

July 28, 2020

Dear Ethics Committee Members,

We thank the Ohio Hospital Association and members of hospital bioethics teams for their careful consideration of ethical principles and fairness when navigating the COVID-19 healthcare crisis. The Ohio Disability and Health Program at the Ohio State University Nisonger Center is a CDC-funded program to promote the health of Ohioans with disabilities. We are working to address critical issues concerning Ohioans with disabilities during times of medical scarcity. The Ohio Disability and Health Program collaborated with the Partnership for Inclusive Disaster Strategies and the Ohio State University Center for Bioethics to write this letter. **The purpose of this document is to ask Ohio hospitals to develop policies to ensure that patients with disabilities have the same access to life-saving medical treatment as patients without disabilities, in compliance with legal and ethical guidelines.** We appreciate the complexity of developing and implementing crisis standards of care when planning for critical care scarcity. Medical allocation decisions are always painful and require the consideration of several, sometimes competing, ethical principles. Recently, bioethicists and hospital systems proposed resource allocation guidelines that contain ethically problematic provisions with respect to people with disabilities. Leading bioethicists agree that guidelines must explicitly state that medical resources will not be allocated on the basis of morally irrelevant considerations, such as sex, race, religion, disability, insurance status, wealth, citizenship, social status, or social connections.^{1,2,3}

On March 28, 2020, the U.S. Department of Health and Human Services released [guidance for health care providers](#) prohibiting discrimination on the basis of race, color, national origin, disability, age, sex, and religion related to COVID-19 care and treatment rationing. The Ohio Hospital Association provided [further direction](#) on how hospital systems may ensure that the goals and intent of the HHS guidelines are realized. **In the attached brief, we address the ethical, moral, and legal basis for ensuring that people with disabilities are not denied medical care on the basis of their disability.** We will demonstrate that people with disabilities are disadvantaged because of the pervasive negative biases and inaccurate assumptions about the quality of life of people with disabilities. When quality of life, quality life years, or disability adjusted life years are considered in medical rationing decisions, people with disabilities are unfairly disadvantaged, not because they have lower quality of life, but because they are wrongly assumed to have lower quality of life. We provide resources to guide hospital ethics committees in creating equitable critical care protocols. If you have questions or would like to discuss these issues, please contact us at nisongerodhp@osu.edu.

We appreciate your consideration of these important issues and welcome the opportunity to work with your hospital as it relates to these decisions.

Sincerely,



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Ohio

Disability & Health Program



THE OHIO STATE UNIVERSITY
COLLEGE OF MEDICINE



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Three inaccurate assumptions about disabilities can compromise quality health care

- 1) people with disabilities significantly differ from people without disabilities*
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- 3) people with disabilities have poor quality of life*

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Recovery forecasts and medical futility judgements beyond short-term survivability lack empirical evidence. Common approaches to achieve the “greatest good,” disadvantage people with disabilities and may violate civil rights laws.

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Why are people with disabilities at risk in health care settings?

Negative and inaccurate assumptions about disabilities have an adverse effect on the health and quality of health care for people with disabilities. In the context of medical scarcity, these widely held beliefs can be deadly. The perception of disability clearly elicits pity, compassion, and desires to be helpful, but it also elicits distinctly negative reactions such as disgust and anxiety, and manifests in behaviors and judgments such as the tendency to blame individuals for their disabling conditions and the inclination to avoid contact with people who have disabilities.⁵ **When compared to race, sex, and religion bias, disability bias has been reported to be among the strongest implicit and explicit responses.** These negative beliefs were evident across genders, ethnicities, age groups, and political orientations and even among participants who themselves had disabilities.^{6,7} **Health care providers are not protected from prevalent social attitudes and biases.** In fact, they are drawn to the profession and trained to restore their patients to full health.⁸ This mindset proves challenging when confronted with a patient who has a permanent disability. Health care providers may feel frustrated or defeated at the outset because public health has already failed to prevent or heal the disability.⁹ Negative beliefs have been reported by medical students,^{10,11} nursing students,¹² other health professional students,¹² physicians,¹³ and nurses.¹⁴ **Implicit bias¹⁵ among health care professionals¹⁶ against people with mental health conditions may play an even greater role in quality of health care.** Legitimate health complaints by patients with a history of mental health disorders are often assigned little credibility as health care staff attribute all complaints of distress to the mental health condition.¹⁷

Common, inaccurate, and damaging beliefs

1. **One damaging perception is that the patient with a disability differs in significant, meaningful, and somewhat undefined ways from other patients and from the provider.** This belief is prevalent with respect to patients from different ethnic or racial backgrounds and when caring for patients with disabilities.¹⁸ Regardless of year or clinical experience, medical students and residents viewed patients with disabilities more negatively and as more different than able-bodied patients.¹⁹ This finding reflects a perception that it is more difficult or less appealing to provide health care to such a patient.
2. **A second barrier to quality care for patients with disabilities is the inability assumption.** People without disabilities tend to underestimate the abilities of people with disabilities, assuming lower levels of cognitive ability, independence, and interest in improving and maintaining current function. Robey and colleagues²⁰ found that even caregivers of adults with disabilities had infantilizing implicit attitudes toward people with disabilities. With the assumption that the patient is extremely limited, the next logical and inaccurate assumption made by health care providers is that patients with disabilities are incapable of contributing to their own health care or health care plan and decisions. The health care provider acts with benevolence on behalf of the disabled patient and, while they have the patient's best interests in mind, they hold inaccurate assumptions and biases that limit the quality of health care.
3. **Finally, health care providers falsely believe that quality of life is severely compromised by disability.**¹⁹ There is significant evidence that an assessment of quality of life by any non-disabled individual will systematically undervalue the quality of life of people with disabilities,

particularly mental disabilities. Such exclusions are precisely the type of subjective decision-making that federal antidiscrimination laws sought to preclude.⁴ When asked to imagine their life after acquiring a paralyzing injury, health care providers estimated their life would be barely worth living. In fact only 18% of emergency care providers including emergency nurses, technicians, residents, and attending physicians imagined they would be glad to be alive after sustaining a spinal cord injury.²¹ This is in stark contrast to the 92% of spinal cord injury survivors who reported having a good quality of life.²¹ This misconception directly affects patient care by limiting the type, scope, and aggressiveness of treatment options considered. One study found that 71% of pediatric residents questioned the aggressive treatment of children with severe disabilities,²² and only 22% of emergency care providers reported they would want to be treated with “everything possible to ensure survival” after a severe spinal cord injury.²¹

Promoting fair allocation when medical resources are scarce

Evidence-based triage means basing triage decisions on individual assessment and medical evidence to prioritize patients with the best chance of surviving to discharge with intensive care.

Triage Team

The primary ethical obligation of physicians is to the wellbeing of individual patients. During a pandemic, the obligation to promote public health and access to care may conflict with the clinical duty to individual patients (AMA Opinion 11.1.2). This conflict between what is best for an individual patient and the global needs of the community of patients overall, can be especially problematic when physicians participate in triage decisions for their patients. While physicians do have critical information about the patient and his/her health status, this information could be shared with the triage team. Separating the triage role from the clinical role is needed to promote objectivity, avoid conflicts of commitments, and minimize moral distress.

To mitigate the impact of this conflict, hospital systems may establish triage teams comprised of an acute care physician, an acute care nurse, an ethicist, and an administrator, one of whom serves as the triage officer. When possible, select panel members with demographic diversity, including a disability voice. This team would be responsible for applying the allocation framework defined by their hospital or health system. The triage officer may collaborate with the attending physician to disclose triage decisions to patients and families, and also be involved in patient or family appeals of triage decisions.²³ Importantly, separating direct patient care from medical resource stewardship responsibilities allows hospital systems to carefully select the health information that is most relevant in resource allocation determination. In most cases, the **risk of biasing the decision making process will outweigh the benefit of sharing medically irrelevant demographic information with the triage team such as race, ethnicity, disability, and socio-economic status.**²

Evidence-based triage

Evidence-based triage is fully consistent with the legal rights of people with disabilities and is ethically preferable to other allocation approaches.²⁴ The Health and Human Services guidance on disability law states that triage decisions should not be based on *stereotypes, assessments of quality of life, or judgments about a person's relative worth based on the presence or absence of disabilities*. Further, the guidance states treatment decisions *should be based on an individualized assessment of the patient based on the best available objective medical evidence*.^{2,3} Evidence-based triage is based on objective medical evidence and explicitly eschews quality of life judgments²³ and the use of quality-adjusted life-years (“QALYs”) in public health emergency response. Furthermore, quality of life judgments would require impractical data collection and are likely to incorporate unjust biases as previously discussed.³

Maximizing life years or life-cycles

A broader conceptualization of accomplishing the “greatest good” is to consider the years of life saved in addition to the number of lives saved. Assuming equal chances of short term survival, the justification for incorporating this utilitarian claim is simply that, all other things being equal, it is better to save more years of life than fewer. While broadly appealing, the determination of life years saved must be based on medical evidence and is quite complex and ethically fraught. Because life expectancy differs by sex, should a woman be prioritized over a man with similar health status? Should social determinants of health such as poverty be considered? The consideration of long-term survival beyond the acute care episode fails to account for the significant uncertainty surrounding long-term survival probabilities. Although morbidity patterns are not known for many types and etiologies of disabilities, recent evidence suggests that morbidity patterns in people with intellectual disability do not differ markedly from those of the general aging population.²⁴ **Without scientifically supported data on the life expectancy of people with various types of disabilities, physicians are likely to invoke the biased and inaccurate assumption that disability confers shorter life span. The maximizing life years saved principle is likely incompatible with disability law.**²⁵

A more nuanced approach is the life-cycle principle that aims to give each individual equal opportunity to live through the various phases of life.²⁶ The ethical justification of the life cycle principle is that it is a valuable goal to give individuals equal opportunity to pass through the stages of life-childhood, young adulthood, middle age, and old age.²⁶ This principle is included as a tie-breaker in the Pittsburgh crisis standards of care guideline where individuals are assigned priority points based on their age group (12-40, 41-60, 61-75, 76+).²³ **Although applying the life-cycle principle in triage decisions is clearly ageist, it is likely consistent with disability law.**

Problems with re-allocating personal medical devices

People who use ventilators in their daily lives should not fear losing their right to these devices if they seek hospital care. The practice of re-allocating personal medical equipment presents a concerning legal precedent and would interfere with the trust in the medical system, giving chronic ventilator users reason to avoid seeking needed acute care. Patients who bring medical equipment with them to the hospital must be allowed to keep such equipment throughout their hospital stay and when they are discharged.

Problems with “no visitors” policy

Due to the highly infectious nature of COVID-19 and the limited supplies of personal protective equipment (PPE), ‘No Visitor’ policies are in effect at many hospitals to protect hospital personnel, patients, and visitors from becoming infected. However, some people with disabilities rely on personal care attendants to assist with activities of daily living including communication, hygiene, and shifting positions to avoid pressure ulcers. Disallowing patients with disabilities a needed support person to assist during their hospital stay likely violates the right to reasonable accommodation per the Americans with Disabilities Act. Accommodations are needed to (1) ensure that a caregiver is permitted to be with the patient starting with admission and through to the care/treatment process, (2) enable personal care attendants and home health nurses to provide care while in the hospital.

Patients admitted to the hospital with personal medical equipment often have personal care assistants who are trained and experienced in managing this equipment. It may be beneficial for hospitals with staffing shortages to permit trained and experienced personal care assistants to continue providing care to their patient in the hospital, even if the hospital has traditionally managed this equipment in less urgent times.

Therefore, it is recommended that hospitals provide reasonable accommodations in their visitor and care policies for persons who need support from known and acknowledged support persons (such as family, direct support professionals, personal care attendants, home health aides, or other designated caregivers) **in accord with the Americans with Disabilities Act.** This should include care that the hospital normally provides exclusively through its own staff, but cannot provide or cannot adequately provide because of limited resources, and that the personal care attendant or home health nurse has been specifically trained to provide. All policies should permit a caregiver to be present to the greatest extent possible.

It is further recommended that hospitals have a protocol in place for providing infection control briefings and providing appropriate PPE to support persons. Designated support personnel should be advised to comply with all hospital infection control procedures and act as facilitators for and in support of medical personnel. The state of New York was first to recognize the unique issues and concerns of those with intellectual and developmental disabilities, and their Department of Health adopted a [model COVID-19 hospital visitation policy](#)²⁷ addressing the needs of people with disabilities admitted to hospitals for whatever reason. Several hospital systems have articulated a disability exception to the no visitor policy such as below from Rush University Medical Center,

"Patients with disabilities who need assistance due to the specifics of their disability may have one designated support person with them. If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider who is knowledgeable about the management of their care, to physically or emotionally assist them during their hospitalization, this will be allowed with proper precautions taken to contain the spread of infection."

What is the law?

Disability should not inform medical allocation decisions for ethical, moral, and legal reasons.

Three laws protect the civil rights of people with disabilities in medical settings: The Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the Affordable Care Act. As such, patients should not be denied medical care on the basis of disability, age, assumed quality of life, or judgments about a person's relative "worth."

Several federal civil rights laws prohibit discrimination on the basis of disability in all healthcare settings, public and private. Where disability is a consideration in most medical futility cases, these decisions implicate numerous federal and state constitutional, statutory, and regulatory provisions, including the Fourteenth Amendment of the US Constitution, the Emergency Medical Treatment and Active Labor Act (EMTALA), Section 504 of the Rehabilitation Act, the Americans with Disabilities Act (ADA), and Section 1557 of the Affordable Care Act (ACA). While still largely unexplored, Section 504, the ADA, and Section 1557 may be relied on to prevent or remedy medical futility discrimination on the basis of disability.²⁸ **The protections afforded by these laws would apply equally to those who become disabled as a result of the public health emergency and those whose disability preceded the emergency.**²⁹

Triage guidelines are more likely to be consistent with the laws to the extent that they focus on documented medical effects of a particular medical condition (e.g., lung function) on response to treatment, rather than on assumptions about the effect of the disability on treatment, on health outcomes, or on quality of life.⁴

Helpful Resources

These resources provide guidance on how to more fairly allocate scarce medical resources.

Included in this package are the:

- “[Crisis Standards of Care](#)” guidelines released by the Ohio Hospital Association, a one-page summary of best practices for fair and unbiased allocation of scarce medical resources, and
- an [Evaluation Framework for existing Crisis Standards of Care Plans](#).

We encourage you to use these materials throughout your hospital network to inform best practices while complying with federal law.

[Ohio Guidelines for Allocation of Scarce Medical Resources \(pages 9, 19, 37, 38\)](#)

[BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 \(COVID-19\)](#)

[Evaluation Framework for Crisis Standard of Care](#)

[Quality-Adjusted Life Years and the Devaluation of Life with Disability: Part of the Bioethics and Disability Series](#)

[Medical Futility and Disability Bias](#)

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