

The Health of the People is the Supreme Law: COVID-19, Disability, and Ethics

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In early 2020, several states including Alabama, Tennessee, and Washington, implemented official guidelines to assist doctors in making difficult choices during triage, which is when rationing of medical supplies is necessary and there must be choices made about who will be given care and who will be left without. States had developed guidelines to assist healthcare professionals during crisis scenarios after the H1N1 pandemic in 2009 raised concerns about the possibility of future pandemics overwhelming health systems' ability to treat all the people who need care. An especially influential book in this regard was *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations*, published that same year by the U.S Institute of Medicine. Crucially, the beginning of the COVID-19 pandemic was the first time these state guidelines were implemented, meaning that only recently have state programs for responding to severe health crises been subjected to the trial of real-world application.

While each of these state guidelines utilized distinct verbiage, what united these policies was the advice to deprioritize disabled people in triage scenarios related to COVID-19. This advice ranged from more general to highly specific. For example, the Washington State Department of Health stated that doctors should consider “weighting the survival of young otherwise-healthy patients more heavily than that of older, chronically debilitated patients” (Ne’eman). Alabama, on the other hand, gave incredibly specific guidance, stating that people with “any of a wide range of underlying health conditions—such as metastasized cancer, AIDS, ‘severe [cognitive disabilities],’ advanced dementia and ‘severe burns’—could” be a deciding factor in whether a patient would receive care. Alabama’s guidelines even included a provision stating that “some people already on ventilators could be removed from them to make space for people impacted by the pandemic” (Sheets). Civil rights organizations such as The Arc of the United States and the Alabama Disabilities Advocacy Program criticized these guidelines, and legal cases were brought against the state health departments on the grounds that they violated the Americans with Disabilities Act (ADA). The ADA’s passage in 1990 was a landmark in the movement to secure rights against discrimination for people with disabilities.

The ADA, along with its amendments passed in 2010, prevents state and national governments from passing laws that discriminate against people with disabilities, and requires states to make public services such as courthouses and schools accessible to people with disabilities. Specifically, Title II of the ADA is the provision that “requires state/local governments to give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities” (ADA.gov). This provision defines state and local government programs as including but not limited to public education, public transportation, social services, courts, voting, and crucially, health care and emergency services. As of April 2020, the Office for Civil Rights in the U.S. Department of Health and Human Services announced that the State of Alabama had removed the discriminatory advice (USDHHS). However, some states have retained their guidelines for use in future pandemics, and it is important to consider the legal status of these guidelines when viewed in terms of the legal precedent they are building upon.

Beginning at least as early as *Hirabayashi v. United States* (320 US 81 [1943]) and continuing up to more recent decisions by the United States Foreign Intelligence Surveillance Court of Review regarding the constitutionality of the USA PATRIOT Act, courts in the United States have routinely argued that in cases of emergency, wartime, and other exceptional circumstances, the suspension of civil rights for certain groups is

required to uphold the “sovereignty” of the constitutional government (Michaelsen 43-46). In *Hirabayashi*, the Court established precedent allowing the government to limit the rights of certain groups in crisis situations. The circumstances surrounding COVID-19 policy bear more than a superficial resemblance to this; state crisis triage guidelines were activated in response to Proclamation 9994 announced by former President Trump in March of 2020, that declared “the COVID-19 outbreak in the United States constitute[d] a national emergency” and authorized the Secretary of HHS to exercise emergency authority. As useful as a case like *Hirabayashi* seems, however, a comparison to triage policy is more complicated than this first glance. Under the Constitution, states are granted police power over issues of public health: police power is the “inherent and plenary power of a sovereign to make all laws necessary and proper to preserve the public security, order, health, morality, and justice” and is a principle that grounds the use of eminent domain powers (Black’s Law Dictionary, via Witt 3)ⁱ. In 1868, Chief Judge Ward Hunt of the high court of New York State claimed that the state government had “absolute control over persons and property, so far as the public health was concerned” (Witt 5)ⁱⁱ. So, the matter of legislating about triage and healthcare crises falls to states and local governments. On the other hand, a case like *Hirabayashi* concerns the power of the national government to suspend the rights of a particular group of citizens during war. This difference indicates that we should turn elsewhere to understand the particularities of the ADA and its role in rulings about state-level health policies, and it raises the crucial question of whether the ADA’s regulation of state-level policies is valid. Answering this question involves weighing several competing clauses in the Constitution, and the best way to approach it is through the history of Supreme Court rulings regarding the ADA.

Precedents regarding the ADA can seem contradictory. However, on closer examination, a throughline appears that grounds the ADA in an important governmental principle, securing its power over state-level policies. In *Board of Trustees of University of Alabama v. Garrett* (531 U.S. 356 [2001]), the Supreme Court was asked to decide a case in which Patricia Garrett, an employee of the University of Alabama, was told to resign by her supervisor when she returned from a “substantial leave from work” necessitated by a diagnosis of breast cancer. In this case, the court decided that the ADA’s provision allowing individuals to sue states was “barred by the Eleventh Amendment”ⁱⁱⁱ (Oyez). In other words, Garrett saw the Court effectively abstain from ruling on the specifics of the case—whether such employment discrimination was legal—and instead emphasize formal concerns about whether an individual can sue a state in Federal court. Three years later, in *Tennessee v. Lane* (541 U.S. 509 [2004]) the Supreme Court decided in an opinion stated by Chief Justice Stevens that the ADA’s requirement for all courthouses to be made accessible to people with disabilities was a valid use of Congress’ powers, because access to courthouses has significant impact on the accessibility of due process for disabled people. The rationale for this decision was that access to due process is a right guaranteed for all citizens by the Fourteenth Amendment. That Amendment establishes due process of law as a fundamental right to which people are entitled, in the absence of which no state or national government can legitimately suspend individuals’ right to “life, liberty, and property.” The majority opinion in *Lane* weighed Fourteenth Amendment protections for citizens more highly than Eleventh Amendment protections for States. Even in *Lane*, though, dissenting opinions contested whether the ADA sufficiently described its protection of those rights that fall under the jurisdiction of Congress’ legislative powers, or whether it left the door open to Congressional overstepping. Chief Justice Rehnquist, for one, argued that Title II of the ADA “does not properly abrogate state sovereign immunity” (*Tennessee v. Lane*, 541 U.S. 509 [2004]). These two cases show where the ADA’s provisions have defended a very specific and circumscribed jurisdiction, and dissenting opinions have laid the groundwork for dismissal of any cases that do not fit that very specific profile. And, by raising the conflict between the Eleventh and Fourteenth Amendments, they offer a window into the crux of the debate.

A relevant recent case in considering the constitutionality of national-level restrictions and requirements on state-executed programs, especially healthcare, came in the form of *Dobbs v. Jackson Women's Health Organization* (597 U.S. ___ [2022]). While not directly related to COVID-19 triage or the ADA, the decision of the Court in *Dobbs* provides a look at the perspectives of the Supreme Court in relation to the power of the national government over states in the realm of healthcare. Whereas in *Tennessee v. Lane* the contested issue was the right of disabled people to access due process, *Dobbs v. Jackson Women's Health Organization* was centered on the right of a pregnant person to obtain an abortion. Leaving aside Justice Thomas' concurring opinion that seemed to call into question nearly a century of established precedent, the Court concerned itself with two questions in *Dobbs*: first, is the freedom to receive an abortion enshrined and protected in the Constitution; and second, does the Court have a legitimate claim to the ability to make legislation, which Justice Alito argues was what happened in *Roe v. Wade* (410 U.S. 113 [1973])? While the first question is not especially relevant to the current paper, the question of the Court's role in making versus interpreting law ought to be considered here. This is the objection brought by Justice Ginsburg against *Roe* in *Speaking in a Judicial Voice*. There, Ginsburg raises the example of *Roe* to elaborate an argument in favor of judicial restraint. She argues that, if the Court had simply declared Texas' law prohibiting abortion in every case where the pregnant person was not in life-threatening danger to be unconstitutional, the national debate about abortion would have proceeded in a very different way. Instead, the Court "shaped" a "doctrinal limb" by enumerating the trimester system, which "displaced virtually every state law then in force" (Ginsburg 239-241). While it may be true that Courts inevitably do make law, rather than simply make judgments about law, the Supreme Court (and the judicial branch as a whole) is the institution of government that is least beholden to democratic accountability, and therefore it should legislate only sparingly. Here, the point of departure between *Roe* and the ADA comes into focus; whereas *Roe v. Wade* was a Supreme Court decision that regulated state-level programs and policies, the ADA and its amendments are legislation passed by Congress.

In the *Lane* decision, the Court's opinion hinged on the fact that the right to due process is explicitly guaranteed to all citizens in the Bill of Rights; however, in the *Dobbs* decision, delivered by Justice Alito, the Court found no precedent or constitutional guarantee of the right to an abortion, and decided that "regulations and prohibitions of abortion are governed by the same standard of review as other health and safety measures" (*Dobbs v. Jackson Women's Health Organization*, 597 U.S. ___ [2022]). The typical standard of review is the state-level standard, meaning that access to abortion ought to be construed as falling under the coercive powers of states. But if Supreme Court decisions are not binding on state-level health policies, can Congress claim such power through legislation such as the ADA?

A crucial case decided in April 2023 makes clear the current Supreme Court's position on this issue. In *Perez v. Sturgis Public Schools* (598 U.S. ___ [2023]), the Court unanimously decided in favor of a disabled student who alleged that the Sturgis Public School District had "supplied [him] with unqualified interpreters and misrepresented his educational progress," and he therefore sought compensatory damages under the ADA. This case hinged on a specific detail about whether lawsuits under the ADA can proceed even if a student is undergoing administrative processes put in place by the Individuals with Disabilities Education Act, but it is a clear statement about the current Supreme Court's stance on the constitutional rights of disabled people and on the relationship between state and local governments and the ADA. The importance of this case cannot be understated for the question of the constitutional status of the ADA. Here, the Court has affirmed simply by hearing the case, rather than rejecting it by reference to *Garrett*, that the ADA is binding on state and local level education programs. The rationale for this decision is that Congress has the power to legislate in ways that protect the fundamental rights of citizens, among those being the right to receive an education. This right is grounded in a government's compelling interest in cultivating an educated nation.

In the same way that a government holds a compelling interest in educating its citizens, the national government has a compelling interest in preserving the health of its citizens—the health of the people is the supreme law, the ground of government without which a government has nothing to govern. Further, in a constitutional republic with internal limitations such as the Fourteenth Amendment that protect citizens against unequal protection of laws, the “people” whose health is the supreme law must be construed in a way that does not categorically disadvantage certain protected classes as described by the relevant laws. In other words, the national government has the power to regulate state healthcare programs to ensure that they are provided in a way that is not biased due to prejudice and discrimination, a power that is rationally related to the need to provide for the health of its citizens. This compelling interest, combined with Congress’ right to legislate in ways that protect the rights of citizens under the Fourteenth Amendment, means that the ADA can withstand challenges to its authority, including from the types of guidelines put in place in response to the COVID-19 pandemic. A caveat to this comes in the attitude of the Court in relation to the Eleventh Amendment. In deciding any case, Supreme Court justices make value-judgments about which constitutional provisions they will emphasize. Does the supremacy clause of Article I outweigh the Eleventh Amendment rights of states? Do the rights of citizens matter more than the formal procedures of law such as those established in the Eleventh Amendment? Is the expansive interpretation of the Eleventh Amendment as seen in *Hans and Seminole Tribe of Florida* a justifiable interpretation? A Justice (or set of Justices) who valued these Eleventh Amendment protections for states with the level of devotion of a Justice Rehnquist would, likely, deliver judgments such as those seen in *Garrett*. On the other hand, a set of priorities less concerned with the sovereignty of states over their citizens may open room for more rulings in favor of disabled people such as what was seen in *Perez*.

Returning to the topic of COVID-19 triage, the HHS OCR reached settlements with at least four states including the removal of guidelines calling for discrimination against people with disabilities. Because each of these cases was settled and therefore none were presented to the Supreme Court, we have no specific precedents from the current Court regarding the powers of the national government to regulate healthcare under the ADA. While the preceding analysis of case law pertaining to the ADA and to the role of the national government in regulating state-level health and education policy has demonstrated that the Court may be sympathetic to the ADA, perhaps an attempt to understand the state guidelines from another perspective can be constructive. What’s more, even the presence of such laws may not be sufficient to ensure that all medical professionals practice a nondiscriminatory attitude toward disabled patients. Polling shows that healthcare professionals and the public still hold prejudicial views of disabled people, and therefore arguments that exhaust themselves at the legal level are insufficient to ensure that disabled people do not face healthcare discrimination (Iezzoni et al.). To this end, a discussion of Peter Singer’s utilitarianism can be a foil to develop precisely why guidelines such as Alabama’s are discriminatory and fail to promote national and state government’s interest in protecting the health of its citizens.

A variety of justifications have been given for the discriminatory guidelines enacted by states in triage situations; the majority of these have centered on a notion of “quality of life” (QOL) and the assumption that non-disabled people have a higher overall quality of life than disabled people. This attitude was found to be prevalent among healthcare professionals in 2021—roughly 80% self-reported believing that disabled people intrinsically experience lower QOL (Iezzoni et al.). Responses to these guidelines have tended to center on this notion of QOL as well, arguing that the willingness to prioritize non-disabled people stems from an underlying “ideology of ableism” that is based on the “notion that that disadvantages of disability are intrinsic and inevitable” and that “disability inevitably diminishes well-being” (Stramondo). In some situations, subjective QOL judgments by medical professionals play a direct role in decisions about who receives care. Disability scholars have noted that communication barriers faced by “non-verbal individuals” and others can impede a healthcare professional’s ability to evaluate quality of life, especially where “alternative communication devices”

are unavailable^{iv}. In such instances, physicians are placed in positions of power relative to patients where they become responsible for assessing the patient's quality of life and acting based on their assessment. (Felt et al. 1773)

However, QOL judgments also play a more indirect role in conditioning triage decision-making. Among those advocating for the prioritization of "young, healthy people" was the well-known utilitarian bioethicist Peter Singer (Singer, *Policy Punchline*). In 2020, Singer advocated for the use of quality-adjusted life years (QALY) to determine who ought to receive the limited medical supplies that doctors found themselves forced to ration. The author John Fabian Witt describes QALYs as a "state-of-the-art" answer to questions about who should be given care; however, Singer had been a QALYs advocate since at least as early as the mid-1990s during broader debates about medical ethics, especially the question of whether cost-effective analysis (CEA) is a reasonable principle for guiding all medical decisions. (Witt 132) In a 1995 article defending the QALY approach against the charge that it induces double jeopardy^v on disabled people, Singer and colleagues write that the most "direct" technique for determining the "appropriate rate of discount for periods in which, as a result of ill-health or disability, the quality of life is poor" involves self-reported data. Researchers should simply ask respondents "how long a period of life in the given health condition they would be prepared to trade for one year of normal health." (Singer et al. 144) If respondents would be willing to give up 3 years of life with paraplegia in order to live one year without the condition, then according to Singer and colleagues we should "discount" the lives of paraplegic patients when calculating who ought to be given care. The patient without paraplegia will then be shown to have a "higher interest in continued life" because each year without paraplegia is equivalent to three years with the condition. In other words, people who are not disabled are as a rule more efficient at converting years of life into utility than are disabled people, because each year of life has higher quality. Each year of non-disabled life "counts" more.

The argument that Singer and colleagues put forward hinges on a couple of premises: first, that those who are disabled (whether through an accident or since birth) will always rank their own quality of life as lower than someone who is not disabled: second, that patients in the head-to-head thought experiments have equal life expectancies. If these two assumptions hold up to scrutiny, are QALYs then an impartial way of deciding who should receive care? Singer and colleagues even go a step further; they claim that if both assumptions are true—if it is true that QALYs are in fact an impartial metric for deciding whose life to prefer, one that would be accepted by rational agents behind a veil of ignorance^{vi}—then it is reasonable to conclude that "double jeopardy is not a sign of injustice or unfairness" (Singer et al. 148). This last claim speaks to Singer's monistic view of value^{vii}. The focus of this paper is not monism or a discussion of it. Nonetheless it is worthwhile to say that a critical and evidence-based approach to medical ethics may require the adoption of a pluralistic approach to value. As it turns out, the two assumptions that underlie Singer's thought-experiments about the impartiality of QALYs do not hold up to scrutiny.

To the first argument, the assumption that people with disabilities will always rank their quality of life as lower than non-disabled people is unsupported by empirical evidence; often, disabled people who are asked to self-report quality of life (QOL) "rate it only slightly lower than when nondisabled people self-report their own QOL." (Amundson). This claim is supported by an array of studies, but perhaps the most famous is a survey from the 1970s that found that people who became disabled through a traffic accident were not less happy one year later than those who won the lottery. (Brickman et al.) Even in cases where disabled people have been shown to report lower quality of life, this is explainable by secondary factors such as access to care and other support systems, social inclusion, and personal qualities like resilience (Barker et al.; Suriá Martínez). What these studies indicate is that, when QOL is reduced for disabled people, it is far from being an inevitable outcome of disability. Rather, it is an effect of institutions and the overall inclusivity of society, as well as the malleable attitudes that people have toward their circumstances. This discrepancy between empirical evidence and the

expectations of non-disabled people like Singer is so significant that some researchers refer to it as a paradox. However, given the popular and misinformed belief that disabled people intrinsically experience a lower QOL—a belief which Singer takes to be axiomatic in justifying QALYs—it is easy to make sense of the discrepancy. Far from paradoxical, the discrepancy is directly related to the ideology of ableism diagnosed by Stramondo and other commentators.

Thus, the first error in the argument in support of QALY metrics is that it relies on self-reported data, and specifically, self-reported data from non-disabled people who imagine what it would be like to be disabled. Although self-reported data is notoriously biased, careful controls can be put in place to avoid extreme bias and represent public opinion more accurately; in Singer and colleagues' argument, however, such controls are not found. It hardly seems surprising that polling about the quality of life with certain (especially chronic) disabilities would be biased and unreliable if it does not include or center on people who are living with the disability in question.

The second point regarding the impartiality of QALY metrics is the assumption that all individuals have the same baseline life expectancy. This is a troubling assumption given that, as Witt points out, “the life expectancy of white Americans was nearly four years longer than that of Black Americans...[and] the average life expectancy of Americans in the top income quartile exceeded that of Americans in the bottom income quartile by ten years” (Witt 132). In fact, throughout the arguments presented in favor of QALYs in “Double jeopardy and the use of QALYs in health care allocation,” there is an assumption that the “patients have a similar life-expectancy.”^{viii} (Singer et al. 148) The only time this assumption is not held as a component of a justification for QALYs is in the thought-experiment of Richard and Otto:

Two other patients, Otto and Richard have not been in any accidents, but they have heart conditions just like those of Michelle and Nina. Without transplants they will soon die, with transplants they will be able to continue to live their lives in full health. But Otto also has an entirely separate incurable medical condition that—while it causes him no problems now—will suddenly flare up and end his life. Because of this, his life expectancy is only twenty years, whereas Richard's is almost twice this—to be precise, 38 years. (Singer et al. 146)

Most important in the discussion of Richard and Otto is the emphasis on the fact that “everything else about Otto and Richard are the same—it is not the case that Otto needs the time to finish his literary masterpiece, or carry through his promising research into a method of achieving perpetual peace” and it is also not the case that Otto belongs to a marginalized demographic group, or that Otto is not as wealthy as Richard. In the hypothetical case of Richard and Otto, the two experience exactly equal levels of social privilege and the only difference in life expectancy comes from the fact that Otto will suddenly die of an incurable condition; on the other hand, most of the concrete decisions wherein medical professionals would apply QALYs would involve patients of widely differing backgrounds in terms of race, sex, gender, sexuality, and socioeconomic status, all of whom would have different life expectancy. These differences in life expectancy themselves stem from broader social forces such as racism, sexism, class oppression, and ableism in healthcare. On the other hand, the Otto-Richard scenario's introduction of differential life expectancy relies on the blameless random chance that resulted in Otto developing a second chronic condition. Understanding that differences of life expectancy are themselves the result of partiality in social systems underscores the fact that, far from impartial, the broader inequalities in life opportunities and circumstances are inherent in the calculation of QALYs for real patients. Disabled patients are subjected to not only double jeopardy, but triple or quadruple jeopardy depending on their other demographic factors. QALYs, reiterating as they do broader social inequities, cannot be seen as impartial.

There is one more defense for QALYs to be considered. Singer bolsters his argument with the claim that QALYs are used in making decisions about who should receive organ transplants. Contrary to this assertion,

an analysis of this type of claim by a team at The Hastings Center found that maximization of life-years was “considered and rejected in allocation decisions about kidney and lung transplants” and further found that “the philosophical justification for maximizing life-years is underdeveloped” (Gaurke et al.) So, if QALYs are neither an impartial nor widely accepted way to make decisions in triage, how should one respond to Singer’s claim that double jeopardy is not a sign of unfairness? It certainly seems irresponsible to outright reject cost-effectiveness analysis as an important principle in medical ethics generally; the use of QALYs in deciding between two or more treatments *for a given patient or when deciding* which treatment to mass-produce does seem to be a crucial part of medical ethics.

Going further, however, what can this argument against Singer’s use of QALYs say about utilitarianism as a general theory of ethics? It is possible to summarize Singer’s argument about QALYs in triage as follows:

1. If our goal in all ethical decision-making should be to maximize happiness (or quality of life) over the largest number of life-years, and
2. If disabled people intrinsically experience lower quality of life as a direct result of being disabled,
3. Then in the interest of maximizing overall quality of life over the largest number of life-years, we ought to deprioritize disabled people in triage situations.

As stated earlier, empirical evidence about disabled peoples’ quality of life does not tend to support Singer’s assumption of a direct link between disability and low QOL. And further, even when such a correlation does exist, the causation can be explained by reference to external factors such as accessibility of aspects of life that non-disabled people tend to take for granted, accessibility that is open to modification through changes in infrastructure and practices. Therefore, a large portion of the difficulties faced by disabled people are socially caused. Given that the low QOL of disabled people could be addressed by altering social conditions and institutions, it follows that the argument that disabled people should be deprioritized in triage does in fact amount to a form of double jeopardy as understood by Harris. If low QOL is itself the result of ill treatment of disabled people by doctors and people close to them, as well as a lack of institutional accessibility, it is unjust to hold those social failings against disabled people when making decisions about who may live and who must die. And this reference to the unjust character of Singer’s application of QALYs to triage leads to a question about Singer’s first premise. Can it be true that our goal in ethical deliberation should always and only be the maximization of happiness, the maximization of utility, for the most people over the longest period? Are there instead other important factors that ought to be accounted for when appraising the morality of a suggested or actualized way of behaving? The preceding discussion of the legal standing of disabled people under the ADA is a gesture toward such an understanding of ethics wherein justice plays a crucial role. Just what role it would play in relation to utilitarian considerations is a question for another paper. But for now, it is possible to explain some of the parameters of the problem.

Where Singer subscribes to a monistic concept of value as *overall utility*, it is necessary to supplement cost-effectiveness analysis (and utilitarian considerations of benefit-maximization more generally) with other principles, especially justice. This would entail a rejection of a monist view of values in favor of a pluralistic view. One famous argument against consequentialism, a core component of utilitarianism, comes from Judith Jarvis Thomson’s essay *Killing, Letting Die and the Trolley Problem* (1976)^x. The idea that we should challenge consequentialism should not be read as the claim that consequences of actions are irrelevant, but rather that there are other important considerations when deciding whether an action is good. Put another way, if consequentialism can fairly be summarized as the view that the sole morally relevant dimension of an action are the resultant consequences, then a minimum condition for rejecting consequentialism is to show that there are other relevant considerations when judging an action as moral or immoral. In that 1976 paper, Thomson

outlines a thought experiment that presents serious difficulties for consequentialism. Two of the most relevant scenarios are as follows:

1. Suppose you are on a trolley, on which the brakes have malfunctioned, and you are rapidly careening toward a group of five railworkers who are unable to move off the track before the trolley reaches them. It is impossible for you to stop the trolley's motion, but you can pull a lever to switch the track the trolley is following, thereby moving it to another track which is populated by one railworker who also will not be able to move off the track. Is it permissible to pull the lever to switch the track?
2. Suppose you are a doctor in the ER at some hospital. One day, a traffic accident occurs, and the ER receives five patients experiencing organ failure, each one in a different organ. Without medical intervention, each of the patients will surely die. However, you happen to know of another patient who, despite being ill, is in possession of a perfectly healthy set of organs that matches the needs of those other patients. That patient has not had any visitors, and, for the sake of the thought experiment, you know that you will not face any negative consequences if they die in your care. Is it permissible to kill the one patient, harvest their organs, and use them to save the lives of the other five patients?

The juxtaposition of these scenarios illustrates a fundamental problem with consequentialism. In both situations, the outcome is numerically the same: one person is sacrificed to save five others, resulting in a net gain of four lives. However, it seems implausible to state that this is the *only morally relevant fact* about these two situations. Most people find that the action taken in scenario 2 involves a degree of agency (and therefore *guilt*) on the part of the doctor who murders a patient, agency that has relevance for deciding whether the action is right or wrong. Unless one is willing to bite the bullet and say that sometimes it is acceptable to kill innocent people, it seems wrong to say that the monistic view of goodness that utilitarianism proposes can or should account for all our moral judgments. However, it remains unclear how best to characterize these other concerns. A discussion of a few pluralistic frameworks for thinking about bioethics that have been developed in recent decades can advance an understanding of how bioethics can help frame triage decision-making and can also sketch out a few problems that need to be addressed in this area.

The very same book that recommended state guidelines for crisis triage and led to the development of the guidelines discussed at the beginning of this paper--entitled *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations* and published in response to the 2009 H1N1 epidemic--can help illustrate what such an approach might look like. A crucial section of that text deals with the "Ethical Framework" for decision-making in crisis situations, a framework that is fundamentally pluralistic: on this view, medical professionals need to weigh a variety of concerns including "fairness [and] the professional duties to care and to steward resources" (Altevogt). In crisis situations, medical professionals need to balance concerns such as cost-effective use of resources, the duty to care for patients, and a principled approach to justice that is grounded in "evidence-based" approaches to resource allocation. Such a framework makes room for cost-effectiveness analysis while remaining flexible enough to avoid subordinating concerns about justice and doctors' responsibilities to patients to this concern for cost-effective treatments.

Another example of such a framework was elaborated by Tom Beauchamp and James Childress in *Principles of Bioethics*, as discussed in *Bioethics: The Basics* (Campbell 44-46). The authors advocate for a fourfold system of values that medical professionals should work to balance. Those four principles are autonomy, beneficence, non-maleficence, and justice. Nurses, doctors, and other medical professionals should strive to ensure that their patients enjoy autonomy to the greatest degree possible in "decisions about treatment or non-treatment, confidentiality, and public health policy" (Campbell, p.44). In the context of COVID-19 and disability, this would mean that patients and, if necessary, their caretakers should have a say in whether a patient would

be taken off a ventilator. It would be unethical for healthcare professionals to make this decision for a patient, even if it meant maximizing utility.

Further, medical professionals should strive to uphold the “ancient medical maxim, *Primum non nocere* (‘first of all, do no harm’)” (Campbell 45). Beneficence and non-maleficence are closely connected. In the context of the preceding discussions, this could reasonably be read to include an injunction to not deprive a disabled patient of a life-saving ventilator—thereby doing harm to that patient—just because another patient who is not disabled also needs it. This is the pair of principles that most clearly draw on utilitarian or consequentialist considerations of effective use of resources and minimizing pain while maximizing benefit to a patient. Finally, as medical professionals make decisions and treat patients, they should strive to do so in ways that are grounded in a notion of justice. As Campbell notes, justice has the potential to introduce a variety of questions into how medical professionals should work, and it is in tension with the idea of maximizing gains for some patients while neglecting the needs of others. However, this tension is healthy and ensures that medical systems can work for all people, including those with disabilities. Turning once more to Campbell, he claims that fair distribution of “benefits and costs...demands a more demanding form of moral reasoning than simply working out potential benefits and harms to individuals.” (Campbell 46) What can this “more demanding form” of ethical philosophy look like? And to what extent can these other principles, supposed to be distinct from utilitarian concerns, in fact be assimilated to a utilitarian position?

A committed utilitarian could reasonably hold that while autonomy, non-maleficence, and justice are important stopping points on the way to utilitarian maximization of quality of life for the most people—in other words, that utilitarian maximization serves as the *ultimate* justification for concerning ourselves with those other principles. Non-maleficence is self-evidently assimilable to a utilitarian position, and it seems plausible to suggest that the goal of ensuring patient autonomy is to maximize a patient’s well-being by allowing them control over their own medical care^{xi}. But the question of justice is one that appears especially thorny. It seems that the utilitarian insistence on maximization of life quality over the largest number of life-years conflicts with a view of justice that insists on the right of each member of society to their due consideration and at a minimum a right to equality of opportunity to benefit from available resources. In fact, Singer’s use of Rawls’ notion of the original position and veil of ignorance to justify QALYs seems mistaken; why would *rational* agents behind a veil of ignorance (meaning, ignorant as to whether they would be disabled or not) *knowingly* choose a society in which they would be systematically disadvantaged in decisions about who should receive medical care if they happened to be born disabled and/or become disabled over the course of their lifetime? Singer’s argument is that

...if they choose a random method of selection in order to avoid discrimination in situations when a treatment cannot be given to everyone, then some with higher interest in continued life will not receive such treatment. To maximize the satisfaction of their own interests, rational egoists would have to choose a system that gives preference to saving life when it is most in the interests of the person whose life is saved. (Singer et al. 148)

But this raises a crucial question; how is it that the rational agent *behind the veil of ignorance* would know that they would be the person who would have the most interest in continuing to live? Isn’t the point of the veil of ignorance that the rational agent would have to decide given a lack of knowledge about where they would fall in the distribution of opportunities and resources? If, using Singer’s terminology, scarce resources were always to be allocated to the party who has the “higher interest in continued life,” the only way this guarantees a maximization of my own interest as a rational agent is if I assume that I will be the patient with a “higher interest in continued life.” But behind the veil of ignorance, I have no grounds to make such an assumption. Given the choice between a guaranteed 50/50 in the scenario where resources are allocated randomly and a chance at being automatically denied access to resources because of characteristics that are out of my control

were I to be born into the group that Singer assumes has a lower “interest in continued life,” it makes more sense to take the guaranteed 50/50. In fact, Singer’s stance from behind the veil of ignorance seems to undercut the power of Rawls’ methodology to show that slavery is unjust: if I can assume that I would be born into the position of a slave master, thereby rationally maximizing my interests, why not decide in favor of slavery? But this is simply a misunderstanding of why Rawls’ method is so powerful: the point Rawls makes is that given the chance to be born into any position in society, I should rationally prefer a society which guarantees equality of opportunity and a minimum of discrimination. If I were asked to decide on the question of slavery from behind a veil of ignorance, I should rationally choose against it; for much the same reason, if asked to decide on a rule discriminating against disabled people in healthcare, it is eminently rational to decide against it—and this is crucial—even if I believe that such a rule would generate a greater amount of overall utility (happiness or quality of life) than the absence of such a rule. Because I simply have no way of knowing where I would end up. A strong statement of justice as a principle in tension with utilitarianism comes from Rawls when he writes that “each member of society is thought to have an inviolability founded on justice which.... even the welfare of every one else cannot override” (“Theory of Justice” 24-25). To reiterate the problems with both of Singer’s premises regarding deprioritizing disabled people in triage, the preceding arguments follow this two-step pattern: in attempting to maximize utility in medical decisions, it is not true that disabled people will as a rule have lesser interest in continued living. A disabled life can be a good life. But even if it were true that disability intrinsically lowered quality of life and inevitably foreshortened life, it still would be unethical to implement a rule discriminating against disabled people in triage, because it would be unjust. Utilitarianism cannot simply override justice by showing that utility would be maximized through discrimination.

One final way to bring justice into bioethics, thereby making the field more rigorous, is to engage concretely with the historical and institutional context in which medical professionals are expected to make decisions. To this end, ethics ought to engage with the traditions and institutions of law in a particular country, the codes of ethics that doctors agree to in becoming licensed professionals, and factors such as international law when conducting work in an international sphere. This may seem troubling at first; are justice and the law to be considered synonymous? Are ethics and law to be seen as coextensive fields? Were this to be the case, one could scarcely envision a way of soundly arguing against existing laws and the way that current institutions are structured. Justice is not simply the set of legal precedents and institutions as they exist now. In fact, one cannot conceive of challenging laws such as segregation of schools without first a conception of justice against which one compares current practices, whether such a conception involves an ideal or the urge to remedy obvious injustices. The question of the relationship between legal and ethical thought, and the problem of the relationship of justice and a concern for utilitarian considerations, will be the subject of future research. This paper begins a dialogue between bioethics and legal philosophy by positing what the outlines of that debate might look like. Combining the philosophy of law and philosophy of science to make bioethical deliberations more concrete and rigorous is crucial in future attempts to deal with pandemics and other catastrophes, as well as the everyday struggles faced by many people. Through a thorough discussion of the trouble with one approach to the ethics of triage—specifically, quality-adjusted life years—and a convincing argument that state guidelines that deprioritize disabled people ought to be considered constitutionally invalid according to the standards set by legal practice in the United States, we can begin to imagine alternative approaches to ethics that can aid a shift in public opinion about triage decisions in future pandemics and health crises.

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Notes

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- ⁱ The validity of governmental use of eminent domain in the service of public health was established at least as early as *Brick Presbyterian Church v. Mayor of New York* (1826) wherein the New York Supreme Court decided that the city had the power to expropriate land that churches planned to use for new graveyards as necessary when exercising its authority to prohibit “nuisances to public health.” (Witt 3)
- ⁱⁱ Decisions about the “absolute control” over citizens in matters of public health have historically been grounded in a principle known as “salus populi suprema lex,” or “the health of the people is the supreme law.” In other words, any government has a compelling interest in maintaining the health of the nation it governs—without a nation, a government has nothing to govern.
- ⁱⁱⁱ The Eleventh Amendment to the Constitution prevents the extension of the judicial power of the United States to “any suit in law or equity, commenced or prosecuted against one of the United States by citizens of another state” (Constitution Center). While the original wording of the amendment does seem to be specific about the fact that it bars “citizens of another state” from suing a state, Court decisions have not held to a literalist interpretation. In *Hans v. Louisiana* (134 U.S. 1 [1890]), for example, the Court’s decision was that states could not be sued by their own citizens in cases where federal law was concerned. In keeping with this precedent just over a century later, *Seminole Tribe of Florida v. Florida* (517 U.S. 44 [1996]) saw the Supreme Court decide that Congress did not have the power to overrule states’ sovereign immunity as described in the Eleventh Amendment, even in issues of commerce.
- ^{iv} Alternative communication devices may include a simple pen and paper for many patients, or a cell phone to type on. A worthwhile project would be to advocate for the inclusion of caretakers and family members in assessments of quality of life, even if they are unable to accompany patients directly, especially in cases where patients are unable to communicate effectively with healthcare professionals (perhaps due to severe cognitive disabilities).
- ^v The concept of double jeopardy as a critique of QALYs is distinct from its meaning in a jurisprudential context. According to John Harris—the author of the article that Singer is responding to in the quoted article—double jeopardy in this context means that “QALYs dictate that because an individual is unfortunate, because she has once become a victim of disaster, we are required to visit upon her a second and perhaps graver misfortune.” (Harris 120)
- ^{vi} The veil of ignorance, also known as the original position, is a thought experiment proposed by John Rawls in his 1985 book *Justice as Fairness*. In this work, Rawls develops the theory that a just and fair society is one that is characterized by whatever institutions a rational agent would prefer if they were looking at a society from this original position, where they do not know any demographic details about where they will be born in the society. A famous use of this method is in arguing against a society where structural racism entails the enslavement of all Black people in the society: while the agent may choose to wager that they will be born as a slaveholder rather than a slave, ultimately it makes little rational sense to prefer the gains of being a slaveholder in a vastly unequal society when we could instead select a society where no one is enslaved, thereby taking no risk of being born into enslavement once we leave the original position.
- ^{vii} A monist in ethics holds that there is one good (whether it be virtue, piety, justice, or hedonic pleasure) that all “moral” acts must have as their aim, and that any goals that contradict this good fall into one of three categories: 1. Those goods that appear to be distinct from the one ultimate good, but that on further analysis can be collapsed into the ultimate good. 2. Those that are contradictory to the ultimate good and therefore are not good at all. 3. Those kinds of acts that do not advance pursuit of the ultimate good and are therefore either irrelevant or costly to the extent that they distract people from pursuing the ultimate good. A pluralist, on the other hand, claims that there are a variety of goods that we should strive for, even if those goods may seem to be contradictory or mutually incompatible. For a utilitarian monist like Singer who emphasizes CEA in questions of medical ethics, the goal of our ethical deliberation should always and only be the most efficient outcome, which means maximization of hedonic well-being—and in the context of triage, maximization of QALYs. If the principle of QALY maximization would be undercut by considerations of double jeopardy, this indicates that we should drop the double jeopardy objection, since “double jeopardy is not a sign of injustice or unfairness” (Singer et al. 148).
- ^{viii} On page 145, in the case of Karen and Lisa, both are assumed to have a life expectancy of 40 years. On the same page, in the case of Michelle and Nina, we are to assume “without the transplant, each will die immediately, and with the transplant, each will live for 40 years” (Singer et al. 145).
- ^{ix} In presenting this research, I have routinely received questions about the relationship between cost-effectiveness analysis and the logic of capitalism. I am sympathetic to this critique, especially when levied against the use of QALYs to decide against disabled people in triage, who are the paradigmatic example of “non-productive” citizens to be shunted by a society that concerns itself first and foremost with productivity and maximization of profits. However, I think that the use of QALYs and cost-effectiveness analysis in deciding between potential treatments for patients (including those with disabilities) is a reasonable and responsible approach to resource utilization that need not be tied to “cost” in the sense of monetary cost. Even under a fully communist mode of economic organization (one without money or private enterprise) the problem of how to use a limited pool of resources remains.
- ^x Given that this essay arose in conversation with Philippa Foot’s approach to virtue ethics, it may be worthwhile to examine the practical side of medical ethics in terms of virtue ethics.
- ^{xi} One should note here that in passing it also seems plausible to argue against this view. Autonomy considered as a *principle* could potentially be secured by introducing a notion such as *regret*. A patient may make a choice concerning their medical treatment and

later come to regret that choice; however, a pluralist could say that it nonetheless remains desirable for that patient to retain the autonomy to make (ideally better-informed) choices about their own life.