A values framework for health system reform

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Prologue: In this election year, proposals for reforming the health care system are a key feature on the campaign trail. These proposals focus overwhelmingly on the problems of access, cost, and quality of care—problems that are not new but that have reached a critical point in light of a recessed economy, increasingly stringent insurance underwriting practices, and growing numbers of unemployed and uninsured Americans. As one observer of the system has stated, “There is no way to adjudicate disputes between the Holy Trinity of cost, quality, and access unless a court of values is available to dispense its wisdom.” In this paper, Reinhard Priester describes the values underlying our current health care system and presents a new framework of values to guide reform of that system. Stating our values structure explicitly, and comparing it with those of our peer nations, also helps to explain why the United States is the only Western nation without universal access to care. Americans have placed individual concerns over the collective good—the converse of values embodied in the social policies of Canada and the European nations with which the United States is frequently compared. “Placing an explicit values framework at the forefront of reform will enable the public to hold policymakers accountable,” the author explains, “so that policies promote and do not detract from underlying values.” Access to care emerges as the preeminent value to guide the U.S. health care system; however, Priester emphasizes, access should reign as “first among equals.” Priester is a research associate at the Center for Biomedical Ethics at the University of Minnesota’s Twin Cities Campus in Minneapolis. He received his law degree from Boston University. This paper summarizes the work of the center’s “New Ethic” research project, whose twenty-five members span the disciplines of medicine, law, ethics, public health, insurance, and community/consumer interests.
The American health care system is under great stress. The long litany of concerns can be summarized into the broad problems of inadequate access to needed services, the high cost of health care, and the unknown quality of services provided. These problems have raised widespread criticism of the present system, with which virtually everyone is dissatisfied. Over the past three years, an astounding number and range of health care reform proposals have been put forward. Many suggest quick-fix economic or financing solutions within the present system, without addressing its inherent shortcomings. Others argue that incrementalism is no longer appropriate and call for dismantling either the entire system or portions of it. Clearly, the consensus that something needs to be done does not extend to what should be done.

Superficially, the frustrations with health care stem from runaway costs and an increasingly complex yet unresponsive system. At a deeper level, they arise from disagreement and confusion about the values that should shape America’s health care system. Most proposals for change ignore or uncritically adopt the current framework of values underlying our health care system. If we do not make explicit the values we should adopt, discussion of change will be hollow and consensus for reform nearly impossible. We as a society will more likely agree on strategies to resolve the fundamental problems of our health care system once we agree on the values on which it should be based.

Why focus on values? In our contemporary culture, the term value is frequently used in a confusing way. In the simplest and most popular usage, values refer to what is desirable or what ought to be—not what is, was, or will be. From this perspective, “health care value” is a concrete phrase referring to what is thought to be good or desirable in our health care system. The framework of values proposed here refers to the configuration or arrangement of values that should guide U.S. health care policy.

Robert Veatch argues that values are unavoidable, since policy making “logically requires a system of values.” Reforming or restructuring the U.S. health care system must therefore begin with values. An explicit values framework will advance health care reform more rapidly and more effectively. Lacking such a guiding framework, our health care policy has been incremental, piecemeal, and reactive and thus has failed to resolve the fundamental problems of inadequate access, high cost, and unknown quality. Systems based on explicit, highly publicized values, such as in Canada, Norway, and several other Western countries, more effectively provide affordable, high-quality health care to all. Furthermore, explicit values can help us reach agreement on what we should reasonably get out of the system, make clear the trade-offs we face, and force us to have more realistic expectations.
Placing an explicit values framework at the forefront of reform will enable the public to hold policymakers accountable, so that policies promote and do not detract from underlying values. Without an explicit framework, the expressed goals of health care policy can be changed indiscriminately. Such a framework can also function as a “yardstick” to evaluate proposals for reform, providing a perspective for analysis and criteria for comparison.

A focus on values illuminates why the United States is the only Western country that does not assure universal (or near-universal) access. The United States shares with Canada and West European countries many cultural, theological, philosophical, and democratic traditions. These countries are demographically similar in age, wealth, and income distribution as well as in types of health care personnel (nurses, technicians, and other health professionals), structure of medical education, and types of technology. Information on advances in research and treatment is quickly shared among these countries. Given these similarities, differences in values alone probably explain why the United States stands separately with a patchwork system that leaves one of every eight people uninsured. Direction for health care reform in the United States can come from better understanding the values underlying systems in other Western countries. All Western health care systems—except for ours—share a commitment to universal access. Furthermore, all of these systems are undergirded by the belief that nations are obliged to provide a strong network of social benefits to all of their citizens. The social welfare systems in West European countries promote the dignity and well-being of all persons and the welfare of society as a whole. In contrast, the United States embraces individualism, sees provider autonomy as the preeminent value, and neglects community-oriented values.

**Current Values Framework**

A set of six influential values has shaped the U.S. health care system since World War II.1 (1) Professional autonomy includes both clinical autonomy of practitioners (that is, independence in making treatment decisions) and regulatory autonomy of the profession itself. (2) Patient autonomy refers to patients’ right to information that is material to making an informed decision about medical care including the right to refuse care. (3) Consumer sovereignty includes individuals’ freedom to choose both their health insurance plan and their own physician. (4) Patient advocacy connotes a mix of values, including caring, service, benevolence, beneficence, fidelity, and effacement of self-interests. It requires health care professionals to single-mindedly pursue the best interests of individual patients, regardless of costs or other societal con-
siderations. The advocacy role has traditionally been limited to benefit-
ing patients (some suggest, patients who pay) and has not included the
ill who are not someone’s patients. (5) High-quality care historically has
been assessed with reference to its process and structure (that is, how and
in what settings medicine is practiced). In the past few years, this focus
has broadened to include outcome (that is, the effect of care on patients’
functional status and quality of life). (6) Access to care, relative to the
other five values, has been vaguely defined. Confusion over its meaning
is compounded by the mingling of two separate but related aspects of
access. One refers to providing care to more people (universality); the
other, to offering more services (comprehensiveness). Most policy dis-
cussions on access have focused on the progress toward universal access.
Determining those services to which people should have access has
come to the fore only since resources have been declared finite.
These six values have been shaped by the values of our broader
society, among them strong faith in individualism, distrust of govern-
ment and preference for private solutions to social problems, belief in
American exceptionalism, a standard of abundance as the normal state
of affairs, the power of technology, and the uniquely American frontier
orientation. Although these values are not universally or consistently
adhered to throughout the United States, they do form part of the ethos
of many elements of our society—including the health care system.
The six values continue to function as ideals that the system never
fully realized; indeed, given the inherent tension among these values, it
is impossible to implement all of them simultaneously. Maximizing pro-
fessional or individual autonomy, for example, interferes with maximiz-
ing access to care. Nonetheless, the values were thought to be reason-
able, achievable goals. A common perception is that the explosive
growth of managed care, aggressive cost containment, shifts toward
prospective payment, and other changes no longer permit us to exercise
these values. In reality, the system never fully implemented them, except
for physician autonomy. Recent changes in health care delivery and
financing have broadened the gap between the expressed values and
their realization.
Recent changes also have altered our conception of some of the values
and threatened the importance of others. For example, because of finite
resources, many argue that the patient’s well-being should be only the
primary, not the sole, allegiance of health care professionals. The gate-
keeper role in a managed care plan, which requires the gatekeeper to
balance a patient’s needs against the managed care tenets of cost-con-
sciousness, similarly challenges the traditional advocacy role.
Reduced commitment to current values. Three problems with the
current values framework justify the need for a new one to guide health
care policy. First among these is a reduced commitment to the current values framework. Ideally, values should guide the development and implementation of health care policy. But the values that have formed the foundation of our health care system have not served that function. There has been a marked lack of commitment to pursuing and implementing them; indeed, discussion of underlying values has been confused and incomplete. U.S. policy over the past two decades has been guided more by economics than by the six values. Most notable was an erosion of the already modest commitment to access. Efforts to expand access were superseded by aggressive initiatives to contain and sometimes merely to shift costs. Health policy aimed at controlling costs through Medicare’s prospective payment system (PPS) and managed care. During the 1980s, profits, market share, competitiveness, and other more commercial and less service-oriented goals eclipsed the value of access. In fact, the meaning of access has never been agreed on. Some argue for a right to health care, others suggest a societal obligation to assure access, while still others view health care as a private consumption good distributed through free markets.

We continue to espouse the same six values, while retreating from them in reality. For example, in today’s more market-driven environment, practitioners want to have professional autonomy and pursue patient advocacy yet are also directly responsible to, and called to account by, cost-conscious government and corporate payers. Cost containment initiatives restrict hospitals’ ability to provide care to uninsured patients, for whom consumer sovereignty is moot. Even insured patients wonder about patient advocacy and quality when their providers have economic interests in the clinical laboratories or imaging centers whose services and products they prescribe. The overriding concern to contain costs is the root of the reduced commitment to our traditional health care values. As James Morone has suggested, we have let our economics come before our ethics.

Misplaced order of values. A second problem with the current framework is that it does not hold the value of access paramount. Access should be the driving value because of health care’s importance in promoting personal well-being, avoiding irreversible harm, and preventing premature death. Everyone should have access to health care to cure or prevent illnesses, mitigate symptoms, and ease pain and suffering.

Norman Daniels has cogently argued that health care derives its moral importance from its effect on the normal range of opportunities available in society. Health care meets basic human needs, as do food, clothing, housing, and education. In his words, an individual’s range of opportunities “is reduced when disease or disability impairs normal functioning. Since we have social obligations to protect equal opportunity,
we also have obligations to provide access, without financial or discriminatory barriers, to services that adequately protect and restore normal functioning. However, since World War II, U.S. health policy has consistently subordinated access to other values, most notably to professional autonomy, patient autonomy, and consumer sovereignty. Professional autonomy has been the dominant value in physicians’ decisions of what specialty to enter, where to practice, which patients to serve, and what fees to charge. The ethical obligations of informed consent, truth telling, and respect for privacy and confidentiality became (in the past two decades) the ideals governing doctor/patient relationships. Similarly, consumer sovereignty has been upheld in consumers’ ability to select a health care plan and provider. Finally, in distributing health care resources, the United States, unlike every other Western industrialized country, relies heavily on choice in the marketplace.

The idea of access for everyone conflicts with several more deep-seated values, such as a strong resistance to government involvement in the health care sector and physicians’ autonomy to choose their patients. Although the value that care should be provided to poor and disadvantaged people is long-standing, its ethical obligation is limited to providing charity for the so-called worthy poor. Unlike the value of access, the charity ethic complements other values of American medicine. Individual and institutional providers are free to select which of the patients unable to pay are worthy of receiving free care. The concept of the worthy poor derives from the peculiarly American notion that for many poor people, poverty is somehow deserved. From this perspective, access to necessities such as health care, and clearly to all of life’s luxuries, depends on personal effort, achievement, or merit.

After World War II, many government programs (for example, the Hill-Burton Program and the Health Professions Education Assistance Act of 1963) had the limited goals of expanding health care resources and services. Other government initiatives (for example, Medicare, Medicaid, and favorable tax treatment of employer contributions to employee health benefits) provided individuals with the financial means to obtain services from the private sector. However, reluctance to interfere with professional autonomy and consumer sovereignty limited the government’s ability to resolve perceived inequities in access.

Entitlement programs such as Medicaid, for instance, gave great weight to preserving the freedom of patients to choose their providers and of providers to choose to participate. The unwillingness of some providers to treat those programs’ patients leaves them with restricted access. The widespread state practice to under-reimburse providers further strapped Medicaid’s services to nonelderly enrollees. Although these cost-conscious policies probably saved some money, they also
reduced provider participation, with the side effect of restricting access. Fewer than 40 percent of the people below the federal poverty line are enrolled in Medicaid today. Some states now seek to increase the number of Medicaid enrollees but restrict their access to certain services. Such changes in the breadth and depth of coverage are a clear retreat from Medicaid’s original intent to provide poor persons with access to the same services as are offered to persons with higher incomes.

Our lukewarm commitment to access has also eroded in the private sector. As employers and government sought to control health spending, providers could no longer shift to paying patients the cost of caring for uninsured patients. This environment has also challenged the traditional social commitment of hospitals to provide emergency services to uninsured people. Many private hospitals responded by “dumping” such patients to a public hospital or by having no emergency facilities.

Omission of community-oriented values. Individualism and personal autonomy have superseded community values in American society. These concepts reflect the views that each individual is his or her own best judge of what is of value or interest and that government is a necessary evil, not a natural vehicle for achieving common aspirations. The needs of the individual have been given priority over those of the community.

The patient-centered Hippocratic tradition is the core of our current values framework. This “ethical individualism” has singularly focused on encounters between an individual practitioner and an individual patient. The provider’s responsibility as the patient’s advocate-narrowly and exclusively centers on the individual patient. Respect for patient autonomy has become (in theory if not always in practice) the guiding principle for provider/patient encounters. The impact of the individual’s treatment choice on the distribution of health care resources or its effect on the interests of others has been considered irrelevant.

Unlike in most other Western countries, a community perspective has not been strong in the United States. Criticisms of our excessive individualism and calls to incorporate community values abound, both inside and outside the health care system. For instance, the Catholic Health Association describes human rights, including the “right to a basic level of healthcare,” in terms of the interdependence of personal and social life. Health care from a community-oriented perspective is viewed as necessary for society to sustain essential social harmonies and ensure its viability. Marion Danis and Larry Churchill argue that in the context of scarcity, “ethical concerns about the fair distribution of health care resources cannot remain detached from the ethics of individual patient care.” When health care resources are limited (that is, scarce relative to needs), individual treatment choices affect the resources
available for others. Using resources for one patient necessarily means that fewer resources will be available to treat others.

In the United States, broad, community-oriented conceptions of human good have seemed unobtainable rationally and totalitarian if imposed politically. Nonetheless, Daniel Callahan argues, “We will not be able to work out the problems of our health care system unless we shift our priorities and bias from an individual-centered to a community-centered view of health and human welfare.”10 The objective is not to get rid of individual autonomy, but to temper the significance of free choice and individualism according to the good of the whole to keep autonomy from being such a “moral obsession” that it “pushes other values aside.”11

Proposed New U.S. Values Framework

The proposed new U.S. values framework retains all six old values but reorders and redefines some of them, reemphasizes several that have been neglected, adds some new ones, and offers more guidance on which values take priority and how to resolve conflicts among competing values. The added values come from many sources, including selected Western countries, several states’ initiatives, national reform proposals, and the professional and popular literature. Some have been around for a long time, albeit largely neglected. Others, although absent in our health care system, have been prominent in foreign systems.

Three nations, in particular, offer credible models for determining the values underlying a health care system. The Canadian model has long been championed by critics of the U.S. system as an attractive and viable alternative. Norway, like Canada, is among the few Western countries to delineate explicitly the values that should guide its health care system. Of all Western systems, (formerly West) Germany’s perhaps most closely approximates the U.S. system: it is professionally dominated and relies on private insurance carriers (“sickness funds”). These carriers offer employer-financed services through private physicians and hospitals, while the federal government establishes the system’s ground rules and provides a safety net for those who do not receive employer-financed coverage. Some of the values of these three countries are somewhat alien to the U.S. system (such as social solidarity and personal security); these values should be added to our own framework, after first being negotiated and interpreted through American society and culture.

Comprehensive and well-known national health care reform proposals (such as those from the National Leadership Commission on Health Care, the Pepper Commission, and the American Medical Association) are additional sources of values. So are state reform proposals. Oregon, Massachusetts, New York, Minnesota, and Hawaii are among the states
at the cutting edge of health care reform. All of the national reform proposals and state initiatives are based primarily on the current values framework, although the relative rankings of specific values vary; some reforms incorporate values that go beyond the current framework.

These health systems, proposals, and plans yield a master list of potential values, which can be pared down to eleven values to guide the restructuring and reform of our health care system (Exhibit 1). The first five are essential values, fundamental for any health care system: without them, a system would be deficient. The next six are instrumental values, primarily a means to help achieve the essential values.

### Essential Values

(1) **Fair access.** Each person should have access to an adequate level of health care. This requires minimizing financial, geographic, and cultural barriers to care; distributing health care resources in a manner acceptable from an impartial point of view; and treating similar health care needs similarly, without regard to the patient’s membership in a group or class. Assuring access to health care, regardless of cause or source of need, is society’s collective responsibility.

While everyone ought to have access to health care, this does not require universal access to all potentially beneficial care. No society can afford to provide every service of potential benefit to everyone in need. And although total resources devoted to health care could be increased, clearly there is a limit (which some argue we have already passed) beyond which our ability to spend money on other important and desirable societal goals, such as education, transportation, and housing, would be constricted. This limit—plus the continued development of new, efficacious, and often expensive technologies; our aging population; acquired immunodeficiency syndrome (AIDS); and other factors fueling the demand for health care—would mean that we still could not

### Exhibit 1

**Proposed Values Framework For The U.S. Health Care System**

<table>
<thead>
<tr>
<th>Essential values</th>
<th>Instrumental values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fair access</td>
<td>Personal responsibility</td>
</tr>
<tr>
<td>Quality</td>
<td>Social solidarity</td>
</tr>
<tr>
<td>Efficiency</td>
<td>Social advocacy</td>
</tr>
<tr>
<td>Respect for patients</td>
<td>Provider autonomy</td>
</tr>
<tr>
<td>Patient advocacy</td>
<td>Consumer sovereignty</td>
</tr>
<tr>
<td></td>
<td>Personal security</td>
</tr>
</tbody>
</table>

Note: Ordering rules for these values are as follows: (1) Each essential value should be maximized to the degree possible without threatening any other essential value. But fair access should be preeminent. (2) Essential values should be achieved before instrumental values, except insofar as instrumental values are a means to achieve essential values.
provide all services to all who could benefit.

In the context of scarcity, everyone should have access to a level of health care “that would permit [them] to achieve sufficient welfare, opportunity, information, and evidence of interpersonal concern to facilitate a reasonably full and satisfying life.” Defining fairness as access to an adequate level of health care is the only way to avoid either an impossible commitment of resources or the abandonment of at least some help to everyone. Each person, regardless of his or her ability to pay, would have access to an adequate level of health care. The specified level would function only as a floor below which no one should fall, not a ceiling.

Inherent in the very idea of an adequate level of care is that it is acceptable for different people to receive different levels of care, depending on where the levels are set. It is unacceptable for some people to receive a very high level of care while others receive virtually no care at all. But it is acceptable for some people to receive a very high level of care while others receive less care, David Eddy has argued, if the lower level of care covers everything that is considered adequate. This is also acceptable if public policy only defines the adequate level while permitting—but not defining—the higher levels. Services not considered basic would be available for purchase in the health care market. Public education offers an analogy: while every American child is assured access to publicly funded education, individuals are free to purchase additional opportunities, such as private music lessons or college classes.

Despite widespread support for the concept of an adequate level of care, there is no consensus regarding what, precisely, it should include. There clearly is a level of services below which a system would be ethically unacceptable, even if the universal access requirement were met. Defining the level to which everyone ought to have access is absolutely crucial for specifying a morally acceptable system. This is where the health care reform debate ought to move, following these substantive guidelines for specifying an adequate level of care. First, the available budget should not drive the definition of what is adequate; instead, only after the level is defined should attention turn to how to pay for it. If resources can only assure universal access to a portion of the defined adequate level of care, then this should be explicitly acknowledged. Second, the process for deciding what is adequate should assure accountability. Those who define the adequate level should be bound by the definition, even though they may use their own funds to buy additional coverage. Otherwise, the procedure would be biased, as Daniels states, with “the ‘haves’ deciding what is ‘important’ to give to the ‘have-nots’.” Also, a representative cross-section of those who will actually receive services deemed adequate should be involved in the
process. Third, since it should apply to all, the adequate level should not be defined with reference to a particular group. Finally, regardless of how adequate care is defined, its content should be constantly revised to incorporate changing information on technology and consumer preferences. The revisions should apply to all.

Universal access requires, first and foremost, that everyone have the financial means to obtain needed care. Since only the relatively affluent are able to pay for their health care out of pocket, this will require some form of universal health insurance coverage. Universal coverage (through public or private health insurance, or some combination) would make it easier for minorities, legal immigrants, illegal aliens, and other underserved people to obtain care, but it would not necessarily result in universal access. Language handicaps, cultural barriers, and unfamiliarity and distrust of the system would continue to inhibit access. These nonfinancial barriers must be overcome, along with the financial barriers.

For access to be nondiscriminatory, health care needs should be treated similarly, without regard to the patient’s age, gender, race, religion, national origin, education, place of residency, sexual orientation, ability to pay, or presumed social worth. Oregon’s reform proposal, for instance, would violate this requirement. It expands Medicaid coverage to all Oregonians below poverty by providing them with a less comprehensive level than is currently prescribed under Medicaid. However, it explicitly exempts from the reduced benefits blind, disabled, and elderly Medicaid enrollees, who will continue to receive the current (higher) level of benefits. Doling out benefits in this way is discriminatory.

Individuals and the private sector should be involved in enhancing access, but the ultimate responsibility rests with the federal government. Unless it assumes this responsibility, the health care needs of many will remain unmet. Although widespread activity on health care issues is under way in most states, there is mounting evidence that such state efforts, although pioneering and sometimes initially successful, may fail.

(2) Quality of care. Health care should maximize the likelihood of desired health outcomes for individuals and populations, be consistent with current and emerging professional knowledge, and be humanely and respectfully provided. This definition of quality, adapted from the Institute of Medicine’s report, Medicare: A Strategy for quality Assurance, has several important characteristics. First, high-quality care is an ideal. Second, emphasis on current and emerging knowledge underscores the constraints placed on health care by technical, medical, and scientific developments. Health care professionals must keep abreast of new information and use the best knowledge base available. Third, the definition highlights the growing importance of outcomes. Previously, quality as-
Assessment and assurance focused on the process and structure of care; high-quality care was that provided by a competent practitioner (with certain qualifications, training, and experience), in the appropriate setting, using commonly accepted procedures, in accordance with accepted medical practice. Outcomes are now an integral component of quality assessment and assurance, and they must be linked to the process of care. Desired outcomes obtained by serendipity do not indicate high-quality care. Fourth, preferences and values of individual patients should help to determine which interventions and associated outcomes are desired.

(3) Efficiency. The health care system should be efficient—that is, should achieve desired outcomes with the least expenditure, thereby providing good value for money spent. Efficiency has two important dimensions, as defined by Mark Pauly and colleagues: minimizing the cost of whatever services are provided, and choosing the services leading to the maximum excess of benefits over cost. An efficient health care system is not necessarily the least expensive, but it obtains the greatest benefit (defined in terms of desired outcomes) for the lowest cost.

Efficient use of resources has not been part of the culture of the medical profession or of the health care system. Few resources are devoted to evaluating medical technologies, and there is much uncertainty about their effectiveness. As a prime example of inefficiency, uninsured people obtain much of their primary care in emergency rooms, instead of physicians’ offices and other less costly settings, because their access to care is restricted. They also often delay obtaining care, thereby turning less costly problems into expensive ones. Unnecessary care, the duplication and oversupply of health care facilities, escalating administrative costs, and the malpractice “system” further contribute to inefficiency.

Among the reasons efficiency has not been an important value is that most Americans have long believed that abundance, not scarcity, was natural. Concerns about efficiency were incompatible with the perception of virtually unlimited growth in knowledge and unlimited availability of useful health care resources. Only in the past decade has it been widely acknowledged that resources are limited and that all needs may not be met. When all health care needs cannot be met, it is inappropriate to simply try to hold down costs—which was the focus of cost containment initiatives in the 1970s and 1980s. We must also pay attention to what works in health care and then add incentives to achieve desired outcomes with the least expenditure.

(4) Respect for patients. The elements of this value are fourfold: First, patients have the right to information to make informed decisions about their care, including information about their provider’s potential conflicts of interest. Second, patients have the right and responsibility to make informed, voluntary decisions about their care (including the right
to refuse care); no care can be initiated without the patient’s (or surrogate’s) informed consent. Third, patients have the right of access to their medical records and the right to protect and control personal information about their health and health care. Finally, patients have the right to be treated with respect and dignity.

Respect for a patient’s autonomy has had a brief, very recent, but powerful history in our current values framework. Historically, medical paternalism prevailed in provider/patient relationships. Now, the relatively modern doctrine of informed consent is generally promoted. Informed consent has two basic parts: first, certain information must be disclosed to the patient before consent is obtained; second, no procedure may be performed on a patient without consent. Informed consent is also a legal doctrine, first articulated by a California court in 1957 and since adopted by statute or court opinion in all states. But despite widespread support, informed consent rarely has been fully implemented, so its impact on fostering greater respect for patient autonomy is uncertain. Although respect for patient autonomy has appropriately become an important value, it should not trump other values. In health care policy, the demands of justice, which require fair access, can (in narrow circumstances) outweigh respect for patient autonomy.

The individual’s right to protect and control personal information requires confidentiality, which, in its simplest terms, means respect for people’s secrets. Confidentiality has never been absolute. Many statutes specify the circumstances in which confidential information can be released to protect others (for example, health care providers must report certain communicable diseases and evidence of child abuse). Professional codes of ethics incorporate such restrictions. The American Medical Association’s (AMA’s) Principles of Medical Ethics, for example, provides that a physician “shall safeguard patient confidences within the constraints of the law.” Rules of confidentiality have also been developed from the standpoint of patients (for example, the American Hospital Association’s Patient’s Bill of Rights).

But patient confidentiality is now under considerable threat beyond the narrow legal exceptions. Major challenges include centralization of medical records, utilization review and other forms of oversight by parties other than the physician and patient, and the intrusive effects of litigation. Hundreds of people—medical records personnel, health care providers, claims processors, health plan administrators, even the patient’s employer—may have access to patient records. One study found that over 100 hospital staff could have legitimate access to a patient’s hospital record and concluded that such sharing of information has diluted confidentiality beyond meaningful existence.

Despite such challenges, confidentiality is crucial because the effec-
tiveness of provider/patient encounters depends on the patient’s willingness to reveal information essential to proper diagnosis and treatment. Assurance of confidentiality encourages full disclosure and is essential for effective treatment. Confidentiality should also be protected simply out of respect for patients’ right to privacy.

(5) Patient advocacy, Health care providers should zealously promote their individual patients’ best interests within established, recognized constraints. Physicians, it has often been said, cannot serve two masters; circumstances that present potential conflicts of interest should always be resolved in favor of the patient. This expansive view of advocacy enshrined the provider’s ideal role as single-mindedly serving the patient’s interests. However, this view is not appropriate today, even as an ideal. Since health care resources are clearly finite, treatment choices for an individual patient will affect the resources available for others. Some patients, therefore, may appropriately receive less than the maximum, if this is necessary to conserve resources to assure universal access to an adequate level of care.

The provider’s advocacy role should be altered in two aspects. First, in addition to serving their own patients, providers must promote the fair and judicious use of resources and advocate for the needs of individuals and groups that have traditionally been left out of the health care system. Second, providers should not do everything that may benefit an individual patient, since doing so may interfere with the ability of other patients to obtain basic services; rather, providers should treat each patient with as full a range of resources as is compatible with treating patients yet to come. But providers should not be required to balance at the bedside the patient’s interests against those of others or of society. They should only be required to adhere to previously established constraints, including a managed care plan’s practice guidelines for appropriate care and coverage limitations of third-party payers. Providers should also be involved in establishing such allocation rules and regulations. However, they should do so as health care administrators, managers, and members of professional organizations—not as bedside clinicians. In short, providers should help to develop allocation rules and then play by the rules. Within those rules, they should continue to advocate zealously for their individual patients’ interests. If providers believe the rules are detrimental to their patients, they should work to change them.

Many argue that asking providers to abide by rules that reflect an organization’s or program’s obligations to meet the needs of groups (such as enrollees in a managed care plan) raises unacceptable conflicts of interest. This criticism is misplaced. Providers have always faced conflicts of interest. For example, in the traditional fee-for-service system, a provider’s income depends on the number and cost of procedures per-
formed. There is little reason to believe that the new conflict between patient and group interests is potentially more harmful than the former conflict between patient and provider interests.

**Instrumental Values**

(6) **Personal responsibility.** This value has two aspects: individual and institutional. First, each person should, within his or her means, share in the costs of health care. Individual financial responsibility requires all people to help bear, to the extent possible, the cost of adequate health insurance and services and the cost of the system as a whole. The financial burden should be progressive: any premiums, co-payments, deductibles, or taxes should be based on ability to pay. Premium subsidies for lower-income people, for instance, could be on a sliding scale based on gross family income, to assure that health coverage will be available to all people while still requiring (almost) everyone to pay at least some of the premium.

Individual financial responsibility can also encourage more appropriate and parsimonious use of services by consumers. A system providing “free care” (that is, no out-of-pocket cost to the individual at the point of service) often leads to overuse. Cost-sharing provisions, such as co-payments and deductibles, can encourage rational economic behavior among consumers without denying them necessary care. However, to assure decreased use of inappropriate services, more information for consumers regarding the outcome of services should accompany such cost-sharing provisions. Moreover, even modest levels of coinsurance adversely affect the health of people who are both sick and poor. Cost-sharing requirements need to be carefully crafted to encourage more appropriate use of the system but discourage underuse, overuse, or other inappropriate use. Cost sharing should not apply to cost-effective prevention measures.

The second aspect of personal responsibility involves providers, the health care system, and society, and their capacity to enable each person to take greater control over his or her own health. Americans are largely free to engage in any number of dangerous activities that place them in need of health care services. But the traditional emphasis on individual freedom needs to be balanced with a corresponding emphasis on personal responsibility. Providers, employers (as purchasers of group health insurance), and insurers are exploring policies to attach financial consequences to people’s lifestyle or behavior when it affects their health. Options include direct taxes on tobacco products, alcohol, and other dangerous substances and higher insurance premiums for those who smoke or take other risks with their health.
However, policies that hold individuals responsible for their injuries and illnesses are open to criticism. First, they presuppose in-depth understanding of causal relationships, but we cannot always be certain that attributions of responsibility are accurate. Second, they conflict with the traditional ethos of physicians and nurses to treat all patients with the same understanding, compassion, and clinical expertise—without regard to patients’ role in the origin of their ailments. Third, they can deteriorate into “victim blaming,” that is, locating the causes of social problems within the individual, rather than in social and environmental forces. Claims of individual responsibility may fail to recognize that lack of education, lack of funds, deep-seated cultural traditions, or other barriers may make it difficult for individuals to take responsibility for their health.

The thrust of the value of personal responsibility, therefore, should be to enable people to take appropriate steps to maintain and improve their health—without attaching blame if they fail to do so. First and foremost, providers, the health care system, and society in general should provide information on risks associated with certain behavior, offer health promotion programs, and implement similar strategies that contribute to good health. Only then may it be appropriate to take additional steps to discourage unhealthy behavior through economic penalties. The penalties, however, should not be so onerous as to prevent or discourage anyone from obtaining needed medical care.

(7) Social solidarity. The health care system should engender a sense of community. Social solidarity represents commitment to bridging gaps between different segments of society by including them in a community. Our public education system, for example, has long reflected this value and promoted community concerns. People without children, or whose children have grown, still vote on school bond issues, and most of them share a sense of responsibility for the educational system. But social solidarity is rarely mentioned in discussions of U.S. health policy. This value is much more familiar to many Europeans, who argue that economic and class differences should not be exacerbated by or reflected in the health care system. In Norway, for example, various commissions have insisted that the health care system must remain a force for societal unity. Norwegians are keenly aware that theirs is a relatively young and geographically isolated nation and that the health care system is one of the most powerful forces unifying the citizenry. The United Kingdom’s health care system serves much the same unifying function. Those who use the National Health Service rarely complain about long waits for elective procedures or the dilapidated conditions of some hospitals (increasingly, however, signs of discontent are emerging). They feel it would be wrong to complain about a system that has treated them fairly,
even if it cannot provide everything they might want or need.

Fairness is clearly the central driving factor behind the value of social solidarity. Leaving any group, class, or segment of society outside the health care system is seen as unfair. But social solidarity also gives a nation a common rallying point. It affirms that all citizens count, and society sees itself as having a stake in each citizen. In Norway, social solidarity means that everyone has access to roughly the same level and quality of care. In the United Kingdom, it means that everyone has access to at least the same minimal package of services. In both countries, the government has an obligation to ensure that health care is available to all in need, regardless of their station or lot in life.

The United States should transfer its sense of social consciousness to support a fairer health care system. Social solidarity provides a common bond among those who use a nationally sponsored health care system and a means to make each person a “stakeholder” in the system. But social solidarity does not simply result from creating a nationalized health care system or insurance program. To flourish, this value requires all citizens to be involved and feel a sense of ownership of their system. It also requires a political mechanism to allow the public to have a real say in how the system serves their needs.

(8) Social advocacy. Health care providers should advance the health of the public and recognize and provide for the health care needs of poor, underserved, and other vulnerable individuals and groups. The preamble to the AMA’s 1980 Principles of Medical Ethics acknowledges that the medical profession has “long subscribed to a body of ethical statements developed primarily for the benefit of the patient” but then states that “a physician must recognize responsibility not only to patients, but also to society.” However, recent changes in the AMA’s principles regarding the latter responsibility reinforce a narrower, patient-centered focus. Section 1 of the AMA’s 1957 medical ethics principles stated that “the primary objective of the medical profession is to render service to humanity with full respect for the dignity of man” (emphasis added). Section 1 of the 1980 principles, in contrast, eliminates any mention of obligations to humanity and thus appears to focus physicians’ responsibility more narrowly on their individual patients; it states merely that “a physician shall . . . provide . . . service with compassion and respect for human dignity.”

The value of social advocacy calls on providers to renew their commitment to advocate for the health care needs of underserved people and of society in general. (This is in addition to their long-standing obligation to advocate for their patients at the bedside.) Providers should advance the health of the public, broadly construed. They should also recognize and help to meet the specific health needs of vulnerable,
underserved individuals and groups. Providers may fulfill these responsibilities in many ways, for example, by participating in health policy making, educating the public on health issues, or being active in organizations that address the health care needs of vulnerable populations.

(9) Provider autonomy. Providers should have freedom to practice medicine to the best of their ability without undue interference from others. Providers should have the freedom to refuse patients (except in emergencies or if refusal is discriminatory) and the opportunity for just compensation for services rendered. Each health care profession should have the freedom to control its education, set criteria for entry into the profession, and control professional certification and standards.

The autonomy of providers—especially of physicians—as traditionally been the dominant value of our health care system. It includes both the clinical autonomy of individual practitioners and the regulatory autonomy of the professions. Many believe professional autonomy was conferred on American medicine around the time of the Flexner report (1910). One reviewer noted that “in essence, organized medicine was granted broad, monopolistic powers over the health care industry (such as it was at the time), in exchange for its promise to provide quality medical care and eliminate the sad state of affairs described by Flexner.”

Others argue that conferring autonomy was based on the public imputation of medicine’s “extraordinary trustworthiness” to promote the public’s interest rather than practitioners’ self-interest. Although recent bureaucratic and institutional changes have chipped away at provider autonomy, it still remains the dominant value of our health care system.

Inherent in conferring autonomy, Frederic Wolinsky states, is the “potential revocation of that autonomy at any point at which the public imputes that the profession has not lived up to its side of the bargain.” That is the situation today. The public was promised too much; our system, driven by the value of provider autonomy, has failed to meet individuals’ and society’s needs. Provider autonomy, though important, should be a means to promote more crucial values, not an end in itself.

(10) Consumer sovereignty. Consumers have the right to information to make informed choices among health care providers (including information on the quality and efficiency of providers) and, where appropriate, the right to select a provider. Consumer sovereignty includes individuals’ freedom of choice in both the market for services (and providers) and the market for insurance (and plans). The clear trend has been toward greater restriction of choice in both markets. Commercial insurance plans initially preserved consumers’ freedom to choose among providers; only for enrollees in prepaid group practices was this freedom significantly restricted. Today, however, restricted choice of providers is a central element of managed care plans and of
many commercial insurance plans. It is often “enforced” through significant financial penalties imposed if individuals choose outside of an identified group of providers. Choice of insurance has been similarly restricted. The vast majority of privately insured Americans now have group (usually employer-provided) health insurance; their choice of plans is thereby limited to those offered by their employer. These plans directly reflect the purchasing decisions made by employers and other group purchasers (ostensibly acting as the consumer’s agent) and only indirectly the decisions of individual consumers.

Consumer sovereignty should remain a value because it functions as a check on the system. Freedom of choice helps to make the system responsive to consumers’ preferences regarding the times, places, and quality of care. In contrast, a system unresponsive to consumers’ preferences would be guided much more by providers’ preferences and thus would lack accountability to patients. Nevertheless, some restrictions on consumer sovereignty are acceptable. It may no longer be feasible in our complex system for individual consumers to make informed, responsible choices among providers, for which consumers would need provider-specific information on the quality and efficiency of care. Individuals rarely have such information or the expertise to evaluate it. Furthermore, acting in isolation, individual consumers do not have the market power to compel changes in the supply side. To preserve an appropriate level of consumer sovereignty, large group purchasers could evaluate all providers and exclude those with poor performance. They should then offer meaningful (albeit limited) choices within the overall plan(s) they offer, so that consumers could make well-informed choices of efficient, high-quality providers.

(11) **Personal security.** The health care system should protect individuals' peace of mind and financial security by meeting their health care needs without impoverishment. The two interrelated elements of this value—peace of mind (knowing that health care needs will be met) and financial security (not being impoverished after paying the bill)—are endorsed in all countries that have some sort of national health system. From the German government’s perspective, for example, feeling safe and secure is “inconceivable” without a health care system that provides needed medical treatment. Although Germany’s workers must contribute to the cost of their health insurance, the mandated comprehensive benefits and liberal public safety net for unemployed people assure that no one has to worry about the financial side of being ill.

Certain health care programs and policies have addressed concerns for personal security of specific groups in the United States. Testimony from older people about their great fear of being unable to obtain needed care was a driving force to get Medicare enacted. Because elders face chronic
and terminal illness more immediately than the rest of the population, a sense of personal security is of particular concern to them. But despite Medicare and other programs assuring access for specified groups, the peace-of-mind element of personal security has not been a value for overall U.S. health care policy. Nor has financial security been upheld; indeed, through the spend-down provisions in Medicaid, for example, eligibility is conditioned on impoverishment.

**Interrelations Among Values**

The relations among the proposed new framework’s values are complex. While the essential values often are mutually reinforcing, they may conflict in some circumstances. Since it may not be possible to provide beneficial care of the highest quality to all persons in need, quality may conflict with fair access. Respecting patients’ choices, such as the wishes of many patients to receive extremely costly, labor-intensive care of only marginal benefit, may undermine fair access and quality. Respect for patients may also conflict with efficiency; if patients are free to choose between two equally effective treatments, but one costs much more, they may not always select the most cost-effective or efficient treatment. Two ordering rules should help resolve possible conflicts.

**Coexistence of essential values.** First, each essential value should be maximized, to the degree possible without threatening any other essential value. But fair access should be preeminent. The preferred strategy to resolve conflicts among the essential values is to modify a simple balancing approach. The essential values should be equal in their priority—each should be maximally satisfied, consistent with respect for the other essential values—but fair access should be first among equals.

The main conflict is between fair access and autonomy (reflecting the classic confrontation between justice and freedom). In our society, the weight of the tension has usually been resolved historically in favor of autonomy. But under the proposed new framework, it would usually be resolved in favor of fair access instead. Individual freedom may thus be restricted if it interferes with assuring access to an adequate level of care for everyone. One patient should not be entitled to every potentially beneficial treatment if it consumes resources to which another patient has a greater claim. The need for health care services that are part of the adequate level of care presents such a greater claim.

When a patient selects a treatment from among the alternatives offered by the provider that is beyond the adequate level of care and, as a result, another patient is denied access to services included in the adequate level of care, the first patient’s choice should be restricted. In practice, this means that until everyone has access to an adequate level
of care, no one may receive services that are not part of the adequate level. Once universal access to an adequate level of care is achieved, however, individuals may obtain (with their own resources) additional services—but only if this does not deny more basic services to another patient.

As a general rule, if achieving universal access to an adequate level of care requires restricting the freedom of choice of an individual provider, patient, or consumer, restricting this aspect of individual autonomy is permissible. But fair access should not override the value of autonomy altogether. Specifically, the pursuit of fair access should not override a person’s right to bodily integrity, which our society has held nearly inviolate. The field of transplantation illustrates the value placed on this aspect of individual autonomy. Despite the chronic shortage of transplantable tissues and organs, one’s freedom to refuse to be a live donor has taken precedence over the need to increase access to transplants.

**Priority of essential values.** Second, essential values should be achieved before instrumental values, except insofar as instrumental values act as means to achieve essential values. The five essential values are fundamental to a health care system; without them, a system would be deficient. Without quality, for instance, patients may be harmed, resources may be used inappropriately, and needs may go unmet. The instrumental values function primarily as ways to help achieve the essential values; some may also, themselves, be values that a health care system should pursue and implement where possible, but not at the expense of any of the essential values. Many people suggest that provider autonomy, for instance, is a value in and of itself. But if fair access cannot be assured without imposing restrictions on a provider’s freedom to choose patients, then provider autonomy may be restricted, for example, by requiring providers to see a minimum number of Medicaid enrollees or other underserved people.

In the proposed framework, provider autonomy is valued insofar as it supports the provider’s role as the patient’s zealous advocate and promotes quality of care. Daniels sees that granting providers “considerable autonomy in clinical decision making is necessary if they are to be effective as [advocates] pursuing their patient’s interests.” Further, providers’ freedom in determining (jointly with the patient) the medically acceptable and appropriate treatment—with minimum interference by government, courts, third-party payers, and administrators—fosters high-quality care.

The other instrumental values similarly promote one or more of the essential values. Consumer sovereignty fosters greater efficiency and promotes quality. When free to choose among health care plans and providers, and armed with appropriate cost and outcome data, consum-
ers could select plans based on their efficiency, quality, and services. Or
group purchasers (as consumers’ agents) could selectively contract for
specific services with particular health care institutions to obtain effi-
cient, high-quality care. The three community-oriented values—social
advocacy, personal responsibility, and social solidarity—help to temper
our excessive individualism. Adding these values, in Philip Clark’s view,
will help the current system to break out of the “narcissistic individual-
ism” that currently undermines “any meaningful public dialogue on
what the goals of [our health care system] should be and the appropriate
means for achieving them.”

The value of social solidarity is more complex and fundamental than
the proposed framework’s other instrumental values. It fosters among all
citizens a recognition of their social, political, and economic interde-
pendence, as well as a perception of shared ownership, and thereby helps
to promote a health care system holding the value of fair access preemi-

ponents. Social solidarity will help to shift U.S. health policy away from its
excessive individualism; in fact, its presence in our social value system
may be necessary for such a shift to occur. The health care systems in
Canada and West European countries are committed to universal access
in part because social solidarity undergirds their social value systems.
The value’s possible role for the United States is similar. Given the long
history of individualism in the United States, a robust social solidarity
principle may help us to establish a fairer health care system. Once
established, a strong sense of community will continue to support a
health care system that provides universal access to an adequate level of
care.

**Conclusion**

Recent health care policy—based on an excessively individualistic
values framework and driven by an overriding emphasis on cost contain-
ment—has failed to remedy the interrelated problems of inadequate
access to needed services, the high cost of health care, and the unknown
quality of services provided. To develop and implement comprehensive
and consistent health policies to address these problems, we need a new
framework of values and a commitment to take it seriously. Our society
must adopt a values framework with “a new blend of ethical priorities,”
in Richard Botelho’s words, and then place it at the forefront of health
care reform.

The proposed new U.S. values framework squarely establishes fair
access as the preeminent value; reemphasizes several neglected values;
adds several community-oriented values; and offers rules to resolve con-
flicts among competing values. This framework should serve as the
moral foundation of America’s health care system and explicitly guide health care policy. It can be a rallying point to build consensus for reform, offer a perspective for analysis, provide criteria for comparing reform proposals, and help to hold policymakers accountable.

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NOTES

2. Center for Biomedical Ethics, Rethinking Medical Morality: The Ethical Implications of Changes in Health Care Organization, Delivery, and Financing (Minneapolis: University of Minnesota, 1989).
3. L.R. Churchill, Rationing Health Care in America (South Bend, Ind.: University of Notre Dame Press, 1987).
12. Oregon’s bold reform proposal has captured the nation’s attention as the first governmental initiative to distribute limited health care resources explicitly. Oregon Health Services Commission, Prioritization of Health Services: A Report to the Governor and Legislature (Salem: Oregon Health Services Commission, 1991). The goal of Massachusetts’s Health Security Act is to provide universal access without major restructuring of the health care system. H.5210, Chapter 23 of the Acts of 1988, enacted 13 April 1988. (Primarily due to the state’s severe economic downturn since the act’s passage, implementation of most of it was postponed in 1991 for three years.) New York’s
UNY*Care proposal would radically reform the system by establishing a single-payer network, while retaining existing payers and employer-based insurance coverage. D.E. Beauchamp and R.L. Rouse, “Universal NY Health Care: A Single-Payer Strategy Linking Cost Control and Universal Access,” The New England Journal of Medicine (6 September 1990): 640–644. The 1991 health care access bill in Minnesota (passed by the legislature but vetoed by the governor) would have established a state plan to provide health care coverage for the uninsured and required all state residents to obtain coverage for at least the level of benefits provided by the state plan. Chapter 335 (House File 2, 1991). Hawaii enacted a health insurance program in 1990 for people who are not working, to complement its existing legislation mandating employer-based health insurance. Hawaii is now the only state capable of assuring universal access.

14. Whether this should include all inhabitants (including illegal aliens), all residents, or only all U.S. citizens is a thorny but unresolved issue.