May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities?

Notes on the Law and Ethics of Disability-Based Medical Rationing

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For years, conflicts over medical rationing have preoccupied participants in health care debates. But they have tended to take place in the abstract—as in discussions of what treatments will be covered under various health care reform proposals that may or may not pass. In many cases, discussions of these issues have tended to the demagogic—as in the trumped-up furor over the supposed Obamacare "death panels."

Thanks to the coronavirus pandemic, the threat of medical rationing is now clear and present. The pandemic hit our country at a time when we did not have adequate medical facilities or equipment to handle the predicted number of cases. Hospitals faced with a crush of patients must now seriously confront questions of how to allocate scarce resources—notably life-saving ventilators—at a time of severe shortage. We now appear close to being in the triage situation that the law, bioethics, and policy literature typically merely hypothesizes. Medical providers will truly be in a position to choose who shall live and who shall die.¹

In their protocols for addressing this situation, hospitals and state agencies often employ explicitly disability-based distinctions. As Ari Ne'eman recounted in a recent piece, Alabama's crisis standards of care provide that "people with severe or profound intellectual disability 'are unlikely candidates for ventilator support," while Tennessee lists "people with spinal muscular atrophy who need assistance with activities of daily living" as among those who will not receive critical care in a situation of scarcity.² The University of Washington Medical Center's guidelines provide that the goal in a crisis situation should be "[o]verall survival," defined as "healthy, long-term survival, recognizing that this represents weighting the survival of young otherwise healthy patients more heavily than that of older, chronically

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¹ Another area in which these debates have not been merely abstract has involved practices governing organ transplantation. Perhaps not surprisingly, similar disability discrimination issues have begun to percolate in that area in recent years. *See* NAT'L COUNCIL ON DISABILITY, ORGAN TRANSPLANT DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES (Sept. 25, 2019), https://ncd.gov/sites/default/files/NCD Organ Transplant 508.pdf.

² Ari Ne'eman, "*I Will Not Apologize for My Needs*," N.Y. TIMES, Mar. 23, 2020, <u>https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html</u>.

debilitated patients."³ Guidelines promulgated by the Washington State government provide that, in deciding whether to administer life-saving treatment to an individual, hospitals should look to the individual's "baseline [*i.e.*, pre-coronavirus] functional status" and should accordingly "consider [pre-existing] loss of reserves in energy, physical ability, cognition and general health."⁴ An individual with a disability, along with several state and national disability rights organizations, recently filed an administrative complaint against the State of Washington alleging that these and other provisions violate the federal disability discrimination laws.⁵

In this essay, written as this crisis unfolds, I argue that disability-based distinctions like these do indeed violate the law. The Americans with Disabilities Act, the Rehabilitation Act, and the Affordable Care Act all prohibit health care providers from discriminating against qualified individuals with disabilities because of their disabilities. The explicit discrimination embodied in policies like those of Washington State on its face violates these prohibitions. Nor can medical providers simply define disabled patients as being "unqualified" because of disabilities that do not affect the ability to ameliorate the condition for which treatment is sought. Longstanding and authoritative interpretations of the law bar the use of such circular techniques to insulate disability discrimination from legal challenge.

Although a proper interpretation of the law may permit medical providers to use disability as a basis for a rationing decision where an individual's underlying disability will kill the individual in the immediate term regardless of the treatment, those circumstances will be narrow. And a proper interpretation of the law requires assurances that such imminent-death determinations will be made based on the best available objective evidence, free from bias against people with disabilities or devaluation of their lives.

Under this interpretation of the law, which I argue is the best interpretation of the existing legal materials, medical providers would retain substantial discretion to make resource allocation decisions in a time of triage. They could make decisions based on non-disability factors. And where those factors do not dictate a decision, they could employ a lottery process. Such a process would be more fair and democratically legitimate than placing the burden on disabled individuals individuals who already experience disadvantage as a result of societal discrimination, and who disproportionately lack access to the political processes that frame policies concerning medical rationing.

In this essay, I defend that reading of the law. Part I demonstrates that practices that expressly use disability as a factor in denying life-saving treatment discriminate because of a disability. Part II argues that it would be inconsistent with the law for a health system to treat a pre-existing disability as rendering an

³ Letter from David Carlson, Disability Rights Washington, to Roger Severino, Director, Office for Civil Rights, U.S. Dep't of Health & Human Services, p. 12 (Mar. 23, 2020) (quoting the hospital's policy), <u>https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint 3-23-20-final.pdf</u>. ⁴ *Id.* at 13 (quoting the policy).

⁵ See id. I am among the counsel to the complainants.

individual un-"qualified" for treatment for a new condition. And Part III addresses the one significant body of precedent that might at first glance appear to stand in the way of these conclusions—the "Baby Doe" cases that date to the 1980s. As that part shows, those cases conflict with more recent, authoritative developments in the law. And they do not apply to the COVID-19 situation even on their own terms.

I. Discrimination Because of Disability

There are three major federal statutes that prohibit disability discrimination in the medical treatment context: the Americans with Disabilities Act; Section 504 of the Rehabilitation Act; and Section 1557 of the Affordable Care Act. The ADA prohibits disability-based discrimination by state and local government agencies in its Title II,⁶ and it prohibits disability-based discrimination by private health care providers in its Title III.⁷ Section 504 prohibits disability-based discrimination by federal executive-branch agencies and recipients of federal financial assistance.⁸ And Section 1557 prohibits disability-based discrimination by health programs that receive federal financial assistance or are operated under a federal program or activity.⁹

Despite some slight variations in language, each of these statutes prohibits discrimination against individuals with disabilities because of their disabilities. And except for ADA Title III, all require that the disabled individual be "qualified" for the benefit or treatment they seek. Title II of the ADA provides that "no qualified individual with a disability shall, by reason of such disability," be "subjected to discrimination" by a state or local government.¹⁰ Title III of the same statute says that "[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation."¹¹ Section 504 phrases the prohibition in this way: "No otherwise qualified individual with a disability" shall, "solely by reason of her or his disability," be "subjected to discrimination under" a federally assisted program.¹² And Section 1557 incorporates by reference the discrimination prohibition in Section 504.¹³

This text raises two interpretive issues relevant to medical rationing decisions. First, are those decisions being made "by reason of" or "on the basis of" disability? Second, are the disabled individuals affected by those decisions "qualified" for the treatment they seek. I deal with the issue of qualification in the next part of this essay. Here, I discuss the issue of discrimination because of disability.

⁶ 42 U.S.C. § 12132.

 $^{^7}$ 42 U.S.C. § 12182; see Bragdon v. Abbott, 524 U.S. 624, 629 (1998) (Title III's definition of a covered "public accommodation" includes a private health care provider).

⁸ 29 U.S.C. § 794(a).

⁹ 42 U.S.C. § 18116(a).

¹⁰ 42 U.S.C. § 12132.

¹¹ 42 U.S.C. § 12182(a).

¹² 29 U.S.C. § 794(a).

¹³ 42 U.S.C. § 18116(a).

Many of the rationing protocols health care providers have been preparing to use in response to COVID-19 plainly inflict discrimination "by reason of" or "on the basis of" disability. Disability is an explicit factor used to deny treatment—a factor that will be decisive in many cases.¹⁴ Although issues about identifying discriminatory intent, determining appropriate reasonable accommodations, or delimiting the scope of a prohibition on disparate impact often raise serious questions under the disability discrimination laws, these protocols raise no such issues. Rather, they are straightforward examples of making treatment decisions because of disability. The harder question, to which I now turn, is that of qualification.

II. Are Disabled Individuals "Qualified" for Life-Saving Treatment?

ADA Title II, Section 504, and Section 1557 (but, notably, not ADA Title III) limit their protection to "qualified" individuals with disabilities. Title II defines a "qualified" individual as someone "who, with or without reasonable modifications to rules, policies, or practices," meets "the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity."¹⁵ The Rehabilitation Act doesn't contain text defining "qualified" (or "otherwise qualified," the language used by Section 504), but cases under the statute apply a similar rule: An individual is "otherwise qualified" if that individual is able, with "reasonable accommodation" if necessary, to perform the "essential functions" of the job or meet the eligibility requirements for a program.¹⁶

A. The General Rule: Disability As Such May Not Be a Basis for Disqualification

The most plausible legal defense of disability-based medical rationing rules is that the affected individuals' disabilities render them un-"qualified" for the lifesaving treatment they seek. At least at the moment that we are in a triage situation, there are not enough ventilators and other resources to go around. A health system needs to deny these resources to *some* people who need them to survive. So long as medical professionals adopt reasonable criteria for making these sorts of tragic choices,¹⁷ the argument would go, those criteria should constitute the qualifications for the relevant benefit. And here, the argument would continue, it is reasonable to

¹⁴ See supra text accompanying notes 2-4. Section 504, unlike the ADA, requires proof of discrimination "solely by reason of" disability. 29 U.S.C. § 794. Where disability status is determinative in a decision, the courts have treated the "solely" requirement as satisfied. In *Lovell v. Chandler*, 303 F.3d 1039, 1053 (9th Cir. 2002), *cert. denied*, 537 U.S. 1105 (2003), for example, the court concluded that the state violated Section 504 even though it was not the plaintiffs' disability alone, but instead their disability combined with the failure to satisfy a "restrictive income and assets test," that led to their exclusion from Medicaid. "[B]ut for their disability," the court explained, the plaintiffs would have received Medicaid under the state's QUEST program. *Id.* As a result, "those disabled persons were denied QUEST coverage by the State solely because of their disabilities; that is, had they been nondisabled, they would have received QUEST coverage." *Id.*

¹⁵ 42 U.S.C. § 12131(2).

¹⁶ School Bd. of Nassau County v. Arline, 480 U.S. 273, 277-278 n.18 (1987). As noted above, Section 1557 incorporates Section 504's discrimination prohibition by reference.

¹⁷ The obligatory citation is to GUIDO CALABRESI & PHILIP BOBBITT, TRAGIC CHOICES (1978).

choose people without underlying disabilities in rationing these scarce resources, because they (and perhaps society) would benefit more from receiving life-saving treatment: They would (by hypothesis) live longer lives afterwards, they would enjoy their lives more, and they would contribute more economically to society.

Whatever one thinks as a philosophical or policy matter about rationing treatment based on quality-adjusted life years—an issue on which there is contentious debate¹⁸—the argument that medical professionals can simply define disability as disqualifying seems directly foreclosed by precedent. In *Alexander v. Choate*, one of its early cases under Section 504, the Supreme Court recognized that states could not be permitted to evade the bar on disability discrimination simply by turning the absence of a disability into a qualification for a job or benefit: "Antidiscrimination legislation can obviously be emptied of meaning if every discriminatory policy is "collapsed" into one's definition of what is the relevant benefit."¹⁹ Thus, the Court held that "[t]he benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled."²⁰

To adopt the absence of an underlying disability as a qualification for receiving life-saving treatment would, at least on its face, appear to conflict with that principle. The disability discrimination laws appear to erect a strong rule that disability *as such* may never be the basis for denying individuals opportunities.

To be sure, disabilities may make it impossible or impracticable for an individual to satisfy eligibility criteria that are defined without reference to disability. A state may legitimately demand that bus drivers operate their vehicles safely; with current technology blindness is simply inconsistent with that requirement. Safe operation of motor vehicles is an interest that can be defined without any reference to disability. The recognition that some disabilities, given the current state of technology, are simply incompatible with that interest reflects a simple and uncontroversial empirical judgment.

But the insertion of disability into the medical rationing context is not like that. Refusing to allocate scarce treatment resources to patients with pre-existing disabilities does not rest on a simple and uncontroversial empirical question. It rests on a series of questions of value: What should we be seeking to maximize when we allocate scarce health care resources? Lives saved, quality of life, prospective economic output of those we save, or what? How do we determine quality of life? Do

¹⁸ For a disability-focused critique, see NATIONAL COUNCIL ON DISABILITY, QUALITY-ADJUSTED LIFE DISABILITY YEARS AND THE DEVALUATION OF LIFE WITH А (2019).https://ncd.gov/sites/default/files/NCD Quality Adjusted Life Report 508.pdf. For a nice summary of the ethical literature on the problematic nature of relying on QALYs in this way, see Jerome Bickenbach, Disability and Health Care Rationing, STANFORD ENCYCLOPEDIA OF PHILOSOPHY (Edward N. Zalta, ed., Spring 2016), <u>https://plato.stanford.edu/archives/spr2016/entries/disability-care-</u> rationing/.

 ¹⁹ Alexander v. Choate, 469 U.S. 287, 301 n.21 (1985) (quoting the Solicitor General's brief).
²⁰ Id. at 301.

impairments to physical or mental functions necessarily limit an individual's quality of life? What if the people who experience those impairments do not think so?²¹ It is practically difficult, if not conceptually impossible, to disentangle our answers to those questions from our judgments about disability and the value of life with a disability.²²

Even when we answer what seem like the purely empirical questions here, our answers are likely to be inflected by our underlying views about disability and (overt or implicit) biases against disabled people. Medical rationing decisions are made in times of great uncertainty. They involve prognoses (about the possibility of recovery and the quality of life following recovery) that are themselves uncertain. It is natural for anyone deciding under such conditions to be guided by their underlying values and biases (even if only unconsciously) in resolving those uncertainties. And there is ample evidence of widespread bias against disability among medical professionals²³ a problem that is exacerbated by the underrepresentation of disabled people among their ranks.²⁴

Philosophers could debate how we should answer these questions. Some, following the views of people like Peter Singer, might argue that we should recognize that many disabilities inherently limit the quality of life, and that the quality of life ought to be central in determining how we will allocate scarce societal resources.²⁵

²¹ For a discussion of these issues, see *infra* text accompanying notes 34-40.

²² Professor Arti Rai argues, for example, that refusing to provide a liver transplant to a person who walks with a cane, out of a concern that an alternative recipient of the liver who has no underlying impairment will experience a higher quality of life, "would systematically allocate medical resources away from all individuals with disabilities, no matter how amenable their other health difficulties were to medical treatment." Arti Kaur Rai, *Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care*, 72 IND. L.J. 1015, 1080–81 (1997). Such a decision, although expressed in quality-of-life terms, would in fact betray a "much broader, highly problematic purpose of categorically judging all persons with disabilities less worthy than nondisabled persons of receiving any sort of medical treatment." *Id.* at 1081.

²³ See, e.g., Carol J. Gill, Health Professionals, Disability, and Assisted Suicide: An Examination of Revelant Empirical Evidence and Reply to Batavia, 6 PSYCHOL. PUB. POL'Y & L. 526, 530 (2000); Tom Shakespeare, Lisa Iezzoni & Nora E. Groce, Disability and the Training of Health Professionals, LANCET, vol. 374, iss. 9704, at P1815 (Nov. 28, 2009); see generally NAT'L COUNCIL ON DISABILITY, MEDICAL FUTILITY AND DISABILITY BIAS 29 (Nov. 20, 2019) ("Several studies have demonstrated that health care providers' opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people. For example, one study found that only 17 percent of providers anticipated an average or better quality of life after a spinal cord injury (SCI) compared with 86 percent of the actual SCI comparison group. The same study found that only 18 percent of emergency care providers imagined that they would be glad to be alive after experiencing a spinal cord injury, in contrast to the 92 percent of actual SCI survivors.") (footnotes omitted), https://ncd.gov/sites/default/files/NCD Medical_Futility_Report_508.pdf; Letter from David Carlson to Roger Severino, supra note 3, at 8-11 (collecting extensive evidence of medical bias against disability).

²⁴ See Samuel R. Bagenstos, *Technical Standards and Lawsuits Involving Accommodations for Health Professions Students*, 18 AMA J. ETHICS 1017 (2016).

²⁵ For Singer's views on using quality of life in resource allocation decisions, see JOHN H. MCKIE, PETER SINGER, HELGA KUHSE & JEFF RICHARDSON, THE ALLOCATION OF HEALTH CARE RESOURCES: AN

Others might take the view that national productivity is the most important factor. Still others might disagree and argue that the quality of life is inherently subjective, and that a purely productivity-focused view improperly reduces human beings to nothing more than "embodied net marginal product."²⁶

One way of reading the disability discrimination laws, though, is as resolving those debates—at least insofar as the question is whether the absence of a disability can in and of itself be a qualification for needed medical treatment. Perhaps because of a fear that disability-based decisions will reflect irrational bias, or perhaps out of some broader commitment to disability equality, Congress decided to bar the use of disability, standing alone, as a (dis)qualification for the receipt of needed benefits from the government or other medical providers.

And there is a good reason—beyond the widely repeated axiom that no one is above the law—to treat the disability discrimination laws as resolving these debates. That reason is democratic legitimacy. People with disabilities have faced a long history of exclusion from democratic participation.²⁷ Often, that exclusion has been overt, as in the denial of the right to vote to those under guardianship.²⁸ Often, the exclusion has resulted from an accumulation of decisions that made it impossible for many disabled people to have access to the political process.²⁹ When government institutions make decisions that deny people with disabilities important benefits, we should therefore worry that those decisions lack legitimacy: They were likely taken without the equal participation of those who are the most affected. We should especially worry when the consequences of those decisions are literally life and death.

By contrast, the enactment of the disability discrimination laws did not exclude the *non*disabled—those likely to lose out from a move that denies medical providers the ability to make disability disqualifying for scarce lifesaving treatments. Perhaps it is best to think of the enactment of the ADA and its sibling laws as a veil-ofignorance moment, in which Members of Congress, accountable largely to members of the nondisabled public who did not know whether they would ever become disabled, restricted the use of disability as a qualification for important benefits. That decision has more presumptive legitimacy than a decision by those operating the health care

ETHICAL EVALUATION OF THE "QALY" APPROACH (Routledge ed. 2016). For Singer's views on disability and the quality of life, see Peter Singer, *Why We Must Ration Health Care*, N.Y. TIMES, July 15, 2009, <u>https://www.nytimes.com/2009/07/19/magazine/19healthcare-t.html</u>.

²⁶ Samuel R. Bagenstos, "Rational Discrimination," Accommodation, and the Politics of (Disability) Civil Rights, 89 VA. L. REV. 825, 876-878 (2003). The phrase comes from Mark Kelman, Market Discrimination and Groups, 53 STAN. L. REV. 833, 835 (2001).

²⁷ For a good discussion of the history of disability-based restrictions on the right to vote, see Kay Schriner, Lisa Ochs & Todd Shields, *Democratic Dilemmas: Notes on the ADA and Voting Rights of People with Cognitive and Emotional Impairments*, 21 BERKELEY J. EMP. & LAB. L. 437 (2000).

²⁸ See Samuel R. Bagenstos, Disability, Universalism, Social Rights, and Citizenship, 39 CARDOZO L. REV. 413, 423–24 (2017).

²⁹ See Matt Vasilogambros, *How Voters With Disabilities Are Blocked From the Ballot Box*, STATELINE, Feb. 1, 2018, <u>https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2018/02/01/how-voters-with-disabilities-are-blocked-from-the-ballot-box</u>.

system to place the burden of resource scarcity on disabled individuals—the very individuals who are most likely to have been excluded from decisions like that.

B. Does Defining the Qualification as "[Comparative] Ability to Benefit" Solve the Problem?

What if we were to take the concept of qualification up a level of generality? Defenders of disability-based rationing might say that the relevant qualification for medical treatment is not the absence of disability but the ability to benefit from the treatment. And just like blindness and the bus driver, perhaps disability in many circumstances just makes it impossible (given current technology) to benefit from a treatment. If a person has a pre-existing condition such as advanced cancer that will inevitably kill them in the next week, and they then acquire coronavirus, is it sensible to say that they will benefit from ventilator treatment for their new disease if they are going to die so soon anyway? Such a person, we might say, is not qualified for treatment for the new condition.

And if we are in a triage situation, perhaps the relevant qualification is not the ability to benefit in some absolute sense, but the *relative* ability to benefit. If there simply are not enough life-saving treatments to go around, might a health care provider reasonably determine that the people who should get those treatments are the ones who are likely to live the longest, or live the fullest lives, as a result of the treatment? What makes a person "qualified" for treatment, on this view, is that the treatment will offer that person a higher marginal number of life years or quality-adjusted life years than the next person.

Perhaps one's disability is relevant to that question even if one will not die immediately after receiving the treatment. If I have a pre-existing medical condition that means that I will die ten years after receiving a successful treatment for my coronavirus, maybe we should give the treatment instead to someone whose posttreatment life expectancy is longer.³⁰ More controversially, if I have a pre-existing medical condition that means that my life will be of a lower quality than that of another patient after receiving a successful treatment for my coronavirus, maybe we should give the treatment to the other patient.

³⁰ Even without considering any underlying disabilities, many people believe that in contexts of medical scarcity we should favor younger people over older people in deciding how to allocate lifesaving treatments. That position might be based on a principle of maximizing the marginal life years saved. If so, it might provide some support for favoring a nondisabled patient over a disabled one who is likely to live for a shorter time after a successful treatment. But it is just as likely that the common support for considering age in medical treatment is backward rather than forward looking—that it "reflects the feeling that everyone is entitled to some 'normal' span of health (usually expressed in terms of life years, e.g. 'three score years and ten'). The implication is that anyone failing to achieve this has in some sense been cheated, whilst anyone getting more than this is 'living on borrowed time'." Alan Williams, *Intergenerational Equity: An Exploration of the 'Fair Innings' Argument*, 6 HEALTH ECON. 117, 119 (1997). On this view, we may legitimately deny treatment to people who have already had their "fair innings" if that is necessary to protect others from being cheated out of the same opportunity.

In times of extreme triage of specific treatments, these arguments of course deserve serious consideration. But there are substantial problems with them. One relates to democratic legitimacy. At any given moment, there is always scarcity of all sorts of health care inputs. Even if, as the economists insist, scarcity is itself a basic fact of life, the pattern of *which* products and resources are scarce in any given place and time is significantly the result of societal decisions. That is especially true in the richest society in human history—one whose health system has a well-documented problem of waste and inefficiency.³¹

Disabled people have a disproportionately small amount of input into decisions about the operation of the health system. They are underrepresented among the ranks of health professionals who constitute the system, and they experience significant barriers to participating in the democratic process that regulates the system.³² A significant point of the disability discrimination laws is to rectify these sorts of inequalities by forcing institutions to take equal account of the interests of disabled people when they make their decisions.

The perceived need to deny ventilators to coronavirus patients with preexisting disabilities results not from scarcity as a natural fact, but from two societal decisions: first, the decision to fail to maintain an adequate stock of ventilators to serve all patients who would need them if a pandemic broke out³³; second, the decision once a pandemic breaks out to use patients' pre-existing disabilities as a basis for denying them the use of those devices. A process in which people with disabilities were equally represented vis-à-vis the nondisabled, and in which the interests of both groups were given equal concern, would not make both of these decisions. An equal process might choose to obviate the second decision by maintaining a sufficient stock of ventilators to serve every patient in the event of a pandemic. Or it might well find the costs of such a policy to be extravagant when considered in light of the other possible uses of societal resources. But it would not then place all of the burden of that decision on individuals with pre-existing disabilities. The combination of both of these policies (allowing scarcity of ventilators, while imposing the life-or-death costs of that scarcity most heavily on disabled people) bespeaks a failure of democratic legitimacy.

But there are other problems as well. When medical professionals or others determine that a disability limits the quality of a person's life, they are making a controversial normative judgment that often does not reflect the views of disabled persons themselves. "A massive body of research has demonstrated that people who

³¹ See, e.g., Austin Frakt, The Huge Waste in the U.S. Health System, NY TIMES, Oct. 7, 2019, https://www.nytimes.com/2019/10/07/upshot/health-care-waste-study.html.

 $^{^{\}scriptscriptstyle 32}$ See supra notes 23-29 and accompanying text.

³³ See, e.g., Lena H. Sun, *Inside The Secret U.S. Stockpile Meant to Save Us All in a Bioterror Attack*, WASH. POST, Apr. 24, 2018 (noting that the budget for the CDC's Strategic National Stockpile "hasn't always been able to keep up with the program's ever-growing list of needs"), <u>https://www.washingtonpost.com/news/to-your-health/wp/2018/04/24/inside-the-secret-u-s-stockpile-meant-to-save-us-all-in-a-bioterror-attack/</u>.

acquire a range of disabilities typically do not experience much or any permanent reduction in the enjoyment of life."³⁴ Professor Elizabeth Emens has extensively detailed the differences between what she calls the "inside" and "outside" views of disability: "From the outside, disability commonly looks like an unhappy place created by an individual medical problem for which the law sometimes provides special benefits to that individual. From the inside, disability often looks like a mundane feature of a no-less-happy life, rendered inconvenient or disabling largely by interactions with the surrounding environment, which legal accommodations alter in ways that sometimes provide benefits to many."³⁵

To choose the "outside" view of disability held by most nondisabled people over the "inside" view held by many disabled people themselves reflects a normative choice.³⁶ That choice might result from the devaluation of life with a disability something that seems to fly in the face of the disability discrimination laws' guarantee of equal treatment. Or it might result from a form of paternalism—an understanding that people without disabilities are better judges of the quality of a disabled life than are people with disabilities. "[P]aternalism has historically been one of the most significant contributors to the disadvantage people with disabilities experience."³⁷ And paternalism was a principal target of the disability discrimination laws.³⁸ Given the well-documented evidence of bias by members of the medical profession against disability, we should be especially concerned that these judgments are being made in a way that suppresses disabled people's interests and reinforces the problem of democratic legitimacy.

To the extent that disabilities do harm the quality of one's life, that is often because of discrimination and societal decisions that have rendered significant opportunities inaccessible.³⁹ To use those harms as a justification for denying lifesaving treatment to disabled people imposes a form of "double jeopardy": Societal discrimination against people with disabilities causes them to experience less full lives, which social institutions then offer as a reason for making the further decision to deny these already disadvantaged individuals essential benefits.⁴⁰

³⁴ Samuel R. Bagenstos & Margo Schlanger, *Hedonic Damages, Hedonic Adaptation, and Disability*, 60 VAND. L. REV. 745, 763 (2007).

³⁵ Elizabeth F. Emens, Framing Disability, 2012 U. ILL. L. REV. 1383, 1386 (2012).

³⁶ See Bagenstos & Schlanger, *supra* note 34, at 776 ("The assumed neutral baseline of non-disability is not, in fact, neutral; the preferences and experiences of people without disabilities are just as conditioned by their situations as are those of people with disabilities. Neither people with nor those without disabilities have epistemic access to the "true" enjoyment of life with a disability.") (footnotes omitted).

³⁷ Bagenstos & Schlanger, *supra* note 34, at 795.

³⁸ Samuel R. Bagenstos, *The Supreme Court, the Americans with Disabilities Act, and Rational Discrimination*, 55 ALA. L. REV. 923, 932 n.70 (2004).

³⁹ See, e.g., Adrienne Asch, *Distracted by Disability*, 7 CAMBRIDGE Q. HEALTHCARE ETHICS 77, 80 (1998).

⁴⁰ John Harris, *QALYfying the Value of Human Life*, 13 J. MED. ETHICS 117, 119-120 (1987). Harris's version of the "double jeopardy" argument takes for granted that disability inherently limits the value of life. *See id.* at 120 ("The first disaster leaves her with a poor quality of life and QALYS then require

It was considerations like these that led the Department of Health and Human Services, in the George H.W. Bush Administration, to reject the 1992 Oregon health reform plan. Oregon's plan implemented a form of rationing. HHS Secretary Louis Sullivan concluded that the rationing relied on quality-of-life surveys that "quantifie[d] stereotypic assumptions about persons with disabilities."⁴¹ And when Oregon's health commissioners conducted their own rankings of which conditions and treatments to prioritize, they relied on factors "including 'quality of life' and 'ability to function"—factors that, in Sullivan's view, "expressly value a person without a disability more highly than a person with a disability in the allocation of medical treatment."⁴² As a result, he concluded, the proposed rationing plan did not comply with the ADA.⁴³

If it is clear that a person's underlying disability will in fact interfere with the efficacy of the life-saving treatment, or that the person will die in the immediate term from that disability with or without that treatment, perhaps it is appropriate to say that the individual is not qualified. Here we would be applying an absolute criterion of benefit rather than the relative one that I have been discussing so far.⁴⁴ But even here, humility should rule the hour. Medical professionals' biases often lead them to make unduly negative prognoses regarding their disabled patients.⁴⁵ Because disability rights law is designed significantly as a check on these biases, the law should not be read to permit health providers to make futility-of-treatment decisions for their disabled patients absent truly objective, persuasive, and reliable medical evidence.

The "direct threat" defense that applies when an entity engages in disability discrimination to prevent a safety risk is instructive here. The law allows such discrimination based on a determination that the individual poses "a significant risk"

 45 See supra note 23.

that in virtue of this she be ruled out as a candidate for lifesaving treatment, or at best, that she be given little or no chance of benefiting from what little amelioration her condition admits of."). If one believes that disability does not inherently limit the value of life, but does so largely if not exclusively as a result of society's treatment of people with disabilities, the double jeopardy point becomes even more powerful. For criticism of Harris's "double jeopardy" argument—though criticism that, like Harris, fails to appreciate the role of societal decisions in causing the harm attached to disability—see MCKIE ET AL., *supra* note 25, at 85-97.

 $^{^{41}}$ Quoted in ADA Analyses of the Oregon Health Care Plan, 9 ISSUES L. & MED. 397, 410 (1994). 42 Id. at 411.

⁴³ See id. at 409-412. For a discussion of the Oregon experience, see Samuel R. Bagenstos, *The Americans with Disabilities Act as Risk Regulation*, 101 COLUM. L. REV. 1479, 1507–08 (2001).

⁴⁴ Professor David Orentlicher endorses a rule like this. See David Orentlicher, Destructuring Disability: Rationing of Health Care and Unfair Discrimination Against the Sick, 31 HARV. C.R.-C.L. L. REV. 49, 72–73 (1996) ("[I]f a disabling illness seriously compromises a person's ability to benefit from an organ transplant, a physician could deny the person an organ. Otherwise, the physician should give the person the same opportunity as other candidates to benefit from a transplant."); see also Rai, supra note 22, at 1080-1081 (arguing that medical resource allocation decisions should not take account of underlying disabilities "when the medical efficacy of the intervention is in no way related to the disability").

that "cannot be eliminated by reasonable accommodation."⁴⁶ Such a determination must rest on "the most current medical knowledge and/or the best available objective evidence" and "an expressly individualized assessment" of the disabled person.⁴⁷ The law imposes these constraints to provide a check on biases that lead to exaggerated fear of safety risks stemming from disability.⁴⁸

The widespread nature of medical bias against people with disabilities justifies a similarly restrictive approach here. Absent a clear, objective basis for concluding that a person will die in the immediate term as the result of a pre-existing disability a determination that should be made through procedures that protect against bias the law ought to be read to prohibit using such a disability as a basis for denying lifesaving treatment that the person seeks. And the law's requirements of reasonable modification and reasonable accommodation apply fully here and should be understood to require medical systems to take steps to ensure that those who are not qualified for life-saving treatments can become qualified.

This does not mean that medical systems must take a first-come, first-serve approach to providing life-saving treatment in triage situations. As Secretary Sullivan explained in his response to the proposed Oregon plan, a system may consider "a wide range of factors" that are "consistent with the ADA."⁴⁹ "These factors include, but are not limited to, the cost of medical procedures, the length of hospital stays, prevention of death, and prevention of contagious diseases"—and indeed "any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities."⁵⁰ If a system does not wish to follow that path, it may allocate treatments on a lottery basis—a process that many people believe would be more fair.⁵¹ But under the best reading of the disability discrimination laws, they may not deny life-saving treatment simply because a patient has a different pre-existing disability.

III. The "Baby Doe" Cases

My arguments here might seem inconsistent with an older line of lower-court cases that rejected challenges to the withholding of medical treatment from newborns with developmental disabilities.⁵² Those cases, known as the "Baby Doe" cases, appear to hold that the disability discrimination laws cannot be employed to challenge medical treatment decisions. In the leading "Baby Doe" case, *United States v. University Hospital*, the Second Circuit said that the Rehabilitation Act's

⁴⁶ 42 U.S.C. § 12111(3).

⁴⁷ Chevron U.S.A. Inc. v. Echazabal, 536 U.S. 73, 86 (2002) (internal quotation marks omitted).

⁴⁸ See id. at 85-86 & n.5.

⁴⁹ ADA Analyses of the Oregon Health Care Plan, supra note 41, at 411.

 $^{^{50}}$ *id*.

⁵¹ For a discussion of different approaches, see Sheri Fink, *The Hardest Questions Doctors May Face: Who Will Be Saved? Who Won't?*, N.Y. TIMES, Mar. 21, 2020, <u>https://www.nytimes.com/2020/03/21/us/coronavirus-medical-rationing.html</u>. ⁵² See

See Johnson v. Thompson, 971 F.2d 1487, 1493 (10th Cir. 1992); United States v. University Hosp., State Univ. of N.Y., 729 F.2d 144, 156 (2d Cir. 1984).

"otherwise qualified" language "cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning."⁵³ The court asserted that "[i]n common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being 'otherwise qualified' to have corrective surgery performed."⁵⁴ It determined that challenges to nontreatment decisions would "invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a 'bona fide medical judgment."⁵⁵ And it concluded, based on a review of the legislative history, that "that congress never contemplated that section 504 would apply to treatment decisions of this nature."⁵⁶

But there are two significant problems with relying on the "Baby Doe" cases here. First, those cases are inconsistent with more recent Supreme Court decisions. As we have seen, the court concluded in *Choate*, decided the year after *University Hospital*, that entities may not evade the bar on disability discrimination simply by turning the absence of a disability into a qualification for a benefit.⁵⁷ By allowing hospitals to employ an infant's disability as the basis for determining that the child was not "qualified" for medical treatment, that is precisely what the "Baby Doe" cases did.

The "Baby Doe" cases relied on the premise that the disability discrimination laws apply only in those contexts Congress specifically envisioned.⁵⁸ But the Supreme Court decisively rejected that premise in *Pennsylvania Department of Corrections v. Yeskey.*⁵⁹ In *Yeskey*, the Court held that Title II of the ADA applies to discrimination against disabled individuals incarcerated in a state's prison system. Although the state argued that "Congress did not envisio[n] that the ADA would be applied to state prisoners,"⁶⁰ the Court found that argument irrelevant. Even "assuming [the state's argument] to be true," the Court held, "the fact that a statute can be applied in situations not expressly anticipated by Congress does not demonstrate ambiguity. It demonstrates breadth."⁶¹ Because Title II applies to any disability-based discrimination by a "public entity," without making a specific exception for prisons, the Court refused to read such an exception into the statute. That conclusion fatally undermines the premise of the "Baby Doe" cases.

And contrary to the "Baby Doe" cases, the Supreme Court has now twice recognized that the disability discrimination laws apply in the "context of medical

⁵³ Univ. Hosp., 729 F.2d at 156.

 $^{^{54}}$ Id.

⁵⁵ Id. at 157.

⁵⁶ Id.; see also Johnson, 971 F.2d at 1493 (adopting Second Circuit's rule from University Hospital).

⁵⁷ Alexander v. Choate, 469 U.S. 287, 301 (1985).

⁵⁸ See Univ. Hosp., 729 F.2d at 157 ("Before ruling that congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute."). ⁵⁹ 524 U.S. 206 (1998).

⁶⁰ Id. at 212 (internal quotation marks omitted).

⁶¹ Id. (internal quotation marks omitted).

treatment decisions."⁶² In *Bragdon v. Abbott*,⁶³ the Court applied the ADA to bar a dentist from refusing to treat a patient because she had HIV. And in *Olmstead v. L.C.*,⁶⁴ the Court held that the ADA imposes significant obligations on states regarding the provision of mental health treatment. The *Olmstead* Court disavowed any holding "that the ADA imposes on the States a 'standard of care' for whatever medical services they render, or that the ADA requires States to 'provide a certain level of benefits to individuals with disabilities."⁶⁵ But it specifically held that States must adhere to the ADA's nondiscrimination requirement with regard to the services they in fact provide."⁶⁶

Notably, when the Supreme Court addressed the "Baby Doe" issue, in *Bowen* v. American Hospital Association,⁶⁷ it did not embrace University Hospital's position that the Rehabilitation Act does not cover medical treatment decisions. Justice Stevens's plurality opinion rested on a very narrow ground. He concluded that a hospital's withholding of treatment to disabled infants did not violate the statute where the parents of those infants refused to consent to the treatment: "without the consent of the parents or a surrogate decisionmaker the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap."⁶⁸ Chief Justice Burger concurred in the judgment to make five votes for Justice Stevens's bottom line, but he issued no opinion to explain his reasoning.⁶⁹

In *Bowen*, not a single justice on the Supreme Court endorsed the Second Circuit's *University Hospital* holding. And the Court's subsequent cases stand in conflict with the Second Circuit's decision. Those decisions do not provide a basis for exempting medical rationing from the disability discrimination laws.

There is a second reason why the lower-court "Baby Doe" cases cannot save the discriminatory medical rationing decisions that are being adopted in response to the coronavirus pandemic. Those cases embraced a rule that the disability discrimination laws do not apply to a decision to deny treatment *based on the disability itself being treated*. The Second Circuit explained its position in *University Hospital*: "Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory'."⁷⁰ The Second Circuit's argument was intuitive. If a disability is the reason why an individual needs the medical treatment in the first place, how can the refusal to provide that treatment discriminate on the basis of disability? There is no comparator who *lacks* that disability who was being treated better. For this reason, the Tenth Circuit, in its case relying on *University Hospital*,

⁶² Univ. Hosp., 729 F.2d at 156.

⁶³ 524 U.S. 624 (1998).

⁶⁴ 527 U.S. 581 (1999).

⁶⁵ *Id.* at 603 n.14.

⁶⁶ Id.

⁶⁷ 476 U.S. 610 (1986).

⁶⁸ Id. at 630 (plurality opinion of Stevens, J.).

⁶⁹ See id. at 648 ("CHIEF JUSTICE BURGER concurs in the judgment.")

⁷⁰ Univ. Hosp., 729 F.2d at 157.

specifically distinguished "hypothesized situations in which the handicap that forms the basis of the section 504 discrimination bears no relation to the medical treatment sought but denied."⁷¹

The refusal to provide coronavirus treatment to patients with pre-existing disabilities is precisely the case that the Tenth Circuit distinguished. A pre-existing condition like a developmental disability "bears no relation to the medical treatment"—a ventilator—that the challenged protocols will deny the disabled patient. Here, unlike the situation in which the courts believed themselves to be in the "Baby Doe" cases, the medical system's action is the refusal to treat one condition based on an individual's having a different disability.⁷² Even on their own terms, the "Baby Doe" cases do not bar application of the disability discrimination laws here.

Conclusion

Under the best reading of the ADA, the Rehabilitation Act, and the Affordable Care Act, the denial of life-saving treatments to individuals who have a distinct preexisting disability violates the law. In a true triage situation—one the coronavirus pandemic may soon present—it may be necessary for the medical system to make tragic choices about how to allocate scarce resources. But denying those treatments to individuals because of their disabilities, when those individuals can benefit from them, is not one of the choices the law permits.

⁷¹ Johnson, 971 F.2d at 1494 n.3.

⁷² I don't mean to endorse the way the "Baby Doe" courts described the cases before them. As I have previously argued, there is ample basis to conclude that those cases in fact did involve the refusal to treat one condition based on the child's having a distinct disabling condition. *See* SAMUEL R. BAGENSTOS, DISABILITY RIGHTS LAW: CASES AND MATERIALS 365 (2d ed. 2014) ("Based on the facts the Court presents, the baby needed surgery for spina bifida, but surgery was not performed because she also had microcephaly and hydrocephalus. The government's argument, as Judge Winter explains in dissent, was that other children with spina bifida would have received surgery, and that the reason Jane Doe did not receive that surgery was because of her other disabilities."). Whether or not that conclusion is correct, the rule the lower courts articulated in the "Baby Doe" cases does not, on its own terms, reach the coronavirus-inspired rationing of ventilators away from individuals with pre-existing disabilities