



Entrenched Inequity

Health Care in the United States of America

Introduction

In 1941, President Franklin D. Roosevelt proclaimed “freedom from want” to be one of the four essential liberties necessary to achieve human security.¹ The polio-stricken President included in his definition of freedom “the right to adequate medical care and the opportunity to achieve and enjoy good health.”² This expansive vision of a right to health, which included both medical care and the preconditions to health, was subsequently incorporated into the Universal Declaration of Human Rights, and has since been enshrined in many international and regional human rights treaties.

Roosevelt’s vision was unfortunately never fulfilled as the United States turned its back on economic and social rights. Health care was commoditized, and for years now, the American health care system has been in a state of ever-deepening crisis. Despite spending far more per capita on health care than any other country, the US continues to have some of the poorest health indicators in the industrialized world.³ It is the only industrialized nation to deny its citizens universal access to medical services. Fully one-third of the population lacks health insurance for at least part of the year. Of the 47 million who are completely uninsured, 73.1% work full or part-time.⁴ Furthermore, the quality of health care for all but the wealthiest patients has declined dramatically, with more people dying each year from avoidable medical mistakes than from car accidents.⁵ Add to these problems the lack of services for Americans in rural areas, discrimination in health care provision and outcomes between whites and non-white minorities, and pharmaceutical and insurance costs that are spiraling out of control, and it is clear the US health care system is in profound predicament.

Recent discussions regarding healthcare reform in the United States tend to focus on how to contain cost growth and excessive expenditures while improving quality of care. There is no shortage of ideas on how to fix the US healthcare system, with proposals ranging from single payer national health insurance to increased reliance on Health Savings Accounts and other market-based solutions. Many of the proposals for reform claim to be “consumer-driven” models, allowing healthcare consumers to extract greater value from the system and much research has been devoted to applying cost effectiveness analysis to a broad spectrum of

healthcare services.⁶ Much of health law scholarship has been devoted to addressing how to reconcile the information, agency and incentive problems in the healthcare domain with a regime that still principally allocates health care through market mechanisms.

By contrast, an approach to healthcare reform rooted in human rights begins with different foundational premises. In a human rights framework, health claims—claims of entitlement to health care and enabling conditions—are reconceptualized as “assets of citizenship.”⁷ The healthcare system, in this view, is construed far more than just a delivery mechanism for services and products to consumers but a site through which to exercise citizenship. It is a core social system, more akin to the justice system than, for example, to the post office which provides a service and competes with any number of private providers. As such, the health system both reflects and contributes to the quality of democracy in a country. In the United States, the fragmented disparate, market-driven, commoditized pieces of health care reflect and contribute to entrenched inequities in American society.

This briefing gives substance to President Roosevelt’s vision by using international human rights principles as a framework for healthcare reform in the US. Posing the familiar problems with the US healthcare system as matters of fundamental rights opens a space for new solutions to problems that currently result in certain people and social groups being systematically harmed by the government’s inaction, as well as by its failure to regulate others’ actions. International human rights norms provide standards by which to evaluate a government’s conduct and can be used to articulate demands for accountability. Acknowledging a *right to health* can shift policy debates from a narrow focus on “efficiency” (which itself can be a spurious notion when many costs—e.g. the loss of productivity due to employee health problems—are externalized) to questions of how to guarantee people an effective voice in policy and programming decisions that affect their well-being.

Traditional approaches to human rights violations have often focused on legislative reform. Yet social movements, such as the civil rights movement in the United States in the 1960’s and human rights movements in numerous countries, have also been effective at mobilizing grassroots political support for substantial policy as well as legislative changes. The US healthcare system has reached a point where critical and dramatic action is needed, which in turn requires the kind of popular support created by a rights-based campaign. Even in a culture profoundly unused to invoking rights claims relating to social programs, during the debates over Congressional reauthorization of SCHIP (State Children’s Health Insurance Program) in the fall of 2007, public rhetoric turned to claims of children’s fundamental rights.

International law offers a framework to promote transformational changes to the system, which would restore *a right to health* to its proper place at the center of healthcare legislation, policies, and practice.

Such a campaign will undoubtedly be an uphill battle. Not only do special interests, ranging from insurance companies to the organized medical profession to Big Pharma, exercise

inordinate influence over political debates relating to healthcare reform, but the United States government has historically resisted guarantees of social and economic rights. For example, the US government has refused to ratify international and regional legal instruments containing social rights guarantees.⁸ Despite President Roosevelt's articulation of a Second Bill of Rights and his leadership in establishing an international system with the United Nations at its center, the US has a poor record of implementing international human rights standards on the domestic level.⁹ Moreover, the legacy of Cold War propaganda persists as an obstacle to healthcare reform, as corporations and conservative pundits continue to suggest that greater government involvement the financing and oversight of health care would constitute "socialized medicine," – a term which apparently continues to have talismanic powers in US social discourse to conjure up deep-seated fear and aversion.¹⁰

The briefing is divided into four parts. Part One examines the legal framework governing the right to health, with a focus on healthcare, in the United States. Part Two discusses the structure of the current US healthcare system and its impact on healthcare delivery. Part Three examines how the US system measures up to international human rights standards. Finally, Part Four presents the briefing's conclusions with respect to what needs to be done to align the US healthcare system with international standards.

This briefing was written before 2009 healthcare reform legislation was introduced into the U.S. Congress and is intended to set out the framework of human rights principles that should guide the design and evaluation of systematic health care reforms.

I. The Legal Framework for the Right to Health

The right to health is enshrined in international legal instruments, many of which were drafted with US leadership. Among the most important are the Universal Declaration of Human Rights (UDHR)¹¹ and the International Covenant on Economic, Social, and Cultural Rights (ICESCR).¹² As is the case with civil and political rights (the right to a fair trial, for example), a government's responsibilities to ensure that its population enjoy the right to health is equally about process and outcome. These responsibilities include access to trained medical personnel, the availability of affordable and acceptable drugs and health services, and the assurance that care is of adequate quality. While the government must work to promote health within the limits of its resources, it cannot be held responsible for ensuring any particular individual's health *per se*, unless their health problems stem directly from discrimination or other human rights violations. *The right to health is not equivalent to a guarantee that one will actually be healthy.*

The focus on health *care* in this report leaves aside many of the salient issues concerning the right to health and its implementation at the national level.¹³ For example, the right to health requires not only that certain minimum standards of care be met or exceeded, but basic preconditions to health also include adequate shelter, food, and sanitation.¹⁴ Also, a right to

health requires that people be safeguarded from health threats such as water and air pollution, as well as workplace hazards.¹⁵ It is worth noting that United States law does contain substantial legislation relating to the regulation of environmental exposures, as well as occupational and safety risks, and—although enforcement has become increasingly deficient in recent years—institutions do exist to monitor compliance with environmental and labor standards.¹⁶

The Right to Health in the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights

The Universal Declaration of Human Rights (UDHR) was one of the first great achievements of the United Nations (UN). Its preamble includes the “four freedoms” enumerated in Franklin D. Roosevelt’s famous speech to the US Congress,¹⁷ and its adoption marked the first time that international law protected the individual rights of citizens within their own countries. Eleanor Roosevelt, elected to serve as head of the UN Human Rights Commission,¹⁸ led the drafting discussions of the UDHR. Her influence is clear throughout the text of both the UDHR and its two implementing Covenants.¹⁹ The UDHR’s provision on the right to health²⁰ is complemented by the provision in the International Covenant on Economic, Social, and Cultural Rights (ICESCR), which is meant to elaborate on its meaning.²¹

Under international law, the over-stated distinction between positive and negative duties has been discarded for a focus on the three dimensions of state obligations flowing from all rights, whether civil and political or economic and social. Governments are obliged to **respect**, **protect** and **fulfill** the rights in treaties they ratify. In relation to health, these obligations imply the following:

Respect: A government must refrain from directly infringing upon the right to health, as it would by cutting funding for doctors working in underserved areas or systematically discriminating against certain populations in its healthcare system, for example.

Protect: A government is responsible for preventing third parties from violating the right to health. Eviscerating environmental regulations arguably violates the right to health, as does allowing price gouging by oligopolistic pharmaceutical companies.

Fulfill: A government must take steps to ensure all citizens have access to basic health services as well as preconditions for health, such as sanitation and water.

The ICESCR sets out the core provision relating to the right to health under international law. However, the provisions of the treaty are quite broad. While they recognize the right of everyone to enjoy “the highest attainable standard” of physical and mental health,²² they do not offer a recipe for implementation, nor do they take a position on the respective desirability of public or private financing for health care.

The UN Committee on Economic, Social, and Cultural Rights (CESCR), the primary body responsible for interpreting the ICESCR, has however developed guidelines on how the right to health should be interpreted at the national level.²³ The first fundamental component of those

guidelines is a *minimum floor* below which no country may fall, which in the case of health means ensuring essential primary health care for the entire population. In its General Comment No. 3, the CESCR clarified steps that should be taken by governments regardless of their “economic and political systems.”²⁴ In General Comment No. 14, the Committee enumerated four substantive interrelated elements which are essential to the right to health: **availability, accessibility, acceptability, and quality.**²⁵

Substantive Elements Required to Fulfill the Right to Health

Availability: Governments must ensure that health care is available to all sectors of the population. This requires that “functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity.”²⁶ It also means that the facilities that exist have to be capable of actually providing care. Basic determinants of health must be present, such as potable water, adequate sanitation, trained medical personnel who receive domestically competitive salaries, and essential medicines. According to the World Health Organization, basic health care also requires universally available immunizations and education about how to prevent and control prevailing health problems in the community.²⁷ In the United States, although there are a substantial number of medical facilities and personnel, these are concentrated in urban and white areas, while rural and minority areas often have insufficient services.²⁸

Accessibility: Health facilities, goods, and services must not only be available, but must also be accessible. Accessibility requires that basic healthcare services must be affordable for every person in society, and “poorer households should not be disproportionately burdened with health expenses as compared to richer households.”²⁹ Access to information about health—including access to information about sexual health—is required. In the US, the approximately 47 million people without health insurance, together with substantial bureaucratic, financial and sometimes cultural and language barriers to obtaining care, reflect failures of accessibility.

Acceptability: Under international law, acceptable health care is that which both meets ethical standards and is culturally appropriate. This requires binding ethical guidelines for doctors and other medical practitioners. If medical personnel do not speak the same language as their patients, an interpreter should be available. In addition, acceptable health care requires that ethical and cultural training be part of a medical education. In the US, disadvantaged minorities receive poorer health care than whites at least in part because there are disproportionately low numbers of minority caregivers, as well as because of unequal treatment of patients based on their race.³⁰

Quality: The state must ensure that health facilities, goods, and services are scientifically and medically sound. Quality requires skilled medical personnel that prescribe medicines and medical procedures appropriately. Health facilities must be adequately supplied with, among other things, scientifically approved and unexpired medicines and hospital equipment, adequate sanitation, and skilled medical personnel.³¹ Although some very high quality health

care is available in the US for the wealthy, studies indicate inconsistent levels of quality throughout the overall healthcare system, and alarming numbers of avoidable errors.³²

Procedural Protections of the Right to Health

A number of *procedural* protections complement the four substantive requirements listed above. The primary procedural protections include **non-retrogression, non-discrimination, participation, access to remedies, and information.**

Non-retrogression: Once a right to health is recognized, retrogression—or backsliding—is generally considered inconsistent with a country’s obligations and a government bears the burden of demonstrating that such retrogression was unavoidable and was as narrowly tailored in its effects and in its duration as possible.

Non-discrimination: Any sort of discrimination—whether on an individual level or system-wide—is a human rights violation. CESCR General Comment No. 14 explicitly prohibits discrimination on the basis of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status.³³

Remedy: When violations of the right to health occur, States must provide remedies. Remedies may redress individual abuses by providing civil or criminal penalties, or they may seek to correct system-wide violations by introducing changes in policy or governing legislation.

Participation: States must ensure that patients are fully able to participate in decisions regarding their own health on both an individual and a collective level. For example, patients should not be excluded from treatment decisions due to insurance company policies. Further, decisions regarding health policy and coverage decisions should be made on the basis of a participatory, public and transparent process.

Information: States are required to ensure that their population receives adequate information and education about medical practices and services (including those related to sexual and reproductive health).³⁴ The procedural requirement for information overlaps with the substantive requirement of accessibility because information is a prerequisite to accessing care. It is also a prerequisite to effective participation.

The emphasis on process in a human rights framework shows that the right to health goes beyond the latest drugs, sterile needles, or any particular service. Rather than implementing piecemeal fixes to discrete problems in the delivery of healthcare apparatus, the government’s obligation to respect, protect, and fulfill the right to health demands that policymakers approach healthcare reform with a view towards promoting improved health care as a dimension of social justice in the United States.

II. The Current US System

The United States is the only industrialized country that does not recognize a government's obligations to provide health care. In 1977, the Supreme Court went so far as to declare it unnecessary for Congress to require government funds for abortion services even when the right to such services were constitutionally protected.³⁵ At the federal level, the closest Americans have come to securing their right to health are programs like Medicare and Medicaid, which are rooted in the idea that the elderly and poor should be guaranteed a minimum level of health services. The State Children's Health Insurance Program (SCHIP), which like Medicaid provides federal funds to states to administer, was enacted in 1997 to expand insurance coverage to families with incomes within a certain percentage above the poverty line. Important as these programs are, the exclusivity of their premise contradicts the notion of a universal right to health elaborated under international law.

There is also a very limited right to emergency care in the United States at the federal level. In 1986, Congress enacted the Emergency Medical Treatment & Labor Act (EMTALA) to supersede disparate and sometimes conflicting common law precedents regarding rights of access to emergency services. Section 1867 of the Social Security Act establishes that all Medicare-participating hospitals that offer emergency services –*i.e.*, virtually all hospitals in the United States–must provide a medical screening examination when a request is made for examination or treatment for an emergency medical condition, including active labor, regardless of the person's ability to pay. If an emergency medical condition is detected, the hospitals are further required to provide stabilizing treatment for the patient and are not required to do any more.

In the US federalist system, much of the operationalization of the few healthcare entitlements that exist occurs at the state level. There is considerable variation among states both in law and practice, which is another factor that breeds inequity from the standpoint of international human rights law.³⁶ Furthermore, even the strongest legal provisions, such as Article 17 in the New York State Constitution, regard provisions of services as attending to the concerns of the “needy”, rather than fully recognizing access to health services as a basic right and a prerequisite to human dignity.³⁷ In many cases, therefore, as currently framed, even essential services and limited benefits can be taken away when the legislature so determines, which is inconsistent with a rights-based view of durable entitlements that are not subject to retrogression.

Even though there are recognitions of the special relationship between physician and patient and the failures of the market model with respect to health care, these are treated as exceptions to the default paradigm. American law and policy still generally approach healthcare as a commodity—either to be doled out to the needy as a matter of charity, or to be regulated through the market. Nonetheless, there have been repeated attempts to establish national health insurance in the United States. In 1915, the American Association for Labor Legislation

campaigned for sickness insurance. The campaign lost ground when the American Medical Association (AMA) reversed its position on compulsory health insurance provided through the state. President Truman officially endorsed a national health insurance scheme as proposed by the Wagner-Murray-Dingell bill, but the bill never came to a vote in Congress since it was vigorously opposed by representatives of organized physicians and pharmaceuticals, who classified it as “socialized medicine.” Associations such as the AMA spent over a quarter of a million dollars in giving out misinformation about the bill and equating it with communism at a time when McCarthyism was on the rise in the United States.³⁸

Some public funding does exist for certain groups (e.g. those over the age of 65, those poor enough to meet Medicaid criteria or children poor enough to meet SCHIP criteria, and the military), but private financing is meant to cover everyone else.³⁹ Although some other industrialized countries also incorporate private financing, there is typically a governmental safety net that ensures equity and access. In the Netherlands, for example, the wealthiest 36 percent of the population is responsible for paying for most of its own care, while public funds cover the rest of the population.⁴⁰ France also has a thriving supplemental insurance market, even though the national health insurance covers the population. The problem with US health care is not the mixture of public and private funding *per se*, but rather the failure of the government to step in and level the playing field in the face of obvious inequities in the system.

Many recent proposals related to health care reform fail to address this underlying problem with the US system. For example, proposals that call for “individual mandates” would require individuals to purchase health insurance in the same way they do auto insurance. From a human rights perspective, health is a right because it is a fundamental, non-optional requirement for human dignity. Driving a car is not. Shifting our society’s responsibility regarding health onto the individual means that existing inequities in our society will likely be once again exaggerated in health provision. Critics of individual mandates, which have been enacted in Massachusetts, have pointed out that the poor will likely have minimum packages of coverage or plans with exceptionally high premiums, while the drivers of inequity in the way medicine is practiced and delivered in this country will be unaffected. Setting aside questions regarding the sustainability of financing of these plans, from a rights perspective that emphasizes the importance of health claims as assets of citizenship, this approach is untenable and unjust.

The Legal Structure

Health care in the United States is financed and delivered according to terms set out in a complex array of federal and state laws and regulations, administered through a complex array of federal and state institutions. Laws range from the specific, such as the requirement that managed care organizations approve hospital stays for mothers who have just given birth,⁴¹ to the general, such as the Employment Retirement Income Security Act (ERISA) preemption provision—a federal statute which essentially prohibits individuals from suing their managed

care organizations.⁴² The legal structure regulating health care is bifurcated into two main branches: laws that regulate government-run programs such as Medicare, and laws that regulate private sector health care groups such as managed care organizations (MCOs).⁴³

The funding framework for government-administered programs stems from a 1965 Amendment to the Social Security Act signed into law by President Lyndon B. Johnson. The Amendment was designed to create safety nets for two groups of vulnerable Americans: the elderly and the poor. The elderly (defined as those over the age of 65) are eligible for *Medicare*, which is financed by federal funds.⁴⁴ The poor (defined differently by each state) are eligible for *Medicaid*, which is financed by a combination of federal and state funds.⁴⁵ Federal funds also provide health insurance coverage for the military and for federal employees.⁴⁶

In December 2003, the Medicare Prescription Drug, Improvement, and Modernization Act (MMA) introduced the most sweeping modifications to the Medicare and Medicaid programs since their creation. The MMA includes two significant changes: first, it splits coverage for prescription drugs off from the rest of health care coverage, creating a new group of “prescription drug plans” to fund those drugs. Second, it provides substantial incentives for private health care providers to enter the Medicare system. Previous attempts by private health plans to enter Medicare have not been profitable, but the new MMA has proven extremely profitable for pharmaceutical companies.⁴⁷ At the same time, the immense complexity that results from what Paul Krugman terms the plan’s “gratuitous privatization” has resulted in delayed implementation, tremendous overhead costs, and the continuation of a system in which elderly and vulnerable Americans have the poorest health care coverage.⁴⁸

Given the MMA’s efforts to involve the private sector in Medicare, the laws governing private sector health care funding are more important than ever. Under President Nixon, the HMO Act (1973) kick-started the managed care industry by requiring all health care providers to accept patients from at least two managed care organizations.⁴⁹ The Act was fueled by the concern that physicians had a financial incentive to provide more health services than necessary.⁵⁰ HMOs were seen as a way to curb waste by penalizing doctors for providing unnecessary services. However, despite some success in eliminating waste, and despite the capacity of HMOs to negotiate drug discounts and ensure quality control, in the 1990’s the organizations began to come under increasingly heavy criticism for depriving their members of needed treatments in order to save costs, for ignoring unprofitable problems of quality, and for creating burdensome administrative barriers to care.⁵¹

Some measures have been taken to curb the worst effects of managed care’s cost-cutting in relation to patient care. However, one reason it is difficult to assess the scope of these concerns—or to address them systematically—is that health care is largely regulated through the courts, one case at a time. Litigation-based regulation is not particularly effective for improving HMOs’ responsiveness because the ERISA preemption provision exempts most managed care

providers from state-based civil liability, including claims of wrongful death and other traditionally state-regulated torts.⁵² Thus, most of the time, individuals cannot sue their HMOs.

The Financial Structure: Who Pays? Who Profits?

The United States spends more on health care per person than any other industrialized country.⁵³ The latest OECD comparison calculated US costs at \$6,401 per person, per year.⁵⁴ Total health costs continue to increase at approximately 7 percent per year, with costs projected to increase from \$2.17 trillion to \$2.88 trillion in 2010.⁵⁵ Yet the US has a lower-than-average physician to patient ratio, has one of the lowest rates of acute care beds per capita among industrialized countries, and is the only one that does not provide universal access to medical services.⁵⁶ The lack of available care is even more acute for minority patients, and in particular for patients who are black or Hispanic.⁵⁷ Where *does* all that money go—if it is not going to increase access and availability? This is a central question for any rights-based reform to consider and address.

There are many reasons why health care in the US is so expensive, ranging from high administrative costs to exorbitant drug costs, as well as inflated salaries paid to physicians who are far more likely to be specialists—and therefore earning more—than are their counterparts in other industrialized countries. As healthcare becomes increasingly reliant on high-tech interventions⁵⁸ and the Baby-boom generation grows older, and the American population grows in size, costs will continue to rise. Health economists have been keen to explore how to contain the growth of these costs through outcomes assessments and examinations of whether certain interventions are medically appropriate.⁵⁹

Less scholarly attention has been devoted to the other manifestations of the failures of a market model: the profits made by health maintenance organizations and pharmaceutical companies, which dwarf those of other industries and suggest significant deadweight loss.⁶⁰ For example, in 2001, as the overall profits of Fortune 500 companies declined by 53%, the top 10 US drug makers increased their profits by 33%, from \$28 billion to \$37 billion. In the first half of 2006, pharmaceutical company profits increased by over \$8 billion dollars, due to the introduction of the new Medicare drug program discussed above.⁶¹ Managed care organizations have also reported high profit growth, by as much as 73% in the second quarter of 2003 (a \$1.8 billion increase over 2002).⁶² Lavish salaries accompany these profits. In 2002, William W. McGuire, the Chairman and CEO of UnitedHealth Group, had a reported net worth of nearly \$530 million.⁶³ Meanwhile, HMO premiums for 2004 increased at an average rate of almost 18%, prompting more companies to require their employees to contribute to their health insurance plans.⁶⁴

Wide profit margins for shareholders in managed care organizations, multi-million dollar salaries for pharmaceutical executives, and vast sums spent on industry lobbying represent hundreds of millions of dollars that are leaving the system without advancing research, delivering care, or paying medical providers. Among healthcare organizations, pharmaceuticals

spend the most on lobbying (\$96 million in 2000) followed by physicians, and healthcare organizations.⁶⁵ Of the 1192 organizations involved in healthcare lobbying, the AMA spent \$17million and the American Hospital Association \$10 million. Couple this waste with rising insurance premiums, a growing population, and the growing costs of providing quality care, and one begins to get a sense of why an increasing number of Americans cannot afford access to even basic care.

III. International Standards in the US Context

Although the US healthcare system provides some of the best care in the world for those who can afford to pay,⁶⁶ overall, the healthcare system falls far short of international human rights standards. Many of the existing problems in the system will only continue to deteriorate as long as health care is considered primarily a commodity, rather than as a basic right. Although the US government is not a party to the ICESCR⁶⁷, this section will examine how the US healthcare system fares with respect to the four interrelated substantive elements identified by the CESCR as essential to the right to health: **availability, accessibility, acceptability, and quality.**

Availability

For health care to be considered “available,” facilities and personnel must exist in sufficient quantity and be located within reasonable proximity to all communities, regardless of their geographic location or racial, ethnic, or cultural makeup. In the United States, health care cannot be considered truly available, given the drastic shortages of care for people living in rural areas and for minorities.

As of 2002, there were approximately 50 million people living in underserved areas in the United States.⁶⁸ Such shortages persist despite the large numbers of doctors who graduate every year from medical school. Federal policy initiatives have successfully doubled the total number of doctors since 1970, but efforts have been based on the faulty assumption that market demand will even out geographical disparities.⁶⁹ Instead, the result has been over-saturation of urban markets, and concomitant under-supply in rural and minority-dominated areas. There is a sharp divide between rural and urban areas in their doctor-patient ratios. Cities such as Washington, D.C., Boston, and San Francisco benefit from a ratio as high as 1 physician per 167 persons,⁷⁰ while rural areas suffer severe medical service shortages.⁷¹ Appalachia, for example, has less than 1 physician per 1000 persons.⁷² The coverage that does exist in rural areas is largely due to training subsidized at the state and federal levels—a fact that underscores the importance of nonprofit (whether governmental or non-governmental) participation in health care delivery.⁷³

Compounding the rural-urban divide is a significant racial gap in the availability of medical services. According to a study published in the *New England Journal of Medicine*, “communities with high proportions of black and Hispanic residents were four times as likely as others to have

a shortage of physicians, regardless of community income.”⁷⁴ In July 2000, the federal government designated 2,706 geographic areas, population groups, and facilities as “primary medical care health professional shortage” areas. These areas encompass 50 million people, a disproportionate number of whom are minorities.⁷⁵ Since then, dozens of reports have continued to document the “raw, festering wound on America’s social conscience” that is the crisis of minority health care.⁷⁶

The lack of healthcare facilities, goods, and services in rural and minority areas in the United States violates the requirement that health care be available. A human rights-based healthcare policy would entail maintaining training programs and incentives for those seeking to practice in underserved areas,⁷⁷ and would focus on ensuring availability for all populations in the United States. This does not mean putting a hospital on every corner, but it does require narrowing the gap in service availability between rural or minority areas and urban or white areas.

Accessibility

Even when health care is *available*, it may not be *accessible*. For example, healthcare in the United States is closely linked with holding a full-time job. And while those that are unemployed can purchase health insurance it is often expensive. Even those with health insurance are frequently subject to large co-payments or pharmaceutical bills that preclude true economic access to health care. They also face growing fears of losing their benefits as employer insurance premiums rise.⁷⁸ This lack of economic accessibility (affordability) is compounded by a lack of access to information concerning health services and issues and by an increasingly complex series of bureaucratic hurdles to access exemptions to payments.

From 2002-2003, approximately one-third of the population lacked health insurance for at least part of the year,⁷⁹ and in 2006, 15.8% of the population lacked health insurance for the full year.⁸⁰ Health insurance is so prohibitively expensive that going without is not confined to the indigent or to those who are unemployed. Indeed, 73% of the uninsured between 18 and 65 worked for part of the year.⁸¹ In short, for those Americans who cannot afford medical insurance, there is very limited meaningful access to health care.⁸²

The uninsured receive less preventive care, less appropriate care for chronic illnesses, and fewer hospital services when admitted.⁸³ They are also more likely to die prematurely.⁸⁴ Because they do not enjoy the benefit of negotiated discounts or set fee schedules they also tend to pay more for health services than those with insurance.⁸⁵ Ironically, people without insurance pick up a large portion of the nation’s healthcare tab. In 2001, the uninsured spent \$80.1 billion on health care.⁸⁶

Overall, the lowest income patients and those with chronic health conditions end up carrying the greatest healthcare burden as a percentage of their family income.⁸⁷ The inequity of the US system is reflected in the World Health Organization’s statistical analysis comparing health systems around the world: the US ranks 54th and 55th (tying with Fiji) in terms of the

fairness of financial contribution.⁸⁸ This situation contravenes human rights principles as set forth in the CESCR’s guideline that “poorer households should not be disproportionately burdened with health expenses as compared to richer households.”⁸⁹ Although coverage for the very poorest Americans is offered through Medicaid, this fails to reach millions of Americans who do not qualify as the “poorest” but still have far too little money to afford purchasing their own health insurance and do not have access to it through employment. In addition, many who are eligible for Medicaid do not join because of the program’s administrative burdens and web of complexities.⁹⁰

In addition to issues of financial accessibility and inequity, the US system includes barriers to accessibilities because of the way in which it is structured. With federal, state, and private funding sources, hundreds of individual insurance plans to choose from, and different referral procedures for different types of delivery systems, obtaining basic care can become a bureaucratic nightmare for patients. Although a complicated system may deliver adequate health care, the fact is that the current system *does not*, and part of the reason is its complexity.

The complicated system of billing and payment has become a significant barrier to accessibility. Individuals trying to select an insurance plan face a bewildering array of premiums, co-payments, and services. Wading through all these “choices”—ostensibly created to increase accessibility—is an overwhelming task.⁹¹ When administrative complexities create barriers to accessibility, inhibit the ability to monitor delivery of health services, and deprive people of having a voice in their own treatment, those complexities become human rights concerns.

Acceptability

The United States has a strong history of requiring its physicians and other medical personnel to adhere to minimum ethical guidelines.⁹² Although there are certainly examples of individual practitioners who may violate these ethical requirements, the vast majority of workers in the health profession uphold high ethical standards.

In addition to being ethically guided, acceptable health care must be culturally sensitive under international law. Unfortunately, the US health care system has not found culturally appropriate care to be as important as ethical care and, as a result, there is a significant gap in the quality of care received by minorities. In 1994, the United Nations Special Rapporteur on racism found that in the United States “the consequences of racism and racial discrimination in the field of health are reflected in the disparity in access to health care, the infant mortality rates and the life expectancy of Whites and Blacks or Latino Americans.”⁹³ Fifteen years after his visit, the situation has not improved. It is perhaps not a coincidence that minorities are also more likely to die of cancer and heart disease,⁹⁴ less likely to get preventative care and screening,⁹⁵ and less likely to receive analgesia in emergency rooms for bone fractures.⁹⁶ This is not typically a result of deliberate discrimination on part of medical workers, but instead reflects system-wide inequalities.

In a country where minorities constitute over one quarter of the population (and are projected to constitute one third by 2010), they still represent less than 10% of the health care workforce.⁹⁷ The meager representation of minorities among medical professionals must be addressed by any rights-based evaluation of health care reform. Although the minority health care problem cross-cuts each legal requirement for the right to health, it is particularly relevant to the requirement for culturally acceptable care.

The patient-doctor relationship is critical to effective health care delivery, which requires trust between a physician and patient, a certain level of comfort, and uncompromised communication.⁹⁸ Research indicates that minority patients have a higher level of comfort when treated by physicians of their own race,⁹⁹ and that they are more likely to follow through with necessary treatments and seek preventive care when they are satisfied with their physicians.¹⁰⁰ The reasons vary, and include language barriers and the patient's level of education.¹⁰¹ For African-Americans, a physician's recommended treatment can be compromised by a "mistrust of health professionals that stems from racial discrimination and the history of segregated and inferior care for minorities."¹⁰²

According to a 1995 study by the Pew Health Professions Commission, "a substantial body of literature concludes that culturally sensitive care is good care."¹⁰³ To achieve this, the Commission recommended that medical schools both increase the number of minority students and integrate cultural sensitivity training into the basic medical curriculum.¹⁰⁴ Increasing the number of minority students is also shown to increase access to medical services in under-served communities.¹⁰⁵

Language is also a significant barrier to acceptable –and quality–care. Among the most important laws currently *not* being enforced is the Department of Health and Human Services regulation requiring all medical facilities that accept federal money to provide adequate translation services for non-English speaking patients.¹⁰⁶ The law is particularly important for victims of sexual and intimate partner violence, whose medical needs cannot be met without translation that is provided by a non-family member.¹⁰⁷ One study found that no Spanish speaker could be found at over 50% of the hospitals included in a survey of applicable hospitals, despite the regulation.¹⁰⁸

Despite increasing concern among medical professionals about issues of diversity,¹⁰⁹ the problem remains entrenched in the US health care system. In the early 1990s, projects like the Association of American Medical School's "3000 by 2000" increased the percentage of minorities in medical schools.¹¹⁰ Since then, however, legal attacks on affirmative action policies have taken their toll: over 60% of public medical schools have experienced declines in black and Latino, and other minority student enrollment since 1994, resulting in a collective decrease of 9.1% in the number of minority students enrolled.¹¹¹ Despite the 2003 Supreme Court decision allowing continued affirmative action for educational purposes in professional schools at the federal level, state policies against affirmative action continue to result in declining

minority representation in the medical field.¹¹² Furthermore, federal budget proposals aimed to scale back even further the funding available for programs supporting minority recruitment in the medical profession.¹¹³

A human rights-based reform to the health care system would require all medical institutions to introduce training in cultural competency for all medical personnel. However, it would go further: it would require institutional changes to ensure that minorities have equal access to primary providers who come to know them and have relationships with them and can speak their language or have constant access to interpreters; it would encourage the training of minority health professionals; and it would ensure institutional monitoring and enforcement of racial equality in treatment.

Quality

The United States boasts some of the best physicians and most state-of-the-art medical technologies and techniques anywhere. Top medical programs with stellar reputations for training and research attract students from around the world.¹¹⁴ However, despite these achievements, the quality of care delivered to patients varies widely, and good quality care is unavailable to vast numbers of Americans.¹¹⁵

The Institute of Medicine (IOM)¹¹⁶ has called attention to the growing safety flaws and quality problems in the US health care system.¹¹⁷ The IOM has divided these quality problems into three categories: overuse, under-use, and misuse.¹¹⁸ **Overuse** occurs when health services are provided even though the potential risks outweigh any potential benefits. For example, one study found that sixty percent of patients reporting symptoms associated with the common cold filled prescriptions for antibiotics.¹¹⁹ **Under-use** stems from lack of insurance and lack of preventive care, including when those who are insured fail to seek treatment for which the potential benefits outweigh potential risks.¹²⁰ One example of under-use is that approximately one-quarter of American children have not received appropriate immunizations.¹²¹ Finally, **misuse** includes errors by medical personnel, which can be difficult to document because instances often go unreported.¹²² According to the IOM, “at least 44,000 and perhaps as many as 98,000 Americans die in hospitals each year as a result of medical errors.”¹²³ This is more than the number of people who die in car accidents every year, and more than those that die from HIV-AIDS.¹²⁴

Poor quality health care is expensive: unnecessary treatments cost money, correcting mistreatment costs money, and treatments that could have been avoided by earlier care cost money. However, waste and mistreatment are difficult to fix under the current system in part because payment arrangements are developed by private companies (such as HMOs) whose decisions are based on cost containment or issues of financial access for their members, but necessarily *not* on larger questions about quality of care.¹²⁵ Although health care costs could be reduced by eliminating waste, this process can be expensive in the short term. The problems in

quality are largely because of the current system design, and not because individual providers or products are deficient.¹²⁶ To improve the quality of care and meet international standards requires more than technology assessment or outcomes assessment performed by experts; it requires shifting public debates about healthcare reform in the United States.

IV. Conclusions

The neglect of basic medical services for much of its population and the commoditization of healthcare belies the United States' reputation as a leader in the field of health. As the number of uninsured continues to rise, and the cost of health care spirals out of control,¹²⁷ it is increasingly urgent to rethink the way the US finances health care and the delivery of services, including essential drugs.

Notwithstanding the fact that the United States is one of the few countries in the world not to have ratified the ICESCR¹²⁸, shifts in American's understandings of constituent rights may usefully be informed not merely by the healthcare systems of other industrialized countries but also by the principles enunciated in international human rights law. Reforms rooted in these human rights principles can contribute to lasting improvement in the healthcare situation for the majority of Americans.

Health Care Must be Universally Available and Accessible

Americans living in rural and minority areas must have access to health care services. Ensuring access means more than simply extending health insurance to the uninsured, however. It also means addressing the growing problem of those with health insurance who still cannot afford adequate medical services. The type of health coverage provided is as important as the number of people enrolled in a program.

Universal access to health services requires a fundamental change in the way the US approaches health care. That is, the default for policymaking about health care allocation cannot be guided by the "invisible hand" of the marketplace. Millions of uninsured and underinsured Americans, minority Americans without access to appropriate services, and rural patients unable to access health care facilities all indicate that market forces simply will not fill the gaps in health care coverage. In all other industrialized nations, there is a starting assumption that the state has a role to play in leveling the playing field and providing a safety net in terms of health care.

The way in which universal coverage is implemented tends to be deeply culturally contingent and path dependent. For example, the United Kingdom has a national health service where the government is responsible for financing and delivery of services while Canada has a single-payer system where the government is only responsible for financing services. Other models use private-public mixtures that still incorporate rights-based principles. In France, for example, national health insurance acts as a branch of Social Security, and all residents have equal access to private or public facilities.¹²⁹ No matter what the financing structure, countries

that have successfully implemented universal access to health coverage have in common their refusal to rely solely on market forces to deliver care, and their political commitment to providing universal access as a matter of right.

Increase Quality and Diversity, Including Cultural Sensitivity

To meet international standards, the federal government must take responsibility for ensuring that health care is of good quality and culturally appropriate. This means enforcing existing regulations, as well as expanding cultural competency training and protections for cultural differences. As much as US governments have historically tended to scoff at international treaty obligations, the fact remains that as a state party to the International Covenant on the Elimination of all Forms of Racial Discrimination (ICERD),¹³⁰ the United States is legally bound to address the systematic racial discrimination within the US health care system. In fact, the US government has admitted that minorities receive “less adequate access to health insurance and health care,”¹³¹ and the governing Committee for ICERD has recommended that the United States ensure the right of everyone to access public and private health care.¹³²

Beyond enforcing the laws that already exist, there must also be a commitment to addressing underlying structural factors that increase racial disparities in care, including increasing minority representation within the medical profession and providing funding for medical personnel who are minorities or who wish to practice in underserved minority areas. Cultural competency training should be made an integrated part of training for all physicians and other health professionals. Further, such programs need to be accompanied by institutional change that facilitates greater access to care for minorities.

The parallel and inferior health care system encountered by many minorities is inconsistent with a universal right to available, accessible, appropriate, and quality care. It is also inconsistent with US commitments to prevent contemporary forms of racial discrimination. The piecemeal laws created to provide greater access for minority patients are an important step in the process of recognizing the depth of these issues. A more integral, human rights-based perspective would require placing race disparities in health care in their larger social context and using internationally agreed-upon criteria to evaluate proposed policy solutions.

Health Care Policy Needs to be About The Right to Health

Americans pay more per capita on health care than the population of any other country in the world, and receive far less for the money. Under the current system, a tremendous amount of that money goes towards private-sector profits rather than building new rural care facilities, providing wider coverage, or implementing new quality control measures. Rights-based reform does not dictate financing mechanisms—any mixture of private and public funding may fail or meet human rights standards—but it does require that all Americans enjoy the minimum

standards of availability, accessibility, acceptability, and quality when it comes to their health care.

All Americans should have access to basic health care as a matter of right. Although many initiatives have been proposed for healthcare reform, including universal health insurance, a campaign based on a right to health steps back from questions about how to most efficiently reorganize the financing of the health care system to the *underlying purpose* of the healthcare system. The international norms are then able to provide standards by which to evaluate competing proposals. Framing debates about healthcare reform as a matter of fundamental rights underscores that people must have a voice in the decisions that affect their well-being, and thus demands a participatory process for reform where those who are affected have the opportunity for genuine consultation.

Embracing Roosevelt's dictum that "freedom is no half-and-half affair" would return the human being to the center of health care legislation, policies, and practices. It was the active support of the civil rights community that enabled one of the most important strides towards improving the national health care system—the enactment of Medicare as part of Lyndon Johnson's "war on poverty." The widespread grassroots outreach of civil rights activists of the 1960s, with the support of large unions like the AFL-CIO, lent credibility to the reform and gave it more emotional and social relevance. Like the civil rights movement, the human rights movement can provide a universal and popular language to the cause of health care reform. The time has come for the US to fully recognize the universality of all human rights, and to join others in implementing a healthcare system that fulfils Franklin D. Roosevelt's vision.

Endnotes

- ¹ For more on the evolution of economic and social rights in the United States from Franklin D. Roosevelt's time to the present, see Cass R. Sunstein, *The Second Bill of Rights: FDR's Unfinished Revolution and Why We Need It More Than Ever* (New York: Basic Books, 2004).
- ² The four freedoms include freedom of speech, freedom of religion, freedom from want, and freedom from fear. *Congressional Record*, 1941, Vol. 87, Pt. I. Roosevelt's "Second Bill of Rights" also included the right to work, the right to earn enough for adequate food, clothing, and recreation, the right of farmers and businessmen to fair business practices, markets, and trade, the right to housing, the right to economic security, and the right to education. 11 January 1944 message to Congress on the State of the Union, available at <http://www.worldpolicy.org/globalrights/econrights/fdr-econbill.html>.
- ³ The Commonwealth Fund, *Mirror, Mirror on the Wall: An International Update on the Comparative Performance of American Health Care* (New York: The Commonwealth Fund, 2007).
- ⁴ Percent working calculated according to uninsured between 18 and 64 years old. US Census Bureau, Housing and Household Economic Statistics Division. *Table 6: People With or Without Health Insurance Coverage by Selected Characteristics: 2005 and 2006*, http://www.census.gov/hhes/www/hlthins/hlthin06/p60no233_table6.pdf.
- ⁵ Institute of Medicine, *To Err is Human: Building a Safer Health System* (Washington, DC: National Academies Press, 2000).
- ⁶ For some of this literature, see e.g.: Cutler, David M. and Mark McClellan, 2001. "Is Technological Change in Medicine Worth It?" *Health Affairs* (Sept/Oct): 11-29; Emanuel, Ezekiel, and Victor R. Fuchs, "Solved! It covers everyone. It cuts costs. It can get through Congress. Why Universal Healthcare Vouchers is the next big idea," *Washington Monthly*, June, 2005; Fisher, Elliott S., Douglas O. Staiger, Julie P.W. Bynum, and Daniel J. Gottlieb, "Creating Accountable Care Organizations: The Extended Medical Staff," *Health Affairs*, December 21, 2006:W44-W57; Garber, Alan M., "Cost-Effectiveness and Evidence Evaluation as Criteria for Coverage Policy," *Health Affairs* W4, May 2004: 284-96; Hayward, Rodney A., David M. Kent, Sandeep Vijan, and Timothy P. Hofer, "Reporting Clinical Trial Results to Inform Providers, Payers, and Consumers," *Health Affairs* 24(6), November/December 2005: 1571-81; Kotlikoff, Laurence J. and Hagist, Christian, "Who's Going Broke? Comparing Growth in Healthcare Costs in Ten OECD Countries" (December 2005). NBER Working Paper No. W11833 Available at SSRN: <http://ssrn.com/abstract=875666>; Pearson, Steven, "Health Technology Assessment and Comparative Effectiveness: Recommendations for Improving Health Care Value in the United States," 2007.22.
- ⁷ UN Millennium Project Task Force on Child Health and Maternal Health. *Who's Got the Power? Transforming health systems for women and children*. 2005:11, <http://www.unmillenniumproject.org/documents/maternalchild-complete.pdf>.
- ⁸ The US has not ratified the following international treaties that include economic and social rights: the International Covenant on Economic, Social and Cultural Rights, UNG.A. res. 2200A (XXI) of 16 December 1966 [hereinafter "ICESCR"], the Convention on the Elimination of All Forms of Discrimination against Women, the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, the Convention on the Rights of the Child, the American Convention on Human Rights, and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, 'Protocol of San Salvador'. See the Office of the High Commissioner for Human Rights (<http://www.ohchr.org>) and the Organization of American States (<http://www.oas.org>).
- ⁹ Carol Anderson, *Eyes Off the Prize: The United Nations and the African American Struggle for Human Rights, 1944-1955* (Boston: Cambridge University Press 2003) (Addressing this issue in the struggle for black equality in the United States).
- ¹⁰ Bruce Vladeck, "Universal Health Insurance in the United States: Reflections on the Past, the Present, and the Future," *American Journal of Public Health*, vol. 93(1) (2003), pp. 16-19.
- ¹¹ Universal Declaration of Human Rights, G.A. res. 217A (III), UN Doc A/810 (1948) [hereinafter "UDHR"]. Although the UDHR is a General Assembly declaration instead of a treaty, it may be legally binding on the US as either customary international law or as authoritative interpretation of the UN Charter. See Henry J. Steiner & Philip Alston, *International Human Rights in Context: Law, Politics, Morals* (Oxford: Oxford University Press, 2000), p. 143.
- ¹² International Covenant on Economic, Social and Cultural Rights (ICESCR), G.A. Res. 2200 (XXI), UN Doc. A/6316 (1966) [hereinafter "ICESCR"]. The US signed the ICESCR on 5 October 1977, but has not yet been ratified, which is required to make it legally binding. However, the US signature indicates its support of the ICESCR provisions, and makes its terms politically binding. In addition, the US is part of an international system that views right to health as an essential human right, including the World Health Organization Charter, the Conventions Nos. 102 and 103 of the International Labor Organization, and Rules 22 to 26 of the Standard Minimum Rules for the Treatment of Prisoners

- ¹³ For example, for a discussion of how and why the right to health should be framed in terms of power alignments and the ability to control one's own health, see Alicia Ely Yamin, "Defining Questions: Situating Issues of Power in the Formulation of a Right to Health under International Law," *Human Rights Quarterly* vol. 18(2) (1996) pp. 398-438.
- ¹⁴ UN Committee on Economic, Social and Cultural Rights [hereinafter "CESCR"], *General Comment 14, The right to the highest attainable standard of health*, CESCR, 22nd Sess., para. 4, UN Doc. E/CN.12/2000/4 (2000).
- ¹⁵ ICESCR, art. 12. Also see Brigit Toebes, *The Right to Health as a Human Right in International Law* (Antwerp: Intersentia-Hart, 1998).
- ¹⁶ The Environmental Protection Agency, the Occupational Safety and Health Administration and the Food and Drug Administration are three central institutions engaged in monitoring environmental, occupational and food safety standards, respectively.
- ¹⁷ UDHR preamble, para. 2 ("the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people").
- ¹⁸ Paul Gordon Lauren, *The Evolution of International Human Rights: Visions Seen* (Philadelphia, PA: University of Pennsylvania Press, 1998), p. 218.
- ¹⁹ Together, the Covenants and the UDHR constitute the International Bill of Human Rights.
- ²⁰ UDHR article 25(1) reads: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control." For a discussion on how article 25 was formulated, see Brigit Toebes, *The Right to Health as a Human Right in International Law* (Antwerp: Intersentia-Hart, 1998), p., 36-40. Initially the right was proposed as "access to medical care," but that was considered insufficient since it left out public health measures. It is clear from the drafting discussion that a right to medical care is essential to the provision.
- ²¹ ICESCR article 12 reads: "1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child; (b) The improvement of all aspects of environmental and industrial hygiene; (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness."
- ²² This phrasing, similar to the constitution of the World Health Organization, was based on suggestion from the United States delegation. The right to health is also recognized in regional instruments including the American Declaration on the Rights and Duties of Man (article 33), the European Social Charter (article 11), and the African Charter on Human and Peoples' rights (article 16), and in other international treaties such as the Convention on the Rights of the Child (articles 23 and 24), Convention on the Elimination of Discrimination Against Women (article 10(a), 11(f), 12, and 14(b)), and Convention on the Elimination of All Forms of Racial Discrimination (article 5(e)(iv)).
- ²³ Those guidelines appear in the CESCR's General Comment 14. General Comments originated in the third session of the Committee and are prepared to assist the State Parties in interpreting and fulfilling their obligations.
- ²⁴ CESCR *General Comment No. 3, The nature of State Parties obligations*, 5th Sess., para. 8, UN Doc. E/1991/93 (1990). ("... in terms of political and economic systems the Covenant is neutral and its principals cannot accurately be described as being predicated exclusively upon the need for, or the desirability of, a socialist or a capitalist system, or a mixed, centrally planned, or *laissez-faire* economy, or upon any other particular approach.")
- ²⁵ CESCR General Comment 14, at paras. 9, 12. There is overlap between these categories, but we have chosen to use a narrow definition of each. For example, we restrict "availability" to geographical availability, and focus in "accessibility" on economic accessibility.
- ²⁶ *Id.*
- ²⁷ Declaration of Alma-Ata, 1978, World Health Organization at Art. VII. Available at: http://www.who.dk/AboutWHO/Policy/20010827_1.
- ²⁸ Grant Makers in Health, *Training the Health Workforce of Tomorrow, Issue Brief No. 12* (Washington, DC: Grant Makers in Health, 2002), p. 2.
- ²⁹ CESCR General Comment 14, at para. 12.
- ³⁰ Brian D. Smedley et. al. (eds.), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2003).
- ³¹ CESCR General Comment 14, at para 12.

- ³² Institute of Medicine, National Academy of Sciences, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, D.C.: Institute of Medicine, 2001), p. 13.
- ³³ CESCR General Comment 14, at para 18.
- ³⁴ *Id.*, at para. 11 (“The Committee interprets the right to health, as defined in article 12.1, as an inclusive right extending... [to] access to health-related education and information, including on sexual and reproductive health.”)
- ³⁵ *Maher v. Roe* (1977), 432 US 464 at 469.
- ³⁶ Under international human rights law, even in a federalist system, the federal government is ultimately responsible for ensuring respect, protection and fulfillment of certain minimum guarantees within its territory.
- ³⁷ The Constitution of the State of New York, article 17 (January 1, 2004) (“The aid, care and support of the needy are public concerns and shall be provided by the state...”). New York’s provision is one of the strongest because it specifies within article 17 that the “protection and promotion of the health of the inhabitants of the state are matters of public concern” Art. XVII §3. Some state provisions— including those from Alaska and Hawaii—do actually require the legislature (in Alaska) or the state (in Hawaii) to provide for “public health.” However, their breadth is limited by federal restrictions like ERISA preemption. See the Constitution of the State of Alaska, Article 7, Sec. 4, The Constitution of the State of Hawaii, Article IX, Sec. 1.
- ³⁸ Maureen Glabman, “Lobbyists That the Founders Just Never Dreamed of,” *Managed Care Magazine* (MediMedia USA, 2002), <http://www.managedcaremag.com/archives/0208/0208.lobbying.html>
- ³⁹ Private financing can be through employment or personal purchase of health care plans.
- ⁴⁰ Carolyn Hughes Tuohy et al., “How Does Private Finance Affect Public Health Care Systems? Marshaling the Evidence from OECD Nations,” *Journal of Health Politics, Policy and Law*, vol. 29(3) (2004), pp. 359-396.
- ⁴¹ 42 USCS Sec. 300gg-4 (1996).
- ⁴² 29 USC. § 1144(a). ERISA is a federal statute that preempts state-based causes of action against applicable employee benefit plans. The purpose of ERISA is to allow broad removal to federal court to ensure a uniform regulatory regime over employee benefit plans. *AETNA Health Inc. v. Davila* (2004), 542 US 200.
- ⁴³ There are several kinds of MCOs. Health Maintenance Organizations (HMOs) are probably most the most talked about MCO, but MCOs also include Preferred Provider Organizations and Point of Service Plans. The payment structures and treatment options for these plans vary widely. For more information, see Stacey Duncan-Jackson et al. “Understanding Managed Care” (Michigan State University: Institute for Health Care Studies, no date), <http://www.healthteam.msu.edu/imc/modules/UMC2003/UMC2003.pdf>.
- ⁴⁴ The current version of Medicare is at 42 USC. 1395 et seq.
- ⁴⁵ 42 USC. 1396 et seq.
- ⁴⁶ Act of Sept. 21, 1958, Pub. L. No. 85-861, 72 Stat. 1447 (codified as amended at 10 USC. Sec. 1077 (1988).
- ⁴⁷ Rep. Henry A. Waxman. “Analysis: Pharmaceutical Industry Profits Increase by Over \$8 Billion After Medicare Drug Plan Goes Into Effect.” US House of Representatives (2006), <http://oversight.house.gov/documents/20060919115623-70677.pdf>.
- ⁴⁸ Paul Krugman. “The Plot Against Medicare,” *The New York Times* (April 20, 2007).
- ⁴⁹ Ester Uyebrara and Margaret Thomas. “Health Maintenance Organization and the HMO Act of 1973.” *The Rand Corporation*, (Santa Monica, CA. 1975)
- ⁵⁰ Stacey Duncan-Jackson et al. “Understanding Managed Care” (Michigan State University: Institute for Health Care Studies, no date), <http://www.healthteam.msu.edu/imc/modules/UMC2003/UMC2003.pdf>.
- ⁵¹ Many of these claims have gone to court. See, e.g. *Plocica vs. NYLCare et al* (1998).
- ⁵² Torts are civil—as opposed to criminal—wrongs that do not result from disputes over contracts. The Supreme Court recently upheld ERISA preemption, but dicta indicate a “rising judicial chorus urging that Congress and the Supreme Court revisit what is an unjust and increasingly tangled ERISA regime”. *DiFelice v. AETNA US Health care*, 346 F.3d 442, 453 (CA3 2003) (Becker, J., concurring), *AETNA Health Inc. v. Davila*, 542 US 200 (2004) (Ginsburg, J., concurring).
- ⁵³ Gerard F. Anderson et. al., “It’s the Prices, Stupid: Why the United States is so Different from Other Countries,” *Health Affairs* vol. 22(3) (2003), pp. 89-105. (“[In 2000] the US level [of per capita health spending] was 44 percent higher than Switzerland’s, the country with the next highest expenditure per capita”).
- ⁵⁴ Organization for Economic Co-operation and Development, *OECD Health Data 2007* (Paris: Organization for Economic Co-operation and Development, July 2007).
- ⁵⁵ Plunkett Research, LTD. *Introduction to the Health Care Industry, Health Expenditures and Services in the US* (2006). <http://www.plunkettresearch.com/Industries/HealthCare/HealthCareTrends/tabid/294/Default.aspx>.

- ⁵⁶ Organization for Economic Co-operation and Development, *OECD Health Data 2007, Acute care beds, Per 1000 population* (Paris: Organization for Economic Co-operation and Development, July 2007).
- ⁵⁷ John Dorschner, "The Minority Health Crisis," *The Miami Herald* (Sept. 13, 2004).
- ⁵⁸ For example, the increasing use of MRIs as a diagnostic tool is expensive. We are not suggesting MRIs should not be used, but only that their increased use is *part of* the reason health care costs continue to rise. Other uses of technology—such as using more email for communication—may help decrease costs, though it is unclear by how much.
- ⁵⁹ See e.g. K. Balcker, K Buckles, A Chandra, "Geographic Variation in the Appropriate Use of Cesarean Delivery: Do Higher rates reflect medically inappropriate use of this procedure?" *Health Affairs*, vol. 25 (2006)pp. 355-367.
- ⁶⁰ US Census Bureau, *Quarterly Financial Report*, Third Quarter 2003, Table D, p. xviii (2003). Public Citizen Congress Watch, *2002 Drug Industry Profits: Hefty Pharmaceutical Company Margins Dwarf Other Industries* (June 2003) available at http://www.citizen.org/documents/Pharma_Report.pdf.
- ⁶¹ Rep. Henry A. Waxman. "Analysis: Pharmaceutical Industry Profits Increase by Over \$8 Billion After Medicare Drug Plan Goes Into Effect." US House of Representatives (2006), <http://oversight.house.gov/documents/20060919115623-70677.pdf>.
- ⁶² Weiss Ratings Inc., http://www.weissratings.com/News/Ins_HMO/20040302hmo.htm. HMO profits jumped from \$2.5 billion to \$4.3 billion during the first six months of 2003. See also Business Wire, "HMOs Earn \$10.2 Billion in 2003, Nearly Doubling Profits, According to Weiss Ratings; Blue Cross Blue Shield Plans Report 63% Jump in Earnings" (2004), http://home.businesswire.com/portal/site/google/index.jsp?ndmViewId=news_view&newsId=20040830005473&newsLanguage=en.
- ⁶³ *Id.*
- ⁶⁴ Hewitt Associates (June 23, 2003) available at <http://was4.hewitt.com/hewitt/resource/newsroom/pressrel/2003/06-23-03.htm>.
- ⁶⁵ Case Western Reserve University. Case Studies shows drug companies are top health care lobbyists. (March 29, 2004), <http://www.case.edu/news/2004/3-04/lobbyists.htm>.
- ⁶⁶ For example, in a study comparing care in Australia, Canada, New Zealand, the United Kingdom, and the United States, the US had the highest survival rates for breast cancer, the lowest waiting times for elective surgery, and the highest likelihood of doctors who would ask for the patient's opinion and discuss the emotional burden of illness. The Commonwealth Fund, *First Report and Recommendations of The Commonwealth Fund's International Working Group on Quality Indicators*, (Washington, DC: The Commonwealth Fund, June 2004), p. vii.
- ⁶⁷ The United States government has signed and ratified the following three international human rights treaties: the International Convention on the Elimination of All Forms of Racial Discrimination (28 September 1966); the International Covenant on Civil and Political Rights (5 October 1977); and the Convention Against Torture and Other Cruel and Inhuman or Degrading Treatment or Punishment (18 April 1988). In addition, it has signed the following treaties: the International Covenant on Economic, Social and Cultural Rights (5 October 1977); the Convention on the Elimination of All Forms of Discrimination Against Women (17 July 1980); and the Convention on the Rights of the Child (16 February 1995). Available at: <http://www.unhcr.ch/>
- ⁶⁸ Grant Makers in Health, *Training the Health Workforce of Tomorrow, Issue Brief No. 12* (Washington, DC: Grant Makers in Health, 2002).
- ⁶⁹ Grant Makers in Health, *Training the Health Workforce of Tomorrow, Issue Brief No. 12* (Washington, DC: Grant Makers in Health, 2002), p. 2
- ⁷⁰ Clara Lee, M.P.P., *Provider Supply and Distribution in the US Health care System: A Primer* (YALE UNIVERSITY SCHOOL OF MEDICINE, LEGISLATIVE ACTION COMMITTEE AMERICAN MEDICAL STUDENT ASSOCIATION, 1996), <http://www.amsa.org/pdf/ushealthprimer.pdf>.
- ⁷¹ Grant Makers in Health, *Training the Health Workforce of Tomorrow, Issue Brief No. 12* (Washington, DC: Grant Makers in Health, 2002), p. 2.
- ⁷² *Id.*
- ⁷³ See, e.g. Montana Board of Regents of Higher Education, Policy and Procedures Manual, Policy 940.25 Rural Physician Incentive Program (providing payment of educational debts for physicians practicing in underserved rural areas).
- ⁷⁴ Miriam Komaromy et al., "The Role of Black and Hispanic Physicians in Providing Health care for Underserved Populations," *New England Journal of Medicine* vol. 334(20) (1996), pp. 1305-1310.
- ⁷⁵ Grant Makers in Health, *Training the Health Workforce of Tomorrow, Issue Brief No. 12* (Washington, DC: Grant Makers in Health, 2002), p. 2.

- ⁷⁶ John Dorschner, “The Minority Health Crisis,” *The Miami Herald* (Sept. 13, 2004). See also Brian D. Smedley et. al. (eds.), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2003).
- ⁷⁷ The Bush Administration’s FY 2005 budget proposal eliminated such funding by 96.3%. Department of Health and Human Services Health, *Resources and Services Administration Overview of Budget Changes*, available at: <ftp://ftp.hrsa.gov/newsroom/HRSA-FY05-budget-proposal.pdf> (“The [Administration’s 2005] budget continues the policy of not funding more general training efforts—primary care, interdisciplinary community projects, training for diversity, and public health.”)
- ⁷⁸ Institute of Medicine, *To Err is Human: Building a Safer Health System* (Washington, DC: National Academies Press, 2000), p. 24.
- ⁷⁹ Families USA, *One in Three: Non-Elderly Americans Without Health Insurance, 2002-2003* (Washington, DC: Families USA 2004). This includes only those under the age of 65, since that is the population ineligible for Medicare. The numbers vary from state to state: 14 states actually had more than one out of three uninsured people (Texas was highest, with 43.4% of the population uninsured).
- ⁸⁰ Genaro C. Armas, “Ranks of Poverty, Uninsured Rose in 2003,” *Associated Press* (August 26, 2004). (The US Census Bureau reported that nearly 45 million people were uninsured in 2003. This includes only those who were uninsured for the entire year.)
- ⁸¹ *Id.* at 5.
- ⁸² Children are particularly vulnerable when they lack health insurance. 36.7% of all the children under the age of 18 in the United States did not have health insurance for some period during 2002-2003. This number is likely to go up as children are increasingly cut from state-run insurance programs in response to state budget deficits. Families USA, *One in Three: Non-Elderly Americans Without Health Insurance, 2002-2003* (Washington, DC: Families USA 2004), p. 7; Leighton Ku and Sashi Nimalendran, “Losing Out: States Are Cutting 1.2 to 1.6 Million Low-Income People from Medicaid, SCHIP and Other State Health Insurance Programs” (Center on Budget and Policy Priorities, 2003).
- ⁸³ Institute of Medicine, *Care Without Coverage: Too Little, Too Late* (Washington, DC: National Academies Press, 2002).
- ⁸⁴ *Id.*
- ⁸⁵ “Medical Fees are Often Higher for Patients without Insurance,” *The New York Times*, (Apr. 2, 2001). See also Irene Wielawski, “Gouging the Medically Uninsured: A Tale of Two Bills,” *Health Affairs* (2000).
- ⁸⁶ Jack Hadley and John Holahan, “How Much Medical Care Do the Uninsured Use and Who Pays for It?” *Health Affairs Web Exclusive* (1):W66-W81 (2003).
- ⁸⁷ *Id.*
- ⁸⁸ Fairness of financial contribution is defined by the World Health Organization as starting “with the concept of a household’s contribution to the financing of the health system. The health financing contribution of a household is defined as the ratio of total household spending on health to its permanent income above subsistence.” World Health Organization, *The world health report 2000 - Health systems: improving performance* (Geneva, CH: World Health Organization 2000), p. 148.
- ⁸⁹ CESCR General Comment 14, at para. 12.
- ⁹⁰ Institute of Medicine, *Uninsurance Facts & Figures: Incremental Approaches to Extend Coverage are Insufficient*, (No date), <http://www.iom.edu/Object.File/Master/17/740/0.pdf>. (“Complex enrollment and re-enrollment procedures create barriers to participating in public insurance programs”).
- ⁹¹ Institute of Medicine, *Uninsurance Facts & Figures: Incremental Approaches to Extend Coverage are Insufficient*, (No date), <http://www.iom.edu/Object.File/Master/17/740/0.pdf>. (“strict eligibility requirements often make public coverage and some private insurance difficult to obtain, including different eligibility rules for members of the same family...complex enrollment and re-enrollment procedures create barriers to participating in public insurance programs.”)
- ⁹² See, e.g. the American Medical Association’s Principles of Medical Ethics (2001), <http://www.ama-assn.org/ama/pub/category/2512.html>.
- ⁹³ Report by Mr. Maurice Glélé-Ahanhanzo, Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance on his mission to the United States of America from 9 to 22 October, UN Doc. E/CN.4/1995/78/Add.1 (16 Jan 1995).
- ⁹⁴ Alice Dembner, “Disparities found in health care for blacks,” *The Boston Globe* (August 2004).
- ⁹⁵ Nancy R. Kressin and Laura A. Peterson, “Racial Differences in the Use of Invasive Cardiovascular Procedures: Review of the Literature and Prescription for Future Research,” *Annals of Internal Medicine* (2001), pp. 352-66 (Showing that minority groups in various health care settings are less likely to receive invasive cardiovascular procedures that improve diagnostic precision, delay death, and relieve symptoms for many patients with coronary heart disease.)

- ⁹⁶ Brian D. Smedley et. al. (eds.), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2003), p. 30.
- ⁹⁷ Grant Makers in Health, *Training the Health Workforce of Tomorrow, Issue Brief No. 12* (Washington, DC: Grant Makers in Health, 2002), p. 8.
- ⁹⁸ Brian D. Smedley et. al. (eds.), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2003), p. 131.
- ⁹⁹ *Id.* at 131-132.
- ¹⁰⁰ Brief of the Association of American Medical Colleges et al as *Amici Curiae* in support of the Respondents at 12, *Grutter v. Bollinger* (US Supreme Court 2003) (No. 02-241).
- ¹⁰¹ Lisa Cooper-Patrick et al., “Race, Gender, and Partnership in the Patient-Physician Relationship,” *The Journal of the American Medical Association* vol. 282 (1999), pp. 583-589.
- ¹⁰² Brian D. Smedley et. al. (eds.), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2003), p. 131.
- ¹⁰³ Pew Health Professions Commission, *Critical Challenges: Revitalizing the Health Professions for the Twenty-First Century* (1995), p. 31.
- ¹⁰⁴ *Id.*
- ¹⁰⁵ A number of studies have shown that students from rural or minority communities are significantly more likely to return to those communities to practice medicine. See, e.g. Association of American Medical Colleges (AAMC), Division of Community and Minority Programs, *Minority Students in Medical Education: Facts and Figures XII* (October 2002) available at: www.aamc.org/publications.
- ¹⁰⁶ 45 CFR 80.3(b)(2) requires all recipients of federal financial assistance to provide meaningful access to persons with limited English language skills.
- ¹⁰⁷ Latina Alliance Against Sexual Aggression, *Eliminating Barriers to Services for Latina/o Survivors of Sexual and Intimate Partner Violence* (Dripping Springs, TX: Latina Alliance Against Sexual Aggression, 2004).
- ¹⁰⁸ Association of Community Organizations for Reform Now (ACORN) and the American Institute for Social Justice, *Speaking the Language of Care: Language Barriers to Hospital Access in America’s Cities* (Washington, DC/Dallas, TX: ACORN and the American Institute for Social Justice, 2004).
- ¹⁰⁹ The AAMC, which has as members every accredited medical school in the United States, has a program designed to “increase diversity in medical education and advance health care equity in the US” See the AAMC website at www.aamc.org/diversity/initiatives.htm.
- ¹¹⁰ The project increased minority enrollment to 12.4% of the total between 1990 and 1994—a 34.5% increase. Brian D. Smedley et. al. (eds.), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2003), p. 121.
- ¹¹¹ *Id.*
- ¹¹² *Grutter v. Bollinger* 529 US 306 (2003) held that affirmative action at Michigan Law School could continue since it was necessary for substantive educational reasons. The AAMC submitted an *amicus curiae* brief (*supra* note 86) in the case in favor of keeping member affirmative action plans, and after the case was published, the AAMC put out a statement specifically defining the affirmative action practiced by its member schools as in accordance with the Court’s decision. See <http://www.aamc.org/meded/urm/statusofnewdefinition.pdf>.
- ¹¹³ The Bush Administration FY2005 budget proposal virtually eliminated federal funding for the Public Health Service Act’s Title VII Health Professions Programs. Department of Health and Human Services Health, *Resources and Services Administration Overview of Budget Changes*, <ftp://ftp.hrsa.gov/newsroom/HRSA-FY05-budget-proposal.pdf> (“The [Administration’s 2005] budget continues the policy of not funding more general training efforts – primary care, interdisciplinary community projects, training for diversity, and public health.”)
- ¹¹⁴ For example, for nine of the past ten years there has been at least one American laureate for the Nobel Prize in Physiology or Medicine. See <http://nobelprize.org/medicine/>.
- ¹¹⁵ Institute of Medicine, National Academy of Sciences, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, D.C.: Institute of Medicine, 2001), p. 13.
- ¹¹⁶ The Institute of Medicine was chartered in 1970 as a component of the National Academy of Sciences. For more information, see www.iom.edu.
- ¹¹⁷ Institute of Medicine, National Academy of Sciences, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, D.C.: Institute of Medicine, 2001).
- ¹¹⁸ *Id.* at 23.

- ¹¹⁹ *Id.* at 226, 292. The report also lists coronary artery bypass grafts as an example of common overuse of health care that demonstrates poor quality. *Id.* at 226.
- ¹²⁰ *Id.* at 227.
- ¹²¹ *Id.* at 250.
- ¹²² *Id.*
- ¹²³ Institute of Medicine, *To Err is Human: Building a Safer Health System* (Washington, DC: National Academies Press, 2000), p. 26.
- ¹²⁴ *Id.*
- ¹²⁵ Institute of Medicine, National Academy of Sciences, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, D.C.: Institute of Medicine, 2001), p. 182.
- ¹²⁶ Institute of Medicine, *Priority Areas for National Action: Transforming Health Care Quality* (Washington, DC: Institute of Medicine, 2003), p. 2. (“[Poor quality care] is due not to lack of effective treatments, but to inadequate health care delivery systems that fail to implement these treatments”); World Health Organization, *Quality of care: patient safety* (Mar 23 2002) at 3 (“Current conceptual thinking on the safety of patients places the prime responsibility for adverse events on deficiencies in system design, organization and operation rather than on individual providers or individual products”).
- ¹²⁷ Paul Krugman, “America’s Failing Health,” *The New York Times*, (Aug. 27, 2004). (“[R]ising health care costs aren’t just causing a rapid rise in the ranks of the uninsured... they’re also, because of their link to employment, a major reason why this economic recovery has generated fewer jobs than any previous economic expansion.”)
- ¹²⁸ Some other countries that have not ratified include: Cuba, Indonesia, Malaysia, Myanmar, Pakistan, Saudi Arabia, and several smaller states of the Pacific. All other industrialized countries have ratified the ICESCR.
- ¹²⁹ For more information on the French health care system, see <http://www.info-france-usa.org/atoz/health.asp>.
- ¹³⁰ International Convention on the Elimination of All Forms of Racial Discrimination, UN General Assembly Res. 2106 (XX) of 21 December 1965 (entry into force 4 January 1969). Entry into force for the United States on 20 Nov. 1994.
- ¹³¹ Reports Submitted by States Parties under Article 9 of the Convention, Third Periodic reports of States parties due in 1999, Addendum, United States of America. Submitted 10 October 2000. UN Doc. CERD/C/351/Add.1 at 20 (English version).
- ¹³² Concluding Observations of the Committee on the Elimination of Racial Discrimination: United States of America, UN Doc. A/56/18 (14 Aug 2001) at para 398.

About This Paper

This briefing was written by Jean Connolly Carmalt, Sarah Zaidi and Alicia Ely Yamin. Jean Connolly Carmalt is the former legal coordinator for the Center for Economic and Social Rights. Sarah Zaidi is former research director and co-founder of the Center for Economic and Social Rights. Alicia Ely Yamin is the 2007-10 Joseph H. Flom Fellow on Global Health and Human Rights at Harvard Law School and an instructor at the Harvard School of Public Health. Yamin is also the chair of the board of directors of the Center for Economic and Social Rights.

About Us

The Center for Economic and Social Rights (CESR) works to promote social justice through human rights. In a world where poverty and inequality deprive entire communities of dignity, justice and sometimes life, we seek to uphold the universal human rights of every human being to education, health, food, water, housing, work, and other economic, social and cultural rights essential to human dignity. Extreme poverty and rising inequality should not simply be considered an inevitable tragedy. Rather, they are often the result of conscious policy choices by governments and other powerful actors (such as corporations or international financial institutions) that undermine people's access to the full range of human rights. CESR therefore seeks to hold governments and other actors accountable to their obligations to respect, protect and fulfill economic and social rights, as well as civil and political rights.



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