals could limit bias. To date, the discussions have primarily been driven by clinicians.²⁷⁶ While the groups have published their work in keeping with the ethical principle of transparency, publication has been limited to medical literature. Proposals have not been widely discussed in the disability community or

271. Ronald M. Green, *Parental Autonomy and the Obligation Not to Harm One's Child Genetically*, 25 J. L. MED. & ETHICS 5, 9 (1996).

272. *See, e.g., id.* (arguing that there is an ethical obligation for a parent to avoid having a child with a disability). *But see* Asch, *supra* note 209, at 1652 (arguing that such a view devalues the lives of persons with disabilities and arguing for a broader view of a satisfying life for a disabled person). Indeed, the dispute between Terri Schiavo's husband and parents that launched her case into the public eye, and the public debates that followed, shows quite vividly the lack of agreement regarding what is a life worth living, including disputes among medical professionals. *See* C. Christopher Hook & Paul S. Mueller, *The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned*, 80 MAYO CLINIC PROC. 1449, 1450–51 (2005).

273. *See supra* Part IV.D.

274. *See* Kass, *supra* note 23, at 1780–81.

275. *See supra* Part II.A.

276. The groups have been comprised primarily of clinicians, although the Task Force had one lawyer on it. Devereaux et al., *supra* note 6, at 64S. The NY Workgroup included several lawyers and ethicists. Powell et al., *supra* note 64, at 20. We were unable to identify anyone from the disability community, although it is possible that some members of the groups were disabled themselves or had experience with disability through a family member or friend. Others have called for broader public debate of allocation proposals. *See, e.g.,* White et al., *supra* note 29, at 137 (calling for a robust public engagement process that “engage[s] a representative sample of citizens, rather than those with the knowledge and resources to seek out the draft guidelines on the Internet”).

literature. Expanding the discussion to the disabled, among others, would be essential to evaluating whether such a criterion could be specified to limit the inherent bias discussed here.

D. Exclusions Based on Medical Effectiveness

Several ethical principles support the use of a medical effectiveness as a criterion for allocating medical resources during a public health emergency. The clearest support comes from the ethical principle that public health interventions must be effective. Under this principle, not only is there no obligation to provide ineffective interventions, public health authorities are constrained from using ineffective interventions. As noted earlier, however, the justification for using “medical effectiveness” may vary with its definition.²⁷⁷ A stricter definition, which focuses closely on whether the medical intervention results in the expected physiologic response, is easiest to defend because it does not allow quality of life decisions in through the back door.

General ethical principles of governance and stewardship support consideration of medical effectiveness. Under these principles, public or scarce resources should not be wasted, as they would if they were put to ineffective medical treatment. Some might argue that a stricter definition of medical effectiveness that is related to short-term medical outcomes, may “waste” scarce resources if they are used for disabled people who may not survive as long as others who are without disabilities. Importantly, however, the principle of effectiveness, legally and ethically, does not require use of the most effective option. Other principles may require choosing a less effective option; for example, the most effective option from a public health perspective (i.e., maximizes population health) may significantly infringe on individual interests, whereas a slightly less effective option might achieve almost as much good, without the burden on individual interests. In such a case, it would be ethically preferable to select the second, less effective option because it better balances the public health goal with competing individual interests.²⁷⁸ Following the same logic, in the case of allocation of scarce resources in a public health emergency, a definition of medical effectiveness that limits disabled people’s access to critical care medicine because of their long-term health and life expectancies violates the principle of distributive justice and society’s moral commitments to providing people with equal opportunities. A stricter (if not the strictest) definition of medical effectiveness better balances these competing moral commitments and ethical principles.

277. See *supra* Part IV.E.

278. Indeed, such evaluations have been used to justify voluntary, universal HIV screening of pregnant women over mandatory programs. INST. OF MED., REDUCING THE ODDS: PREVENTING PERINATAL TRANSMISSION OF HIV IN THE UNITED STATES 109–13 (Michael A. Stoto et al. eds., 1999); see also Kass, *supra* note 23, at 1780.

E. Additional Considerations

The foregoing ethical analysis focuses on the primary components of the allocation protocols that also have ADA or Rehabilitation Act implications. The protocols have other criteria that raise other implications. For example, some protocols exclude based on advanced age,²⁷⁹ whereas others specifically reject using age as an exclusion criteria.²⁸⁰ Still, others argue for use of multiple principles, including the life-cycle principle that would take life-stage into account.²⁸¹ Others rely on a principle of first-come, first-served in the limited context in which the criteria of “[o]rgan system function (and severity of impairment) [; d]uration of ventilator use and duration of benefit[;] . . . [and r]esponse to a trial of mechanical ventilation (if received[])” do not resolve the allocation decision.²⁸² Public health ethics provide support for use of some of these criteria,²⁸³ but, as with the allocation components discussed herein, they should be subject to public discussion and debate. Ultimately, allocation protocols for public health emergencies will only succeed if the public accepts them as reasonable and fair.

VI. CONCLUSION

It is evident that advance planning for public health emergencies must take place, and that it must be done within the parameters of antidiscrimination laws. These issues cannot await resolution by the courts—the application of these protocols will be made in the field when timing is critical. If these issues are not debated openly and collectively in advance, they are likely to be resolved covertly by individuals in times of crises. At the point of litigation, moreover, individuals with disabilities will already be irreversibly harmed.²⁸⁴ Jurors and the judiciary are likely to be more heavily influenced by the chaos surrounding a time of emergency and the need for the government to mount a quick response than they would be swayed by the civil rights of individuals at that time. The protection to be afforded, therefore, must come on the front end of the planning process.

A public health emergency will necessitate hard decisions. Public health authorities and medical professionals need clear guidance so that they can make good decisions under bad circumstances. For protocols to successfully alleviate some of the uncertainty in times of public health crises, moreover, their necessity must be understood and embraced by the

279. Christian et al., *supra* note 10, at 1379; Devereaux et al., *supra* note 6, at 60S tbl.6.

280. Powell et al., *supra* note 64, at 23.

281. White et al., *supra* note 29, at 135–37.

282. Hick et al., *supra* note 52, at 4–6 (noting how to make a determination regarding who should get ventilator support when one patient has received it, a second patient arrives in need of ventilator support, and no other ventilators are available; the fact that the first patient was first becomes relevant to decisionmaking if the other three factors do not demonstrate a “clear-cut difference” preferring one patient over the other).

283. *See supra* Part II.A.

284. Hoffman, *supra* note 1, at 1538–39.

public, particularly those who are likely to be most significantly impacted by them. The real power of the ADA and § 504 lies not in their ability to punish misconduct, but in the guidance they provide in the development and implementation of equitable policies for people with disabilities.²⁸⁵ It is the authors' hope that this Article will move the essential process of planning for public health emergencies forward by providing a framework for thinking critically about existing plans and developing new plans that are more in keeping with society's moral commitment to equal access.

285. See Anderlik & Wilkinson, *supra* note 86, at 1197 ("Law is as much a means of structuring behavior as it is a means of punishing misbehavior.").