



Connecting  
AMERICAN  
Values with  
HEALTH  
Reform

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With liberty and justice for all.

—The Pledge of Allegiance

# Values

## *The Beating Heart of Health Reform*

THOMAS H. MURRAY

The atmosphere was tense. Representatives of the insurance industry were huddled in one corner. The other members of the Task Force on Genetic Information and Insurance, mostly academics and consumer representatives, were bunched across the room. As chair of the task force, I was in the middle, trying to make sense of the disagreement, which was growing more intense by the minute.

Our mandate was to provide recommendations about what health insurers should and should not do with genetic information. This was the early 1990s; there wasn't much information available about an individual's genes, but the avalanche of genetic information was gathering strength. The first few pebbles had arrived recently, and ever larger ones, such as the tests for genes linked to breast and ovarian cancer, would appear soon. We had time—not a lot, but some—to plan for how private health insurers would deal with information about our genetic risks for diseases, from the rare and inexorable progression of Huntington's disease to far more common ones such as Parkinson's, diabetes, and heart disease. Health insurers were accustomed to shaping policies according to the risks people presented. If someone with cancer was like a house afire, someone with a genetic risk of cancer was a house with a smoldering pile of rags in the corner.

The standoff in that room, though, was puzzling. We asked the insurers if they believed that everyone should have access to insurance whatever their risks: Yes, they agreed, everyone should have access to insurance. So, they were in favor of universal access, right? No, they

adamantly insisted, universal access would be the death of the industry. Finally, we understood what frightened them: to insurers, universal access meant that people could sail along without any insurance coverage until the day they became ill, when they could march into the insurer's offices and demand to be covered.

That's not what we had in mind, we explained. Everyone should have to pay their fair share and, when they needed care, their health insurance would be there to cover the cost. We described it as universal *participation*. Fine, said the insurers, we can agree with that.

Among the lessons I learned from chairing the task force (including: Don't fly from England to San Francisco and expect to control a contentious meeting), one stands out for this collection of provocative essays: understanding what's at stake in a public policy debate is as vital as it can be elusive.

*Connecting American Values with Health Reform* is our effort to identify what is at stake amidst the swirling confusion of proposals for delivery systems, financing, cost control, and other details necessary for any practical reform. These details, though, are instruments carrying with them the impedimenta of history, habit, and interests. To see things afresh, it helps to return to foundational questions: What do we want health reform to accomplish? What values should our institutions and practices be built upon, embody, and achieve?

The language of values has another virtue: Unlike health policy mavens, most Americans are baffled by the alphabet soup of program acronyms, economic models, and the difference between cost-benefit and cost-effectiveness analyses. Heck, most of us can't explain the difference between Medicare and Medicaid. But we all understand what values are, and we can defend our prefer-

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Thomas H. Murray, PhD, is president of The Hastings Center.

ences among them. Which leads to another reason The Hastings Center undertook this project.

Values can be wielded like cudgels to batter your opponents. That, unfortunately, has been all too common in recent political discourse. But values worth taking seriously—including all the values addressed in this collection of essays—are far more subtle, multifaceted, and interesting ideas that can cross political boundaries. Liberty, Bruce Jennings reminds us in an echo of Isaiah Berlin's classic formulation, includes both *freedom from* and *freedom to*—and each of those meanings of liberty deserves attention in health reform. Liberty can mean the *freedom from* the imposition of a particular health plan and physicians; but it also demands a health care system that does not deny a would-be entrepreneur the *freedom to* pursue her vision, a freedom not available to the parent of a child with diabetes, for whom health insurance would be unaffordable outside the protective umbrella of a large group policy.

We chose the authors of these essays to represent a broad spectrum of beliefs. We assigned each of them a particular value to address, but we did not tell them what to say about it, other than to display the complexity residing within each value and spell out the policy implications of taking that value seriously for American health reform.

*Core American values, rather than existing in ineluctable tension with one another, form a sturdy, mutually reinforcing foundation for health reform.*

*Universal participation may be a concept whose time has finally come.*

In reading these essays, I found moments of great illumination and insight along with occasional areas of disagreement; familiar ideas displayed in new and revealing aspects; new arguments, distinctions, and concepts. I was provoked, enlightened, and occasionally surprised. I hope that other readers will have a similar experience.

Most of all, I came away convinced that values are the beating heart of health reform, that these authors have begun a marvelous conversation about those values, and that the implications for American health reform are concrete and vitally important. A handful of ideas stand out.

First, simplistic understandings of values are deceptive and harmful to private insight and public discourse. Liberty, properly understood, is not the opposite of equality; justice, not the opposite of liberty; and responsibility, both personal and social, is crucial to the full realization of liberty and justice. Efficiency, an instrumental value rather than an end in itself, is intimately related to quality, solidarity, stewardship, and justice. Core American values, rather than existing in ineluctable tension with one another, form a sturdy, mutually reinforcing foundation for health reform.

Second, when we acknowledge, as we must, that our goal is health, we are obliged to think much more broadly than our patchwork system of health *care*. Healthy children, healthy adults, and healthy communities are the outcome of many factors—from decent housing and safe areas for play and exercise to good jobs and schools. Health care, crucial for episodes of acute illness and for the care of chronic diseases, is a significant but not dominant determinant of a community's health. As responsible stewards of community resources, we should invest our finite public funds according to where they will do the most good. At times the best investment for health may be in education, job creation, or environmental protections, not in health care.

Third, the practice of individual underwriting in health insurance—making it harder to get the sicker you are—should be given a prompt funeral and buried with a stake through its heart. A concept such as actuarial fairness—which makes good moral sense in commercial insurance where risks are voluntary and the losses measured in money—has no place in deciding who gets access to the health care they need.

Fourth, efficiency and communal responsibility are essential if we are to have an affordable, effective, and sus-

tainable health care system. This will require, at a minimum, systematically studying and improving the quality and effectiveness of what we do in the name of health care. It will also require restructuring incentives so that providers are rewarded for results rather than for the numbers of procedures or tests they perform. There is good evidence that such changes would also lead to a higher quality of care.

Finally, the concept the task force developed more than fifteen years ago—universal participation—may be one whose time has finally come. The core idea is simple enough: everyone should be responsible for participating in whatever way is appropriate; when anyone needs health care that is reasonably effective and not financially ruinous, the care will be there for them. I was delighted to find the concept, if not the term, endorsed so often in these essays.

Whatever combination of private and public programs we choose, it's a good time to connect American values with American health reform. ★



**State of New Jersey**  
OFFICE OF THE GOVERNOR

I AM PLEASED to present to you The Hastings Center's volume, *Connecting American Values with Health Reform*. The issues that are analyzed in this volume are of enormous importance to New Jersey and to the United States, and they have and will continue to be of great importance to me as governor of New Jersey.

Health care policy is often described as an arena of intense partisan and ideological division. But there are also important areas of consensus that reflect agreement about some basic, core values. Health care reform will be most successful if it draws on these common values.

Both progressives and conservatives want to expand access to care. Everyone recognizes that lack of access for low-income people violates our national commitment to civil rights and that it ultimately threatens the viability of the mixed public-private health insurance system. In 2008, New Jersey passed a major expansion of our FamilyCare program to mandate health coverage of children and to provide free or subsidized health insurance to low- and middle-income families, and this bill received massive Republican and Democratic support.

Both progressives and conservatives want to contain health care costs. Progressives recognize that relentless cost increases will crowd out other social priorities and that low-income people bear the heaviest economic burden when health insurance costs compete against annual raises. I am a proud progressive, but it is because of my core principles that I know we have to act when I see New Jersey's bill for health care now having grown to almost a third of the state budget. I and my administration have worked hard to make progress on reducing health care cost growth, including significant reductions in excess hospital capacity and reforms to the insurance market.

Both progressives and conservatives want to build health care IT infrastructure and recognize that—as with interstate highways (another area of political consensus)—without government intervention, health IT will not be developed. Both progressives and conservatives understand the compelling moral and policy case for investing in prevention and not just in illness treatment.

These themes represent major common ground from which to work toward national health reform.

The essays included in this book can help to elucidate the beliefs that we share, and where disagreements over principle are more intractable. But to make progress on the areas on which we agree, we will also need to overcome the sense that health reform is a zero-sum game in which one ideology and one party can only win if the other loses. It is my hope that this volume can help us to recognize that getting health care right reflects American values.

A handwritten signature in black ink, reading "Jon S. Corzine".

**Jon S. Corzine**  
Governor  
State of New Jersey

Liberty without equality is a name  
of noble sound and squalid result.

—L.T. Hobhouse

# Liberty

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## *Free and Equal*

BRUCE JENNINGS

America is the child of John Locke, the great philosopher of liberalism and natural rights. This commonplace observation holds a key to understanding the politics of health reform in the United States. The tradition of liberalism (in the philosophical sense of the term) is still the context of our political morality, our constitutional law, and much of our public policy. Liberty is the fundamental value of American politics; not the only one, to be sure, but the fundamental one nonetheless. Liberty has been central to the ethical justification for health reform in the past, and it will continue to be in the future.

As a fundamental value in American life, liberty has several interesting characteristics. It is talked about a lot; the word itself is often used, both in political and everyday speech, but even when the word is not spoken, the idea is there. Liberty is pretty much synonymous with freedom and, in bioethics jargon, with “autonomy.” Liberty often goes incognito, its resonance embedded in other values or ideas that on the surface seem to be about something else. For instance, liberty resides in terms like privacy, choice, property, civil rights, entrepreneurialism, markets, dignity, respect, individuality. Values so ubiquitous are often taken for granted and not sufficiently scrutinized. They therefore have great political power yet are vulnerable to cynical misuse and manipulation. Liberty is

no exception, and we need to think carefully and critically about its history, meaning, and political implications.

Properly understood, liberty should be compatible with other ethical values that have often been pitted in conflict with it, such as equity. Such a conflict has been thought to arise, for example, when allowing all individuals the freedom to accumulate as much as they can undermines the capacity of the entire society to ensure that each individual receives a fair share. Why is this clash between appropriation and redistribution seen as a clash between liberty and equity? In order to set up this conflict in the first place, one must conceive of liberty as the unbridled expression of possessive individualism. But this is not the only or the most fruitful way to understand liberty. Herein lies my principal point: *progress in establishing an ethical and political justification for health reform depends on reconciling liberty and equity, at least in the arena of health affairs.* We must break out of the ideological grid that sets liberty and equity in opposition, indeed in a zero-sum relationship such that one of these values cancels out the other. The health reform conversation has to be reframed at the grass roots level so that a new way of seeing what liberty is and what it requires will grow out of that conversation. One tenet of this movement should be that equity in access to health care, reduction in group disparities in health status, and greater attention to the social determinants of the health of populations and individuals are all policy goals through which liberty will be *enhanced*, not diminished.

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**Bruce Jennings, MA**, is director of of the Center for Humans and Nature and a senior consultant at The Hastings Center. He teaches ethics at the Yale School of Public Health.

## ***Unveiling the Statue of Liberty*** by Edward Moran

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### **What Liberty Has Meant**

The history and politics of health reform is an object lesson in this regard. In the past, appeals to the value of liberty have most often been made by opponents of governmental involvement and structural change. In the street language of American politics throughout the twentieth century, the main threat to liberty was “socialism” (a.k.a. big government), and the key plank of the indictment against health reform plans, from Woodrow Wilson through Bill Clinton, was the specter of “socialized medicine.” The main ally of liberty in the same period was free market competition. Health reformers struggled (mostly in vain, it must be said) against this interpretation of liberty. They countered with an appeal to the language of rights and to the countervailing value of equality. (Equality’s aliases are equity, fairness, social justice, solidarity.)

Stepping back, we can see that health reform has been caught in the same web of dichotomies and conflicting values that have ensnared every other facet of progressive and welfare state measures during the last century. Some of the worst snarls in this intricate web are: (1) individual responsibility and choice versus social assistance; (2) market initiative and competition versus governmental regulation and bureaucratic red tape; (3) efficiency versus entitlement; (4) autonomy (rugged individualism) versus elite paternalism (Big Brother, the nanny state, father knows best); and finally, at the personal, gut level, (5) fear of losing current benefits and quality services versus guilt based on a sense of justice and concern for those excluded from the current system, especially children and the “de-

servicing” poor. I believe that we will never be able to resolve these dichotomies or untangle this web. Instead, what we need to do is to change the subject and reconceptualize the terms of these past dead-end debates.

The most recent large-scale health reform effort in the United States, during President Clinton’s first term in the early 1990s, featured each of these snarls. No doubt there are many reasons why this plan was defeated in Congress, perhaps not the least of which was that big business ultimately decided that it could get a better deal to hold down health care costs from a private managed care approach than it could from Clinton’s combination of managed competition and a global health care budget. But at the level of public opinion, the debate tended to center more around individual liberty versus social equity. A mainstay of the attack on the Clinton plan—policy experts dismissed this as obvious nonsense, but it had a

significant political effect—was the fear of losing personal liberty, and in particular, fear of losing the freedom to choose one’s own doctor and to control one’s own health care. The television advertising campaign against the Clinton plan, sponsored by a health insurance industry trade group and featuring the concerned middle-class couple Harry and Louise, focused on the loss of liberty and the erosion of quality that the plan would bring about. These professionally produced ads used the concept of liberty very artfully.

What is it about liberty that turns it into an arrow in the quiver of opponents of health reform? Is there a way to reframe it and to develop an alternative way of using it? Is there any reason to think that such a reformulation would have any traction in forthcoming political debate and the policy process? These will become increasingly important questions, I believe, in the round of health reform debate that is now beginning.



## What Liberty Should Mean

The concept of liberty has two different facets, which are usually referred to as “negative liberty” and “positive liberty.” Negative liberty is about being *free from* obstacles or constraints: it is about having freedom of choice—even the freedom to make mistakes and poor choices. Having personal security and civil rights ensures negative liberty. Positive liberty is about being *free to* have options—being enabled or empowered to make choices or realize personal goals. Having the right to freedom of speech is a negative liberty; having access to an education that gives you something thoughtful to say is a positive liberty. Positive liberty is about having others do something for or with you that gives you the opportunity to change your life or achieve your goals. In a nutshell: negative liberty is about “don’t tread on me”; positive liberty is about “I need you to help me up.”

The libertarian interpretation of liberty and the privatized market model of health care err by focusing too exclusively on the negative side of liberty. Health care is inextricably bound up with the value of liberty, not simply because it prevents illness from limiting your life decisions, but also because it enables you to use your freedom more richly, to live your life in more meaningful and worthwhile ways. Health care is not simply about preserving you from the “outside” interference of others or of disease; it is also about obtaining the active assistance of others so as to enhance the types of activities you can pursue and the kinds of relationships you can have. Thus, health care is as much about positive liberty as it is

## *Establishing an ethical and political justification for health reform depends on reconciling liberty and equity.*

about negative liberty. And what is true of *health care* is true as well of health itself, or of *health status*.

The positive, relational, and enabling side of liberty is what links it to equity. The zero-sum relationship between liberty and equity is an optical illusion that comes from an exclusive focus on negative liberty. Positive liberty is the concept that reminds us that the well-being of one individual is not a function of isolation but of context, community, and mutual interdependency. Equity is about mutual flourishing; negative liberty is about individual flourishing no matter what the condition of others; positive liberty is about the connection between individual flourishing and mutual flourishing. Positive liberty reminds us that no single individual, no matter how wealthy or powerful, can really be free except in a context of social justice and the common good.

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### ★ Policy Implications ★

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The health reform debate of the coming years will have a broader focus than past reform debates. It will not just be about acute-care health insurance reform and access to clinical, treatment-oriented medical services and technologies. Instead, it will take up the larger structural determinants of health and health promotion. The access to acute care and high technology clinical services is very important to particular individ-

uals at particular times, but such access has been shown to have little effect on population health as a whole. And even at the individual level, the most important and challenging policy goal is access to health, not merely access to clinical medical care. Building a system that generates or promotes health requires that people have access to many specific and positive aspects of their natural and social environments. Achieving greater health for the whole population—a healthier nation—will require large-scale social reform and institutional transformation. These changes point in the direction of a more global kind of equity and social justice.

The role of liberty will change in health reform debates when two things happen. First, we must see that health reform involves equitable access to the social preconditions of health, as well as to health care. Second, we must see that when anyone lacks such access, the liberty of all (not just of those who experience the inequity) is compromised. This, I believe, is where the health policy conversation is going in the years ahead, and as this shift occurs we will rethink the meaning and uses of the value of liberty in political argument. Liberty rethought can then be one of the touchstones for a democratic, grass roots movement for health reform that will demand health justice in a nation of free *and* equal persons. ★

Nothing is to be preferred before justice.

—Socrates

# Justice and Fairness

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## *Mandating Universal Participation*

PAUL T. MENZEL

Convictions about justice are a deep and persistent force in health care. It seems distinctly unjust and unfair, for example, that one victim of a disease dies or is permanently impaired and financially devastated, while another with the same disease is readily cured and lives financially unscarred.

Yet convictions about what is unjust do not necessarily steer us quickly toward universal access to basic care. Beyond political and economic self-interest, conflicts between justice and allegedly competing values like liberty may intrude. Also, there are different senses of justice itself, varying widely across the moral and political spectrum. Those who think it unjust that one person can be ruined by an illness that leaves somebody else, who has greater resources, unscathed, are looking to a relatively egalitarian sense of justice. That sense pushes toward universal access and its equitable financing. Some libertarian views of justice, on the other hand, contend that those who have no contractual or special relationship with the unlucky victim of disease—and have not themselves exacerbated her plight—have no obligation to assist her.

Despite these complications, several claims about justice and fairness may be based broadly enough in U.S. moral and political culture to guide society's debate. A case for mandated universal coverage built on seven such claims is outlined below, followed by a discussion of how such a policy embraces the values of liberty and justice.

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*Paul T. Menzel, PhD, is professor of philosophy at Pacific Lutheran University and has published widely on philosophical questions in health economics and health policy.*

### **Why Mandated Universal Coverage Is Just and Fair**

*We have already collectively decided to prevent hospitals from turning away the uninsured. In such a context, allowing insurance to remain voluntary is unfair to many of the insured. The obvious way to alleviate this unfairness is to mandate insurance.*

Since 1989, by federal law (the Emergency Treatment and Labor Act), hospitals have been prohibited from refusing acute care to those who cannot afford to pay. Consequently, \$100 billion of care is annually “cost-shifted” onto patients who can pay, almost all of whom are insured. This shift raises the average annual health insurance premium roughly \$1,000 for every insured family. Some of the uninsured are working families and young singles; when they need emergency care and get it at little cost, others who are economically similar but have chosen to insure end up invisibly footing part of the cost. Arguably, those uninsured who so benefit without bearing any share of cost are unfairly free-riding. Only two actions can avoid this: either repeal the rescue requirement on hospitals, or mandate insurance. Few support the former, so let's face the matter and mandate insurance.

*A mandate that everyone be insured is unfair unless insurance is affordable, but in any multipayer system, affordability requires both income-related subsidies and restrictions on the behavior of insurers.*

Given the cost of even basic insurance, many people of modest means who do not qualify for Medicaid cannot reasonably afford insurance without a subsidy. In addi-

tion, insurance will not be affordable for anyone who already has health conditions likely to require higher-than-average annual expenditures unless insurers are prevented from carving out their favored clientele by means of preexisting condition exclusions and “risk-rated” premiums.

*Unless insurance is mandatory, it is unfair to bar insurers from using preexisting condition exclusions, waiting periods, and risk-rated premiums.*

Feasible access to insurance for the people who most need it suffers greatly when voluntary insurance that permits the healthiest to go without coverage gets combined with wide latitude for insurer strategies to recruit optimal subscribers. The effective path to access, however, is not merely to bar insurers from using such strategies. To do so would expose them to potentially lethal economic risk (through “adverse selection”). It would also raise premiums for healthy young people, who in turn would be even less likely to insure; thus the number of uninsured might actually increase! People who want to postpone insurance, thinking its expense to be a poor bargain given their current good health, should not be allowed to pick their time to get insured. To receive benefits in times of crisis, people need to pay in all along.

*Justice between the well and the ill requires that they share most of the financial burdens of illness, as well as insurance.*

Mandating insurance together with sharply restricting insurers’ practices is not only practically necessary to achieve access. It also fundamentally aligns with justice between the ill and the well. Some principle of just sharing between them emerges from widely held convictions about the importance of assuring equality of opportunity. One attractive version of such a principle is that the financial burdens of medical misfortune ought to be shared relatively equally by well and ill alike, except when people can be reasonably expected to minimize those burdens by

their own choices—by avoiding overeating that exacerbates (or even creates) diabetes, for example. It follows that the cost of insurance should seldom depend heavily on a person’s health conditions.

*We can’t have it all: setting hard priorities among different health care services (“rationing,” if you will) is not unjust or unfair to patients who would have regarded such limits as wise and prudent prior to becoming ill.*

Everyone has reason to worry about the expenditures providers and patients will run up. Once insured—and once ill—patients will want to get and providers will want to provide all the care that has any prospect of net benefit, regardless of how small the benefit is, or how expensive its cost. Every system of insurance thus needs to police the care it provides, restricting care at the margins of (low) benefit and (high) expense. Call those limits “priority setting,” “practice guidelines,” “rationing,” or whatever: they are absolutely necessary to

control costs in a system of insured care. They are not unfair to patients just because the patient might have benefited from the marginal care withheld. If knowledgeable subscribers, in selecting insurance beforehand and having to pay for it with premiums or taxes, would have decided that such care was not worth its higher premium cost, then subscribers’ own values are the source of the limitations that define “wise and prudent” insurance.

*Justice does not require universal access to all care, but only to “basic” care. Justice can tolerate additional, more expansive tiers of health care for those who choose to pay for it with their own additional means.*

From whose perspective—the relatively wealthy subscriber, or the person of more modest means—should the decision about the boundaries of

wise and prudent insurance be made? Arguably, the person of modest means. The first demand of justice in health care is for universal access to care that has been proven effective and whose expense-to-benefit ratio is not so high that it leads thoughtful, middle-class subscribers to pull it from the package they are willing to fund. The compelling obligations of those who are well to help fund care for the sick, and of the relatively wealthy to help fund insurance for the relatively poor, stop at this line. People can continue to argue about whether health insurance should be more insulated than this from variations in affordability, but in a society committed to only modest measures of income redistribution generally, collective action will be out of balance if it guarantees everyone access to care above this line. Of course, some will wish to include greater coverage, including unproven care of highly speculative benefit. So be it: they are free to buy up to it with their

## *Justice does not require universal access to all care, but only to “basic” care.*

own devices. Keeping the package of basic care relatively lean and thus affordable to subscribers and sustainable for taxpayers will never be easy, and pressures from particular interest groups will often need to be resisted.

*Financing insurance through the current taxable income exclusion for employer-paid premiums is highly regressive and hardly just. If purchased insurance continues to play a major role in health care, a less regressive, fairer subsidy for access is required.*

Currently, roughly half the population is insured through employer-sponsored plans, whose premiums are excluded from the employee’s taxable income. This roughly 40 percent tax subsidy (when the employer’s and employee’s FICA and Medicare taxes are included) is distinctly regressive, benefiting those in the higher tax brackets the most. Such a structure

for the society's primary incentive for purchasing insurance is hardly fair. A second questionable aspect is the subsidy's lack of any limit on the premiums excluded; cost control in health care is thus discouraged, and general affordability aggravated further. Even if health insurance remains significantly based in individual or employer subscription, a capped tax credit is fairer. It would also likely be more effective in persuading lower-income employees and low-payroll employers to insure.

### How Mandated Universal Coverage Supports Liberty

Some claim that individual liberty and responsibility conflict with both universal access and any form of mandatory or societal insurance. Mandating insurance may be just and fair, but it certainly appears to limit liberty, and whatever relatively uniform level of "basic care" is used to define universal access rides roughshod over the often very different views individuals have about what health services merit funding. The challenge in countering such a view is to consider liberty in its fuller context, as bound up with responsibility—where both are connected to justice and fairness:

- Lack of access to basic care severely undermines people's ability to be responsible for themselves and their families. Untreated illness has this effect, and so does the financial hardship (even bankruptcy) often caused by uninsured medical expenses.

- The prevention of unfair free-riding—a driving force behind the move to mandatory insurance—is itself based in the value of individual responsibility: no one should get to ride the system without contributing to its upkeep.
- The principle of just sharing between the well and the ill is key to the argument for universal access to basic care, but it is grounded on convictions about equal opportunity for human well-being. That focus of justice on equal *opportunity*, not on equal well-being itself, inherently includes liberty and responsibility. The enterprise of achieving justice is therefore not a matter of "leveling," but of expanding and energizing.
- Even limitations on covered services—that curse of health care politics, "rationing"—may at bottom be tied to the concept of liberty, insofar as these limitations reflect our liberty as citizens to determine what and how much will be spent on health care, using *our* values.

Arguments for universal access and mandatory insurance that invoke justice and fairness can thus be based in fundamentally liberty-friendly values. There is broader room for moral and political agreement than at first meets the eye.

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### ★ Policy Implications ★

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- Insurance for basic care must—at least eventually—be mandatory and universal.
- If the system retains employer or individual premiums, they must not be significantly higher for people who are likely to be chronically ill than for those who are likely to be well.
- Guaranteed, universal access should be to a limited scope of care that is of proven effectiveness and reasonable cost-effectiveness. Costs must be controlled, even if this requires setting priorities and excluding some kinds of care. People should be at liberty, however, to buy more inclusive insurance.
- Both single- and multipayer systems can be just. Any multipayer system will have to set a common framework for basic insurance and sharply restrict insurers' efforts to recruit the most profitable subscribers. Financial incentives should promote fair competition both among private insurers and between private and public insurance.
- The current tax subsidy for private insurance—the uncapped exclusion of employer sponsored premiums from taxable income—should be changed to a subsidy that is less regressive and more effective at controlling costs. ★

Man is condemned to be free; because  
once thrown into the world, he is responsible  
for everything he does.

—Jean-Paul Sartre

# Responsibility

## *Shane and Joe*

JIM SABIN

**W**e in the United States are deeply committed to “responsibility” as a core American value. Being responsible and taking responsibility are good. Being irresponsible is bad. But “responsibility” means very different things to different people. As a result, calling for “responsibility” in U.S. public discourse is like waving a red flag at a convention of bulls—it elicits passion, rancor, and disorderly conflict.

There’s no better place to go to understand the two main ways Americans take responsibility as a guiding value than the movies, especially westerns. Take the 1953 classic, *Shane*, in which little Joey Starrett is torn between two icons of responsibility—his father, Joe, the homesteader, and Shane, the mysterious gunslinger cowboy. Joe and Shane embody the two poles of responsibility in U.S. moral discourse.

Joe exemplifies responsibility as social solidarity—building a caring community that takes responsibility for the welfare of its members. Joe is committed to farm, family, and his nascent frontier town. For homesteaders like Joe, the emblem of responsibility is barn-

raising, a ceremony in which the community joins together to help individuals meet a basic need.

Shane exemplifies responsibility as individual action—making your own choices, doing what has to be done, and doing it on your own. For cowboys like Shane, the emblem of responsibility is the six-gun and the self-reliance and strength that comes from skill at knowing when and how to use one.

These contrasting images of what responsibility means—communal barn-raising versus individualistic cowboy gunslinging—lie behind the current competing

*Values come from the gut, not the mind.  
Our visceral responses to the values that  
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health care reform proposals. They are also the source of some of the passion, rancor, and disorderly conflict we have seen in our ineffectual previous efforts at health care reform.

Our love affair with the myth of the heroic cowboy enhances the attractiveness of market-based reform proposals. But in place of

the cowboy, market proposals envision a heroically empowered “consumer.” This swaggerer is armed with confidence, information, and choices when striding into the health care “marketplace” to make prudent “purchases” of high-quality, low-cost health care. The consumer enforces change via purchasing power and the invisible hand of the market, not a six-gun. Some of the intuitive emotional appeal of reform proposals that depend on competitive

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**Torn between two models of responsibility.** Left to right: Brandon de Wilde as Joey, Van Heflin as Joe Starrett, and Alan Ladd as Shane.

market forces comes from our cultural ego ideal of the self-reliant cowboy, who is always prepared to put “skin into the game” of life.

We can also discern the high value we place on heroic cowboys like Shane in the language of obituaries. The dead person is extolled for having “fought a brave battle” against an illness that ultimately prevailed. An old joke speaks to the worldview behind all our talk about fight: In India, death is a potential step away from reincarnation and toward Nirvana. In Europe, death is an existential tragedy we all must face. In the United States, death is optional. When I was growing up, boys were taught that only sissies give up a fight. That macho approach to life may be well suited to trench warfare, but its usefulness as a guide for health care reform is limited.

### Good Guys and Bad Guys

Proposals that emphasize universal coverage—like the single-payer plan—are enhanced by our beloved myth of social solidarity in an Edenic, barn-raising frontier. Building on the vision of a caring community that joins forces, the single-payer plan envisions a society that pools its resources to minister to the health care needs of the individual. The energy for change comes from social cooper-

ation—citizens contribute funds via their taxes to allow patients and clinicians to collaborate on behalf of health.

Like westerns, health care reform proposals envision villains as well as good guys. In *Shane*, the bad guys are ranchers and their hired thugs. For market proposals, the bad guys are the demanding, entitled individuals—free-riders who expect others to satisfy their expensive tastes in health care, but who are unwilling to take responsibility by putting any of their own financial skin into the game. For single-payer proposals, the bad guys are insurers who siphon money away from health care and into corporate profits and executive pay packages.

These are wildly oversimplified cartoon images of our major health care reform proposals. But values come from the gut, not the mind, and the gut is not a sophisticated thinker about the nuances of alternative policy options. In addition to the logic and facts on which competing proposals are based—and the vested interests that support and oppose the different options—our visceral responses to the values they embody are a significant part of what attaches us to the policies we favor and sets us against competing options.

In 1993, during the Clinton health care reform process—and forty years after Joey mournfully

called “Shane! Come back!” at the end of the film—two new icons entered the U.S. health care reform dialogue—Harry and Louise. In one advertisement, Harry and Louise are sitting at their kitchen table. In the background an ominous voice says “the government may force us to pick from a few health care plans designed by government bureaucrats.” Harry and Louise agree—“Having choices we don’t like is no choice at all. They choose. We lose.” In another, Harry asks Louise about the insurance practice of community rating. She replies disapprovingly, “Everyone pays the same rate, no matter their age, even if they smoke or whatever.” Their friend Pat reports that his health insurance costs more than doubled with community rating—treating everyone the same was a disaster for his community. Harry is shocked—“Congress can do better than that!”

Harry and Louise put nails into the coffin of the Clinton health reform proposal. Their power came from looking like ordinary Americans and drawing on core American values. They invoked an intrusive nanny state that imposes limited choices on the population and takes away the opportunity to chart one’s independent path in life. The attack on community rating raises the specter of people who refuse to take responsibility for their own choices (“smoking or whatever”) or for the embarrassing fact that they’ve become old and costly. Like Shane, Harry and Louise want individuals to be “free” to make their own choices and to take responsibility for any burdens their health care needs place on others.

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## ★ Policy Implications ★

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One reason the Massachusetts health care reform plan has attracted so much attention nationally is the way it addresses the deeply rooted American standoff between the proponents of individual responsibility (Shane) and societal responsibility (Joe Starrett). The architects of the Massachusetts plan like to point out that it requires everyone to take responsibility. Individuals are required to purchase health insurance but are free to choose among a large number of private (“nongovernment”) plans. Employers are required to contribute. The state is required to pay for those too poor to buy their own insurance.

Nobody loves the Massachusetts plan—it is too awkward and complex to be lovable. Libertarians hate the individual mandate. Single-payer advocates hate the failure to create a

public plan that covers everyone. But it threads its way through the minefield of competing values well enough to be acceptable to a substantial majority and to evade the accusation of being “socialized medicine.” At this point, the opposition is too small and too divided to undermine public support.

Much like the Massachusetts plan, the ostensibly oxymoronic political philosophy of “libertarian paternalism” (described recently by Richard Thaler and Cass Sunstein in their book *Nudge*) seeks to bridge the gap between those who make individual freedom the top value and those who put the social good into first place. Libertarian paternalists favor policies that engineer choice in ways that influence people’s behavior without closing off their options. In health care, libertarian paternalists would support tobacco taxes (nudging me not to smoke but still giving me the

choice) and tiered pharmacy benefits (letting me get the pricier, branded drug if I wish, but forcing me to pay more). In principle, a libertarian paternalist could support the Massachusetts mandate for individually purchased insurance because those who object to the mandate can pay the tax penalty alternative instead, and those who follow it can choose their insurance from a long list of options.

In his inauguration speech, President Obama invoked responsibility as a major theme—“What is required of us now is a new era of responsibility—a recognition, on the part of every American, that we have duties to ourselves, our nation and the world.” It sounds as if the president wants to side with both Shane and Joe Starrett. That’s a direction our forthcoming health care reform policy debate should take. ★

We must all hang together or assuredly  
we shall all hang separately.

—Benjamin Franklin

# Solidarity

## *Unfashionable, But Still American*

WILLIAM M. SAGE

Illness, we are often told, is a private matter. Accordingly, none must interfere in the medical decisions that emerge from the confidential relationship between physician and patient. Yet evidence of interdependence is ubiquitous in health care. One person's malady can harm families, workplaces, clubs, churches, and sometimes entire communities. Similarly, a suffering patient must rely on many individuals, associational groups, corporate entities, and government agencies for support and assistance. It is, therefore, unsurprising that various social units claim an interest and a voice in maintaining health and treating disease.

However, explicit solidarity has long been out of vogue in America's value system, despite persistent lack of affordable medical care. Instead, the public has prized scientific innovation, consumer sovereignty, and personal autonomy, and has installed physicians as benevolent oligarchs to oversee these functions. The resulting system delivers idiosyncratic care at enormous expense to most Americans, while a sizable minority often goes without.

Calls for solidarity in American health care reach receptive ears mainly when spoken in fear—recently of pandemic disease, bioterrorism, and natural disaster. Although crisis is a perpetual and therefore meaningless adjective in health policy debates, calamity seems to breed togetherness. Foxholes tend to convert libertarians into communitarians as well as atheists into believers. Special

concern is provoked by novel pathogens, runaway technologies, and random, large-scale events.

The economic downturn, with its emerging consensus that something must be done to universalize the U.S. health care system, presents an unexpected opportunity to revisit health solidarity. Whether hard economic times are sufficiently calamitous to become a unifying force remains to be seen. If so, we should be grateful that the streets are littered merely with dead businesses, not with dead bodies, and that toxic assets rather than toxic agents are responsible.

Beyond these base emotions, one can identify three sources of solidarity that reflect American society's better nature. I shall call them mutual assistance, patriotism, and coordinated investment.

### **Mutual Assistance**

Mutual assistance rooted in both compassion and expectation of reciprocity accounts for the bulk of U.S. health solidarity. Misfortune attributable to chance or resulting inevitably from the passage of time—not temptation or moral failing—typically triggers collective support to prevent avoidable deaths, ameliorate suffering, and save victims' families from impoverishment.

Sharing the financial risk of poor health can be accomplished through processes of varying formality, ranging from charitable campaigns (such as donations to hospitals) to means-tested entitlements (Medicaid) to full-blown social insurance (Medicare Part A). These efforts openly redistribute wealth but greatly assist recipients

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and, at least for voluntary charity, enhance the well-being of donors. Health is a natural area for mutual aid because those contributing believe that those receiving aid are seriously ill and thus have no higher use for resources than medical care. This mitigates concerns that aid might discourage self-help and promote welfare dependency. Mutual assistance is strongest when donors can identify with potential beneficiaries; nations with the most generous social insurance programs tend to be those that are demographically homogeneous.

Mutual assistance occurs in private health insurance as well as public programs. Group rates for employment-based coverage redistribute resources from healthier to sicker members of workplace risk pools. Americans readily accept this mode of mutual support because they identify with fellow workers. It is undoubtedly made more palatable by the selective subsidy awarded employee benefit plans under the federal tax code, by lack of transparency regarding the magnitude of the transfer, and by the widely credited fiction that the money involved is the employer's rather than the employees'.

Similarly, Americans routinely empower health care providers to make decisions about how to distribute shared resources because they can imagine lives being saved. A seldom-noted aspect of the backlash against managed care derived from perceptions that HMOs were converting otherwise acceptable cross-subsidies into corporate profits and thereby depriving the health care system of needed funds. Historically, physicians charged higher fees to wealthy patients and offered free service to poor ones, a practice that eventually yielded to the bureaucratic constraints of government programs and lack of equal charity from suppliers of necessary diagnostic and therapeutic complements. Nonprofit hospitals continue to redistribute in this fashion, reflecting the social mission assigned them by their constituents and the insistence of the taxing authorities

that charity care should be the touchstone for “community benefit.”

### **Patriotism**

**P**atriotism is a less common source of interconnectedness in American health care. America's commitment to tolerance and liberal pluralism is very effective at creating associational groups with shared values, which in health care spawns agendas as diverse as those of the American Cancer Society, the Hemlock Society, Physicians for Human Rights, and the Association of American Physicians and Surgeons. But it is not very effective at motivating large national projects during peacetime.

*The severity of the economic downturn—and the aggressive response it has provoked—creates an opportunity to overcome entrenched political positions and recalibrate public values in support of solidarity.*

Building loyalty to centralized governments, fostering political stability, and avoiding class warfare—the conventional explanations for the welfare states of Western Europe—seem unnecessary given our long-standing federal union, our melting-pot heritage, and our belief that continued upward mobility serves as a social safety valve. Even in post-cold war America, compulsory redistribution to achieve explicit ideological goals of equality in health care access sounds disturbingly Soviet (“from each according to his ability, to each according to his need”). Accusations of “socialized medicine,” most recently hurled by former New York City Mayor Rudy Giuliani during his brief 2008 presidential campaign, retain rhetorical impact because we continue to fear state intrusion into intimate personal and family decisions.

America's preference for low taxation further discourages a collectivist political orientation. Proposals for government to assume responsibility

for health care are widely perceived as fiscal power plays—schemes not only to raise revenue, but also to divert private spending on health into other, unspecified government projects. Many Americans suspect that the inevitable result would be reduced investment in facilities and innovation, quality reductions, supply constraints, and rationing. These concerns are reinforced by the American medical profession—a grass roots army of talented small businesspeople who, with fierce conviction if little historical justification, continue to construe their social prominence and financial success as the result of rugged individualism rather than

sheltered competition and lavish public subsidy.

Nevertheless, patriotism partially motivates several core features in the U. S. health care system. Those who render military service to the nation are repaid in part with health care: the Veterans Health Administration is the largest component of the Department of Veterans Affairs and provides lifetime benefits to millions of individuals. The enactment of Medicare can be viewed similarly, as health security to compensate generations of Americans who worked through two world wars and the Great Depression and who became old and infirm during the sustained period of peace and prosperity that followed. As evidenced by the temporal connection between Medicaid and the civil rights movement, patriotism to redress prior regional and national discrimination can also generate health solidarity.

## Coordinated Investment

A third source of health solidarity is a loosely organized but potentially powerful array of coordinated investments that Americans can make to safeguard and advance their futures. The objective of these activities is to increase overall welfare, not to define citizenship or to redistribute resources from better- to worse-off. Traditional public health functions fall into this category. Epidemics and disasters generate widespread willingness both to contribute funds and to submit to physical restrictions in order to prevent additional physical harm and to keep critical infrastructure functioning.

Equally important is reducing spillover economic harm through prevention and control of noncommunicable chronic diseases—many of which derive from smoking, poor nutrition, and lack of physical activity. Unconstrained government spending on chronic disease crowds out other productive uses of public funds. The burden of chronic disease also diminishes both near-term workplace productivity and long-term prospects for overall economic growth. This collective project is a more controversial exercise of government authority because, at first glance, interventions appear aimed at protecting individuals from the consequences of their own conduct rather than someone else's. However, research on social networking reveals that many chronic health conditions are “communicable” through shared norms, and that improved design of workplaces, schools, and communities can alter common environments and reduce risk factors.

The production of medical knowledge as a public good is another established form of coordinated investment, as is support for hospital construction, education of health professionals, and patenting of biomedical technology (at least following the enactment in 1980 of the Bayh-Dole Act, which encouraged commercialization of publicly sup-

ported research). Surprisingly, far fewer resources have been directed at improving the productivity of health care providers on the assumption that professional self-governance and market discipline are sufficient to generate and disseminate best practices. Recently, however, policy-makers have come to understand that decades of regulation and subsidy have artificially fragmented health care delivery and rewarded unproductive behavior, rekindling interest in public support for health informatics and comparative effectiveness research.

A final, widely accepted justification for coordinated investment in health care is the elimination of waste. Reducing “waste, fraud, and abuse” in Medicare has maintained universal political appeal for decades while, unfortunately, providing little actual relief from persistent growth in expenditures. Today's proponents of tax-financed universal health coverage argue, somewhat more persuasively, that leaving a large percentage of the U.S. population uninsured reduces access to cost-effective primary care, wastes expensive emergency services, and misses opportunities to prevent, detect, and offer timely treatment for disease. In Texas, for example, the most marketable argument for health reform among the general public is that roughly \$1,500 of the annual premium paid by each insured family is spent on care for the uninsured. The risk of this approach, of course, is that voter sentiment could turn from “please spend my money more wisely” to “please give me my money back.”

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### ★ Policy Implications ★

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Many strands of social solidarity exist in American health policy, even if an explicit commitment to universal health coverage continues to elude us. The severity of the economic downturn—and the aggressive response it has provoked—create an opportunity to overcome entrenched

political positions and recalibrate public values in support of solidarity. In my view, however, three barriers must be removed in order to create a more accessible, affordable, and productive health care system.

First, federal fiscal politics cannot continue to impede collective investment in restructuring health care—an investment that will almost certainly have a large long-term payoff. In addition to funding the marginal costs of expanding coverage, the trillion dollars or so that have been committed as economic stimulus can provide the activation energy (in both knowledge and infrastructure) necessary to transition the health care delivery system to a new, more efficient equilibrium.

Second, “medical individualism” cannot be allowed to paralyze the debate. Americans have built a mental wall between supporting aggregate change and resisting personal change that entrenched interests exploit by portraying every serious reform proposal as a threat to one's own care or the care of one's family. Effective reform must connect individual services to population health at as many junctures as possible.

Third, health is a major component of America's long-term creditworthiness and prosperity in both our public and private sectors. Industry stakeholders must accept that those who receive government support in these difficult times cannot merely continue business as usual, and the general public must agree that the stakes justify shared sacrifice and require sustained commitment to a common purpose. ★

Knowledge is limited, whereas  
imagination embraces the entire world, stimulating  
progress, giving birth to evolution.

—Albert Einstein

# Medical Progress

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## *Unintended Consequences*

DANIEL CALLAHAN

Writing in 1780 to his friend Joseph Priestly, the British scientist, Benjamin Franklin said that with an increase in the “power of man over matter, . . . All diseases may be prevented or cured, not excepting that of old age.” The great American Revolutionary War physician, Benjamin Rush, was no less utopian in prophesying that there will someday be a “knowledge of antidotes to those diseases that are thought to be incurable.”

A powerful faith in science as a basic human value, matched by an equally strong belief in medical progress, has been a central feature of American culture from the start. Although medical research was slow in gaining momentum, by the second half of the nineteenth century it was well under way, and it moved forward thereafter at a rapid pace. The establishment of the National Institutes of Health just before World War II, and its steady growth since then, has been a testimony to an unprecedented congressional bipartisanship and public enthusiasm. Some 80 percent of Americans say they support medical research as a high-priority national goal, and the NIH’s \$28 billion annual budget shows it.

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The fruits of medical progress—and its first cousin, technological innovation—are not hard to discern. From the near-conquest of infectious diseases by means of vaccines, antibiotics, and antivirals, to a reduction of deaths from heart disease and many other lethal diseases and a resulting increase in life expectancy for almost everyone, it is a faith that has been well rewarded. We are as a nation healthier and more prosperous because of it.

Yet it has been, as a value, remarkably little explored, as if its patent benefits put it beyond all inquiry. Any ethical interest has focused almost exclusively on byproducts of the drive for progress, such as human subject protection in clinical trials and, lately, the use

of embryos for research purposes. Given the massive role of research as part of our economic, medical, and political life, there is a good deal more that can be said about the value of progress as a whole, and a number of issues worth some intense inquiry. Five that have policy implications have caught my eye.

There is, first, the role of research and technological innovation as a main driver of health care costs. Any number of economic studies and the Congressional Budget Office have identified either new technologies or the intensified use of older ones as responsible for about 50 percent of annual cost increases, now averaging an unsustainable 7 percent a year. Our technological benefit is

turning into our economic bane. Though only a minority of medical technologies have been assessed for efficacy and a good cost-benefit ratio, they are the front line of American health care: doctors are trained and well paid to use them, industry makes billions of dollars selling them (and resists any cost controls), and the public loves and expects them. There is, moreover, a profound ambivalence among many economists about technology. They recognize it as the leading economic problem for American health care, but they are fearful of any moves that might harm technological innovation.

There is, second, the comparative role of medical care and background social conditions in improving health. Any number of technical estimates over the years trace some 60 percent of improvements in health status to socioeconomic factors, particularly education and income. Medical care, then, accounts for no more than 40 percent in general—though the health status of the elderly is an exception, and medical technology in particular accounts for their improved health in recent decades. One could make a good case that improvements in education and job creation could be a better use of limited funds than better medical care. Social and economic progress may be the kind we most need, and that kind of progress would have double and even triple benefits beyond improved health; a good education, for example, improves both individual health and the economic well-being of society.

Third, if throwing technology at illness in the name of progress is an increasingly expensive and economically destructive way to go, what might a more sensible idea of progress be? My vote would be to aim for a better balance between cure-oriented and care-oriented medicine. The emergence of chronic disease as the most difficult and expensive kind to manage is demonstrating the failure of cure-oriented medicine to do away with the nation's major killers,

which are heart disease and cancer. Patients must now learn, with medical help, how to live with and probably die with their condition. By “care-oriented medicine,” I mean not just good palliative care, but well-coordinated medical assistance to manage disease, further coordinated with social and family help.

Fourth, much has been made for years of the power of disease prevention as the best way to save money, to save lives, and to improve our health. Those are at best half-truths. In the end, sickness and death can be forestalled but not conquered, the costs deferred but not eliminated. The only likely way to assure a good outcome for prevention programs is to make clear to the public that high-cost technologies will be severely limited when the final illness arrives. The carrot is that prevention will give us a longer life with a higher quality. The stick will be the message that you should take care of yourself and not expect medicine to save you when your time runs out—that is no longer an option.

Fifth, Americans already live, on average, a long life of seventy-seven years. There is no need to go out of our way to chase life extension, or the denial of death, as the sine qua non of medical progress. We need progress in removing the health disparities that keep millions from reaching seventy-seven, in reducing the social and economic burden of disease, and in coping with newly emergent conditions (like obesity and asthma in children) and medical threats (such as antibiotic resistance). The NIH has always given priority to the most lethal diseases, with heart disease at the top of the list. Increasingly, I would argue, our priority should be the (now) slow way those diseases kill us, as well as the diseases and conditions that don't kill us (or not quickly) but make life a misery. Poor mental health, severe arthritis, frailty in the old, deafness and vision impairment, and Parkinson's and Alzheimer's disease fall into that latter category.

I mention, finally, two other places where progress is needed. One of them is to change the ratio of primary care physicians to subspecialists. Our ratio is now sliding below 20 percent for the former and rising to close to 80 percent for the latter. A failure to change that ratio (it is 50/50 in Europe) will make it almost impossible to pursue the new goals I have identified. The other is to bring the drug and device industries under greater economic and medical control. Their idea of progress is an expensive pill or device that will meet medical needs, and—via the route of medicalizing every seen and unseen ache, pain, and travail—turn all desires for surcease into insistent needs.

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### ★ Policy Implications ★

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The pursuit of progress in health care has led to an unsustainable rise in health care costs without a corresponding or equitable increase in health benefits. Reexamining its effects should lead to a realignment in the way progress is valued and to accompanying shifts in policy. We should adopt policies that promote care-oriented rather than cure-oriented medicine; changing the ratio of primary care physicians to subspecialists is one important step we could take in this direction. Further, we should address social and economic issues, both as an alternative way of promoting health throughout the lifespan and to achieve broader personal and societal well-being.

Serious progress would mean turning back the clock: learning to take care of ourselves, to tolerate some degree of discomfort, to accept the reality of aging and death (not to mention the near-death experience of erectile dysfunction), and to see our personal doctor as someone as likely to talk with us as to have us scanned. That cluster of backward-looking ideas is what I think of as commonsense, affordable progress. ★

There is a sacred realm of privacy for every man and woman where he makes his choices and decisions—a realm of his own essential rights and liberties into which the law, generally speaking, must not intrude.

—Geoffrey Fisher, Archbishop of Canterbury

# Privacy

## *Rethinking Health Information Technology and Informed Consent*

LAWRENCE O. GOSTIN

Above all values, Americans prize freedom—the right of individuals to control all aspects of their lives, including the personal and the economic. In many ways, both major political parties embrace individual freedom, with Democrats stressing personal freedom and Republicans economic liberty. What is often absent in political discourse around freedom, however, is the common good and an appreciation of when rigid adherence to individualism is inimical to collective welfare.

A core American value—privacy—is closely linked to freedom and clearly illustrates the tensions between the individual good and the collective good. Privacy is a foundational individual good that respects personal dignity and protects patients from embarrassment, stigma, and discrimination. Privacy is also a collective good that has societal value because it encourages individuals to participate in socially desirable activities such as biomedical research, health care quality assurance, and public health surveillance and response. Taken too far, however, privacy can seriously harm activities necessary for the public good. Privacy relating to medical records, for example, encourages individuals to access treatment and

participate in research. However, if taken too far, it can thwart valuable societal activities such as quality assurance, cost-effectiveness studies, and epidemiological research if essential data are withheld from clinicians, risk managers, and researchers.

The prevailing model of privacy, both as formulated in theory and as enshrined in national policy, is doubly harmful. This model purports to safeguard privacy but actually fails to fully protect personal health information. At the same time, it significantly undermines socially valuable activities. President Obama's stimulus package, the American Recovery and Reinvestment Act (ARRA), authorizes \$20 billion for health information technology, which is a cornerstone of the president's health care reform proposals. Unfortunately, ARRA and accompanying health care reform proposals do little to change the current privacy paradigm and, if anything, reinforce its flaws.

### Privacy and Consent

With regard to health information, the most well-accepted definition of privacy is the right of individuals to control the collection, use, and disclosure of their personal medical information. Thus, individuals retain the right to strictly limit others' access to their personal data. Many scholars and policy-makers even assert that

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patients “own” everything to do with their body, including human tissue, DNA, future cell lines, and personal medical records.

The way modern laws and regulations assure these entitlements is to grant patients a right to fully informed consent. The Health Insurance Portability and Accountability Act, for example, adopts this model by giving patients the right to authorize most uses of their personally identifiable data.

Granting this right certainly makes sense when the data are to be used for purposes detrimental to the individual and society, such as discrimination in health care, employment, or insurance. However, it makes much less sense when each individual has the power to withhold information needed to achieve com-

protected. Instead of relying chiefly on strict individual control of data by means of informed consent, it would erect meaningful privacy and security safeguards.

### **The Failure of Consent**

**A**lthough consent is a dominant theme in law and ethics, in practice it fails to adequately protect personal privacy and is detrimental to valuable social activities. Multiple studies have demonstrated that patients do not read or understand complex privacy notices and consent forms, which are mostly designed to shield institutions from liability. Patients are also often asked to give consent when they are sick and incapable of making complicated decisions.

*The prevailing model of privacy fails to fully protect personal health information and significantly undermines socially valuable activities.*

elling public goods such as quality assurance, cost-effectiveness studies, medical records research, and public health investigations—even when potential harms to the individual are negligible.

I propose an entirely different conception of privacy. Privacy should be understood as an individual’s interest in avoiding embarrassing or harmful disclosures of personal information, while not significantly limiting equally valuable activities for the public’s health, safety, and welfare. This conception allows that individuals have an interest in limiting access to personal data sought by insurers, employers, commercial marketers, and family or friends. But they would have a much-reduced interest in limiting the access of those engaged in highly beneficial, well-defined activities for the public’s welfare.

This would require a fundamental shift in the way in which privacy is

This means that consent is a poorly designed tool to prevent the most common causes of privacy invasion. Most professionals who access medical records—such as health care workers, health plan administrators, and lab technicians—are already authorized to do so. At the same time, many of the most visible and worrying privacy invasions occur due to security breaches, such as when data are left on laptops or databases with inadequate security.

Relying heavily on consent rather than on strong privacy and security assurances shifts the focus from meaningful safeguards to conceptual and often toothless ones. It provides patients with few real choices and burdens the health system with a new level of bureaucracy and expense. Furthermore, the prevailing model fails to safeguard personal health information both because it leaves gaps and because it is inconsistent.

The gaps in federal regulation leave many patients without protection against privacy invasions. Consider the “HIPAA Privacy Rule,” which regulates “protected health information” held by “covered entities” such as health plans and health care providers. Personal data held by many entities that are not covered, such as pharmaceutical companies, remain unregulated. At the same time, the “Common Rule,” which regulates human subjects research, applies principally to investigations supported by the federal government. Research carried out with private funding is often unregulated. This is in sharp contrast to most other countries, in which privacy regulations are not limited to particular health care transactions or funding sources, but instead apply to all health data.

Federal regulation and oversight of privacy is also inconsistent because of the marked and confusing differences between the Privacy and Common Rules. The standards for future consent, anonymized data, and recruiting patients vary under the two rules, leading to contrary results. There is no ethically principled reason for this patchwork of regulation.

### **Undermining Socially Beneficial Activities**

**A** primary focus on consent is also harmful to the social good. Investigators report a diminished ability to recruit participants, obstacles in accessing stored tissue and genetic datasets, and increased complexity in IRB procedures, causing some hospitals and physicians to opt out of research. A universal requirement for consent, moreover, creates selection bias, which significantly limits the generalizability of results and leads to invalid conclusions.

Rigid understandings of privacy also hamper quality assurance and public health activities. There is a lack of clarity about whether privacy and research regulations apply to these vital activities. As a result, clinics, hospitals, and public health agen-

cies feel highly constrained when they seek access to or use personally identifiable health records.

The prevailing conceptualization of privacy as synonymous with strict individual control also defies common sense. We all have our own pet likes and dislikes, which is fine if each decision only affects the individual making it. However, allowing each person to make her own decisions in ways that disrupt the common good causes a deep social problem. Think of the consequences of granting individuals a virtual veto over each and every proposed use of their personal information for the foreseeable future. A patient might say, for example, that her information can be used for research on heart disease but not for research on AIDS or STDs. This effectively thwarts a great deal of health services research, and the same could be said for databases used for quality improvement or public health.

The perverse effects of privacy rules make life more difficult for investigators, physicians, and agency officials charged with carrying out research and public health activities. They undermine equally compelling individual and societal goods: scientific discovery, medical innovation, cost-effective health care, and methods of prevention that confront the

nation's most pressing health problems. These are critical if health care reform is to succeed.

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★ Policy Implications ★

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What is urgently needed is a bold approach that would make federal regulations more effective in safeguarding privacy, more uniform and fairer in application, and less likely to impede socially beneficial activities. A new framework to the oversight of health records would emphasize data security, privacy, transparency, and accountability. Mandated security would include state-of-the-art systems with secure sign-on, encryption, and audit trails. Privacy safeguards would require that data be used only for well-defined and legitimate public purposes, with strict penalties for harmful disclosures. Security and privacy procedures would have to be transparent and actors held fully accountable. By focusing on fair informational practices, patients would gain strong privacy protection, with the assurance that their personal information would not be disclosed to their detriment and that data would be protected against security breaches.

To achieve public confidence, the new system would require careful ethical oversight focusing on mea-

sures to protect data privacy and security, harms that could result from data disclosure, and the potential public benefits. An alternative framework could also include a certification for entities that undertake large-scale data collection for defined health purposes or to link data from multiple sources for the purpose of providing more complete, anonymized datasets. Federal monitoring and enforcement would ensure regulatory compliance, and legal sanctions would prohibit unauthorized attempts to make donors of anonymized data identifiable again.

Information technology certainly will be a key component of national health care reform, but it will fail unless policy-makers safeguard privacy and facilitate responsible research, quality assurance, and public health. President Obama wants to achieve both cost-effective health care and strict privacy. But the stimulus package and his health care reform proposals do little to resolve the fundamental flaws of an antiquated model for safeguarding privacy. The success of health reform depends upon our ability to develop as rapidly and completely as possible our understanding of what works in health care, and an awareness that a false sense of privacy works against that urgent need.★

Try to become not a man of success, but  
try rather to become a man of value.

—Albert Einstein

# Physician Integrity

## *Why It Is Inviolable*

EDMUND D. PELLEGRINO

To deem itself civilized, a society must protect the personal integrity of its citizens. Without such protection, the integrity of the society itself unravels as more and more effort goes into protecting individuals against the chicanery of their fellow citizens. Perhaps this is why Plato called integrity “the goodness of the ordinary citizen.”

If integrity is the characteristic value for the ordinary citizen, then it’s even more important for those whose social roles are defined primarily in terms of personal trust—doctors, lawyers, ministers, and teachers. Ordinary citizens cannot be healed—or provided with advocacy, spiritual counsel, or learning—without trust in these helping professions. (Unfortunately, history recounts how some physicians in every age have failed in the trustworthiness integral to medicine.) When such professions lack integrity, those who need their services will seek to protect themselves by assuring greater individual or public control over their relationships with these professions.

For a variety of reasons, this is what is happening in medicine in today’s complex societies—especially now that medicine’s power to alter human life is unprecedented. The result is that the center of gravity for individual decisions has shifted sharply away from the physician to the patient. That power shift has been reinforced in law

(witness the burgeoning of malpractice lawsuits and insurance) and public policy as well. However, one may rightly ask: Is the good of the patient better served when he takes charge and directs his own care, or does the erosion of trust in the physician’s integrity put the patient in danger of being morally abandoned by the physician?

I contend that autonomy gives patients the moral right to reject care and protects their human dignity, but that patient autonomy need not interfere with the integrity of the physician—*unless* that right is expanded in such a way that patients can demand and even direct the details of clinical care. But if autonomy is understood as a right to demand care, it not only violates the integrity of the physician, it also endangers the care of the patient. For the benefit of both patient and doctor, patient autonomy must be understood in such a way that it can coexist with physician integrity.

### **The Nature of Integrity**

Classically, personal integrity has been understood as a person’s commitment to live a moral life. The woman or man of integrity is honest, reliable, and without hypocrisy. He will admit mistakes, be remorseful, and accept the guilt that follows wrongdoing. The person of integrity fulfills the obligations of his private and his professional life, which are consistent with each other. He or she follows his conscience reliably and predictably. This pursuit is intrinsic to the person’s identity. To violate it is to violate that person’s humanity.

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In the patient-physician relationship, *both* parties are entitled to protection of their personal integrity. However, the values, beliefs, and norms that comprise integrity may well be very different—and present different challenges—for doctor and patient. The physician needs to contend with an increasingly pluralistic society that can create pressure to compel him or her to accommodate patients' differing religious, cultural, or personal beliefs. Also, the special nature of the patient-physician relationship (which derives from the fact that being sick and being healed are predicaments of special vulnerability), the growth of personal freedom of choice, the systematization of patient care, and the trend toward legal resolution of moral conflicts promise to increase the demand for personal and/or public control of the physician's clinical decisions. All these factors encourage erosion of the physician's personal integrity.

On the patient side, the sick or injured person—in a state of distress, pain, and suffering—is compelled to seek out and depend on the physician who professes to know how to help. The sick person and his family are asked to make choices among therapies, choose when life support may be discontinued, and decide how vigorously the terminally ill patient shall be treated. Throughout all this, the patient and family must trust the physician—or more likely a team of physicians, nurses, social workers, chaplains, etc.—each offering a slightly different rendition of the choices. Often, the physician and other caregivers are of different minds, and none may know what the best choice is. This uncertainty leads to lack of trust and may prompt the patient and family to go in desperation from Internet site to Internet site, and to nontraditional healers or marginal practitioners, in search of answers and of someone they think they can trust. Because, in the end, someone must be trusted.

## The Empowerment of Autonomy

Vulnerable patients have always worried about whether their physicians possessed the competence they claimed and could be trusted to use it wisely and well. Until recently, however, they had little power to challenge the authority and sometimes authoritarianism of their physicians. Today, we live in a time of self-assertion. Autonomy, the most quoted principle of bioethics, empowers patients to challenge physicians' knowledge and judgment. Patients now have the moral and legal rights to be informed and to give or withhold consent. Increasingly, patients and surrogates understand autonomy as empowering them to demand the care they want. Autonomy has expanded to the point that it conflicts with the physician's moral or professional judgments.

The effect on the physician-patient relationship has been profound

Without sanctioning obvious harm, they should yield to patients who choose a less effective treatment, or a treatment of no proven use, or even one that violates the physician's beliefs about what is right and good. Furthermore, some physicians believe that in the name of patient autonomy they must protect all confidences even when others may be harmed—for example, not reporting the incapacitated driver who is a public danger, or not revealing HIV infection to sexual partners. Others may take it as an act of beneficence to exaggerate the severity of disease or disability to increase the patient's insurance coverage.

More subtle—but perhaps more important—is the physician's growing reluctance to urge the course that he or she believes is preferable for *this* patient. Despite protestations that they know what is best for themselves, patients do make wrong choices. For the physician to suggest otherwise is to fail to respect the trust he

*Is the good of the patient better served when he takes charge and directs his own care, or does the erosion of trust in the physician's integrity put the patient in danger?*

and complex. On the one hand, it has made that relationship more open, more adult, more transparent, and more attentive to the patient's values and wishes. Some of the edge has been taken off physician arrogance and self-assurance, and the patient's dignity as a person is better respected. These benefits have, however, been accompanied by trends that are dangerous to the patient and unjust to the integrity of physicians. For one thing, many physicians feel they are required to satisfy patient or family demands or be guilty of "paternalism"—the original moral sin of modern bioethics.

To avoid paternalism, some physicians and ethicists argue that physicians should be morally neutral.

has promised. Refusing to "bias" the patient's choice by revealing one's own choices—and perhaps persuading the patient to change his mind is not a true violation of autonomy. Rather, *not* to do so violates the principles of beneficence and trust. Beneficence does not equal "paternalism," which relies on deception, treating the patient as a child, or coercing a choice and is itself maleficent. To cooperate in a wrong choice is complicity with what is wrong, and leaving the patient to decide difficult issues about which the physician himself may be uncertain is complicity in harm. Rather, what the patient needs is a physician who protects the moral right of patients to reject any or all treatment after the options have

been frankly disclosed, and who will not use deception or ill-placed emphases to change the patient's mind.

### **Overriding Physician Integrity**

The desire for autonomy and unhindered freedom of choice has led to law and policy that override the physician's objections to certain procedures, including abortion, assisted suicide, euthanasia, some methods of assisted reproduction, and embryonic stem cell research and therapy. This is not the place to argue the ethical issues of these practices. However, refusing to participate in them is essential to the moral and professional integrity of many physicians. Manipu-

lating law and policy to make providing them mandatory by threatening loss of license or specialty certification is an assault on the very person of the objecting physician.

The trajectory of efforts to compel health professionals to provide care they find objectionable is toward relaxation or abolition of conscientious objection privileges. At this writing, there are organized attempts in the courts to block a new federal regulation that protects health workers who refuse to provide objectionable care. The ultimate goal seems to be to eliminate legal protections of conscientious objection entirely.

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### ★ Policy Implications ★

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As we approach another round of health care reform, the medical profession and the public must together find the balance that preserves both patient autonomy and physician integrity, for the benefit of both patients and physicians. Given how essential trust is in medical and health care encounters, we cannot trust physicians who shun responsibility, and we do not want patients abandoned in the midst of critical health and medical care decisions. For a morally viable relationship in a democratic society, both autonomy and integrity must be sacrosanct. ★

Whether for life or death, do your own work well.

—John Ruskin

# Quality

## *Where It Came From and Why It Matters*

FRANK DAVIDOFF

A movement has emerged within health care over the past several decades that sees *quality* as the combined and unceasing efforts of everyone involved in health care—professionals, patients and their families, researchers, payers, planners, and educators—to make the changes that will lead to better outcomes, better system performance, and better professional development; in other words, better health, better care, and better learning. This sweeping view recognizes that the pursuit of quality and safety is a dynamic process, not a static and narrowly focused endpoint. People associated with the quality movement accept this pursuit as both a moral responsibility and a serious applied science. They also believe unequivocally that everyone in health care has two jobs when they go to work every day: to provide care, and to make it better—a view that is entirely congruent with the idea that “unceasing movement toward new levels of performance” lies at the very heart of professionalism.

Several centuries ago, the widespread adoption of commercial values arguably paved the way for the flowering of science. This essay explores the seemingly unlikely proposition that commercial values have also served as the principal catalyst for the quality movement in medicine when they have come up against the decidedly non-commercial values that medicine has held sacrosanct. Improving the quality of health care is likely to be crucial in the success of health care reform, in part because, like sci-

ence, improvements in quality can bring benefits that serve as a powerful counterweight to the potentially corrosive effects of commerce on professional and social relationships.

### Guardians and Gifts, Science and Commerce

Medicine has historically shunned commerce. Until quite recently, for example, it was not acceptable for doctors and hospitals to advertise. The admonition to “shun trading” is a key element in what the scholar and social critic Jane Jacobs has called the “guardian moral syndrome”—a code of tightly linked moral values that governs one of the two systems of human survival, “taking” (the other being “trading”). In public life, the guardian moral syndrome, which includes the exertion of prowess, adherence to tradition, and the dispersing of largess, is expressed most clearly in government, but also in the military and religion—all of which support themselves through the taking of taxes, tithes, and territory.

Since healers were initially members of a priesthood, it should not be surprising that from its beginnings, health care was essentially a creature of the guardian moral syndrome. Of course, like everyone else, healers need to put bread on the table. But since they neither taxed nor tithed, they were forced to engage in trading. Until about fifty years ago, however, they did so on a limited scale; to a substantial degree, they relied instead on nonfinancial rewards from the “gift relationships” inherent in medical practice. That is, they relied on deferred and uncertain (but ultimately increased) rewards offered in response to

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their gifts of care and healing. Rather than devoting themselves to the immediate, calculated exchange that defines commerce (such as contracts, investment, capital, and interest), healers felt themselves to be rewarded through their high social status, enormous respect, and great professional autonomy.

The underlying moral values of health care in the West changed at a glacial pace, if at all, until about the beginning of the nineteenth century. That was a time of enormous social and intellectual change: the latter stages of the Enlightenment, the be-

concept of money rests entirely on trust.

### **Medicine Becomes a Commodity**

The scientific awakening slowly made its way into medicine during the nineteenth century, leading to many new, more rational, and improved ways to care for patients, including anesthesia, antisepsis, and x-ray imaging. But until about the time of World War II, the guardian moral syndrome continued to dominate health care's social values, and explic-

sion: patients are now considered "customers," doctors and hospitals advertise product lines, and medical insurance companies consider money spent on clinical care to be the "loss ratio." The preoccupation with quality and safety in health care has emerged exactly in parallel with this surge in medical commercialism. The commercial values of comfort, industriousness, thrift, and efficiency have been instrumental in industry's development of an entire science of improvement and safety that is now slowly working its way into health care. And although it would be hard to prove conclusively that the two are related, the striking resemblance between these commercial values and the Institute of Medicine's rules for achieving quality—which include transparency and the free flow of information, continuous decreases in waste, and customization based on patients' needs and values—argues strongly for a causal connection.

*Commercial values have served as the principal catalyst for the quality movement in medicine when they have come up against the decidedly noncommercial values that medicine has held sacrosanct.*

ginning of the end of slavery, the spread of democracy and republicanism, the emergence of the industrial revolution, and the rapid evolution of science. Jacobs argues that a major—and perhaps *the* major—force that drove most of these social changes was the progressive shift from the small-scale exchange of goods and services (much of it in gift relationship mode) into full-blown commercial enterprises.

Commerce depended for its success on the assertion of its own moral "syndrome," which consisted exactly of the moral values that science needed in order to flourish. In commerce, as in science, the questioning of dogma—dissent—became a virtue rather than a heresy. Likewise, meticulous observation, insatiable curiosity, and innovation were prized qualities rather than distractions; the generation of new knowledge was recognized as a productive investment, rather than a threat; and honesty and transparency became the bedrock of marketplace conduct, for the very

it concern for quality and safety remained strangely muted.

Two events that emerged in the 1940s were instrumental in prompting medicine to take quality and safety seriously: the discovery of antibiotics, with their seemingly miraculous power to cure humanity's traditional scourge, infectious disease, and the evolution of improved study designs and statistical methods, which made possible the subsequent development of quantitative clinical research. The arrival of potent pharmaceuticals, plus better ways of documenting their effectiveness (not to mention better surgical techniques), led to a sweeping epiphany: what doctors do actually "works"! Equally important, most of these dazzling new interventions could be separated from the "learned intermediaries"—namely, doctors—who delivered them, which made it easier to give them commercial value and to buy and sell them in the marketplace.

And to be sure, during the past thirty years, health care has become at least as much a business as a profes-

### **The Value of Quality**

Both commercial and guardian enterprises are essential in well-functioning societies: when either has pushed the other aside, the result has generally been disastrous. Consider, for example, the devastation that has resulted from total government control of economies such as in the Soviet Union and, more recently, Zimbabwe; or, conversely, the chaos and destruction that has occurred when radical free-market policy has replaced most major governmental functions, as in the recent history of Indonesia, Chile, Argentina, and South Africa, among other places. Further, the two moral syndromes must be held together in tension: they cannot be blended together into some entirely new enterprise, nor can they be rigidly separated. The only viable option then is for the two enterprises to develop a symbiotic relationship that leaves intact the values characteristic of each, but at the same time fosters close, respectful interaction between them. This is what hap-

pens, for example, when government legislates a goal, such as increased automotive fuel efficiency, but leaves it up to industry to figure out how to accomplish that goal, whether by improving engines, or making vehicles lighter, or developing some other, entirely new strategy.

As things stand now, a complex and often contradictory mix of guardian and commercial moral values is roiling the health care system. For example, the moral obligation felt by providers to do everything possible to meet every patient's medical needs can be seen as a form of guardian "largess" that supports—and is supported by—commercial interest in financial gain, but at the same time conflicts with the commercial values of thrift and efficiency. And the fragmenting effects of commerce on social relationships can result in distressing "buyer beware" scenarios. Take, for example, the recently proposed system of consumer-driven care, in which trust in physicians, based on unverifiable assertions about the cost and quality of individual physicians' services, could be converted from a purely instrumental good into a commodity that would be bought and sold; a marketplace for

such behavior could end up pitting physicians and patients against one another as suppliers and customers.

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★ Policy Implications ★

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For it to be successful, health care reform will need to manage extremely effectively the tension between guardian and commercial values that currently pushes and pulls medicine in wildly different directions. If it fails to do so, we are likely to face increases in the fragmenting effects of commerce, including increases in the damaging effects of conflicts of interest, particularly in clinical research; worsening of the destructive drive for "hamster wheel" productivity in clinical practice; and further distortion of undergraduate, graduate, and continuing medical education under pressures of money and time—while at the same time we could fail to overcome guardian legacies such as inefficiency, uncontrolled largess, and difficulty in responding to patients' values and preferences.

But if we're clever and tough enough to build in "moral syndrome-friendly" interaction throughout a reformed health system, there's no

telling how much better off patients, providers, and everyone else might be. In fact, the many existing examples of syndrome-friendly interactions that support *both* better clinical outcomes *and* increased efficiency already give some cause for optimism. Thus, pay-for-performance, although hardly a panacea, honors the principle of making better clinical "widgets," rather than just more clinical "widgets." Pragmatic clinical trials are beginning to provide valuable information on the comparative effectiveness of new and existing interventions, strengthening further the marriage between effectiveness and efficiency. And exploration of the business case for quality suggests that better care can save "dark green dollars"—real, bankable savings, that is, not just the "light green dollars" of potential, on-paper savings.

Finally, consider patient-centered care, a concept that found little support in medicine over the centuries, but that is now emerging as a core precept in medical quality improvement. It seems right that the longstanding and widely honored commercial adage "The customer is always right" is creeping into patient care. Who would have guessed? ★

The highest and best form of efficiency is the spontaneous cooperation of a free people.

—Woodrow Wilson

# Efficiency

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## *Getting Clear on Our Goals*

MARC J. ROBERTS

Some major fault lines in the current health reform debate arise out of conflicting notions about the definition and goals of efficiency. There is, however, a simple and intuitively appealing concept of efficiency that I believe should be a central virtue of any health reform effort: To be efficient means *to use our resources in the best possible way to achieve our ends*. This makes “efficiency” an instrumental ideal—a goal whose meaning depends on whatever substantive ends we embrace.

Economics offers some distinctions that can help us think about our choices. Consider the distinction economists draw between “static” and “dynamic” efficiency. Static efficiency is a short-run, “at any given moment in time” formulation; it requires that a society operates within a given production process as defined by the available technology and organizational systems. Achieving static efficiency requires production or technical efficiency (ensuring that goods or services are produced at minimum cost) and allocative efficiency (ensuring that the right set of goods are produced and distributed to the right individuals). Dynamic efficiency looks at the long term, but it is not quite so well-defined. It refers to the rate at which our capacity to produce outputs improves over time. Dynamic efficiency requires being efficient in our use of research and development resources in producing new products and processes.

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Defining either static or dynamic efficiency requires us to further specify our aims. We do need minimum cost production regardless of our goals. However, as discussed below, we can only decide what to produce (how to be allocatively efficient) once we specify our goals. Dynamic efficiency requires a trade-off, too, since the more we spend on research today, the less we have to consume today—even if we are better off tomorrow. Moreover, our goals should determine what new products and processes we should try to develop, as well as how to trade current consumption against future gains. When it comes to health policy, two of the most widely used formulations of “efficiency” incorporate very strong assumptions about those goals.

### Two Perspectives on Health System Efficiency

Public health practitioners often define the goal of efficiency in terms of maximizing the overall or average health of a target population. As attested to by Web sites full of statistics about overall life expectancy, infant mortality, and so on, much discussion and analysis takes this form. More complicated versions of this approach require us to develop some complex index—like “Quality Adjusted Life Years”—that combines the morbidity and mortality consequences of various diseases. There are enormous ethical and practical problems in such a task, since many important value judgments are subsumed in the process of index construction. For example, how do we value pain relief versus saving lives, or mental health versus physical health? How do we value saving the young

versus the old, or the productive versus the disabled?

This view of efficiency is oriented toward *need*—toward what experts believe will produce the “biggest bang for the buck” in order to make everyone healthy. Historically, the roots of this view—now often called cost-effectiveness analysis—are in engineering and in the use of quantitative techniques to improve military operations during and after World War II (what came to be called “operations research” and “systems analysis”). In those cases, the goal to be achieved was specified in concrete terms like “enemy planes shot down.”

The “health/needs” camp includes advocates of “effectiveness research,” who push for increased use of clinical protocols and drug formularies and who want to eliminate what they see as inappropriate (and wasteful) variations in patterns of care across the country. They believe we could get more with less if only care was delivered rationally.

By contrast, health care economists typically define “efficiency” in terms of satisfying individuals’ desires to the maximum extent possible. (This implicitly assumes that the existing distribution of income is either acceptable or will be “fixed” by someone else). They seek *Pareto optimality*—a state in which no one person can be made better off without someone else being made worse off. Thus being “better off” is defined in terms of each person’s own subjective level of well-being.

This approach focuses on *demand*: giving people what they want in order to make them happy. It is embodied in cost-benefit analysis, which was developed after World War II when Congress ordered the Army Corps of Engineers to limit itself to projects for which the “benefits exceeded the costs.” From the beginning, the task was to value a diverse set of gains and costs in comparable ways. Not surprisingly, these came to be expressed in monetary terms, based on the value that beneficiaries placed on various outcomes.

Those who advocate for consumer-driven health care, higher co-payments and deductibles, and the substitution of savings accounts for insurance are in the “happiness/demands” camp. They believe that we can control costs only if consumers compare the benefit of more costly and elaborate care with their potential gains in happiness from, say, more costly and elaborate cars, and choose accordingly.

In terms of static efficiency, both the health/needs and the happiness/demands groups favor improved technical or production efficiency. Both also want to be “allocatively” efficient, but they have different views on what this implies because of their different goals. This is demonstrated

sources in nonproductive ways, we have major problems with allocative efficiency as well.

Ironically, both the health care economics and public health approaches to efficiency tend to ignore the *distribution* of gains. Equity, as they consider it, is a value that conflicts with efficiency. But this is an illegitimate and rhetorical sleight-of-hand that seeks to capture the social legitimacy of “efficiency” for those not concerned with distribution. A society could surely decide that helping those who get less care, suffer more, and die younger is especially important, and then ask, “Are we efficiently meeting our goals of making the worst off better off?” Indeed, advocates of greater justice within the

*The only way the impending avalanche of health care costs can be reduced is if we focus our health care research on innovations that decrease costs rather than on innovations that drive them up.*

in their conflicting attitudes toward fostering generic drugs: the “health” camp most wants cost-reducing changes in practice, while the “happiness” camp is content with innovation that increases cost as well as performance, provided the gains are something people will pay for.

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★ **Policy Implications** ★

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**I**n my view, efficiency in terms of health outcomes has to be a major concern in U.S. health reform. We have the highest health care costs in the world among industrial countries (between 50 percent and 100 percent higher than most) and similar—or worse—health outcomes. With roughly 40 percent of all our costs going into nonclinical activities (administration, sales, paper processing, and profits) we clearly could use a major improvement in technical efficiency. And since there is also much evidence that we overuse scarce re-

American health care system would be wise to focus on what I propose to call *distributive efficiency*, since funding for improving equity will always be limited. We must make sure, for example, that “safety net” hospitals that disproportionately serve the poor are every bit as technically efficient as other hospitals—which, alas, has not always been the case.

Finally, the biggest health policy challenge facing most industrial countries at this moment is enhancing dynamic efficiency—finding new ways to treat patients that reduce the costs of care. Aging societies, with increasing chronic disease, will face significant cost pressures for many years to come. And the citizens of increasingly wealthy and secular societies are also likely to want more costly health care over time.

The only way the impending avalanche of health care costs can be reduced is if we focus our health care research on innovations that decrease

costs rather than on innovations that drive them up. To do that, we need to create a market for cost-reducing innovations. And to do *that*, we need to move from fee-for-service payment (which often encourages the overuse of expensive new drugs and proce-

dures) to bundled payments for episodes of illness or capitated payments that cover all of a given person's costs for the year. Only then will hospitals and doctors find that efficiency—which research shows, ironically, also often produces better clinical

outcomes—is in their interest. And only then will our entrepreneurs and scientists have an incentive to develop those cost-reducing innovations, thereby really increasing our efficiency where it counts. ★

A wise man should consider that health  
is the greatest of human blessings.

—Hippocrates

# Health

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## *The Value at Stake*

ERIKA BLACKSHER

Few dispute the need for health care reform in America. Two problems—access and cost—attract the most commentary, and for good reasons. The ranks of uninsured Americans, which have increased annually for the last six years, are likely to reach 50 million in this economic downturn, and health care expenditures are predicted to top \$2.5 trillion in 2009. Both problems are unsustainable features of American health care. But these problems share company with a third that has gone largely overlooked. Our health system, if it can be so called, is not designed to produce *health*. Indeed, health *care* is but one determinant of health, and by some measures it is a relatively minor one. Despite the trillions spent on medical services, the United States ranks poorly on key measures of health. For example, according to 2004 World Health Association data, the United States ranks forty-sixth in average life expectancy out of 192 nations.

Addressing this gap in our national health reform debate requires a fundamental reorientation in our thinking about health care and its relationship to health. Reform needs to include measures that will help keep people healthy and better manage their illnesses should they fall ill. We should standardize insurance benefits, refocus services on primary care, reward the management and prevention of chronic disease, create information systems that track patient populations, expand community health centers. We should also assess (and act on) the health im-

pact of policies in sectors other than health care, such as taxation, agriculture, housing, urban planning, transportation, and education. Such reforms will not only produce a healthier nation but also reduce the stark health inequalities that separate Americans who are better off from those who are worse off.

### Health and Value

This perspective on health system reform turns on a value rarely identified, defined, or defended in explicit terms. That value is health itself. Health is thought to be a good in several respects. First, people may value health because it contributes directly to their sense of well-being; in this sense, it is an *intrinsic* good—a good that people enjoy for itself. But even if people do not consciously appreciate their health when they have it, losing it will make them aware that they rely on some level of it to pursue their interests and to act on their plans. Health, in this sense, is also an *instrumental* good that enables people to manage and control their lives. Health is also a *collective* social good that can contribute to a nation's productivity and reduce absenteeism and health care costs.

Health may seem too simple an idea to define or too obvious a value to defend in a debate over health system reform. Questions abound, however, about how to define and produce it and how to balance it with other values. Is health an expansive idea that relates to human well-being, or a narrow idea that relates to bodily function? The World Health Organization defines health as “a state of complete physical, mental and social well-being and not

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merely the absence of disease or infirmity.” Critics charge that the WHO account is too vague and reduces all dimensions of well-being to health; they define health more narrowly as the absence of disease. But both approaches involve value judgments that are likely to be contentious. WHO’s definition requires well-developed ideas about the good life; the narrower, biomedical constructs require consensus on notions such as what counts as normal functioning and what counts as suffering. Still other definitional complexities and

gotiate a number of American values likely to supply resistance. One source of resistance will be those who view such policies as an infringement on individual liberty. The precise meaning of liberty may take slightly different forms, depending on the different objections. Policies that ban products (such as trans fats) or that regulate activities (such as driving without a seat belt) may be said to interfere with individuals’ freedom of choice. Others may take aim at government programs and the taxes they entail, based on a principled rejection

freedom expressed in those choices. Policies that remake these social conditions—for example, ensuring that everyone has a nearby grocery store that sells fresh produce, a primary care physician, a pharmacy, and safe venues for recreation and social gatherings—can enhance people’s freedom to make healthier choices. So some forms of collective action can *enhance* people’s liberty.

That these social conditions are often the product of widely endorsed public policies suggests that the call for personal responsibility should be accompanied by an awakening of our sense of shared responsibility. The idea is not foreign to U.S. political culture; indeed, it seems to be at the center of our new president’s philosophy. President Barack Obama has called for a “new era of responsibility” that makes demands not just of individuals, but also of families, communities, and society at large. This big-tent conception of responsibility should be directed at promoting health for all.

## *Health care is but one determinant of health, and by some measures it is a relatively minor one.*

controversies exist. But no matter how we measure health, the United States compares poorly to other wealthy countries and even to some middle- and low-income countries.

While we need not agree on a particular concept of health in order to agree that we are an unhealthy nation, how we conceive of health has implications for how we think about improving it. Because the biomedical conceptions of health rest on conceptions of disease and disability, they run the risk of channeling our collective attention and action toward medical services that respond to disease and disability—and away from broader social systems that prevent disease and promote health. Universal access to timely, high-quality primary care certainly would help to improve health outcomes and reduce health inequalities. But even with universal coverage, disparities in disease and injury will remain because it takes more than health care to ensure health. For example, medical services make a mere 10 to 15 percent contribution to reducing premature death. In addition, factors that contribute to health include health-related behaviors, genes, and social, economic, and environmental conditions.

The pursuit of health equity in this political culture will have to ne-

of the role of government, save its activities related to national defense, law enforcement, and judicial institutions that protect individual rights. These positions share a concern with what people are free *from* and may find common cause with a second plank of resistance to any robust health equity agenda—the view of health as individual responsibility. Individuals, not the state, are responsible for improving their health, and if they fail at that, it is individuals who must shoulder the consequences.

Of course, everyone knows of people who have managed, even against great odds, to change deeply ingrained ways of living and improve their health. But many people don’t manage that, and members of socioeconomically marginalized and minority groups are disproportionately among those who maintain poor health habits. This fact should cause us to rethink and reframe the question of responsibility and how we think about liberty. The significance of class and race for health habits does not suggest that members of socially disadvantaged groups are all choosing in lockstep; rather, it suggests that their choices are systematically constrained by living, learning, and working conditions that can limit people’s choices and perhaps the

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### ★ Policy Implications ★

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The social determinants of health are particularly salient in this era of chronic disease, whose causes can be traced to the conditions in which we grow up, live, learn, work, and play. Health habits related to diet, exercise, and tobacco use make an indisputable contribution to the onset and progression of chronic diseases and help explain some of the disproportionate disease burden among lower socioeconomic groups. But health habits do not explain all of it. Low socioeconomic status itself contributes to premature mortality and excess morbidity. Researchers do not yet know which markers of class exert the most profound influence on health, but low educational attainment, low-wage jobs, poor-quality housing, and polluted and dangerous neighborhoods, along with the stress and social isolation these experiences may induce, all plainly play a role. The vagaries associated with being

poor or near poor exact an especially heavy toll on the health and development of children, often with lifelong effects.

If the organizing principle of health reform is the production and the fair distribution of health, then we will need to rethink what a health system is. What might such a system look like and what sort of policies would it entail? Promising policies and programs have been recom-

mended, and some are already being implemented in states and cities around the country. These interventions include measures aimed at several different levels. Some focus on neighborhood conditions: they seek to improve housing stock, create safe areas for exercise, and enhance the food supply (such as by banning trans fats and by supporting farmers' markets, for example). Other interventions focus on at-risk families and

children, by providing income supports, securing nutrition, and enriching educational environments and opportunities. Yet other possible interventions promote educational attainment and improve work conditions and benefits for adults. These measures cannot guarantee health for all. But they can promote a fair *opportunity* for health for all. And that is a very American value. ★

...and the call for Stewardship of the  
collective resources...is clear ...

—Thomas Aquinas

# Stewardship

## *What Kind of Society Do We Want?*

LEN M. NICHOLS

To exercise stewardship, or not—that is the question. Why put the point that way? Because one path leads to an abundant life, and the other is a dishonest, if elaborate, form of suicide.

Stewards distinguish themselves first by accepting responsibility, and then by acting on that responsibility to preserve, protect, and nurture something precious, through recurrent threats, for the purpose of delivering that precious thing to future generations.

Who may confer and who must accept responsibility for stewardship of our health resources and the health of our population?

Some libertarians today argue that society is a myth, that no one has responsibility for the outcome of hundreds of millions of health-related decisions, and that anyone who asserts such responsibility and tries to act upon it is both an arrogant tyrant and an existential threat to the essential freedoms upon which our nation was founded. Nothing (and no tiny group of argumentative people) has ever been more profoundly wrong.

Thomas Jefferson, that true student and teacher of liberty, amended John Locke's famous trilogy (life, liberty, and estate) and wrote that all people have an inalienable right to life, liberty, and the pursuit of happiness. Jefferson also wrote: "Liberty is to the collective body, what

health is to every individual body. Without health no pleasure can be tasted by man; without liberty, no happiness can be enjoyed by society." What does the right to life mean if one does not also have access to known and widely available life-preserving and life-enhancing diagnoses and treatments? How can one meaningfully pursue any individual definition of happiness if one cannot afford essential care for a sick child, a breadwinner, or a disabled spouse or parent? In short, what is life and happiness without health?

At the same time, what is happiness if "too much" of your hard-earned income or wealth is taxed away, even if it is taxed to pay for the critical needs of others? Especially if "too much" is defined subjectively (as it must be in the end), based on one's personal understanding of the facts?

### Crisis and Covenant

For an unusual but very helpful way of answering these questions, put recent work by the Institute of Medicine alongside some ancient teachings in Leviticus, the third book of the Torah and of the Old Testament in the Christian bible.

The Institute of Medicine's 2009 report, *America's Uninsured Crisis: Consequences for Health and Health Care*, affirmed and updated its 2002 conclusion that roughly twenty thousand Americans die every year because they do not have access to routine but efficacious care because they lack health insurance. This means that over the fifteen years since we stopped debating the Clinton plan for comprehensive health reform, we have lost

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*The Gleaners,*  
by Jean Francois Millet

three hundred thousand of our fellow citizens to our collective failure to ensure coverage for all. No one doubts that the main reason the vast majority of the uninsured lack coverage is cost. That is to say, we effectively ration care—and life—by income, and every student of and participant in our health care system knows it.

Chapter 23, verse 22, of Leviticus admonishes the landowner at harvest time to leave a bit of the crop in the field so that it may be “gleaned” by the poor and the alien. Later books written by Moses and by later prophets (as well as the Qu’ran) used the more frequently taught and remembered formulation, “widow, orphan, and stranger.” Why was feeding the hungry such an important admonition? Because otherwise those on the fringes of community might starve, having no established property right to food (you had to be an adult male to own land in ancient Palestine)—and preventable starvation was simply unacceptable. It violated the sacred covenant with God. Every human being was made in the image of God and therefore had the right to participate in the life of the community—the right to life. Landowners were called to be stewards of their own “estate,” and of the fruit of their labors (in Locke’s sense), so that no one would starve, even those who did not share family, tribal, or even religious connections. Even in America, where social solidarity is nowhere near prophetic or even European standards, we have food stamps and food banks. We honor the ancient covenant to feed the hungry in every community.

Health care has become like food. It is a unique gift, capable of sustain-



*That is what stewardship is: leaders have to take care to set rules and make key choices to prevent imbalances that would lead to unacceptable outcomes.*

ing and enriching lives stricken with illness. Since all of us could be stricken with serious illness, since all of us could lose our job and our insurance tomorrow, all of us are also potential “strangers,” which is to say that our commitment to the covenant is ultimately self-interested, as it was in biblical times. That does not make it less sacred.

At the same time, it is important to read the call for stewardship implicit in Leviticus carefully. Leviticus does not say to bring the poor home and cook for them; it says, Leave some of the harvest in the field for them to glean. Our oldest obligations have always been mutual: it is perfectly and morally acceptable to expect personal responsibility from the beneficiaries of our covenantal largess.

Leviticus also does not say to leave all the food that one poor person might want, nor does it admonish the landowner to make sure that

everyone has the exact same amount of food. Leviticus expects the landowner to exercise *stewardship* over his resources so that his own self-interest is preserved, as well as the fundamental requirements of fellowship within the community. That is what stewardship is: leaders have to take care to set rules and make key choices to prevent imbalances that would lead to unacceptable outcomes, such as some being left out altogether or the land being overworked or abused and losing its productive capacity.

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★ **Policy Implications** ★

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Mapping this ancient lesson onto stewardship requirements for our health care system seems straightforward to me. Political, economic, and health system leaders—the “landowners”—must make sure that our system serves all of us at a basic level (and not just all Americans, but

all residents and visitors, if you interpret “stranger” in the Biblical sense, as I am recommending). At the same time, rules and choices must be made so that the system will be sustainable over time, and thus able to serve all of us in the future.

Those rules include restructuring insurance markets to make them both fairer and more efficient. We should require all insurers to end discrimination based on health status and all individuals to purchase insurance (or enroll in a public program for which they’re eligible). The choices include a sliding scale subsidy schedule that ensures affordability,

and reforming payment structures in the Medicare program to realign provider incentives so that they engender a far more efficient delivery system. The savings from this, plus reducing the current regressive tax subsidy for employer-provided health insurance, should be enough to make our financing and delivery systems sustainable over time.

Changing the system along these lines will likely require constant re-evaluation of system performance in access, quality, and cost dimensions. At the moment, spending 16 percent of the national gross domestic product (almost twice the average in de-

veloped nations) yet leaving 16 percent of our population out of the system (while other developed nations typically include all of theirs) is *prima facie* evidence that our system needs a fundamental realignment of incentives and redistribution of access rights. Such change simply cannot be afforded, however, unless we also simultaneously undertake an effort akin to the “parting of the waters” to improve the efficiency of our health care system. This will not be easy, but the payoff in social cohesion will be worth it, and the ancient admonition of stewardship demands no less. ★



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