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The Dichotomy of Utilitarian Maximization and Primum Non Nocere in the Unprecedented Times of COVID-19: Ethics, Standards of Care, and Protecting Vulnerable Populations

Sarah Polites

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Sarah Polites*

I. INTRODUCTION

Thoughts and threats of pandemics have sprouted sporadically throughout history. While not all amount to the magnitude of the Spanish Flu of 1918 or COVID-19, they are still a harsh reality with potential for detrimental effects to all aspects of society. We routinely have preparedness training protocols for mass casualty events such as active shooters, bombings, fires, and natural disasters. However, despite the pressing threat of a pandemic, why is it that we did not have the same preparedness protocols in place? As we can learn from other disasters and mass casualty trainings, the best time to prepare for a pandemic is when one does not exist. As the current COVID-19 pandemic continues to rapidly unfold right before our eyes, there is still room for improvement in our response to alterations in standards of care due to a large influx of patients. Specifically, the development and implementation of hospital emergency plans should be rooted in ethics and substantive and procedural values, while providing adequate protections for vulnerable populations, and alleviating the burdens and magnitude of moral distress of healthcare providers.

According to the American Hospital Association, there were 6,090 hospitals in the United States in 2019, comprised of 919,559 staffed beds, with just under twelve percent of those beds dedicated to intensive care across the age spectrum.[1] As we saw with COVID-19, many of these hospitals have been affected by surges of people infected with SARS-CoV-2 at different times over the trajectory of the pandemic. However, that should not mean they must act individually to

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[1] *Fast Facts on U.S. Hospitals, 2021:* AMERICAN HOSPITAL ASSOCIATION, https://www.aha.org/statistics/fast-facts-us-hospitals (last visited March 1, 2021).

develop policies and protocols for the unprecedented surges of patients ranging from more routine care to the high acuity critically ill. Enacting specific legislation addressing alterations in hospital operations and triage guidelines to allocate scarce resources can alleviate the burden of the already-stressed health care system.

Some states have already established guidelines for activating altered standards of care, triage, and allocation guidelines in the event resources become scarce. Given the widespread nature of this pandemic and the moral distress experienced by healthcare providers, every state should formulate a specific set of operating procedures in accordance with their duty to plan. The existence of a well-thought-out plan prior to experiencing a surge in disease allows for ethics to be adhered to, the most vulnerable to be protected, and legal challenges to be avoided. Enacting legislation on the above provides a clearly defined process that is uniform to all hospitals and health systems in the state during an unprecedented time, which alleviates the burden on the hospitals and individual healthcare providers.

Overall, this paper discusses the shifts in standards of care that can occur during pandemics and the impacts of those shifts on healthcare providers and the patient population, specifically, vulnerable populations. Part II addresses the medical background of coronavirus and guidelines from the Institute of Medicine (IOM) for developing emergency plans during a pandemic, as well as specific examples of plans implemented during COVID-19. Part III describes potential legal issues that can arise during development and implementation of triage and resource allocation guidelines. Part IV provides an overview of state plans and legislation developed for pandemics. Part V puts forth recommendations for equitable development and implementation of pandemic emergency and triage plans, so that vulnerable populations receive adequate protections.

II. BACKGROUND

a. Medical Background

Infectious diseases continually pose challenges for public health, particularly pathogens that cause pandemic influenzas. The family of coronaviruses are known to exist in humans and animals. They are single-stranded DNA viruses that have the potential to cause respiratory, gastrointestinal, and neurological disease.[2] In December 2019, a rapidly spreading novel coronavirus, SARS-CoV-2, originated in Wuhan, China, causing the infectious disease, COVID-19. [3] On January 30, 2020, the World Health Organization declared a public health emergency with cases of COVID-19 rapidly spreading across the world leading to lockdowns, overwhelmed hospital systems, and far too many deaths.[4] COVID-19 was declared a pandemic on March 11,2020. It quickly became one of the deadliest pandemics affecting billions of people worldwide in some capacity.[5]

SARS-CoV-2 can be spread through respiratory droplets while coughing, talking, or sneezing, as well as through prolonged exposure to someone who is infected.[6] There is also a chance for transmission through contact with infected surfaces and aerosol transmission. Severity of the disease ranges from asymptomatic to severe.[7] Symptoms also vary widely and include any combination of fever, cough, shortness of breath, fatigue, muscle pain, nausea, headache, weakness, nasal congestion, loss of taste or smell.[8]

b. Institute of Medicine (IOM) Recommendations for Crisis Standards of Care

The following section provides a background of the recommendations and guidance provided by the Institute of Medicine (IOM) for developing emergency plans during a pandemic.

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[2] W. Joost Wiersinga, Andrew Rhodes, Allen C. Cheng, Sharon J. Peacock, Hallie C. Prescott, *Pathophysiology, Transmission, Diagnosis, and Treatment of Coronavirus Disease 2019 (COVID-19): A Review*, 324 *JAMA* 782 (2020).

[3] *Id.*at 784

[4] *Id.*

[5] *Id.*

[6] *Id.* at 783

[7] *Id.*

[8] *Id.*

It will specifically address the purpose for these recommendations, the adherence to the equitable processes of transparency, consistency, proportionality, and accountability, the duties to plan, care, and steward resources, the dichotomy between ordinary and crisis standards of care, and lastly, examples of crisis standards of care plans implemented during the COVID-19 pandemic.

i. Purpose

Long before COVID-19 was even on our radar, many were warning of the potential for the next public health emergency. Given the potential for a pandemic, there have been great strides to develop procedures and guidance on how to appropriately manage a disaster. The IOM endeavored to provide comprehensive guidance on standards of care to be implemented in the event of a disaster where resources become scarce in 2009 due to the lurking threat of the H1N1 virus at that time.[9] This guidance was intended to lay the groundwork for creation of formal legislation for crisis response as well as further development of uniform crisis standards that could apply broadly.[10]

ii. Equitable Processes

The IOM outlines various principles and values that should be adhered to while developing and implementing crisis standard of care plans. The equitable processes specified are transparency, consistency, proportionality, and accountability.[11]

Transparency is a building block of trust between the community and the leaders.[12] It allows for awareness of the processes and procedures that are being developed and implemented. By being transparent and engaging a diverse group of people in the process, vulnerable populations can be adequately represented and less likely to be adversely impacted by the decisions made.[13]

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[9] INSTITUTE OF MEDICINE, GUIDANCE FOR ESTABLISHING CRISIS STANDARDS OF CARE FOR USE IN DISASTER SITUATIONS: A LETTER REPORT, 1 (2009).
[10] *Id.* at 8.
[11] *Id.*
[12] *Id.* at 31.
[13] *Id.*

Transparency can also alleviate patient fears when they are informed of the different processes of the hospital. Examples of transparency specific to the COVID-19 pandemic are publishing the amount of hospital beds available, the number of positive tests, informing the public of how a facility is kept clean and sanitized, safety measures put into place such as air filters, partitions, or increased hand washing requirements, and isolation guidelines for patients who are positive for SARS-CoV-2.

The next equitable process is consistency, which ensures that the proposed processes and procedures are applied to all populations regardless of race, age, disability, ethnicity, socioeconomic class, payment ability, preexisting conditions, perceived worth, past use of resources, or treatment obstacles.[14] Consistency goes alongside fairness, because when hospitals provide consistent care and have consistent resources, the result is promotion of fairness among the community. Proportionality is relative to the degree of the emergency and the available resources.[15] Lastly, accountability centers around the decision makers and those implementing the standards of care.[16] Accountability is another means to build trust, not only between a health care professional and a patient, but between the governor and the general population, and even the administrators and the employees.

iii. Duties to Plan, Care, and Steward Resources

In addition to the equitable processes and ethical principles, there are also duties to care, plan, and steward resources.[17] The duty to care centers around the existence of a responsibility to provide care in a crisis due to training, positions held, and professional norms.[18] The duty to plan establishes that obligations exist for government and hospital leadership to create a catastrophic

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[14] *Id.*
[15] *Id.*
[16] *Id.*
[17] Jonathan P. Leider, et.al., *Ethical Guidance for Disaster Response, Specifically Around Crisis Standards of Care: A Systematic Review*, 107 AJPH e2 (2017).
[18] *Id.* at e4.

response plan.[19] This was carried out in most states through their initiatives in creating crisis standards of care plans and guidelines and algorithms for triaging scare resources in the event of a patient surge. A duty to steward resources is our obligation to utilize the resources we have efficiently so that their benefit can be maximized.[20]

iv. Standards of Care

The operation of society during public health emergencies is unique. The IOM concluded that the overarching ethical framework shifts to utilitarian maximization, resulting in making decisions based on the population as a whole and doing what is best for the greater good.[21] Recent examples of this are mask requirements, social distancing, curfews, and specific guidelines for vaccination.

A similar shift occurs in the day-to-day operations of health care, as well. Traditionally, healthcare providers abide by the medical standard of care, which is described by the IOM as "…the type and level of medical care required by professional norms, professional requirements, and institutional objectives."[22] Healthcare providers follow the principle of *primum non nocere*, or "first, do no harm," when treating patients.[23] Ethically, the approach to patient care falls under a deontological framework, which regards each person as valuable and stresses equality of care.[24] The American Medical Association (AMA) Code of Medical Ethics echoes these principles, specifically, Principle VIII stating, "[a] physician shall, while caring for a patient, regard responsibility to the patient as paramount."[25] However, this is not feasible under the constraints of a public health emergency, thus, requiring the ethical shift to utilitarian maximization. This shift

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[19] *Id.*
[20] *Id.* at e5.
[21] *Id.* at 30.
[22] *Id.* at 45.
[23] Brandy X. Lee, M.D., M.Div.; John L. Young, M.D., M.Th., *Clinicians' Need for an Ecological Approach to Violence Reduction*, 20 AMA JOURNAL OF ETHICS 91 (2018).
[24] Paul S. Chan, M.D., M.Sc.; Robert A. Berg, M.D.; Vinay M. Nadkarni, M.D., M.S., *Code Blue During the COVID-19 Pandemic*, CIRCULATION: 13 CARDIOVASCULAR QUALITY AND OUTCOMES 261 (2020).
[25] AM. MED. ASS'N, CODE OF MEDICAL ETHICS (2001).

can be morally distressing for healthcare providers, which is a reason why the duty to plan is integral.[26]

Adhering to the duty to plan, the IOM recognizes during a public health emergency there will be surges of patients and rapidly changing conditions. These patients can range from stable, requiring routine medical-surgical care, to critically ill, requiring critical care. The unpredictability of patient surges can become overwhelming and burdensome, on top of possibly experiencing shortages of necessary supplies, equipment, beds, and personnel. As a result, three standards of care were defined—conventional, contingency, and crisis standards of care. They can be thought of as a spectrum that a hospital or health system can operate under during a public health emergency.[27]

It is the recommendation of the IOM to adhere to certain principles while developing crisis standards of care guidelines. The recommendations are that the guidelines engage the community, are grounded in ethics, provide clarity in terms of what their indicators are, what triggers a shift to crisis standards of care, as well as how responsibilities of personnel change during this shift in care, contain processes that are evidence-based, and are developed with awareness and assurances regarding legal authority.[28]

The IOM defines "indicators" as a "measurement or predictor that is used to recognize capacity and capability problems within the healthcare system, suggesting that crisis standards of care may become necessary and requiring further analysis or system actions to prevent overload."[29] Examples of indicators are high call volumes and wait times for emergency medical services, low availability of hospital beds, intensive care beds, or ventilators, shortage of resources such as

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[26] Leider, *supra* note 11, at e2.
[27] INSTITUTE OF MEDICINE, *supra* note 9, at 14.
[28] *Id.* at 4-5.
[29] *Id.* at 61.

medications or oxygen, or high rates of staff illness.[30] "Triggers" are defined as "evidence of use of crisis standard-of-care practices that require an institutional, and often regional, response to ameliorate the situation."[31] Examples of triggers are utilizing unconventional spaces for patient care, inadequate specialty staff, and lack of supplies that impact quality and safety of patient care.[32]

"Conventional" standard of care is defined by IOM as utilizing "usual resources to deliver health and medical care that conforms to the expected standards of care of the community."[33] These are the conditions under which the hospital typically operates. In between conventional and crisis is a contingency surge response. There are certain adaptations that occur with a contingency response; however, it aims to keep operations as close to normal as possible.[34] Lastly, crisis standards of care are implemented when resources are insufficient, and conditions make it impossible to meet the ordinary standard of care.[35] Crisis standards of care are defined by IOM as:

> A substantial change in usual healthcare operations and the level of care it is possible to deliver, which is made necessary by a pervasive (e.g.,pandemic influenza) or catastrophic (e.g., earthquake, hurricane) disaster. This change in the level of care delivered is justified by specific circumstances and is formally declared by a state government, in recognition that crisis operations will be in effect for a sustained period. The formal declaration that crisis standards of care are in operation enables specific legal/regulatory powers and protections for healthcare providers in the necessary tasks of allocating and using scarce medical resources and implementing alternate care facility operations.[36]

The main goal of a hospital or health system is to stay within the conventional and contingency response models as much as possible. This can be accomplished through preparation.[37] When a crisis standard of care is triggered, the hospital should make every effort to

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[30] *Id.*
[31] *Id.*
[32] *Id.* at 64.
[33] *Id.* at 14.
[34] *Id.* at 15.
[35] *Id.* at 15.
[36] *Id.* at 18.
[37] *Id.* at 15.

return to either contingent or conventional standards as soon as possible.[38] Crisis standard of care is a last resort, and not a phase that is entered voluntarily.[39]

It is also recommended that efforts are consistently implemented which can include the use of different teams and committees constantly evaluating best practices and decision tools, information sharing, protecting the mental health of the population, and developing specific response plans for persons with disabilities who have different needs than the general population.[40] Additionally, it is proposed that neighboring states work together and communicate during a public health emergency.[41] These recommendations all ensure that crisis plans are made fairly, in an equitable manner, and with transparency.[42]

Even though there are alterations in normal operations, ethical principles do not get abandoned during a public health emergency.[43] "Healthcare professionals are obligated always to provide the best care they reasonably can to each patient in their care, including during crises."[44] In the event of limited resources, health care providers are obligated through ethics and justified through ethical principles to utilize available resources to maximize life.[45] What crisis standards of care do not do is eliminate accountability or permit actions that disregard ethics.[46]

After the crisis standards of care are developed and an emergency or disaster exists, implementation of these plans requires coordination. There are a lot of moving parts in terms of patient volume, hospital capacity, resource utilization, and availability of resources. Over the course of the emergency, there are a spectrum of surge responses ranging from conventional to

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[38] *Id.*
[39] *Id.*
[40] *Id.* at 8.
[41] *Id.*
[42] *Id.* at 9.
[43] *Id.* at 6.
[44] *Id.*
[45] *Id.*
[46] *Id.*

contingency to crisis.[47] Conditions can rapidly change and should be monitored closely to ensure the hospital is operating on the proper standard of care.

When a crisis standard of care needs to be activated, it is imperative that fairness, equitable processes (transparency, consistency, proportionality, accountability), community and provider engagement, education, and communication, and the rule of law (authority and environment) are adhered to.[48]

Fairness includes the duties to care, steward resources, and is also inclusive of maintaining trust.[49] Fairness is achieved when those who are affected consider the standards fair.[50] Transparency applies to the design and decision-making process.[51] This is important when ensuring protections of vulnerable populations. The policy considerations and decision-making process will have an effect on the most vulnerable in our society.

Community engagement requires collaboration among leaders, residents, healthcare providers, and formal authorities in an effort to develop successful crisis standards.[52] Engagement of the community should involve an open dialogue throughout the entirety public health emergency. It is not limited to the planning phase or post-emergency.[53] While the emergency is ongoing, community leaders and the residents should have constant communication, relaying information to provide awareness of the situation, providing mental health check-ins, bereavement resources, and resources for resiliency strategies. Community engagement is a great way to build trust between community leaders and vulnerable populations.[54] It is imperative throughout the

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[47] *Id.* at 14.

[48] *Id.* at 18-9.

[49] INSTITUTE OF MEDICINE, *supra* note 9, at 19.

[50] *Id.*

[51] *Id.*

[52] INSTITUTE OF MEDICINE, *supra* note 9, at 36-37.

[53] *Id.*

[54] *Id.*

community engagement process that vulnerable populations, such as minorities and people with disabilities, are advocated for and are treated equitably.[55]

v. Examples

Despite COVID-19 being a daily concern, not every area of the country had the same level of impact. Some states had emergency plans prepared before COVID-19 became an issue, due to the recommendations the IOM made in anticipation of a public health emergency. Others still do not have a concrete plan in place. The University of California developed crisis plans for their health system that mimicked the State of California's plans.[56] These plans included specific algorithms identifying triggers and indicators for moving between conventional, contingency, and crisis standards of care, how the situations would be reassessed, guidelines for special patient populations such as post-operative surgical patients and those waiting to receive a solid organ transplant.[57] Specifically, University of California identified how they engaged the public and methods of transparency.[58]

III. Legal Issues

a. Triage and Resource Allocation

Due to the amount of people who require medical care and the resources required in a pandemic, scarcity of those resources is a big concern. Triage guidelines can be developed that provide clear indications and steps for determining how scarce resources will be fairly distributed.[59] These triage guidelines should aim to save the most lives as possible.[60] Specifically, "[t]hese

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[55] *Id.*

[56] UNIVERSITY OF CALIFORNIA, ALLOCATION OF SCARCE CRITICAL RESOURCES UNDER CRISIS STANDARDS OF CARE, https://www.ucop.edu/uc-health/reports-resources/uc-critical-care-bioethics-working-group-report-rev-6-17-20.pdf (last visited April 25, 2021) [hereinafter *Allocation of Scarce Critical Resources*].

[57] *Id.*

[58] *Id.*

[59] Govind Persad, *Disability Law and the Case for Evidence-Based Triage in a Pandemic*, 130 YALE L.J. F. 26 (2020) [hereinafter *Evidence-Based Triage*].

[60] *Id.* at 27.

proposals agree on the importance of saving more lives, saving more years of life, and not using quality-of-life judgments."[61]

Triaging of patients should not be done arbitrarily as that leads to discrimination against vulnerable groups. When there are surges of patients with a need to triage, it is ethically sound to start by considering the likelihood of the person deriving a medical benefit from the proposed interventions.[62] Clinical judgement alone is not preferred because this is a subjective method and leads to results that are inconsistent and cannot be broadly applied.

Scoring systems can be taken into consideration in order to provide for a more objective approach to triaging patients.[63] However, there is still some debate about which scoring system is best. Scoring systems have not been reliable or predictive of a patient's clinical course for COVID-19 or other respiratory illnesses, making them limited in their applications.[64] The most common scoring system utilized in is the Sequential Organ Failure Assessment score (SOFA).[65] It was originally developed to collectively determine the risk of mortality for patients admitted to intensive care that were diagnosed with a bloodstream infection.[66] It consists of six data points that assign a point value to how well different organ systems are functioning.[67] The different categories are neurological, blood, liver, kidney, and hemodynamics/blood pressure.[68] The points of the categories are added up to determine the overall score. The higher the score, the higher the likelihood of mortality.[69]

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[61] *Id.*
[62] *Id.* at 29-30.
[63] *SOFA Score: What it is and How to Use it in Triage,* ASPR TRACIE, https://files.asprtracie.hhs.gov/documents/aspr-tracie-sofa-score-fact-sheet.pdf (last visited April 25, 2021) [hereinafter *SOFA Score*].
[64] *Id.*
[65] *Id.*
[66] *Id.*
[67] *Id.*
[68] *Id.*
[69] *Id.*

Despite its objectivity, the SOFA score has some inadequacies. First, it was developed for a collective application to a patient population, specifically those with blood stream infections, not necessarily to assess patients individually.[70] Second, it was not an accurate predictor of mortality for patients diagnosed with H1N1, or patients with respiratory failure, generally.[71] This can be problematic and limiting when triaging COVID-19 patients being that it is a respiratory illness.[72] Additionally, while the SOFA score is facially neutral, it does have the potential to have a disparate impact on minorities and certain people with disabilities based on pre-existing conditions.[73] If utilizing the SOFA score for COVID-19 triage, it is recommended that it is not used in isolation to act as an exclusion for receiving scarce medical resources.[74] It is further recommended that if it is used, it should be to establish daily trends in a patient's clinical condition or for patients being considered for the same resource, as opposed to using it as a screening tool.[75] The resulting score does have some value as scores that are either very high or low did correlate with the general prognosis of the patient.[76]

b. Vulnerable Populations

i. Minority Populations

COVID-19 brings light to issues engrained in our society regarding vulnerable populations. Vulnerable populations such as minorities and people with disabilities are disproportionately affected by the pandemic in a variety of ways. However, these have been long standing problems in society that have failed to receive adequate remedies in the past.

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[70] *Id.*
[71] *Id.*
[72] *Id.*
[73] *Id.*
[74] *Id.*
[75] *Id.*
[76] *Id.*

It is well acknowledged through the law that minorities and people with disabilities require protections to prevent discrimination. Minority populations have a higher incidence of morbidity and mortality due to COVID-19 as a result of structural racism.[77] At baseline, minority populations have a higher incidence of comorbidities such as diabetes, hypertension, lung disease, chronic kidney disease, and obesity due to racial bias and lack of access to health care.[78] Specific to COVID-19, they also have a higher rate of exposure due to the fact that they tend to hold jobs that put them in the category of being essential workers during the pandemic.[79] In order to alleviate this disparate impact, the utilitarian approach to managing the pandemic must be balanced with distributive justice.[80] It is imperative that any scoring system or protocol utilized to ration care, not only considers, but addresses past discrimination.[81] For example, the SOFA score takes into consideration how well a patient's kidneys are functioning, requiring assessment of the patient's creatinine level or urine output.[82] This has the potential to disparately impact minorities because they have a higher likelihood of having pre-existing chronic kidney disease. A potential remedy for this is to subtract a set number of points from the overall score for minorities to remedy past harms. Currently, some triage guidelines adjust SOFA scores for patients who are pregnant, essential workers, or are awaiting an organ transplant.[83] This same adjustment should extend to minorities that experience a disparate impact during the triaging process due to past harms that are a result of structural racism.

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[77] Denise M. Dudzinski, et. al., *Ethical Lessons from Seattle's Early Experience with COVID-19*, 20 THE AMERICAN JOURNAL OF BIOETHICS 68 (2020).

[78] *Id.*

[79] *Id.*

[80] Ann-Marcia Tukpah, et. al., *COVID-19 Racial and Ethnic Inequities in Acute Care and Critical Illness Survivorship*, 18 ANNALS OF THE AMERICAN THORACIC SOCIETY 23 (2021).

[81] *Id.*

[82] *SOFA Score, supra* note 63

[83] *Allocation of Scarce Critical Resources, supra* note 56, at 30.

Discrimination on the basis of race in the provision of medical care is prohibited by Title VI of the Civil Rights Act of 1964.[84] Specifically, Title VI states that "[n]o person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."[85] Title VI also prohibits the use of criteria or methods of administration of care that are discriminatory. Additionally, race discrimination is also prohibited by Section 1557 of the Patient Protection and Affordable Care Act.[86]

ii. Disability

People with disabilities are also a vulnerable population requiring protection. The Americans with Disabilities Act of 1990 (ADA), Section 504 of the Rehabilitation Act (Rehab Act), and Section 1557 of the Affordable Care Act (ACA) provide legal protections for people with disabilities to ensure that they will not be denied care or subject to discriminatory rationing principles due to disability, so long as the person would otherwise benefit from treatment.[87] The ADA prohibits disability discrimination by state and local government agencies and healthcare providers.[88] The Rehab Act prohibits disability discrimination at the federal level, specifically federal agencies, and recipients of federal financial assistance.[89] Lastly, the ACA prohibits disability discrimination by federally-funded or federally-operated health programs.[90] The presence of a disability does not serve as a justification to withhold life sustaining treatment and

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[84] The Civil Rights Act of 1964, 42 U.S.C. § 2000d.
[85] *Id.*
[86] Patient Protection and Affordable Care Act §1557, 42 U.S.C. § 18116 (2018).
[87] Amy L. McGuire, et. al., *Ethical Challenges Arising in the COVID-19 Pandemic: An Overview from the Association of Bioethics Program Directors Task Force*, 20 THE AMERICAN JOURNAL OF BIOETHICS 23 (2020).
[88] Americans with Disabilities Act of 1990 § 202, §302 42 U.S.C. § 12132 (2018).
[89] 29 U.S.C. § 794(a) (2018).
[90] Patient Protection and Affordable Care Act, *supra* note 86.

equity should not be sacrificed for efficiency. Absent these protections, people with disabilities would be unprotected from "ruthless utilitarianism."[91]

However, the existence of a disability does not give a person absolute priority in the triage process. Samuel Bagenstos argues two issues related to rationing of resources relevant to people with disabilities. "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?"[92] This is an important distinction and highlights the unique nature of disability discrimination laws. They are not necessarily an absolute ban on discrimination, only a ban on discriminating against those who have a disability and are "qualified." The first question Bagenstos raised is simply addressing the presence of a disability. This can be any type of disability, regardless the impact on someone's outcome if they were to contract COVID-19. Where the analysis gets complex is whether the person with a disability is *qualified* to receive treatment. Bagenstos addressed the complexity of this issue basically by questioning where the line really gets drawn.[93] Is it the absolute ability to benefit from treatment, or perhaps the relative benefit of treatment?[94] Additionally, how long does the benefit have to last? In the healthcare context, these can almost always be argued in a way that discriminates against the person with a disability. In terms of the level of generality while assessing the above questions, people with disabilities would most likely derive the greatest benefit, although perhaps not a significant benefit, if decisions were based on relative benefit. The question of absolute benefit and length of benefit will most likely always be answered by providing treatment to the person without the disability

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[91] Office for Civil Rights, *Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19),* U.S. DEP'T HEALTH & HUMAN SERVS. (Mar. 28, 2020) https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.

[92] Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical Rationing Protocols"* 130 YALE L.J.F. 5-6.

[93] *Id.* at 11.

[94] *Id.*

Bagenstos also proposes that perhaps this is more an issue of distributive justice and equality would mean that there were enough ventilators for everyone.[95] This seems to partially address the issue; however, it completely ignores the fact that ventilators are machines dependent on many other resources to work. They require a place to be set up, oxygen supply, a professional with a specialized skill set to take care of the patient and the ventilator, and equipment to monitor the patient on the ventilator. Quality and quantity of life arguments can go along the same vein of the absolute or relative benefit argument. They are subjective and can easily create an argument against a person with a disability.

IV. State Plans and Legislation

States are best suited to create plans for crisis standards of care and triaging guidelines because they have first-hand knowledge of their nursing homes, long-term care facilities, group homes, hospitals, and healthcare systems. They are able to have the overarching view of the operation of the facilities, as well as how the crisis standards of care and triaging guidelines can be implemented. States are also in the best position to know when and where assistance is needed, and which areas are faring better than others. Although it is not a perfect solution, states are in a better position than the federal government and can provide more uniformity than if crisis plans and triaging protocols were left up to the individual facilities. While there should be federal mandates to create crisis standards of care and triage guidelines, ultimately, the individual states can provide the most comprehensive plans. There are twenty-nine states that have developed crisis standard of care plans, and all are highly variable.[96] Sixteen of these states addressed ethical considerations for health equity in their Crisis Standards of Care guidelines.[97]

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[95] *Id.* at 12.
[96] Emily C. Cleveland Manchanda, et. al., *Crisis Standards of Care in the USA: A Systematic Review and Implications for Equity Amidst COVID-19*, JOURNAL OF RACIAL AND ETHNIC HEALTH DISPARITIES (2020).
[97] *Id.*

The development of crisis standard of care plans at the state level allows for equitable resource allocation.[98] Leaving this process to the individual hospitals allows for wide variations criteria for triage allocations and activation of crisis standards of care. Failure of the states to formulate ethically sound crisis standards of care guidelines shifts the burden to the individual hospitals that are providing care. This will most likely trickle down to the actual healthcare providers, as they should have some input on the decision-making process. Additionally, if a hospital fails to develop adequate protocols, the burden will fall on the healthcare provider at the bedside. This can have tremendous negative implications from a public health perspective because the process for rendering care will default to how the practitioners ordinarily practice.[99] These practices can give rise to implicit and explicit bias resulting in grave injustices, especially in institutions with little to no diversity. Lack of adequate planning also directly contraindicates utilitarian maximization due to the subjective nature of the decisions being made, as opposed to having an objective process.

V. Recommendations

a. Vulnerable Populations

The COVID-19 pandemic exposed flaws that are deeply embedded in society. With the devastation and despair COVID-19 has propelled to the surface, perhaps the open wounds affecting the most vulnerable can finally start to become properly healed. While some of these wounds have become more obvious during the pandemic, such as disparate impact on minority groups, there are others, such as disability discrimination, that tend to be more subtle. However, it is paramount that the most vulnerable members of our society are properly advocated for and protected during a time when they need it the most. Hopefully, the magnification of these issues by COVID-19 can be the catalyst for change.

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[98] *Id*.

[99] *Id*.

Rationing of medical care was most likely not a thought that came across the minds of most Americans before coronavirus. Many areas of the country narrowly avoided the implementation of crisis standards of care; however, some were not as lucky. The thought of becoming ill with a virus that has no definitive treatment and no guarantee for survival can cause fear. Now compound that fear with the thought of rationing of medical care and it becomes terrifying. However, for those with disabilities and minority groups, this might not be the first time they have experienced that fear. They might constantly have an underlying fear that one day, someone might decide that their life is not worth living due to their disability or the color of their skin.

As a society, we should endeavor to protect those most vulnerable, even though many live a life that is impossible for others to understand. Their fears of being disposable should be alleviated, especially now that even for a brief time, those same fears are able to be experienced by others. Even though there are robust laws for general protections against discrimination due to race and disability, we need to do more in terms of protections during a public health emergency.

First, minorities and people with disabilities should have a seat at the table where the decisions and formalized processes are being made. It is sometimes difficult to appreciate the potential disparate impact a procedure or policy will have if it is facially neutral.[100] This is especially pressing in the private sector, such as in the board rooms of health and hospital systems, because these policies and procedures have the high likelihood of going unchecked. This is significant because there are areas of the country where the clientele under normal circumstances might be predominantly Caucasian.[101] However, as we have seen with COVID-19, that can quickly change due social determinants of health and the higher incidences of minorities and people with disabilities requiring hospitalization and high levels of care.[102] Even though these policies and

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[100] *Crisis Standards of Care in the USA, supra* note 96.
[101] *Id.*
[102] *Id.*

procedures that have been developed can be well-intended, if you are not a minority or a person with a disability, then it can be close to impossible to see the disparate impact. By including minorities and people with disabilities in the decision-making process, it allows for different viewpoints to be taken into consideration where they otherwise might have been overlooked.

Second, in a more general sense, there should be in-depth education and competencies for health professionals over the course of their education. This can ensure that as a society we are able to produce disability and race conscious health care professionals. Ableism and racism should have no place in this world, and they certainly should not be as highly prevalent as they are in health care.

Specific to disabilities, during the medical decision-making process the issue of quality of life often arises. Quality of life is important; however, quality of life is also rather subjective. Even though someone might not have a quality of life equivalent to or better than the person judging it, does not mean that they do not have *a* quality of life. When people with disabilities are asked to rate their quality of life, they often give it a high rating and are rather happy.[103] However, when physicians are asked to perform the same rating for people with disabilities, they rate their quality of life terribly low.[104] Low quality of life ratings by physicians are particularly prevalent for those with cognitive or mobility issues due to the false impression that perhaps their life is less valuable or not as worthy of living because of personal bias. This is evidence that even though there are laws protecting people with disabilities, there is still much progress to be made in healthcare to eliminate discrimination in medical decision-making, as well as when creating public health emergency plans. This disparity in quality of life scoring also speaks volumes about how those

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[103] National Council on Disability, *Quality-Adjusted Life Years and the Devaluation of Life with Disability*, https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf (2020).
[104] *Id.*

who do not live with a disability view people with disabilities as worse off or with little to no intrinsic value.[105]

To further illustrate how the pandemic impacts people with disabilities, a handful of states, including Alabama, Connecticut, Pennsylvania, Tennessee, and Utah had provisions in their triaging guidelines that were discriminatory and in violation of the ADA, Section 504, and Section 1557. Alabama included language within their triaging guidelines that those with neurological issues may be poor candidates to receive mechanical ventilation.[106] This led to *Smith v. Ivey*, which held that people with mental disabilities should have equal access to ventilators.[107] The other above listed states had similar guidelines, and these were eventually amended to prevent discrimination of people with disabilities during resource allocation.[108]

Michael Hickson and Sarah McSweeney are two examples of the discriminatory treatment that can occur absent formal guidelines for crisis standards of care, triaging, and allocating scarce resources.[109] They were both in their forties and were people living with disabilities. In the case of Michael, intersectionality also comes into play because not only was he disabled, but he was also African American.[110] Michael was a quadriplegic as a result of a brain injury who contracted COVID and was denied escalation in care.[111] His wife objected but physicians at the hospital said he did not have much quality of life and a court appointed guardian made the decision alongside the doctors to withdraw care.[112] He passed away six days later. Sarah was non-verbal and after being brought to the hospital for a fever and trouble breathing, doctors pressured her caretakers to

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[105] *Id.*
[106] McGuire, *supra* note 87.
[107] *Smith v. Ivey*, CIVIL CASE NO.: 2:20-cv-237-ECM, M.D. Ala. (2020).
[108] McGuire, *supra* note 87
[109] Natalie M. Chin & Jasmine Harris, EXAMINING HOW CRISIS STANDARDS OF CARE MAY LEAD TO INTERSECTIONAL MEDICAL DISCRIMINATION AGAINST COVID-19 PATIENTS, http://thearc.org/wp-content/uploads/2021/02/Intersectional-Guide-to-Crisis-Care_FINAL.pdf.
[110] *Id.*
[111] *Id.*
[112] *Id.*

sign documents stating that she would not be resuscitated again due to her quality of life.[113] She passed away from a treatable cause.[114]

Third, to provide the most comprehensive protections for our most vulnerable, each state should develop crisis standard of care and triage guidelines. Absence of guidance results in discriminatory standards and arbitrary decision-making.[115] Currently, twenty-nine out of fifty states have a formal, state-wide crisis standard of care plan. Standardized guidelines by state accomplish multiple goals. They satisfy the ethical duty to plan.[116] This relieves the burden of hospitals having to create guidelines themselves and provides more transparency by having these plans available to the public for review. It also alleviates disparate treatment in certain communities because it guarantees that all hospitals and health systems within the same state have the same operating procedures for triaging patients and triggering a crisis standard of care.[117] This can serve to quell the burdens and fears that someone would be overlooked for medical care or seen as having a life that is less valuable.

Additionally, the creation of these guidelines by the state does not guarantee that they will not contain discriminatory practices. However, it is a more transparent process and is easier to reconcile areas that are discriminatory as opposed to each individual hospital operating under their own framework and guidelines. Abiding by the substantive and procedural values, as well as the ethical framework established in the Institute of Medicine's guidelines for developing crisis standards can vindicate the legacy of people such as Michael Hickson and Sarah McSweeney. Adhering to the framework will also help ensure the vulnerable are adequately protected moving forward.

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[113] *Id.*
[114] *Id.*
[115] *Crisis Standards of Care in the USA*, *supra* note 96.
[116] Leider, *supra* note 17
[117] *Crisis Standards of Care in the USA*, *supra* note 96.

VI. Conclusion

In conclusion, the development of comprehensive crisis standards of care documents can help alleviate the burdens of moral distress on the health care system and preclude arbitrary decision-making or defaulting to utilizing a deontological framework as opposed to utilitarian maximization. A sound ethical framework for triage guidelines and crisis standards of care that are standardized at the state level can make great strides to heal inequities that exist amongst us in society. While their elimination of these injustices through more formal processes is not absolute, they certainly do a lot to alleviate discriminatory practices. All fifty states should abide by their ethical duty to plan by creating crisis standards of care documents and triage guidelines. Lack of planning by the state threatens vulnerable populations, puts health care workers at an increased risk of moral distress, and leaves them open to liability.

Additionally, discriminatory practices can be mitigated by including minorities and people living with disabilities in the important decision-making process of creating these guidelines. Moving forward, in-depth education and competencies during the training period for health care professionals should be mandatory. Ableism and racism are highly prevalent in the health care system and lead to unnecessary discrimination.