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FROM MARKET COMPETITION TO SOLIDARITY? ASSESSING THE PROSPECTS OF US HEALTH CARE REFORM PLANS FROM A HUMAN RIGHTS PERSPECTIVE

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ABSTRACT

Although the crisis of health care in the United States is widely acknowledged—marked by poor health outcomes, high costs, unequal access, and widening health inequities—its structural underpinnings have not been adequately addressed, and reformers have settled on promoting piecemeal measures to avoid disruption. The human right to health care offers an analytical and advocacy framework for shifting the health care reform debate from individualist, market-based approaches to the collective responsibility for health care as a public good. Based on an assessment of the health care reform proposals put forward during the US 2008 presidential primaries, the article argues that the emerging consensus among Democrats and health care advocacy organizations on incremental, market-based reforms ignores issues of equity, participation, and accountability. Alternately, the newly popularized concept of shared responsibility would reconnect rights to responsibilities and thus reinforce the public obligation to protect and provide health care. The article concludes by introducing the Human Right to Health Program, run by the National Economic and Social Rights Initiative (NESRI) and the National Health Law Program (NHLP), which seeks to advance the recognition of health care as a human right in the US by supporting grassroots partners and allies in their struggle for universal and equitable health care.

INTRODUCTION

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 social and economic rights. However, the failure to develop a health care system that guarantees equal access to care for everyone can be directly attributed to successive US governments' resistance to recognizing the human right to health and health care.

Human rights offer a normative framework that enables activists and policy-makers 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 in the United States 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 founders to help build a strategic base for a uniquely “American” human rights discourse. Other reformers find it expedient to assert their independence from Europe 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 run-up to the 2008 presidential election 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 guaranteed, equitable access to 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 moral core 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 article focuses a rights-based lens on the US health care system and the current political debates surrounding its reform, in particular the health care policy proposals emerging in the 2008 presidential primaries. The essay begins by reviewing the distinctive characteristics of the US health care system, then looks at the political culture and values underlying this system. In particular, 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 common 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 enables us to expose these tensions and consider solutions.

Subsequent sections of the article explore recent health reform efforts at state level, then return 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 most leading presidential contenders. These strategies appear to have set the parameters of the US health care reform debate for the rest of the presidential campaign and beyond. The article’s concluding section explores opportunities for advocacy and practice, in particular the possibility of using state-based 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 (NHeLP).

HEALTH CARE IN THE UNITED STATES: THE FAILURE TO PROTECT HEALTH

The United States spends more than twice as much on health care yet reports poorer health outcomes than other industrialized countries.¹ Most people in the US 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 inequalities, the role of the health care system itself in perpetuating 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 US health care system fails to fulfill the purpose of protecting health. Financing and delivery structures are largely commercialized, and a 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 in the US 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 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% 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 US 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 united by the civic religion of patriotism, not by solidarity in relation to positive rights and substantive public goods.

HEALTH CARE REFORM DEBATES: THE EMERGENCE OF “SHARED RESPONSIBILITY”

Political culture in the US has shown few instances of policy-making 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 expenditures, by policyholders expecting to insure against actuarial risk, by employers passing costs on to employees, and by public programs shifting responsibility to private contractors, it seems utopian to expect any form of agreement on how to ensure that everyone receives the care they need. Yet as mainstream political discourse and policy-making 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 US health care reform debates: the idea of shared responsibility. This concept was linked to the influential 2006 health care reform in Massachusetts.⁹ It quickly gained national traction in Democratic circles, with the Chairman of the Senate Finance Committee, Senator Max Baucus, referring to health coverage both as a right and as a shared responsibility.¹⁰ While references to a right have yet to acquire political meaning and currency, the reframing of health policy in terms of shared responsibility indicates a confluence of the individualist notion of personal responsibility so prominent in American political culture, and the recognition that health care is a social obligation rather than a commercial product. Most Democratic presidential candidates in the 2008 campaign based their health care reform policies, specifically the proposed mandates for individuals and employers, on the principle of shared responsibility. 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.¹¹

In response to this consensus emerging 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 was reflected prominently in 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, in particular, by women of color in the US.¹² 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 drew on the traditional discourse of responsibility, they added 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 provide tax subsidies for the purchase of insurance. This approach, however, continues to place the primary burden on the individual. Health care remains subject to a private purchase decision, except that this decision is now mandated and subject to 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 punitive functions vis-à-vis individuals, providing a safety net and enforcing compliance with its rules. Health care remains a private matter and is not valued as a public good that belongs to and is supported by all individuals.

Nevertheless, this model 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 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 actually 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 address 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.¹³ Reforms can be incremental, progressing toward universal availability of and access to 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. It contains costs by preventing disease and ill health, not by denying care to those who need it.

In the context of current US debates, it is particularly important to put forward a meaningful interpretation of universal access. Among many health care reformers, including all Democratic presidential candidates, 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 policy-makers were forced to acknowledge 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.

As leading Democratic candidates' reform plans relied on the insurance industry as gatekeepers to health care access, however, 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 merely denotes more affordable access to some form 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 — that candidates remained unwilling to adopt.

In this context, the relationship between the principles of universality and equity is 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 univer-

sality, especially not in a policy setting where universality merely signifies a conglomerate of individuals whose needs are presumed to be the same. While Democratic 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.¹⁴ 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. Insofar as equity is neglected or misunderstood in reform proposals, the human rights framework offers basic 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 US health care that denies the exercise of rights — the private industry that treats health care as a consumer product.

RECENT REFORM EFFORTS: EXPERIENCES AT STATE AND LOCAL LEVELS

A progression toward a right-based perspective can be observed in a few 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. Constitutional amendments on the right to health have been introduced in Michigan, Minnesota, North Carolina, and

Oregon. In Wisconsin, the state government declared that “every Wisconsin resident has a right to health care access,” — after 11 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.¹⁵ 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.”¹⁶

States across the country have also taken a lead in implementing health care reforms. While mostly incremental in nature, these approaches can provide real improvements for state residents, as well as drive policy debates, serve as laboratories for reform ideas, and underscore the need for practical change. Since 2003, several states have enacted market-based reforms intended to significantly broaden access to insurance coverage, including Maine, Massachusetts, and Vermont; and in 11 additional states, comprehensive reform plans are under consideration, featuring an assortment of similar strategies, including mandating insurance coverage and expanding eligibility for public programs.¹⁷ Other states have pursued a simple strategy of expanding Medicaid and SCHIP, as these are partially state financed and attract substantial federal matching funds. Such expansions seek to cover groups beyond the constituency required by federal law, and some have done so explicitly with the objective of moving toward universal coverage. New Jersey, for example, has expanded insurance coverage to children from families with incomes up to 350% of the federal poverty level, and additionally offers the opportunity for all families with uninsured children to buy into state-sponsored health care.

Some recent reform efforts, however, have been scaled down or have failed to get necessary political or legislative support altogether. In California, for example, a comprehensive plan based on individual and employer mandates failed to gain approval in the state senate. Pundits see this as a sign that the momentum for state-level reform has faltered, together with the economy, and predict a negative fall-out for federal health care reform. What they fail to understand is that an economic slowdown, in fact, reveals the structural problems underlying such market-based reforms. Since all comprehensive state efforts, as well as proposals by the presidential candidates, rely on commercial health care financing, they

do not address the immense costs of private health insurance to taxpayers and thus are 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 California plan.¹⁸ Clearly, the fiscal limits of market-based reforms are more readily exposed under tight economic conditions.

HEALTH CARE REFORM AND THE 2008 PRESIDENTIAL PRIMARIES

Human rights principles offer a framework for assessing the health care reform proposals put forward during the 2008 presidential primaries. Health care reform was identified early on as a key issue in the presidential campaign. In a large initial field of candidates, 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.¹⁹ Other Democrats followed suit. Viewed from a human rights perspective, the proposals of the leading Democratic candidates were almost indistinguishable from each other. Most Democrats favored 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 shift from employer-based coverage to the individual insurance market, whereas Democrats called for better regulation of the health insurance market.

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.²⁰ Only the proposal by Democrat 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 and health care as a human right, although Senator Barack Obama's plan referred to a right to health insurance, and, as the campaign

progressed, Senator Hillary Clinton started speaking about health care as a moral right.²¹ 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 presidential 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, but not by 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 increase access to some form of health insurance. Deregulation proposals are likely to 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 favoring individual mandates — or similar measures designed to achieve universal coverage — might encourage incremental steps toward access to health care for all, they also move new resources into the private insurance industry without any guarantee that these will 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 (to the public and to individuals) 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 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. Existing market incentives encourage cost containment only to protect profits in the short term. Such cost containment measures often lead to contradictory policies and, in fact, cause additional cost inflation. For example, insurance companies seek to reduce costs by imposing penalties on patients for visiting their doctor, but at the same time, they pay physicians and hospitals based on the number of visits received. Such inconsistencies have detrimental effects on costs and health outcomes, while serving a common purpose: to allocate health care according to profitability, not medical necessity.

Despite these shortcomings of market-based reform plans, the candidate field in the 2008 primaries included only one contender, Congressman 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 perform 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 driven, particularly in the early stages of the primary campaign, 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, 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 emphasis 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 Senator John 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.

POPULAR HEALTH CARE REFORM IDEAS: 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 proposed reforms could potentially lead to a single-payer model, if people were to prefer the new public plan option — offered by all major Democrats — over private insurance.²² 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 is 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 contribute to a public good, limited accountability of private and state actors, and restriction of universal rights to eligibility-based entitlements. That said, basic solutions may lie simply in delimiting obligations, accountability, and rights, which could provide a useful starting point for comprehensive, rights-based reform.

For example, mandating individuals to buy insurance and employers to offer coverage creates a new obligation, much to the chagrin of libertarians and other “free-market” advocates. The rationale is to reduce the number of uninsured people and stop employers from dropping coverage for their employees.²³ 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, the government has to assume a responsibility of its own — that is, to provide adequate, sliding scale subsidies.²⁴

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, as owners of an insurance product, or as “offenders” punished by the law if they fail to comply with the purchasing mandate. While 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 were 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 proposals already require employers that do not offer coverage to contribute to a public health fund, which increases their public obligation considerably. Specific rules could require 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, individual mandates, as currently conceived, represent a culmination of the individualization and commercialization of health care in the US. Yet the obligations introduced through individual 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, 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 would be shared more equally by society as a whole. Health care would become 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 of the current 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 can help shift incentives toward quality care through setting standards for prices, profits, and services, this approach does not achieve anything more than containing the negative impact of an industry, through

punitive enforcement measures where needed. A constructive re-envisioning of health care financing would instead 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.²⁵ 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 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 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 can 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 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 recognizing the right to health. Nevertheless, a commitment to both expanding and strengthening entitlements could generate valuable momentum for more comprehensive reform plans, in addition to securing much needed improvements in access to care for low-income people.

SUPPORTING GRASSROOTS INITIATIVES FOR ADVANCING THE RIGHT TO HEALTH CARE

For decades policy-makers have failed to address the unnecessary structural barriers that the US health care system poses to providing care for everyone. As health care issues feature more prominently in public and policy discourse, opportunities have opened up to tackle those barriers.

One effort that seeks to explore and exploit these opportunities, with a view to fundamentally shifting 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 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. To chart new opportunities for advocacy during a crucial period of national political deliberation, the program has published a human rights assessment of health care reform plans, discussed above, which will be further developed into an analytical tool for evaluating emerging reform proposals at local and state levels.

A key focus of the Human Right to Health Program's work 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 did not 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 public program expansion in Montana, in the expectation that this campaign will help advance broader programmatic goals, including a shift in the health care reform discourse. The program is also exploring the feasibility of establishing local universal health care zones, possibly through expanding community health centers — which provide care regardless of an individual's ability to pay — and using them as the vehicle for delivering primary care for all local residents. While still in its infancy, the Human Right to Health Program is finding resonance with a growing range of state-based and local groups in settings across the US. With its collaborators and partners, the program is developing and testing strategies to build from pragmatic, smaller-scale initiatives toward a movement for rights-based health care reform at national scale.

In the context of US politics, however, a preference for incremental approaches has led many reformers to reduce policy-making 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, or non-dislocating, nature of reforms a touchstone for their support.²⁶ At the same time, those organizations advocating a single-payer system — which would, of course, entail significant dislocation — fail to gain much traction in policy-making circles, despite popular support. For example, while Obama stated that he favored a single-payer system in principle, in practice he put forward a solution that he considered less disruptive.²⁷

Perhaps the difficult push for dislocation can benefit from step-by-step interventions to change the terms of the debate and shift perspectives on popular issues. Working on a particular reform effort could facilitate such interventions and secure crucial political gains. Health care activists operate on an ideological terrain as much as a practical one. With the right tactics, incremental reforms might have a strategic value far beyond any substantive change that they may achieve. This requires engaging in practical reform efforts with a firm normative framework in place, rather than relying on discursive change through 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 or supporting issue campaigns on the ground, it may be possible to build a broader, long-term movement 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 of the regulatory framework for insurance companies could help make the case that the for-profit industry must not undermine the protection of health. 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.

As a new Administration prepares to take office in 2009, human rights and health care activists in the United States have an unprecedented opportunity to push policy-makers 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.

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