

The Role of Physicians in Battling the Undervaluing of Patients with Disabilities in Cost-Effectiveness Analysis

INTRODUCTION

Health care providers are increasingly facing pressures that may conflict with their professional ethics and responsibilities to their patients. Among those pressures are a variety of barriers to providing care. Barriers are often thought of as preventing the sick from accessing care, as obstructing the efforts of individuals to establish a physician-patient relationship of any kind, but practicing physicians and other providers are acutely aware that many barriers impact existing patients, including those who have health care insurance. Some of those barriers are indirect. For example, requirements to spend less time per patient in order to maximize revenue for the physician's employer can be a barrier to the most clinically appropriate care, one that applies even to patients who have been able to at least access care systems and have an established provider. In a recent study by the Physician's Advocacy Group, a majority of physicians felt that non-physician ownership of practices harms patient care, and specifically identified pressures to spend less time with patients as a result of non-physician ownership.¹ Health care providers concerned about financial pressures from corporate owners and

¹ Physicians Advocacy Group, The Impact of Practice Acquisitions and Employment on Physician Experience and Care Delivery, available at: https://www.physiciansadvocacyinstitute.org/Portals/0/assets/docs/PAI-Research/NORC-Employed-Physician-Survey-Summary-Final.pdf?ver=3GHfAFW86lZ-LwW2Mk_7Pg%3d%3d (accessed December 9, 2023).

investors² have sought solutions, including consideration of unionization,³ something many physicians and pharmacists would not have considered appropriate until recently. Barriers have also been prominently identified in federal health programs. There has been much recent attention to concerns that Medicare Advantage programs may be erecting prior authorization barriers to care recommended by a patient's physician. That attention has risen to the level of congressional hearings, and the Department of Health and Human Services recently published a Proposed Rule requiring more accountability for these prior authorization barriers.⁴ These are procedural barriers; they have the effect of interfering with the provider's clinical judgment about what care the patient should receive and also raise concerns about equity and injustice.

Beyond these procedural barriers, there are structural barriers. For example, structural racism is a heavily studied and documented yet still persistent aspect of contemporary health care in the United States.⁵ Less obvious than the legacy of

² Concerns related to corporate ownership and control of health care are neither new nor one-dimensional. An accessible overview is Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry*, 2nd Ed., New York: Basic Books (2017).

³ See, for example, Naom Scheiber, *Why Doctors and Pharmacists are in Revolt*, The New York Times, December 3, 2023, available at: <https://www.nytimes.com/2023/12/03/business/economy/doctors-pharmacists-labor-unions.html>.

⁴ The proposed rule addresses issues of equity in seeking to reduce burdens and barriers created disproportionately among disadvantaged populations. <https://www.federalregister.gov/documents/2023/11/15/2023-24118/medicare-program-contract-year-2025-policy-and-technical-changes-to-the-medicare-advantage-program>.

⁵ The literature is extensive. Interested readers would do well to start with any of these excellent recent books: Dayne Bowen Matthew, *Just Medicine: A Cure for Racial Inequality in American Health Care*. New York: New York University Press (2015); Rupa Marya and Raj Patel, *Inflamed: Deep Medicine and the Anatomy of Injustice*, New York: Farrar, Straus and Giroux (2021); Daniel E. Dawes, *The Political Determinants of Health*, Baltimore: Johns Hopkins University Press (2020)(see especially Chapter 7, The Future of Health Equity Begins and Ends

separate hospitals for white and non-white patients, but equally damaging to the trust that is inherent in the physician-patient relationship, is the legacy of misinformation about Black and Latino patients that remains identifiable in health care today. But negative stereotyping is not restricted to color, national origin, age or gender (though stereotyping of each of those groups remains easily observable). There is also mounting concern about negative stereotypes of persons with physical or cognitive impairments that lead to disability labeling. While individual “disabilities” may not in reality be anything but a different ability (not hearing is a heavily contested example), there are broad assumptions made that sometimes arise from medicine and sometimes from law.

These barriers evolved in parallel with dramatic increases in the cost of health care services and resulting efforts to control those costs. The use of various cost-effectiveness measures, most notably Quality-Adjusted Life Years (QALYs), is one of the most widely deployed approaches to controlling costs. This paper briefly describes the QALY concept, identifies criticisms, significantly including the disparate impact of QALY-derived measures on resource allocation decisions, and advances the argument that physicians have an ethical obligation to advocate for their individual patients as well as patients as a whole.

COSTS and COST-EFFECTIVENESS

with the Political Determinants of Health); and Keisha Ray, *Black Health: the Social, Political and Cultural Determinants of Black People's Health*, New York: Oxford University Press (2023).

Health care expenditures in the U.S. accounted for nearly 20% of gross domestic product (GDP) in 2021, compared to 7% of GDP in 1970; using a per capita measure, in 1970 the U.S. spent \$1,951 per person, and by 2021, spent \$12,914 per person in constant 2021 dollars.^{6,7,8} Controlling these rising health care costs is a key goal of policymakers and payers. A standard methodology is cost-effectiveness analysis, an approach which compares alternative interventions using some outcome measure, most often using the measure of cost per Quality-Adjusted Life Year (QALY).⁹ Cost-effectiveness assessments purport to be neutral tools to assist payers in evaluating whether a health care intervention is cost-effective. While these assessments may be of use in determining the value of population-wide interventions (for example, vaccinations or cancer screenings), they become significantly less useful as the size of the population that could benefit from the intervention decreases. At the same time, the likelihood that a person needs a medical intervention increases dramatically as they move along a continuum of health.

Researchers grappling with how to value a health care intervention in order to report on an intervention's cost-effectiveness have tried for decades to quantify the

⁶ Matthew McGough, Aubrey Winger, Shameek Rakshit and Krutika Amin, *How has U.S. spending on health care changed over time?* Peterson/KFF Health System Tracker, available at: [https://www.healthsystemtracker.org/chart-collection/u-s-spending-healthcare-changed-time/#Total%20national%20health%20expenditures,%20US%20\\$%20Billions,%201970-2021](https://www.healthsystemtracker.org/chart-collection/u-s-spending-healthcare-changed-time/#Total%20national%20health%20expenditures,%20US%20$%20Billions,%201970-2021).

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⁸ Government data on health care spending is available at <https://www.cms.gov/files/document/highlights.pdf>.

⁹ Gopol Sreenivasan, *Why Justice Requires Rationing in Health Care*, in Rosamond Rhodes, Margaret P. Battin and Anita Silvers, Eds., *Medicine and Social Justice: Essays on the Distribution of Health Care*. New York: Oxford University Press (2012), pp. 143-153.

value of health and life. Those efforts have necessarily attempted to derive broadly if not universally applicable conceptions of the negative value of particular states of disease and disability. The lesson of that effort for policymakers has been what medical professionals treating patients already knew: persons living with any chronic or serious illness or disability will place highly variable value on health care interventions and states of health. As many of these cost-effectiveness scoring tools rely on the use of QALY measures to determine coverage limits for a substantial array of patient treatments, a review of the evolution of QALYs and their first cousin DALYs (Disability-Adjusted Life-Years) will provide helpful background for those advocacy efforts.

QUALITY-ADJUSTED LIFE-YEARS

Simply put, QALYs place a value on discrete health outcomes; they “combine the length of survival with a measure of the quality of that survival and assume that given a choice a person would choose a shorter life of higher quality over a longer life of poor quality.”¹⁰ Even simple examples become complicated quite quickly. Patients live with different health states and perceptions of those states differ; for example, a person who is young may place a different value on the ability to run than does an old person. To attempt to systematize these differing values, proxy measures were created to allow “assignment of utility values to health states for any disease or treatment program.” These early

¹⁰ Leah McClimans, Outcome Measures in Medicine, Miriam Solomon, Jeremy R. Simon and Harold Kincaid, Eds., *The Routledge Companion to the Philosophy of Medicine*. New York: Taylor and Francis (2017), p. 338.

efforts led to the QALY, metric still relied on today to attempt to assess the value of a health intervention.

Now more than 50 years old, the QALY measures disease burden by combining years of life and health related QoL from a societal perspective into a score. The QoL score is based on eight health state values that attempt to combine an estimate of the severity of a medical condition with the likelihood the medical condition reduces a person's potential. The health state value of "healthy" is assigned a perfect score (1.000) and the health state value of "dead" is assigned a zero (0.000). Notably, the eight-point scale is tilted towards a healthy person's point of view of a "healthy state." The health state value of "slight problem" is assigned a score of 0.9999, "severe problem" is assigned a score of 0.80 and "completely disabled" is assigned a score of 0.40. The QALY multiplies the QoL weight by the number of additional years of expected life when a patient receives a particular health intervention. Simply put, what the QALY approach does is attempt to quantify (using qualitative measures) the effect of a particular intervention on both the quality and duration of a life.¹¹ While QALYs focus on the effect of interventions, DALYs focus on the burden of disease on population.¹² There is a lack of research adequate to determine whether substituting DALYs for QALYs will have a material effect on policy decisions, but other considerations may

¹¹ E. Haavi Morreim, Quality of Life in Health Care Allocation, in *Encyclopedia of Bioethics, Rev. Ed.*, Vol. 3, Warren Thomas Reich, Editor in Chief. New York: Simon and Schuster (1995), pp. 1358 – 1361.

¹² Federico Augustovski, Lisandro D. Colantonio, Julieta Galante et al., Measuring the Benefits of Healthcare: DALYs and QALYs – Does the Choice of Measure Matter? A Case Study of Two Preventive Interventions. *Int. J. Health Policy Manag* 2018, 7(2), 120-136, 121.

have more impact than the choice of QALY or DALY, and there appears to be no consistent preference in the literature for one over the other.¹³

CRITICISMS OF QALYs

Cost-effectiveness analysis has been the subject of substantial ethical criticism.¹⁴ One of the criticisms is of the fundamental idea of quality of life. The concept of quality of life (QoL) is philosophically elusive; there is little agreement how it should be defined.¹⁵ As individual terms, both 'life' and 'quality' are ambiguous, and a variety of conceptions are readily identified in the literature. QoL arose as a concept in medical ethics debates with the rise of medical technology following World War II, primarily in situations in which conflicts have arisen regarding the withholding or withdrawing of medical treatments.¹⁶ Conceptions of QoL appear not only in the micro context of bedside clinical ethics, but also in the more macro environments of coverage and resource allocation decisions. They might take the form of attributing different values to different health states; for example, a person who cannot walk because of a broken leg might value the health state of being able to walk more than that of not being able to walk. Similarly, a provider might value the ability of their patient to walk, and act accordingly by recommending or providing treatment that would assist the person in being able to walk again. Ultimately, as James J. Walter observes, "The spectrum of definitions and

¹³ *Id.* at 124.

¹⁴ Mooreim, *op cit.* at note 22.

¹⁵ James J. Walter, Quality of Life in Clinical Decisions, in *Encyclopedia of Bioethics, Rev. Ed.*, Vol. 3, Warren Thomas Reich, Editor in Chief. New York: Simon and Schuster (1995), pp. 1352 – 1357.

¹⁶ *Id.* at 1352.

positions representing quality of life makes it difficult to identify any one quality-of-life ethic for analysis or critique.”¹⁷

Especially for people with disabilities, quality of life should not be judged or prioritized from the perspective of anyone but the patient. Haavi Mooreim puts it succinctly:

“We can itemize and tally the physical impediments in a person’s life . . . yet we know well that some people with grave disabilities will deem their quality of life to be excellent, as they find joy and meaning in things that able-bodied persons might overlook. As a result, many studies of medical interventions . . . that do assess quality of life are subject to criticism because the QoL measures are so flawed.”¹⁸

From the perspective of patients and their physicians, a patient presenting with an illness or injury has a medical condition that is at least temporarily preventing the person from experiencing “perfect health.” As such, a QALY that generates a higher score on QoL from a societal perspective will be inherently skewed towards the preferences of people who do not live with chronic illness or disability. A person who does not use a wheelchair every day is likely to say using a wheelchair every day would lead to a lower QoL. The person who uses a wheelchair every day, or has any chronic illness or disability may be deemed to have a lower QoL even if he have not been asked.

The QALY multiplies that lower QoL by the number of additional years the patient is expected to live, potentially resulting in a score that is consistently worse for a person seeking medical treatment than a person who is not seeking medical treatment. For example, in the standard QALY calculation, patients who may have co-occurring

¹⁷ *Id.* at 1357.

¹⁸ E. Haavi Morreim, *Limits of Science and Boundaries of Access*, in Rosamond Rhodes, Margaret P. Battin and Anita Silvers, Eds., *Medicine and Social Justice: Essays on the Distribution of Health Care*. New York: Oxford University Press (2012), p. 416.

illnesses or disability have a lower QoL weight. As such, a health intervention that extends the life expectancy of that person would still receive a lower number of QALYs because the person with the medical need starts out with a lower perceived QoL weighting. With such fundamental ambiguities in the concept of QoL, it seems clear that the QALY measure, in its reliance on QoL, is also fundamentally flawed. But even if there could be agreement on an ethically valid conception of QoL, the use of the QALY metric would remain subject to ethical criticism.

QALYs, and their more specific cousins DALYs, are utilitarian. In other words, the focus is on the goal of the 'greatest good for the greatest number' rather than the needs, preferences and values of an individual patient. On its face, that has the merit of producing "allocations that at least seem fair in that they evaluate every allocation decision according to the same singular standard."¹⁹ But that inescapably means that QALYs "use a societal point of view instead of an individual point of view"²⁰ with the result that the actual preferences of individuals and their physicians are discounted. Dan Brock, then Director of the Division of Medical Ethics at Harvard Medical School, described the larger problem:

[The] utilitarian or consequentialist approach [of QALYs] suffers from the familiar problem that it looks only to the overall benefits to a population without any direct concern for how these benefits are distributed to distinct individuals. It does not matter who receives how much benefit so long as resources are used to maximize overall benefit. Distributive justice and fairness, however, concern how individuals are treated relative to other

¹⁹ Rosamond Rhodes, *Justice Pluralism: Resource Allocation in Medicine and Public Health*, in Rosamond Rhodes, Margaret P. Battin and Anita Silvers, Eds., *Medicine and Social Justice: Essays on the Distribution of Health Care*. New York: Oxford University Press (2012), p. 60.

²⁰ McClimans, *supra* note 21 at 339.

individuals – which inequalities between individuals or groups are just or unjust.²¹

More specific criticism of QALYs include that they are ageist, potentially sexist and racist, and that they could lead to prioritizing interventions for individual whose medical conditions are less expensive to treat.²²

There have been efforts to redeem the QALY framework. One approach, the Equal Value of Life (EVL) framework, proposed changing the QoL portion of the QALY equation so that an intervention that was likely to extend a person's life was calculated at the "healthy" health state value of 1.00. This calculation change sought to equalize the value of a medical intervention that extends life, regardless of a person's QoL score. This alternative, published in 1999 in *Health Economics*, "accommodates a concern about QALYs that has been expressed by many, including the organizations of patients and the disabled, who understandably are skeptical about having healthy people make judgements about quality of life on their behalf."²³ The proposed approach, though used in some prominent cost-effectiveness analysis models, did not rectify the structural bias in QALYs against people living with a chronic illness or disability. To the contrary, this adjustment to the QALY that attempts to rectify the systematic diminishing of the QoL

²¹ Dan W. Brock, *Priority to the Worse Off in Health Care Resource Prioritization*, in Rosamond Rhodes, Margaret P. Battin and Anita Silvers, Eds., *Medicine and Social Justice: Essays on the Distribution of Health Care*. New York: Oxford University Press (2012), p. 155.

²² John Harris, QALYfying the value of life, *Journal of Medical Ethics* 13(3), 117-123 (1987). The criticisms voiced by Harris, now almost 40 years on, remain valid. His article is worth reading and easily accessible at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1375658/pdf/jmedeth00262-0007.pdf>.

²³ Erik Nord, Jose Luis Pinto, Jeff Richardson et al., Incorporating societal concerns for fairness in numerical valuations of health programs. *Health Economics*, Vol. 8 Issue 1 (1999), pp. 25-39.

value for a person with a chronic illness or disability has only served to shift the bias of whether a health intervention can be considered cost-effective away from interventions that improve QoL toward interventions that extend life.

Physicians who put the patient at the center of shared decision-making approaches when choosing interventions and treatments seek to elicit preferences from the patient about treatment, and use their professional judgment and expertise to inform the patient of alternatives and potential outcomes of each as they choose an intervention together. Where the original QALY calculation devalues any patient with a QoL below a score of 1.000, the revised EVL ignores the value a patient places on those consequences, on how a treatment is likely to affect their lives. If a patient prefers a treatment that gives them the ability to continue to work, even if that treatment is not likely to provide a meaningful extension of life, the new QALY in the form of the EVL still systematically disregards a patient's preferences.

Determining cost-effectiveness for medical interventions depends on the perspective of the stakeholder. Analytic perspectives commonly considered include: ²⁴

1. Healthcare payer: A payer's perspective in determining cost-effectiveness includes only the monetary costs incurred by the payer. This focus is on the monetary costs of providing the medical intervention to the patient.
2. Healthcare sector: This perspective includes the monetary costs of providing the medical intervention to the patient, including the monetary costs to the patient.
3. Limited societal: This perspective goes beyond the monetary costs of the intervention and includes patient time and caregiver time, productivity loss and

²⁴ David D. Kim, Madison C. Silver, Natalia Kunst, Joshua T. Cohen, Daniel A. Ollendorf and Peter J. Neumann, Perspective and Costing in Cost-Effectiveness Analysis, 1974-2018. *Pharmacoeconomics* 38, 1135-1145 (2020), available at: <https://link.springer.com/article/10.1007/s40273-020-00942-2>.

spillover effects outside of the realm of the healthcare sector, for example, lost educational opportunities.

4. Societal: This perspective represents the overall view of the public and includes monies that could be spent on purposes other than medical interventions. The societal view would weigh the value of spending on medical costs vs. education, for instance.

The perspective of the stakeholder conducting the cost-effectiveness analysis matters considerably. A team from Tufts University School of Medicine, Yale University School of Medicine, and the University of Oslo analyzed the database of cost-per-QALY studies in the Tufts Medical Center's Cost Effectiveness Analysis Registry²⁵ and compared nearly 7,000 cost-per-QALY ratios published between 1974 and 2018, finding only 18% to save costs and increase QALYs.²⁶ This might be because three-quarters of the cost-per-QALY studies took the perspective of the healthcare payer or sector. Too often, the perspective of a patient that might include anything beyond the monetary cost to the payer or the healthcare sector as a whole is not used as a basis for cost-effectiveness, and in turn is not used to decide who will be permitted to access interventions or treatments that may decrease symptoms or improve QoL.

CONSIDERATIONS OF DUTY IN PHYSICIAN ADVOCACY

From the argument that cost-effectiveness analysis based on QALYs creates barriers and inequities for patients seeking care arises the question of physician responsibility to advocate for removal of those barriers and inequities. Physicians' duty of advocacy and fidelity to each and every patient has a long history and multiple sources of authority.

²⁵ <https://cevr.tuftsmedicalcenter.org/databases/cea-registry>.

²⁶ Kim et al., supra note 25.

The sources of authority are found in the writings of medical ethics, law, and philosophy. Hippocrates, the celebrated Greek physician, was born on the Island of Cos in the fifth century B.C., living from approximately 460 to 375 B.C. No doubt adding to his reputation at the time, he claimed descent from the mythical Aesculapius, son of Apollo the Physician.²⁷ Among the works attributed to Hippocrates,²⁸ the “oath” remains relevant and illuminating in its guiding principles for physician behavior. In part, Oath states:

I swear by Appollo the Physician and Aesculapius . . . and all the Gods and Goddesses . . . bound by stipulation and oath according to the law of medicine, but to none other. I will follow that system of regimen . . . and abstain from whatever is deleterious and mischievous . . . into whatever houses I enter, I will go into the for the benefit of the sick, and I will abstain from every voluntary act of mischief or corruption . . . while I continue to keep this oath unviolated, may it be granted to me to enjoy life and the practice of the arts, respected by all men, in all times. But should I trespass and violate this oath, may the reverse be my lot.²⁹

Other writings of Hippocrates also go to the heart of physician advocacy on behalf of patients. One of these writings includes the following aphorisms:

²⁷ Jan Schouten, *The Rod and Serpent of Asklepios, Symbol of Medicine*. London: Elsevier Publishing (1967).

²⁸ There is actually no evidence that ‘Oath’ was written by Hippocrates of Kos, whose approximate dates are generally agreed as 460-375 B.C. Oath has long been believed to date to approximately 400 B.C., certainly during the Hippocratic period, but modern scholarship is consistent that the author is unknown, and some scholars now place Oath as written much later, well after the death of Hippocrates. For an excellent recent study, see Stevn H. Miles, *The Hippocratic Oath and the Ethics of Medicine*, New York: Oxford University Press (2004). The enduring legacy of Oath is discussed in Vivian Nutton, Beyond the Hippocratic Oath, in Andrew Wear, Johanna Geyer-Kerdesch and Roger French, eds., *Doctors and Ethics: The Earlier Historical Setting of Professional Ethics*, Amsterdam: Editions Rodopi B.V. (1993) pp. 10-37.

²⁹ Michael M. Domach, *Introduction to Biomedical Engineering*. Upper Saddle River: Pearson College Publishing (2004), p. 12. This is but one of myriad versions of the text, but it serves to make the deontological point.

Life is short, and the art long, the occasion fleeting; experience fallacious, and judgment difficult. The physician must not only be prepared to do what is right himself, but also to make the patient, the attendants, and externals cooperate.³⁰

Of course, there is a valid criticism of the overly paternalistic view that physicians should 'make' the patient do anything, but the idea of the physician as advocate for the patient is easily salvaged.

American medicine took a step forward in advancing fidelity toward patients with the founding of the American Medical Association in 1847.³¹ At that time, American medicine had become in large part very commercialized, and physicians had concentrated on furthering self-interests.³² By the middle of the nineteenth century, concern among physicians solidified over into efforts to organize and improve the profession. Following a failed effort in 1846, the delegates met again in 1847, this time in Philadelphia. Two notable things emerged from this convention: the founding of the American Medical Association, and the adoption of a 15-page code of ethics, which opened by declaring

Physicians should . . . minister to the sick with due impressions of the importance of their office; reflecting that the ease, the health, and the lives

³⁰ *Id.*

³¹ Among the many works describing the founding of the AMA, see Robert B. Baker, Arthur L. Caplan, Linda Emmanuel and Stephen R. Latham, Eds., *The American Medical Ethics Revolution: How the AMA's Code of Ethics Has Transformed Physicians' Relationships to Patients, Professionals, and Society*. Baltimore: The Johns Hopkins University Press (1999). Envisioned to celebrate the sesquicentennial of the AMA, the work is scholarly yet accessible.

³² Ann Anderson, *Snake Oil Hustlers and Hambones: The American Medicine Show*. Jefferson, North Carolina: McFarland and Co.(2004). Maxwell J. Mehlman, *Can Law Save Medicine?*, J. Legal Med. 36(2), 2015, p. 122.

of those committed to their charge, depend on their skill, attention, and fidelity.³³

According to the AMA Principles of Medical Ethics, “The medical profession has long subscribed to a body of ethical statements developed primarily for the benefit of the patient...” including several principles related to avoiding discrimination. “A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights; . . . shall, while caring for a patient, regard responsibility to the patient as paramount; and . . . shall support access to medical care for all people.”³⁴

It is now axiomatic that a physician’s first and paramount duty is to the patient. That duty, with roots in the turmoil of the evolving profession during the eighteenth and nineteenth centuries, has acquired more specific contours through the imprint of state and federal law. In California, CACI No. 502 illuminates a physician specialist’s duty. It states: “A [specialist type] is negligent if [he/she] fails to use the level of skill, knowledge, and care in diagnosis and treatment that other reasonably careful [specialist type] would use in similar circumstances.” This level of skill, knowledge and care is sometimes referred to as the ‘standard of care.’³⁵ In a frequently cited case, the California Appeals Court outlines another physician duty, the duty to advocate. In facts

³³ John Bell and Issac Hayes, Code of Ethics (1847) reprinted in Robert B. Baker, Arthur I. Caplan, Linda Emmanuel and Stephen R. Latham, Eds., *The American Medical Ethics Revolution: How the AMA’s Code of Ethics Has Transformed Physicians’ Relationships to Patients, Professionals, and Society*, Baltimore: The Johns Hopkins University Press (1999), p. 324.

³⁴ American Medical Association, *Principles of Medical Ethics*, available at: <https://code-medical-ethics.ama-assn.org/principles> (accessed December 13, 2023).

³⁵ The Judicial Council of California Civil Jury Instructions, CACI 502, Standard of Care for Medical Specialists, Revised October 2004.

that were set in 1977, the 1986 case of *Wickline v. State of California* stated that the plaintiff's attending physician should have advocated for the patient's continued stay in the hospital if he felt it was necessary, after the payor denied further hospital coverage, thus establishing an affirmative duty to advocate by physicians who feel they have recommended medical necessary care that has been denied or delayed.³⁶ In a later California case, *Khajavi v. Feather River Anesthesia Medical Group*, the court found that a statute citing *Wickline*, California Business and Professions Code 2056, encouraged physicians to advocate for medically necessary care in two settings: "(1), an appeal from a payor's decision to deny payment, and (2) to protest a decision, policy, or practice that the physician reasonably believes impairs his or her ability to provide medically necessary care."³⁷

The Americans with Disabilities Act (ADA) is perhaps the most prominent federal legislative effort, now more than thirty years old.³⁸ The ADA and other federal law prohibits nearly all health care providers from engaging in practices that subject individuals with disabilities to specified forms of discrimination.³⁹ Discrimination in the form of overt animus against someone in a protected category is a violation of law, but so would be denying access to a benefit or providing a person with a disability with

³⁶ *Wickline v. State of California*, 192 Cal. App. 3d 1630, 1646 (1986).

³⁷ *Khajavi v. Feather River Anesthesia medical Group*, 100 Cal. Rptr. 2d 627, 638 (2000).

³⁸ The Americans with Disabilities Act of 1990, as amended, 2008, Pub. L. No. 101-336, 104 Stat. 328 (1990).

³⁹ The Americans with Disabilities Act at 42 U.S.C. §§ 12101–12213 (2010); Section 504 of the Rehabilitation Act at 29 U.S.C. § 794; and Section 1557 of the Affordable Care Act at 42 U.S.C. § 18116.

“aid...that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others.”⁴⁰ A limitation is that the ADA has limited reach where administrative agencies such as the Department of Health and Human Services use their statutory rulemaking authority to promulgate measures that apply in a non-discriminatory manner to all beneficiaries.

Ethical codes and legal proscription aside, perhaps the most compelling statement comes from philosopher Hans Joans:

In the average course of treatment, the physician is obligated to the patient and to no one else. He is not the agent of society, nor of the interests of medical science, the patient’s family, the patient’s co-sufferers, or future sufferers from the same disease. The patient alone counts when he is under the physician’s care. By the simple law of bilateral contract, he is bound not to let any other interest interfere with that of the patient’s in being cured.⁴¹

The legal responsibility to refrain from discriminatory practices, combined with the medical profession’s code of ethics, including the American Medical Association’s Declaration of Professional Responsibility requirement to “Treat the sick and injured with competence and compassion and without prejudice,”⁴² are in conflict with current approaches to control costs in the health care system by reducing spending on people living with disabilities. Awareness of this conflict, paired with an intention to deliver

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

⁴¹ Hans Jonas, *Philosophical Reflections on Experimenting with Human Beings*, *Daedalus*, Spring 1969, 219.

⁴² American Medical Association Declaration of Professional Responsibility <https://www.ama-assn.org/delivering-care/public-health/ama-declaration-professional-responsibility> (accessed December 12, 2023).

disability-competent and accessible care, should be a top concern of providers. As in all areas of patient care, physician leadership and advocacy are essential.

CONCLUSION

Providers make treatment recommendations for patients, not for populations or actuaries, and while they certainly should be sensitive to the impact of cost on a particular patient, they should resist pressure from payors or employers to conduct a financial triage on the interests of their patients. Instead of accepting without question resource allocation decisions based on the ethically and clinically inadequate concept of a QALY, providers can play a role in advocating for health care spending assessment tools that do not systematically discriminate against categories of patients. Further, as providers are bound by legal requirements and ethical standards to be responsible to the patient, provide competent medical care and support access to medical care for all, they can serve as important advocates for the patient perspective regarding access to treatments which may result in greater resource consumption, but may in the end result in lower overall costs and loss of function or even life.