

Chapter 3

**From Private Profits to Public Goods?
A Human Rights Assessment of
Health Care Reform**

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The dysfunctional state of health care in the United States is debated vigorously among politicians and the public alike, but few see health care reform as part of a movement to advance human rights in the social and economic spheres. However, the failure to develop a health care system that guarantees equal access to care for everyone can be directly attributed to successive administrations' resistance to recognizing the human right to health and health care.

Human rights offer a normative framework that enables activists and policymakers to develop analytical and advocacy tools for assessing and changing policy and practice. Incorporating the right to health care as a starting point for health care reform is not intended as a symbolic declaration or as shorthand for promoting a specific type of health care system. Rather, doing so reflects an understanding that the crisis in health care is linked to the disregard of social and economic rights in the US more generally. Caught in a political paradigm that designates human needs as personal, market-driven choices, health care has been excluded from the shrinking domain of public goods.

These patterns reflect what is often seen as a characteristically American hostility toward any shared public obligations beyond the physical safety of individuals and their property. Contesting this view, some health care activists seek to re-appropriate and reinterpret core elements of American history and ideology to bolster their arguments for a universal and equitable health care system. They invoke the precept of "unalienable rights" declared by America's framers to help build a strategic base for a uniquely "American" human rights discourse. Other reformers find it expedient to assert their independence from European and Canadian health care models and proclaim an American health care "solution." At the same time, activists are aware that a change in language does not necessarily trigger a change in policy, as the debates in the 2008 presidential election campaign confirmed. For example, while Democratic candidates were united by a general commitment to universal health care, what they meant was, in fact, access to insurance coverage for citizens, not equitable provision of care for all.

Rights-based health care activism steers clear of rhetorical solutions, at the same time as it seeks to reframe the health care debate, recapture ideological terrain conceded to the Right, and advance a positive vision for change. Using

the vantage point of a human rights framework, ethical principles—or “values”—are the premise for action rather than a variable shaped by opinion research. These principles are needed to give a normative basis to reform debates, in addition to providing analytical tools to guide policy and practical initiatives. In this approach, analysis replaces “messaging” driven by political expediency and instead leverages theoretical and empirical findings to make a case for re-envisioning health care as both a right and a public good.

This chapter focuses a rights-based lens on the US health care system and the ongoing political debates surrounding its reform. In particular, it reviews the health policy proposals of the 2008 presidential election campaign and primaries, thereby offering a historical perspective on the reform positions that are shaping health policy under the Obama administration. I argue that the long election campaign brought about a consensus among Democrats and major health advocacy groups, at the expense of side-lining single-payer advocates. This consensus now forms the basis for health care reform efforts by the Obama administration and characterizes the positions adopted by key stakeholders in Congress.

The chapter begins by reviewing the distinctive characteristics of the US health care system and then looks at the political culture and values underlying this system. It reflects on the notion of “shared responsibility,” which emerged as a normative frame in the 2008 Democratic primaries. While signaling a discursive opening for conceiving health care as a public good, it does little to address persisting tensions and blind spots in influential health care reform proposals, notably around issues of universality and equity in health care. A human rights analysis helps exposing these tensions and devising solutions.

Subsequent sections of this chapter explore health reform efforts at state level, and then returns to the national scene to further analyze the rhetoric and substantive content of reform proposals put forward during the presidential contest. A human rights lens is used to evaluate the possibilities and limits to constructive change associated with a set of health care financing and delivery strategies included, in different combinations, in the health plans of leading presidential contenders. These strategies appear to have set the parameters for the health reform approach of the new administration. The chapter’s concluding section explores opportunities for advocacy and practice, in particular the possibility of using local and state reform efforts to advance the right to health care in the US. In closing, it discusses the strategy adopted by the Human Right to Health Program, a national collaborative program of the National Economic and Social Rights Initiative (NESRI) and the National Health Law Program (NHLP).

The Failure to Protect Health in the United States

The United States spends more than twice as much on health care yet reports poorer health outcomes than other industrialized countries.¹ Most people are acutely aware of the high costs of health care, both to them as individuals and to the public at large. What remains more opaque, however, are the reasons for the mismatch between the exorbitant financial resources spent on health care and the unmet health needs of the population. While persisting health problems can to some extent be attributed to deep-seated social and economic inequities, the role of the health care system itself in perpetuating health inequities and poor health outcomes has not been widely understood. Recent data suggest that around 101,000 deaths a year can be attributed to the underperformance of the US health care system.²

The fragmented health care system fails to fulfill the purpose of protecting health. Financing and delivery structures are largely commercialized, and the powerful health care industry has a fiduciary obligation to shareholders and investors to make a profit, rather than to deliver and improve care. In this context, health care is treated as a commodity, traded in the marketplace via intermediaries, the insurance companies. It is offered to individuals in the form of a product or service that they, as consumers, can choose to buy or forgo. Insurers grow their business by selling and managing insurance policies in a way that avoids, whenever possible, the delivery of an actual service, that is, health care. This has grave consequences for health outcomes: studies have shown that maximizing profit generally correlates with minimizing care, unnecessary suffering, loss of health, and higher mortality.³

Yet there is a deeply-ingrained resistance to recognizing the fundamental flaws of a commodity-based approach to health care. The dominant belief in “free markets” asserts that supply and demand of health care will self-regulate and that competition will cut costs. It accepts that access to health care is restricted to those who can afford to buy it, but assumes that prices will be reasonable because supply and demand are linked. With most products, consumers limit their demand based on price. But in the case of health care, demand is not price-sensitive, as choice disappears as soon as an individual falls sick. Supply, on the other hand, is most profitable if care is either charged at expensive rates, in the case of providers, or avoided altogether, in the case of insurers. Unlike other businesses, insurance companies do not need to deliver a product or service in order to make money, and thus operate under incentives to reduce care.

In this market-based system, immense resources are being expended to meet industry imperatives rather than people’s health needs. Advocacy organizations estimate that 350 billion dollars could be saved in administrative costs by moving from fragmented, for-profit financing structures to a single-payer model.⁴ Instead, in the current market, cost containment is pursued by pricing people out of insurance coverage, denying coverage to those with health risks, limiting coverage benefits, and penalizing doctor visits. Many people are thus denied their basic health rights.

A public safety net is in place—albeit under constant political and financial pressures—to support the most vulnerable populations. Children and parents living in poverty are entitled to public insurance programs, as are older people. Such public programs generally have more comprehensive medical benefits and operate more cost effectively than private health plans, although suitable providers, especially for Medicaid recipients, can be harder to find due to low public reimbursement rates. Fiscal analyses show that a large part of US health care is already publicly funded: according to official figures, 46.1 percent of all health expenditures are paid by the government, including programs such as Medicaid, Medicare, State Children’s Health Insurance Program (SCHIP), Veterans Health Administration, and community health centers.⁵ With additional public funds used for health care tax subsidies to employers and premium payments to private insurers for covering public employees, it is estimated that the government pays for the majority of health care expenditures.⁶ At the same time, 47 million people remain uninsured, and evidence suggests that 22,000 preventable deaths each year can be attributed to a lack of insurance coverage.⁷ Moreover, even among those with insurance, many lack access to adequate care due to insufficient coverage benefits, high deductibles, and unaffordable co-pays.

Despite the high human and financial costs and the extremely inequitable distribution of health care in the US, there remains a resistance to devising a national health care system that could guarantee appropriate care for all. This can best be understood in the context of American exceptionalism. Health care activists run up against a political culture that regards social and economic well-being as private matters, entitlements to public services as a sign of dependency, and diversity as a barrier to shared obligations. Community ties occur primarily as bonds between individuals of common backgrounds and faiths, and society at large is held together by the civic religion of patriotism, not by solidarity in relation to positive rights and substantive public goods.

The Emergence of “Shared Responsibility”

Political culture in the US has shown few instances of policymaking driven by a sense of social connectedness and mutual obligations. The solidarity required to recognize and pursue a public good, as opposed to defend negative freedoms, has been in short supply. While universal health care featured as an ambition of the Progressive Movement at the beginning of the 20th century, it was not until President Johnson’s Great Society that Medicaid and Medicare brought public health care to key disadvantaged groups, specifically the poor and the elderly. Since then, few comprehensive health care initiatives have been pursued and none has succeeded.⁸ Instead, the increasing commercialization of health care financing and delivery since the 1980s has taken health care reform in the opposite direction, pushed by the political muscle of the insurance and

pharmaceutical industries and culminating in hospital takeovers by Wall Street investors. Health care has become a private purchasing “choice,” publicly traded on the stock market.

In a system characterized by insurers seeking to avoid risk and costs, by policyholders expecting to be assessed on actuarial risk and insured mainly against catastrophic events, by employers passing costs on to employees, and by public programs shifting responsibility to private contractors, it seems utopian to expect an agreement on how to ensure that everyone receives the care they need. Yet as mainstream political discourse and policymaking have eschewed the notion of solidarity, the repercussions of this approach, measured in human lives and financial costs, have become increasingly visible.

It is at this juncture that a new concept has emerged in health care reform debates: the notion of shared responsibility. This concept was linked to the influential 2006 health care reform in Massachusetts, which was initially driven by a campaign to anchor the right to health care in the Massachusetts’ Constitution.⁹ Unlike the notion of a right, however, the concept of shared responsibility quickly gained national traction in Democratic circles. Barack Obama, as a presidential candidate, and Senator Max Baucus, as the Chairman of the Senate Finance Committee, referred to health coverage as both a right and as a shared responsibility.¹⁰ In the second presidential debate, then Senator Obama went a step further when—given the choice between characterizing health care as a right, responsibility or privilege—he stated that it should be a right. However, references to a “right” have yet to acquire a meaning beyond political rhetoric; as such they represent both an achievement of and a challenge to human rights advocates.¹¹ While the preamble of the 2008 Democratic Party Platform stated a general belief in health care as a basic right, its health care reform plan was based not on rights but on the principle of shared responsibility.¹² Many health care advocacy organizations joined this discourse, eager to argue that, while public support for significant government involvement in health care may not be forthcoming—despite some evidence to the contrary—all could agree on sharing responsibilities among individuals, business, and government.¹³ This reframing of health policy in terms of shared responsibility indicates a confluence of the individualist notion of personal responsibility so embedded in American political culture, and the recognition that health care is a social obligation rather than a commercial product.

In response to this consensus within Democratic circles, Republicans took to emphasizing the much more familiar notion of personal responsibility. The imperative of personal responsibility—for oneself, but not for others—is deeply ingrained in American political tradition, and most prominently reflected in the mythic pioneer spirit, insistence on self-reliance, denunciation of entitlements as government “handouts,” and acceptance of the government’s punitive role. In this discourse, responsibility is not the corollary but the opposite of a human right, based not on an agreement of how to live together but on a withdrawal

from all but the most limited social connections. This individualist notion of responsibility formed the core of Republican health care reform proposals.

Wielding sticks and carrots for healthy behaviors, Republican candidates looked to the individual for health care solutions. They called on people to be healthy rather than use health care, intending to penalize health care use with high deductibles and co-payments, and to reward those deemed fit, active, and thin. Such intervention in people's private lives—through prescribing how to attend to their own bodies—is accepted as part of the government's punitive role, at the same time as a positive, proactive approach to providing health care is not. That an emphasis on personal responsibility can go hand in hand with coercive interventions that violate a core human right—the freedom to make decisions about one's own health—is apparent in the history of forced sterilization and, more recently, forced contraception suffered by women of color in the US.¹⁴ In current reform debates the notion of personal responsibility is also used to explain health disparities, which are attributed to behavioral differences. A focus on individual behavior rather than socio-economic determinants of health and the structures of health care financing and delivery necessarily remains blind to the discrimination and racism inherent in the current system, as well as its underlying inequities.

While the health care reform plans put forward by leading Democrats and other reformers draw on the traditional discourse of responsibility, they add the crucial element of reciprocity, thus turning responsibility into a shared obligation—for the individual to purchase insurance, the employer to offer coverage or contribute to public health care costs, and the government to offer some form of public insurance as well as tax subsidies for the purchase of private or public coverage. This approach, however, continues to place the primary burden on the individual. Access to health care remains dependent on a private purchase decision, possibly subject to a mandate and penalties if not taken as instructed. In exchange, the government offers to subsidize this purchase, and employers provide coverage options. In this understanding of shared responsibility, the public sphere is allocated basic protective and possibly punitive functions vis-à-vis individuals, providing a safety net and enforcing compliance with its rules. Yet health care remains a private matter and is not valued as a public good that belongs to and is shared equitably by all people.

Nevertheless, the concept of shared responsibility offers an opportunity for human rights activists by introducing an element of social obligation into health care policy debates and conferring a more active role on government. While health care continues to be conceived as a personal obligation for individuals, who need to acquire care in a market exchange with primarily private insurers, the government is seen as an arbiter of this market transaction.

This reframing of responsibility may amount to only a very small change in practice, as it does not obligate the government to ensure that individuals actual-

ly receive health care, but it creates a discursive opening for restoring the link between responsibility and rights. While personal responsibility without rights entails a dynamic of conditional rewards and punishment, such as public subsidies for buying insurance or penalties for failing to do so, in a rights framework it is the government's responsibility to guarantee that everyone can exercise their rights—for example, by automatically providing coverage for all and ensuring that private actors do not interfere with the right to health care.

The Role of Human Rights Principles in Health Care Reform

According to human rights principles, the development of a health care system must focus on the most disadvantaged people while aiming to meet the needs of all. As defined in key international documents, those principles require that health care be available, accessible, acceptable, and of good quality for everyone, on an equitable basis, everywhere in the country.¹⁵ Reforms can be incremental, progressing toward universal access to and availability of care, but they must not regress and endanger existing access to services.

While there is no specific human rights model for health care financing and delivery, the principles of the right to health care form a framework against which any development or proposal can be assessed. In a health care system based on human rights, the financing and delivery of care prioritize the protection of health over any other considerations. Such a system does not restrict care at the expense of good health in order to cut costs or gain profit. Instead, it contains costs by allocating and regulating spending equitably, reducing waste and realigning incentives, and by prevention and early detection of ill health rather than by denying care to those who need it.

In the context of current reform debates, it is particularly important to put forward a meaningful interpretation of universal access. Among many health care reformers, and key leaders in the Obama administration and Congress, a consensus has emerged that access to health insurance should be universal. Initially pursued as an effort to increase coverage specifically of children, this notion has developed gradually, prompted by the rising number of uninsured people during the two Bush administrations. As policymakers recognized a link between the uninsured and the insured, with costs being passed on to the latter by the insurance companies, part of the problem was framed as a “free rider” issue, apportioning blame to uninsured people. Only recently have Democrats taken a more holistic approach, supporting universal insurance coverage as a principle.

Yet the campaign for the presidency revealed that all leading Democrats continued to rely on the insurance industry as gatekeepers to health care access, and that their rivalry about whose plans were more “universal” amounted to little more than a contest over who could create more consumers to buy insurance policies. Moreover, the focus on affordable insurance largely fails to take

into account that access, to be truly universal, must not only be genuinely affordable but also equitable and comprehensive. As long as “universal” health care only denotes more affordable access to increasingly limited forms of insurance coverage for a broader spectrum of citizens, the concept of universality serves merely as an empty reference to a normative discourse—the discourse of human rights—whose substantive standards have not yet resonated with mainstream reformers.

In this context, the relationship between the principles of universality and equity can be highlighted as a particularly uneasy one. Despite manifest inequities among racial, ethnic, and income groups with regard to health care access, quality of care received, and health outcomes, none of the reform plans has put forth a strategy for addressing inequities, other than seeking to facilitate access to insurance for all individuals. However, equity cannot be subsumed under the principle of universality, especially not in a policy setting where universality merely signifies a conglomerate of individuals whose needs are presumed to be the same. While Democratic presidential candidates assumed that disadvantaged groups would benefit equally from any policy proposal made, they also pointed to a need for continued and expanded safety net programs.¹⁶ This amounts to an implicit acceptance of a multi-tier health care system, in which low-income people, including a disproportionate share of racial and ethnic minorities, are assigned different access routes to coverage and care than the general population. In fact, the health plans of both presidential nominees, then Senator Obama and Senator John McCain, perpetuated inequities and exclusions by maintaining distinct tiers of access to different levels of care, and by excluding the health needs of disadvantaged groups from the debate. Their rhetoric of “access for all” quickly disintegrated into fragmented measures designed to protect the access some people already enjoy. Insofar as equity has been neglected or misunderstood in reform proposals, the human rights framework offers important guidance by requiring a prioritization of disadvantaged groups in the pursuit of the universal exercise of rights.

Universality is not the only human rights principle that resonates in current debates. Many health advocacy organizations have adopted guidelines for reform that include principles such as adequate quality of care and sufficient availability of care everywhere. Activists fighting health disparities have long applied criteria such as cultural appropriateness, non-discrimination, and equity. However, there is no unifying framework that links universality with equity, provider availability with affordability of coverage, or the struggle against health disparities with the demand for universal access. Moreover, some cross-cutting human rights principles, especially participation and accountability, receive little attention. Participation tends to be subsumed under the notion of choice—as long as individuals have an ostensible choice about which health services to consume, they are thought to be active participants. Many activists

see consumer rights as the strongest vehicle for health care reform, thus inadvertently reinforcing the very aspect of health care that denies the exercise of rights—the market that treats health care as a consumer product.

Recent Reform Efforts: Experiences at State and Local Levels

A progression toward a rights-based perspective can be observed in some recent reform efforts. A small number of states, counties, and cities across the country have signaled that they recognize the right to health, and some urge the federal government to ratify relevant international treaties. A handful of states attempted to amend their constitutions to include the right to health care. These primarily citizen-led efforts in Massachusetts, Michigan, Minnesota, North Carolina, Oregon, and Florida did not lead to new constitutional provisions, but some were crucial to building a broad-based health care reform movement and facilitating the passage of specific reform measures. In Wisconsin, the state government declared that “every Wisconsin resident has a right to health care access,” —after eleven counties and cities across the state had adopted advisory resolutions supporting guaranteed access to universal health care—and used this as the basis for covering all children under a new public insurance plan.¹⁷ In the cities of Seattle and Tacoma, Washington, voters approved local ballot measures affirming the “right of all citizens to appropriate, high-quality health care that is accessible and available to all.”¹⁸

During the Bush administration, states across the country took a lead in implementing health care reforms. While mostly incremental in nature, these approaches often provided real improvements for state residents, as well as driving policy debates, serving as laboratories for reform ideas, and underscoring the need for practical change. Since 2003, several states have enacted comprehensive, market-based reforms intended to significantly broaden access to insurance coverage, including Maine, Massachusetts, and Vermont; and many more states had been close to adopting comprehensive reform plans prior to the economic recession.¹⁹

Whenever state-based reform efforts were scaled down or failed to get political or legislative support, pundits were quick to blame the faltering economy and growing budget constraints. What they failed to understand is that an economic downturn, in fact, reveals the structural problems underlying such market-based reforms. While single-payer plans were proposed in many states, the reform proposals that gained most traction relied on commercial health care financing and did not address the immense costs of private health insurance to taxpayers. They were thus vulnerable to funding shortfalls triggered by high insurance premiums, as confirmed by the Legislative Analyst’s Office in California, whose analysis contributed to the rejection of the market-based California plan.²⁰ Clearly, the fiscal limits of market-based reforms are more readily exposed under tight economic conditions.

The 2008 Presidential Election Campaign

Human rights principles offer a framework for assessing the health care reform proposals put forward during the 2008 election campaign. Health care reform was identified early on as a key issue. In a large field of candidates going into the primaries, Democrat John Edwards was the first to publish a health care plan, in March 2007. He identified universal access to insurance coverage as a key objective and proposed a set of market-based reform measures, featuring mandates for providing and purchasing insurance.²¹ Other Democrats followed suit. Viewed from a human rights perspective, the proposals of the leading Democratic candidates were almost indistinguishable from each other, mostly featuring a multi-payer, mixed public-private system with some form of mandates for employers and individuals. There were also few substantive differences among the health care proposals of Republican candidates. Most Republicans relied on appeals to personal responsibility for preserving health and gave private insurers and public programs the power to reward healthy behaviors. Both Democrats and Republicans offered tax subsidies for the purchase of insurance. For Republicans, this subsidy was linked to market deregulation and a concerted shift from employer-based coverage to the individual insurance market, whereas Democrats called for better industry regulation.

Measured against all dimensions of a rights-based approach to health care, none of the reform proposals met human rights standards, with Republican plans, in particular, failing to address basic human rights principles.²² Only the proposal by Democratic Representative Dennis Kucinich, reflected in a congressional bill—the Expanded and Improved Medicare for All Act (HR 676)—fulfilled most principles. No other candidate recognized health care as a human right, although then Senator Obama’s plan referred to a right to health insurance and then Senator Hillary Clinton spoke about health care as a moral right.²³ Neither of them, however, linked this to the freedoms and entitlements entailed in the human right to health, nor to the government’s obligation to respect, protect, and fulfill such a right.

The candidates’ health plans generally performed most poorly on the human rights standards of equity and participation. Democrats noted the existence of health disparities but failed to recognize that such inequities are fueled by a segregated system in which the care that people receive is dictated by their status, their coverage source, and the neighborhood that they live in, rather than their needs. No candidate addressed how people could take part in shaping health care planning and implementation. Both participation and equity constitute blind spots in a perspective that regards health care as a product to be bought rather than a right to be exercised.

In a comparison of the potential human rights impact of the different proposals, plans based on deregulation would mostly benefit the healthy and wealthy, whereas plans including mandates to provide or purchase insurance could improve access to some form of health insurance. Deregulation proposals would likely increase the number of people rejected by private insurers and push others into buying high-deductible, low-benefit coverage. This could lead to a reduction of both insurance rates and access to health care, and thus constitute a human rights violation. While proposals for expanding insurance coverage might encourage incremental steps toward access to health care for all, they would also move new resources—in form of tax subsidies—into the private insurance industry without any guarantee that these would primarily be spent on health protection.

This assessment shows that the approach to health care reform adopted by candidates did not differ fundamentally between parties with regard to their reliance on market-based initiatives. The failure to meet the standards of the human right to health care can largely be attributed to the candidates' pursuit of a market-centered over a people-centered approach to health care. From the outset, both Democrats and Republicans based their proposals on an imperative to reorganize the financing of health care, rather than on an assessment of the population's health needs. Their intention was to reduce costs and to increase insurance coverage, with Republicans stressing the former and Democrats the latter. To achieve these goals, candidates from both parties wanted to create more consumers to purchase coverage as a market product and a means to gain access to care. In focusing on improving the insurance marketplace, they neglected the challenges that market incentives pose to equitable access to quality care.

Moreover, these types of reforms would allow neither Democrats nor Republicans to pursue effective cost containment strategies, contrary to stated intentions. Most analysts of market-based reforms agree that the only way to effectively contain costs within a market system is through restricting the actual use of health care. Thus costs controls are imposed on people in need of care, rather than on corporations in pursuit of profits. The health care plan of the Republican nominee, Senator McCain, exemplified this approach.²⁴ It sought to achieve economic rather than health objectives, effectively allocating health care according to profitability, not medical need. Yet despite foregrounding costs concerns, McCain's proposals identified neither the underlying reason for high spending, nor the unequal distribution of costs and gains, characterized by waste and excess on the one side, and scarcity of care on the other. Instead, the plan pursued an expansion of the private insurance business through eliminating employer tax credits, which would have likely resulted not in reducing overall spending but in further shifting profits to companies and costs to individuals.

Corporations in the private market exist to maximize their profits, and therefore the drive for profits will always, without fail, trump the delivery of care services, which are recorded as financial losses on insurance company bal-

ance sheets. In proposing to replace a system in which certain care benefits are secured for all policyholders (defined-benefit system), to one in which each person receives what they are able to pay for (defined-contribution system), McCain's plan would have restricted access to treatments, drugs, and other health services for those unable to afford them, and thus exacerbated the existing rationing of care on the basis of income.

The health plan of the Democratic nominee, then Senator Obama, was similarly flawed, even though it focused on increasing insurance coverage rather than on market-based cost-shifting. Yet coverage does not automatically improve access to care: even if everyone were able to buy some kind of insurance product, this would indicate little about their ability to visit a doctor, and even less about their experience during that visit. Moreover, the focus on retaining the private coverage system also reinforces the model of health insurance as a business, whereby insurers shift costs to patients and providers, as distinct from a social insurance model, where costs and benefits are shared equitably. In a market-based system, policyholders are required to pay their own actual or expected health care costs in premiums, which leave them unprotected from the potential financial consequences of ill health. Rather than being insured against sickness, policyholders effectively subscribe to a payment plan based on their expected use of health care. As this model has become increasingly unaffordable, individuals have been forced to buy cheaper, high deductible policies that protect their assets—not their health—in case of catastrophic sickness. Obama's plan did not consider spreading risks and costs across a large population, with contributions based on ability to pay, despite proposing additional measures to regulate the industry. The plan instead perpetuated the misunderstanding of health coverage as a personal payment plan or assets insurance.

Despite these shortcomings of market-based reform plans, the 2008 candidate field included only one contender, Representative Kucinich, who called for the full public financing of health care. His proposal of a single-payer system, akin to the Canadian model, appeared to be largely compatible with human rights principles. However, single-payer is not the only model that can meet those standards. For example, both a national health service such as the British NHS, and multi-payer, public insurance models, as operated in Germany and France, also performs well, as care is provided, at least in principle, to everyone on an equitable basis.

Examples from other countries did not feature in the candidates' reform proposals. The framing of their ideas was initially driven by an amorphous concept characteristic of American political discourse: choice. Rooted in individualist, free-market ideology, the promise of choice figured prominently in the debates held during the primaries, without acknowledging the lack of actual choices suffered by health care users in the US today. Compared to the principle of solidarity, on which national health insurance systems are based, the empha-

sis on consumer choice hampered a serious consideration of public financing models. On the Democratic side, Clinton prominently highlighted choice as a key value (reflected in the title of her plan, “American Health Choices Plan”), as did McCain on the Republican side. However, while McCain coupled this with an appeal to personal responsibility, both Clinton and Obama followed Edwards in incorporating a notion of shared responsibility. Importantly, over the course of the primaries, the Democrats’ focus shifted from choice to shared responsibility, signaling a constructive change in perspective. This emerging view of health care as a collective undertaking, while far from embracing the idea of solidarity, might help bridge the gulf between market choice models and an appreciation of health care as a common good, financed publicly. In the longer term, it may make national social insurance models that highlight choice, such as the French and German systems, more appealing to mainstream reformers.

Assessing the Prospects for Change

The closest that any of the leading Democratic candidates came to considering a public financing system was Edwards’ indication that the ensemble of his proposed reforms could potentially lead to a single-payer model, if people were to prefer the new public plan option—also a key element of Obama’s proposals—over private insurance.²⁵ Whether this comment was intended as a nod to voters favoring a single-payer option or as a realistic scenario of out-competing the market, it revealed that the Democrats’ market-based reform plans formed a patchwork of stopgap measures. These proposals assembled existing public programs, employer-based coverage, insurance market reforms, a new public plan, and tax subsidies, held together by the thread of responsibility, shared—albeit unevenly—among individuals, employers, and the government. No explicit duties were assigned to the private health care industry, although a regulatory framework was designed to allocate some responsibility to commercial insurers and providers.

A human rights analysis of the various reform ideas shows that it is primarily the very limited responsibility and accountability conferred on the private sector and the government that are bound to impede the development of a financing structure that prioritizes health. None of the proposed reform measures obligates the private health care industry or the public sector to fully respect, protect, and facilitate access to quality care, as the human right to health demands. The entrenched view of health as a private matter of choice and personal responsibility—only inadequately supplemented with expectations of burden sharing—means that risks, costs, and benefits are not pooled in a system of health protection. While the government has been able to create and expand entitlements to health care, such entitlements are merely conditional. They are allocated according to government-set eligibility criteria, some of which may be changed at the government’s discretion.

At least three major problems mar the main health care reform ideas that gained prominence over the course of the 2008 presidential campaign: limited obligations to protect a public good, limited accountability of private and state actors, and restriction of universal rights to eligibility-based entitlements. Basic solutions may lie simply in delimiting obligations, accountability, and rights, which could provide a useful starting point for rights-based systemic reform.

For example, mandating individuals to buy insurance and employers to offer coverage would create a new obligation, much to the chagrin of libertarians. The rationale is to reduce the number of uninsured people and stop employers from dropping coverage for their employees.²⁶ From a practical perspective, this requires making insurance affordable, which in turn, entails either providing public subsidies—indexed to premium prices—or controlling the prices charged by the insurance industry. As all proposals rely on the former, supported by the insurance lobby, the government has to assume a responsibility of its own—that is, to provide adequate, sliding scale subsidies.²⁷

Yet the proposed mandates allow both the government and employers to shift the primary burden onto individuals, while failing to encourage income and risk solidarity. The government does not have to guarantee access to coverage and care, and employers can pass costs on to their employees or make individuals dependent on a particular job. Even with subsidies and employers' contributions, individuals are largely left to fend for themselves, either as buyers of insurance products from vendors with a vested interest in obstructing access to care, or as "offenders" punished by the law if they fail to comply with the purchasing mandate. While candidate Obama's plan avoided this punitive approach by limiting individual mandates to children, it also cast individuals in the role of purchasers of insurance policies. With or without explicit mandates, people would be forced into the marketplace to buy a product, rather than obligated to share costs and benefits with all members of society.

Some strengthening of employers' responsibilities could be achieved through regulatory mechanisms. Most reform proposals require employers that do not offer coverage to contribute to a public health fund, which increases their public obligation considerably. Specific rules could also mandate coverage of part-time and low-income workers and set a minimum percentage of premiums to be paid by employers, minimum health benefits to be covered, and maximum cost-sharing levels to be paid by employees.

Even with maximum employer regulation, however, coverage mandates represent a culmination of the individualization and commercialization of health care in the US. Yet the obligations introduced through mandates could also constitute a tipping point. If mandates were to be conceived as a universal obligation on individuals and employers to contribute to social health insurance, with a legal obligation to protect health and provide comprehensive care benefits, and if the government were obligated to contribute on behalf of those who have a

limited ability to pay or those who are unemployed, health care costs, risks, and benefits could be shared more equitably by society as a whole. Health care would take on some characteristics of a public good, yielding assured benefits for everyone in the form of guaranteed public or publicly regulated services.

Yet this option was not included in the scenarios presented by the major presidential candidates. In their proposals, the health sector remained a marketplace dominated by the private insurance industry. As financial incentives in a market setting exert a constant pressure to curtail care, the challenge of making insurers answerable to public obligations and securing accountability may prove insurmountable. For-profit companies seek to contain their own costs by limiting access to care, yet doing so increases costs to others, who have to pay for the companies' profits and overhead expenditures. If these costs are not fully controlled by regulation, they can potentially derail any subsidized reform plan. Few reform proposals seek to control what proportion of income received by insurers through premium payments is spent on actual care, and none plans to control premium prices or cost-sharing. While stricter regulation could help shift incentives toward quality care through setting standards for prices, profits, and services, this approach would merely contain the negative impact of an industry that adds no value to health services. A constructive re-envisioning of health care financing would need to develop scenarios that do not rely on participation by the private sector.

In the current system, however, even public programs such as Medicare are increasingly contracting with private insurers as intermediaries, despite evidence against the efficiency and quality of such interventions.²⁸ At the same time, public programs retain the character of entitlements, which means that those who meet the eligibility criteria have a right to the public health care that is available, and they are, in principle, not subject to the vagaries of the marketplace when accessing care. Therefore, an expansion of entitlements to public programs, as entailed in many state-based reform efforts, could be part of a progression toward realizing the right to health care for all. As long as needs-based eligibility thresholds are designed to attend to disadvantaged groups first, rather than to maintain a divided system of care, differential access to care may be compatible, on a temporary basis, with human rights principles. Eligibility-based entitlements could progress toward universality if pursued with the option of raising thresholds to the point of their effective elimination.

However, entitlements are distinct from human rights in that they apply only to a limited scope of people, which makes them potentially divisive by excluding certain people with similar needs. Moreover, entitlements are also subject to restrictions imposed by government. In fact, the US has a complex structure of different layers of entitlements, some much stronger than others. At the top tier, Medicaid entitlements, based on federal eligibility criteria, guarantee access to public programs which, in some form, have to be maintained by public funds. Second tier entitlements, such as those conferred by State Children's

Health Insurance Program (SCHIP), guarantee only the eligibility, not actual access, for a program, provided that the criteria are met. For example, if SCHIP funding falls short of covering all eligible children, some of those children may have to wait to exercise their eligibility until new money becomes available. In this case, it is likely that eligibility criteria will be changed and become stricter. Importantly, eligibility thresholds for entitlements can be lowered as well as raised, depending on funding availability or political will. This introduces significant insecurity and uncertainty to public entitlements and, viewed from a human rights perspective, could amount to prohibited retrogressive action.

Health care reforms based on expanding public programs are therefore not automatically on a trajectory to advancing the right to health. Nevertheless, a commitment to both expanding and strengthening entitlements could generate valuable momentum for rights-based reforms, in addition to securing much needed improvements in access to care for low-income people.

Building a Right to Health Care Movement

For decades policymakers have failed to address the unnecessary structural barriers that the US health care system poses to providing universal care. As health care issues feature prominently in public and policy discourse, and with the Obama administration's attempt to shepherd a reform package through Congress, opportunities have opened up to tackle those barriers.

One effort that seeks to explore and exploit these opportunities, with a view to fundamentally shift the American perspective and policy on health care, is the Human Right to Health Program, run jointly by the National Economic and Social Rights Initiative (NESRI) and the National Health Law Program (NHeLP). The Human Right to Health Program pursues practical changes at the local and state level in order to generate momentum for a paradigmatic shift toward the human right to health care in the US. The program takes its normative principles from the social and economic human rights framework, and it supports local and state-based groups across the US in using this framework in their efforts to move toward universal, equitable health care that is accountable to the people. To chart new opportunities for policy and programmatic change during a crucial period of national political deliberation, the program has developed an analytical framework of human rights principles and standards that enable an assessment of emerging reform initiatives at local, state, and federal levels.

A key focus of the Human Right to Health Program is on fostering and supporting participatory processes at the state level. From a human rights perspective, a crucial ingredient of successful reform initiatives is the practical involvement of those who are denied their rights. Many health care reform efforts have faltered because they fail to seek the participation of those who are least able to access appropriate care, or because the reforms were driven by those who

sell health care, rather than by those who need and use it. To help ensure meaningful participation and leadership by those most affected, the Human Right to Health Program supports concrete actions by grassroots groups in different states. For example, the program is accompanying a campaign for the right to health care in Montana, which includes exploring the feasibility of establishing local universal health care zones. Testing a strategy of building on and expanding best practices to deepen an understanding of human rights standards, the program has identified community health centers as a potential model for rights-based delivery of care. Community health centers are governed by users, driven by health needs and provide care regardless of an individual's ability to pay, and as such could be developed into a hub for administering and delivering primary care for all local residents.

Over the course of the presidential campaign, the Human Right to Health Program has experienced a growing resonance of the human right to health frame with a range of national, state-based, and local advocacy groups. A number of organizations and advocates have started using human rights language and arguments. To move beyond rhetorical acceptance, the Human Right to Health Program, with its collaborators and partners, is developing and testing strategies to build from pragmatic, smaller-scale initiatives toward a sustainable movement for rights-based health care in the US.

In the context of US politics, however, a preference for incremental approaches has led many reformers to reduce policymaking to the art of softening more radical initiatives from the Right. It may be in the same tradition that leading health policy organizations have adopted a cautious approach to reform ideas, to the point of making the incremental nature of reforms a touchstone for their support.²⁹ At the same time, those organizations advocating structural change in form of a single-payer system fail to gain much traction in policymaking circles, despite popular support. For example, while then candidate Obama stated repeatedly that he favors a single-payer system in principle, in practice he put forward a solution that he considered less disruptive.³⁰

In fact, most reform plans released during the transition to the Obama administration were touted as comprehensive but amounted to not much more than a piecemeal reorganization of health care markets, driven by fears of disrupting the existing system despite its acknowledged malfunctioning. The political imperative has been to avoid so-called dislocation wherever possible, primarily in order to protect what is available to some people, to the detriment of the very real disruption faced by many others. With more and more people losing coverage, suffering from poor health, dying prematurely, or facing health care related bankruptcy, dislocation has effectively become a constant in many people's lives.

Resistance to significant social and economic change despite momentous upheaval in the current system can be expected to accompany reform efforts under the new administration. Just as the 1965 establishment of Medicare was

preceded by fear mongering about disruptive changes, activists and serious reformers today face an uphill struggle when attempting to push back the market's encroachment on people's basic rights. But just as advocates then succeeded in carving out health rights and protections for everyone in old age, today's reformers have an opportunity to ensure that those rights become universal and equitable.

With the exception of single-payer proposals, however, current reform ideas by key members of the Obama administration and Congress remain within the constraints of a multi-tier marketplace that segregates its health care "consumers," despite seeking to expand it with a new public plan option. In the midst of an economic recession this approach misses an important opportunity for structural change offered by a new public awareness of rights and responsibilities. In the context of government bailouts for the corporate sector, people increasingly call on government's protective role, as evidenced by their support for the government's obligation to protect human rights, including the right to health care.³¹ Perhaps the difficult push for dislocation can also benefit from step-by-step interventions to change the terms of the debate and shift perspectives on popular issues. Health care activists operate on an ideological terrain as much as a practical one. With the right tactics, small scale reform efforts at a local level might have an ideological and strategic value far beyond any substantive change they may achieve. This requires engaging in practical reform efforts with a firm normative framework in place, rather than relying on discursive change through merely technical, negative, or polling-driven messaging.

From this vantage point, campaigns for specific practical or policy reforms can be assessed for their potential of furthering the recognition of the right to health care. By accompanying issue campaigns on the ground, it may be possible to build broader, enduring support for real change.

Not all reform efforts lend themselves to promoting this goal, but activists can explore which initiatives can be framed in a way that builds support for a rights-based perspective. For example, public program expansions may facilitate a debate on how to move from entitlements to rights, and how to address health disparities. Reforms to the regulatory framework for insurance companies could make the case that the for-profit industry must not undermine the protection of health. An expansion and strengthening of community health centers would help build a model of care based on human rights. Of course, such practical measures to improve access to health care for more people, especially from disadvantaged groups, also deserve support in their own right.

Building a movement for the right to health care may require deepening our deliberation about the interplay between rights and responsibilities. The right to health care entails a collective responsibility for ensuring that everyone can exercise this right. Society, through government, is obligated to guarantee, and possibly provide, an adequate and equitable health care financing and delivery

system, and individuals need to contribute to this shared public good according to their means. As social beings, we are able and obliged to exercise solidarity in the presence of different capacities and needs.

With the Obama administration in office, human rights and health care activists have an unprecedented opportunity to push policymakers to recognize people's rights and take responsibility for turning health care into a public good, in the pursuit of better health outcomes for individuals, communities, and society as a whole.

Notes

1. See, for example, World Health Organization, *The World Health Report 2000 — Health Systems: Improving Performance* (Geneva: WHO, 2000).

2. E. Nolte and C. M. McKee, "Measuring the Health of Nations: Updating an Earlier Analysis," *Health Affairs* 27/ 1 (2008): 58-71.

3. S. Woolhandler and D. Himmelstein, "When Money Is the Mission—The High Costs of Investor-Owned Care," *New England Journal of Medicine* 341/6 (1999): 444-46; B. Landon, S.L. Normand, A. Lessler, A.J. O'Malley, S. Schmaltz, J. Loeb, and B. McNeil, "Quality of Care for the Treatment of Acute Medical Conditions in US Hospitals," *Archives of Internal Medicine* 166, 11/25 (2006): 2511-17.

4. See L. Rodberg and D. McCanne, "Upgrading to National Health Insurance (Medicare 2.0): The Case for Eliminating Private Health Insurance," Physicians for a National Health Program, July 13, 2007, www.pnhp.org. See also, S. Woolhandler, T. Campbell, and D. Himmelstein, "Costs of Health Care Administration in the United States and Canada," *New England Journal of Medicine* 349 (2003): 768-75.

5. Centers for Medicare & Medicaid Services, *National Health Expenditures Aggregate, Per Capita Amounts, Percent Distribution, and Average Annual Percent Growth, by Source of Funds: Selected Calendar Years 1960-2006*.

6. A. Bitton and J. Kahn, "Government Share of Health Care Expenditures," *Journal of the American Medical Association* 289 (2003): 1165.

7. US Census Bureau, *Income, Poverty, and Health Insurance Coverage in the United States: 2006* (Washington, DC, 2007); S. Dorn, *Uninsured and Dying Because of It: Updating the Institute of Medicine Analysis on the Impact of Uninsurance on Mortality* (Washington, DC: Urban Institute, 2008).

8. For a comprehensive analysis of health care reform efforts from a human rights perspective, see A. Irwin, L. Rubenstein, A. Cooper, and P. Farmer, "Fixing the U.S. Healthcare System: What Role for Human Rights?" in *Bringing Human Rights Home: Portraits of the Movement* 3, ed. C. Soohoo, C. Albisa, and M. F. Davis (Westport, CT: Praeger Publishers, 2008), 173-208.

9. "Here in Massachusetts, we are trying out a new universal health plan built on individual and shared responsibility," John Kerry, "Health Care for All Americans," speech prepared for delivery at Faneuil Hall, Boston, MA, July 31, 2006. For information on the efforts to make health care a constitutional right in Massachusetts, see <http://www.healthcareformass.org/about/amendment.shtml>

10. Max Baucus, "Remarks before the National Health Policy Conference," February 13, 2007, <http://www.senate.gov/~finance/press/Bpress/2007press/prb0201307.pdf>; Max Baucus, *Call to Action: Health Reform 2009*, November 2008; *Barack Obama's Plan For A Healthy America*, May 2007 (no longer available on official website). The revised Obama/Biden plan removes all references to health care as a right.

11. While a poll showed that 72 percent of Americans consider health care a human right, this general commitment remains to be translated into political and policy currency; see The Opportunity Agenda, *Human Rights in the U.S. Opinion Research with Advocates, Journalists and the General Public* (New York / Washington DC 2007), 14.

12. Report of the Platform Committee, *Renewing America's Promise*, August 13, 2008. <http://www.democrats.org/a/party/platform.html>.

13. In 2003, a *Washington Post*/ABC poll found that 62 percent of respondents preferred a government-run and tax-financed universal health insurance program to the current private health insurance system. More recently, in a December 2007, California poll, 54 percent of respondents supported a single-payer health insurance system, *Associate Press/Yahoo Poll*, Wave 2, December 2007, <http://news.yahoo.com/page/election-2008-political-pulse-voter-worries-highlights>. Compare S. Collins and J. Kriss, *The Public's Views on Health Care Reform in the 2008 Presidential Election* (New York: The Commonwealth Fund, 2008).

14. See D. Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Pantheon Books, 1997).

15. Core principles of the right to health in the ICESCR are outlined in Committee on Economic, Social and Cultural Rights (ESCR Committee), General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. No. E/C.12/2000/4 (2000).

16. Hillary Clinton published separate plans for different racial/ethnic groups; however, these plans are all basically identical and do not expand in substance on her general plan. H. Clinton, *American Health Choices: Hillary Clinton's Plan to Ensure Affordable, Quality Healthcare for All African Americans; The American Health Choices Plan: Impact on Hispanics; The American Health Choices Plan: Hillary Clinton's Plan to Ensure Affordable, Quality Health Care for All Asian Americans and Pacific Islanders* (September 2007) <http://www.hillaryclinton.com/feature/healthcareplan/>. Similar assumptions on the benefits of reforms for disadvantaged groups can be found in Obama's *Plan for a Healthy America*.

17. Wisconsin Department of Health and Family Services, *Badger Care Plus: Governor Doyle's Plan to Provide Health Insurance for All Kids* (2006).

18. <http://tacomayesonproposition1.org/default.aspx>

19. For an overview of health care reform efforts in the states, see, for example, *State Coverage Initiatives (SCI)* at <http://www.statecoverage.net>; *State Coverage Initiatives, State of the State 2007, Building Hope, Raising Expectations* (Washington DC: Academy Health, 2007).

20. Legislative Analyst's Office, "Health Care Security and Cost Reduction Act," January 22, 2008.

21. John Edwards, *Universal Health Care through Shared Responsibility* (2007) <http://www.johnedwards.com/about/issues/health-care-overview.pdf>

22. *Pursuing A New Vision For Health Care: A Human Rights Assessment of the Presidential Candidates' Proposals*, (NESRI / NHeLP, January 2008), and the follow-up assessment *Human Right to Health Care: Nominees' Plans Lag Behind Public Demands* (NESRI / NHeLP, August 2008), <http://www.nesri.org/programs/health.html>.

23. "Hillary Clinton's February 12 Speech: Transcript," *New York Times*, February 12, 2008.

24. "Straight Talk on Health System Reform" <http://www.johnmccain.com> (last updated June 2008, no longer available).

25. K. Sack, "Health Care up to Public, Edwards Says," *New York Times*, January 25, 2008.

26. Between 2000 and 2007, the total number of employers offering coverage declined by 9 percent, from 69 percent of employers to 60 percent; Families USA, *Too Great A Burden: America's Families at Risk* (2007), <http://www.familiesusa.org/>.

27. In Massachusetts, state subsidies for premium payments have been found inadequate, resulting in large numbers of people being exempted from the individual mandate, while others struggle with high deductibles and co-payments. See, for example, M. Rukavina and C. Pryor, "Tying up the Loose Ends of Healthcare Reform," *Boston Globe*, April 18, 2007.

28. The Congressional Budget Office reported that payments for Medicare beneficiaries enrolled in private Medicare Advantage plans are 12 percent higher than in the traditional Medicare program; Congressional Budget Office, *The Medicare Advantage Program: Enrollment Trends and Budgetary Effects* (Washington, DC: April 11, 2007). <http://www.cbo.gov/ftpdocs/79xx/doc7994/04-11-MedicareAdvantage.pdf>.

29. The Commonwealth Fund, for example, has adopted minimum "dislocation" as a criterion for assessing health care reform proposals; S. Collins and J. Kriss, *Envisioning the Future: The 2008 Presidential Candidates' Health Reform Proposals* (New York: The Commonwealth Fund, 2008).

30. L. MacFarquhar, "The Conciliator: Where Is Barack Obama Coming from?" *New Yorker*, May 7, 2007.

31. Opportunity Agenda, *Human Rights in the U.S.*, 22. See also B. Roehr, "One in three people in the US want to see 'radical change' in health care," *British Medical Journal* 336 (May 2008): 1150.