

THE RIGHT TO HEALTH IN THE UNITED STATES OF AMERICA WHAT DOES IT MEAN?

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*This report is dedicated to ensuring the vision of
FDR's second bill of rights for all Americans.*

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ABOUT THE CENTER FOR ECONOMIC AND SOCIAL RIGHTS

The Center for Economic and Social Rights (CESR) was established in 1993 to promote social justice through human rights. In a world where poverty and inequality deprive entire communities of dignity and even life itself, CESR promotes the universal right of every human being to housing, education, health and a healthy environment, food, work, and an adequate standard of living.

CESR's mission is to advocate for social justice using human rights tools and strategies. For more than ten years we have contributed to the development of a human rights culture that integrates economic security, social equality, and political freedom as established in the Universal Declaration of Human Rights. We build relationships with civil society groups and strengthen local initiatives for economic justice by connecting them with international institutions and legal mechanisms for protecting human rights.

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EXECUTIVE SUMMARY

In 1943, President Franklin D. Roosevelt proposed a ‘Second Bill of Rights’ for Americans, declaring ‘freedom from want’ to be one of four essential liberties necessary for human security. Roosevelt’s definition of freedom included “the right to adequate medical care and the opportunity to achieve and enjoy good health.” The right to health was subsequently enshrined in the Universal Declaration of Human Rights, drafted with American guidance, and has since been recognized in numerous international and regional human rights treaties.

Unfortunately, the United States turned its back on Roosevelt’s vision, and as a result our health care system is in a state of ever-deepening crisis. Despite spending far more per capita on health care than any other country, U.S. has some of the poorest health indicators in the industrialized world. 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 44 million who are completely uninsured, 78.8% work full or part-time. The lack of available care is especially acute for those living in rural areas, and for minorities. The disparities are so stark that whites in the U.S. are expected to live six years longer on average than African-Americans.

This record can be largely attributed to the notion that health care is simply one commodity among others, a privilege for those who can afford it rather than a fundamental human right for all. With a system that values profits over people, it is no surprise that health care costs continue to spiral out of control for ordinary Americans even as HMOs and pharmaceutical companies accumulate record-breaking profits.

Only a new approach recognizing the right of every American to adequate health care can address the magnitude of the current crisis. This report attempts to give substance to President Roosevelt’s vision by using international human rights principles as a framework for health care reform in the U.S. The report gives four basic recommendations:

Health care policy needs to be about the right to health. The current debate over health care reform tends to bog down in ideological disputes and arguments over economic efficiency. In contrast, a human rights approach would focus on the *underlying purpose* of the health care system. The core human rights demand is for outcomes consistent with internationally-recognized standards—regardless of whether the health system is private or public. Framing health care reform as a matter of right establishes a mechanism for government accountability and encourages public participation in the decisions that affect our lives and well-being.

The health care system needs to be simplified. The current system has become bewilderingly complex, making it more difficult than ever for individuals to access health care. 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 has become a bureaucratic nightmare. Despite the vast array

of putative “choices”, the U.S. health care system frequently delivers inadequate and poor quality health care, and entails wasteful expenditures on administrative and litigation costs. Policymakers must streamline and simplify the system to make it more understandable and accessible.

Health care must be universally available and accessible. Basic human rights principles hold that health care must be accessible and affordable to all, irrespective of race, gender, religion, geography, and income. The increasing costs of providing services combined with the waste and inefficiency apparent in the current system result in fewer and fewer people having access to basic health care. Policymakers must ask at the outset how well a given plan will work to cover all—not most, or more, but *all*—people in this country.

Quality and diversity must increase, including cultural sensitivity. Despite the U.S. reputation for providing some of the best health care in the world to those who can afford it, there are numerous indications that overall quality of care is inconsistent and inadequate. Quality enforcement and measurement must be part of any reform plan. Moreover, minorities in the U.S. receive even poorer health care thanks to dramatically lower rates of minority health providers, lack of health services, and systematic discrimination. Under-representation of minorities in the health care workforce must be addressed, and proactive measures must be taken to reverse discriminatory practices and inequalities built into the current health care system.

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.” Today, the human rights movement can provide a universal and populist language for the cause of health care reform. The time has come for the U.S. to fully recognize the universality of all human rights through a health care system that fulfils Franklin D. Roosevelt’s vision of freedom for all.

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 right to health was subsequently included in the Universal Declaration of Human Rights, drafted with American guidance, and has since been enshrined in many international and regional human rights treaties.

In the U.S. today, this freedom remains unrealized. Forty-four million Americans lack health insurance completely. A full third of Americans live without health care for at least part of the year. And 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.³ 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 U.S. health care system is in profound crisis.

How is this possible when the United States spends more per person on health care than any other industrialized country in the world?⁴ The health care crisis in this country is more complex than questions of rising costs or lack of insurance, and as important as those elements may be, any successful reform of the health care system must take a broader approach to understanding the problems.

Can an international human rights framework offer anything new to the debate over the American health care crisis? We believe that it can. Posing the familiar problems with the U.S. health care 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

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* (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 INSTITUTE OF MEDICINE, NATIONAL ACADEMIES PRESS, *TO ERR IS HUMAN: BUILDING A SAFER HEALTH SYSTEM* 26 (2000b).

⁴ Organization for Economic Co-operation and Development, *OECD Health Data 2004, Table 9: Total expenditure on health, Per capita U.S.\$ PPP* (June 2004). The United States spends an average of \$5267 per person per year. This is 50% more than the next highest spender, Switzerland, which spends \$3445 per person on health care. Switzerland also has higher life expectancies and lower infant mortality rates than the U.S., which are two key factors in evaluating the success of a country’s health care system. *Id.* at Tables 1 and 2.

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" (itself a spurious notion when many costs—e.g. the loss of productivity due to employee health problems—are simply "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, the human rights movement has also been an effective instrument for mobilizing grassroots political support for substantial policy, as well as legislative, changes. The U.S. health care 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. A human rights framework offers a path forward for those who advocate major changes to the system which would restore *health* to its proper place at the center of health care legislation, policies, and practice.

This will be a long and difficult struggle. The United States government has historically resisted guarantees of social and economic rights, and has refused to ratify international and regional legal instruments intended to ensure these rights.⁵ Despite President Roosevelt's vision of a Second Bill of Rights, and his leadership in establishing an international system with the United Nations at its center, the U.S. has a poor record of implementing international human rights standards on the domestic level.⁶ Moreover, the legacy of Cold War propaganda persists as an obstacle to health care reform, as corporations and conservative pundits continue to suggest that government involvement the health care system would constitute "socialized medicine."⁷ Health care, they argue, is a commodity, and those health guarantees that do exist in the U.S., generally at the state level, should best be thought of charity, rather than as legally enforceable obligations.⁸

⁵ The U.S. has not ratified the following international treaties that include economic and social rights: the International Covenant on Economic, Social and Cultural Rights, U.N.G.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.unhchr.ch>) and the Organization of American States (<http://www.oas.org>).

⁶ C. Anderson, *EYES OFF THE PRIZE: THE UNITED NATIONS AND THE AFRICAN AMERICAN STRUGGLE FOR HUMAN RIGHTS, 1944-1955*. Cambridge University Press (2003) (Addressing this issue in the struggle for black equality in the United States).

⁷ B. Vladeck, *Universal Health Insurance in the United States: Reflections on the Past, the Present, and the Future*, 93 AM. J. PUB. HEALTH 16-19 n.1 (2003).

⁸ The states with such provisions include: Alabama, Alaska, Arizona, California, Colorado, Georgia, Hawaii, Idaho, Indiana, Kansas, Louisiana, Michigan, Missouri, Montana, Nevada, New Mexico, New York, North Carolina, Oklahoma, Ohio, Pennsylvania, South Carolina, Texas, Utah, Washington, and Wyoming.

CESR has produced this report as part of its ongoing advocacy work calling on the U.S. to view health as a fundamental human right, rather than as a commodity to be profited from or as charity for the needy. A rights-based view of health argues that that access to health care services and drugs not depend on income (or lack thereof), age, employment, place of residence, or race.

The report is divided into four parts. Part One examines the legal framework governing the right to health. Part Two discusses the structure of the current U.S. health care system and its impact on health care delivery. Part Three looks at how the U.S. system measures up to international human rights standards. Part Four offers rights-based recommendations for health care reform.

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 U.S. leadership. Among the most important are the Universal Declaration of Human Rights (UDHR)⁹ and the International Covenant on Economic, Social, and Cultural Rights (ICESCR).¹⁰ 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 a certain 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.¹¹ For example, the right to health requires not only that certain minimum standards of care be met or exceeded, but also that people be safeguarded from health threats such as water and air pollution, as well as workplace hazards.¹² Basic prerequisites of good health also include the rights to shelter, food, and means of adequate sanitation.¹³

Universal Declaration of Human Rights Article 25

- (1) 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.
- (2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

(Source: UDHR, U.N.G.A. res. 217A (III), U.N. Doc A/810 at 71 (1948))

⁹ Universal Declaration of Human Rights, U.N.G.A. res. 217A (III), U.N. Doc A/810 at 71 (1948) [hereinafter "UDHR"]. Although the UDHR is a General Assembly declaration instead of a treaty, it may be legally binding on the U.S. as either customary international law or as authoritative interpretation of the U.N. Charter. See Henry J. Steiner & Philip Alston, *INTERNATIONAL HUMAN RIGHTS IN CONTEXT: LAW, POLITICS, MORALS* 143 (2d ed. 2000).

¹⁰ ICESCR. The U.S. signed the ICESCR on 5 October 1977, but has not yet been ratified, which is required to make it legally binding. However, the U.S. signature indicates its support of the ICESCR provisions, and makes its terms politically binding. In addition, the U.S. 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

¹¹ 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*, 18 *HUM. RTS. Q.* 398 (1996).

¹² ICESCR, art. 12. Also see B. Toebes, *THE RIGHT TO HEALTH AS A HUMAN RIGHT IN INTERNATIONAL LAW* (1998).

¹³ U.N. 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, U.N. Doc. E/CN.12/2000/4 (2000).

A. *THE RIGHT TO HEALTH IN THE UDHR AND ICESCR*

The Universal Declaration of Human Rights (UDHR) was one of the first great achievements of the United Nations (U.N.). Its preamble includes the “four freedoms” enumerated in Franklin D. Roosevelt’s famous speech to the U.S. Congress,¹⁴ and its adoption marked the first time that international law protected the individual rights of

International Covenant on Economic, Social & Cultural Rights

Article 12

(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.

(Source: ICESCR U.N.G.A. res. 2200A (XXI) of 16 December 1966 (entry into force 3 January 1976, in accordance with article 27))

citizens within their own countries. Eleanor Roosevelt, elected to serve as head of the U.N. Human Rights Commission,¹⁵ led the drafting discussions of the UDHR. Her influence is clear throughout the text of both the UDHR and its two implementing Covenants.¹⁶ The UDHR’s provision on the right to health¹⁷ is complemented by the provision in the International Covenant on Economic, Social, and Cultural Rights (ICESCR), which is meant to elaborate on its meaning.

Governments are obliged to enforce the human right to health fall in three distinct ways: they must **respect** the right, they must **protect** the right, and they must **fulfill** the right.

Respect. A government itself must not to violate the right to health, as it would by cutting funding for doctors working in underserved areas, 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 monopolistic pharmaceutical companies.

Fulfill. A government must ensure all citizens have access to basic health services.

¹⁴ 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”).

¹⁵ Paul Gordon Lauren, *THE EVOLUTION OF INTERNATIONAL HUMAN RIGHTS: VISIONS SEEN* 218 (1998).

¹⁶ Together, the Covenants and the UDHR constitute the International Bill of Human Rights.

¹⁷ For a discussion on how article 25 was formulated, see Toebes, *supra* note 12 at 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.

The UDHR and the ICESCR form the backbone of the human right to health under international law. However, the provisions of the two treaties are general. While they recognize the right of everyone to enjoy “the highest attainable standard” of health,¹⁸ they do not offer an exact recipe for implementation, nor do they take a position on the respective desirability of public or private financing for health care. The U.N. 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.¹⁹ 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.”²⁰ 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.**²¹

B. 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.”²² 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.²³ In the United States, although there are a

¹⁸ 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)).

¹⁹ General Comments originated in the third session of the Committee and are prepared to assist the State Parties in interpreting and fulfilling their obligations.

²⁰ CESCR *General Comment No. 3, The nature of State Parties obligations*, 5th Sess., para. 8, U.N. 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.”)

²¹ CESCR General Comment 14, *supra* note 13 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.

²² *Id.*

²³ Declaration of Alma-Ata, 1978, World Health Organization at Art. VII. Available at: http://www.who.dk/AboutWHO/Policy/20010827_1.

substantial number of medical facilities and personnel, these are concentrated in urban and white regions, while rural and minority regions have insufficient services.²⁴

Accessibility. Health facilities, goods, and services must not only be available, but must also be accessible. This means that basic health care 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.”²⁵ Access to information about health—including access to information about sexual health—is required. In the U.S., the millions of people without health insurance, substantial bureaucratic barriers to obtaining coverage, and the systematic discrimination preventing minorities from receiving adequate health care constitute significant barriers to 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. Medical personnel should also, whenever possible, share the same culture and language as their patients. In addition, acceptable health care requires that ethical and cultural training be part of a medical education. In the U.S., 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.²⁶

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, potable water and sanitation services, scientifically approved and unexpired medicines and hospital equipment, adequate sanitation, and skilled medical personnel.²⁷ Although high quality health care is available for a price in the U.S., studies indicate inconsistent levels of quality throughout the health care system overall, and large numbers of avoidable mistakes.²⁸

C. 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-discrimination, participation, access to remedies, and information**.

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,

²⁴ GRANT MAKERS IN HEALTH, TRAINING THE HEALTH WORKFORCE OF TOMORROW, ISSUE BRIEF NO. 12 2 (2002).

²⁵ General Comment 14, *supra* note 13 at para. 12.

²⁶ NATIONAL ACADEMIES PRESS, UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE (Brian D. Smedley, et. al. eds., 2003).

²⁷ CESCR General Comment 14, *supra* note 13 at para 12.

²⁸ INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, CROSSING THE QUALITY CHASM: A NEW HEALTH SYSTEM FOR THE 21ST CENTURY 13 (2001).

health status (including HIV/AIDS), sexual orientation and civil, political, social or other status.²⁹

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. For example, patients should not be excluded from treatment decisions due to insurance company policies.

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).³⁰ The procedural requirement for information overlaps with the four substantive categories because having access to information regarding medical facilities, treatments, quality, and conditions is the first step to any successful preventative measure or treatment.

The four substantive elements and their four procedural counterparts show that the right to health goes beyond the latest drugs or sterile needles. Instead, it requires a more holistic approach to improving health for the largest possible number of people. The government's obligation to respect, protect, and fulfill the right to health demands that policymakers approach health care reform with a view to promoting good health care overall rather than implementing piecemeal fixes to discrete problems.

II. THE CURRENT U.S. SYSTEM

The United States is the only industrialized country that does not recognize the human right to health. In 1977, the Supreme Court went so far as to declare it unnecessary for Congress to require that health care meet minimum standards as part of its provision for public welfare.³¹ At the federal level, the closest Americans have come to securing their right to health are the Medicare and Medicaid programs, which are rooted in the idea that the elderly and poor should be guaranteed a minimum level of health services. Important as these programs are, the exclusivity of their premise contradicts the universality of health rights elaborated under international law. The focus on the poor and elderly is also found at the state level where services are often conditioned on legislative approval.³² Even the strongest provisions, such as Article 17 in the New York State Constitution, frame health services as charity, rather than recognizing access to health services as a

²⁹ CESCR General Comment 14, *supra* note 13 at para 18.

³⁰ *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.”)

³¹ *Maher v. Roe*, 432 U.S. 464, 469 (1977).

³² *See* note 8.

basic right and a prerequisite to human dignity.³³ Thus, as currently framed, even the most essential services and limited benefits can be taken away.

Instead of regarding health as a human right, the U.S. generally approaches health care as a commodity—either to be doled out to the needy as a matter of charity, or to be provisioned by the private sector for maximum profit. While some public funding does exist for certain groups (e.g. those over the age of 65, those poor enough to meet Medicaid criteria, and the military), private financing is meant to cover everyone else.³⁴ Although some other countries use this basic model, there is usually much less reliance on the private sector. In the Netherlands, for example, the wealthiest 36 percent of the population is responsible for paying for its own care, while public funds cover the rest of the population.³⁵ The problem with U.S. health care is not the mixture of public and private funding per se, but rather the heavy reliance on a private sector whose bottom line dictates a focus on profits over people.

A. THE LEGAL STRUCTURE

Health care in the United States is financed and delivered according to terms set out in federal and local laws. Laws range from the specific, such as the requirement that managed care organizations approve hospital stays for mothers who have just given birth,³⁶ 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.³⁷ The legal structure regulating health care is

Historical Efforts for National Health Insurance

As early as 1915, the American Association for Labor Legislation campaigned for sickness insurance after running a strong state-by-state campaign for worker's compensation. 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. The bill never came to a vote in Congress since it was vigorously opposed by representatives of organized physicians and pharmaceuticals, who officially classified it in campaign after campaign as “socialized medicine.”

Associations such as the AMA and drug houses 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. The AMA remains a significant lobbying force, having spent about \$17 million in lobbying expenses in 2000.

(Sources: Maureen Glabman, “Lobbyists That the Founders Just Never Dreamed of,” *MANAGED CARE MAGAZINE*, (2002), 93 *AM. J. PUB. HEALTH* n.1 (2003)

³³ The Constitution of the State of New York, article 17 (January 1, 2002) (“The aid, care and support of the needy are public concerns and shall be provided by the state...”). Two state provisions—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.

³⁴ Private financing can be through employment or personal purchase of health care plans.

³⁵ Carolyn Hughes Tuohy et al., *How Does Private Finance Affect Public Health Care Systems? Marshaling the Evidence from OECD Nations*, 29 *J. HEALTH POLITICS, POL'Y & L.* 359, 360-61 (2004).

³⁶ 42 USCS Sec. 300gg-4 (1996).

³⁷ 29 U.S.C. § 1144(a). ERISA is a federal statute that preempts state-based causes of action against applicable employee benefit plans. The purpose of ERISA was to allow broad removal to federal court to

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).³⁸

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.³⁹ The poor (defined differently by each state) are eligible for Medicaid, which is financed by a combination of federal and state funds.⁴⁰ Federal funds also provide health insurance coverage for the military and for federal employees.⁴¹

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 private plans are optimistic about profit potential under the new MMA.⁴² Whether increased privatization of Medicare will result in better delivery of health care for the elderly remains to be seen.⁴³

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. In 1973, the HMO Act kick-started the managed care industry by requiring all health care providers to accept patients from at least two managed care organizations. The Act was fueled by the concern that physicians had a financial incentive to provide more health services than necessary.⁴⁴ 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

ensure a uniform regulatory regime over employee benefit plans. *AETNA Health Inc. v. Davila*, _____ U.S. _____, No. 02-1845 (2004).

³⁸ 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., INSTITUTE FOR HEALTH CARE STUDIES, MICHIGAN STATE UNIVERSITY UNDERSTANDING MANAGED CARE (no date).

³⁹ The current version of Medicare is at 42 U.S.C. 1395 et seq.

⁴⁰ 42 U.S.C. 1396 et seq.

⁴¹ Act of Sept. 21, 1958, Pub. L. No. 85-861, 72 Stat. 1447 (codified as amended at 10 U.S.C. Sec. 1077 (1988)).

⁴² JOHN RHODES, DELOITTE & TOUCHE, LLP, THE MEDICARE MODERNIZATION ACT OF 2003: UNDERSTANDING AND PLANNING FOR ITS IMPACT ON THE HEALTH CARE SUPPLY CHAIN (2004).

⁴³ Congressional Budget Office., A Detailed Description of CBO’s Cost Estimate for the Medicare Prescription Drug Benefit. CBO. July 2004 *available at* <http://www.cbo.gov/showdoc.cfm?index=5668&sequence=0>.

⁴⁴ Duncan-Jackson et al., *supra* note 38 at 3.

HMOs to negotiate drug discounts and ensure (profitable) quality control, the organizations have 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.⁴⁵

One reason it is difficult to address these concerns is that health care is being regulated through the courts, one case at a time. Litigation-based regulation is not particularly effective for improving HMOs 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.⁴⁶ This means that, most of the time, individuals cannot sue their HMOs. Until the ERISA statute is revisited, this gap in enforcement will persist.

B. THE FINANCIAL STRUCTURE: WHO PAYS? WHO PROFITS?

The United States spends more on health care per person than any other industrialized country.⁴⁷ The latest OECD comparison calculated U.S. costs at \$5,267 per person, per year.⁴⁸ Yet the U.S. 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.⁴⁹ The lack of available care is even more acute for minority patients, and in particular for patients who are black or Hispanic.⁵⁰ Clearly, much of the money spent on health care is not going to improve people's health. Where that money *does* go is a central issue for any rights-based reform.

There are many reasons why health care in the U.S. is so expensive, ranging from high administrative costs to high drug costs. As health care becomes increasingly reliant on high technology⁵¹ and as the American population grows and ages, costs will continue to rise. However, beyond the inevitable inflationary and technology-based increases, numerous inefficiencies in the current system prohibit greater access to care. These inefficiencies start with private sector profits.

⁴⁵ Many of these claims have gone to court. *See, e.g.* Plocica vs. NYLCare et al (1998).

⁴⁶ 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 U.S. Health care, 346 F.3d 442, 453 (CA3 2003) (Becker, J., concurring), *AETNA Health Inc. v. Davila*, _____ U.S. _____, No. 02-1845 (2004) (Ginsburg, J., concurring).

⁴⁷ Gerard F. Anderson et. al., *It's the Prices, Stupid: Why the United States is so Different from Other Countries*, 22 HEALTH AFFAIRS 89, 91-92 n. 3 (2003) (“The U.S. level [of per capita health spending] was 44 percent higher than Switzerland's, the country with the next highest expenditure per capita”).

⁴⁸ OECD Health Data 2004, Table 9, *supra* note 4.

⁴⁹ Organization for Economic Co-operation and Development, *OECD Health Data 2004, Table 5: Acute care beds, Per 1000 population* (June 2004).

⁵⁰ John Dorschner, *The Minority Health Crisis*, MIAMI HERALD (Sept. 13, 2004).

⁵¹ 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.

The profits recorded by pharmaceutical corporations are unusually high.⁵² Indeed, in 2001, as the overall profits of Fortune 500 companies declined by 53%, the top 10 U.S. drug makers increased their profits by 33%, from \$28 billion to \$37 billion. Managed care organizations have reported high profit growth, by as much as 73% in the second quarter of 2003 (a \$1.8 billion increase over 2002).⁵³ Since 1998, aggregate net-worth of the HMO industry has increased by 70%, from \$23 billion to \$39 billion as of June 2003. 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.⁵⁴ 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.⁵⁵

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 simply leaving the system without advancing research, delivering care, or paying medical providers. Among health care organizations, pharmaceuticals spend the most on lobbying (\$96 million in 2000) followed by physicians, and health care organizations.⁵⁶ Of the 1192 organizations involved in health care 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 it becomes clear why an increasing number of Americans cannot afford access to even basic care.

The Costs

- In 2000, health care expenditures were 13% of U.S. Gross Domestic Product compared to the OECD average of 8%.
- In 2002, health care spending was up \$1.6 trillion (9.3%) from the previous year

(Sources: Anderson et al., *supra* note 47 at 91-92, CENTERS FOR MEDICARE & MEDICAID SERVICES PRESS RELEASE, available at <http://www.cms.hhs.gov/media/press/release.asp?Counter=935>)

⁵² U.S. 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.

⁵³ Weiss Ratings Inc., available at 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 BUS. 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), available at http://home.businesswire.com/portal/site/google/index.jsp?ndmViewId=news_view&newsId=20040830005473&newsLang=en.

⁵⁴ *Id.*

⁵⁵ Hewitt Associates (June 23, 2003) available at <http://was4.hewitt.com/hewitt/resource/newsroom/pressrel/2003/06-23-03.htm>

⁵⁶ Case Western Reserve University. Case Studies shows drug companies are top health care lobbyists. (March 29, 2004) available at [Case study shows drug companies are top health care lobbyists](#)

III. INTERNATIONAL STANDARDS IN THE U.S. CONTEXT

Although the U.S. health care system provides some of the best care in the world (for those who can afford to pay),⁵⁷ overall, the U.S. health care system falls far short of international human rights standards. The immensely complicated system disadvantages both doctor and patient, and it disproportionately benefits intermediaries such as HMOs. The existing problems in the system will only worsen as long as health care is considered first and foremost a commodity, rather than as a basic right. This section will examine how the U.S. health care 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**:

A. 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. Availability also means that professional personnel receive competitive salaries. 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.

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.⁵⁸ 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,⁵⁹ while rural areas suffer severe medical service shortages.⁶⁰ Appalachia, for example, has less than 1 physician per 1000 persons.⁶¹ The coverage that does exist in rural areas is largely due to training subsidized

“An estimated 50 million people live in... underserved areas...[S]erving their needs would require 13,000 physicians.”

(Source: GRANT MAKERS IN HEALTH, ISSUE BRIEF NO. 12 (2002))

⁵⁷ For example, in a study comparing care in Australia, Canada, New Zealand, the United Kingdom, and the United States, the U.S. 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. FIRST REPORT AND RECOMMENDATIONS OF THE COMMONWEALTH FUND’S INTERNATIONAL WORKING GROUP ON QUALITY INDICATORS, June 2004 at vii.

⁵⁸ GRANT MAKERS IN HEALTH, *supra* note 24 at 2.

⁵⁹ CLARA LEE, M.P.P., YALE UNIVERSITY SCHOOL OF MEDICINE, LEGISLATIVE ACTION COMMITTEE AMERICAN MEDICAL STUDENT ASSOCIATION, PROVIDER SUPPLY AND DISTRIBUTION IN THE U.S. HEALTH CARE SYSTEM: A PRIMER (1996).

⁶⁰ GRANT MAKERS IN HEALTH, *supra* note 24 at 2.

⁶¹ *Id.*

at the state and federal levels—a fact that underscores the importance of nonprofit (whether governmental or non-governmental) participation in health care delivery.⁶²

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.”⁶³ 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.⁶⁴ 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.⁶⁵

The lack of health care facilities, goods, and services in rural and minority areas in the United States violates the requirement that health care be available. A rights-based health care policy would entail maintaining training programs and incentives for those seeking to practice in underserved areas,⁶⁶ and would focus on ensuring availability for every person 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. A rights-based approach to health care reform eschews faulty assumptions about market forces and instead seeks to make sure health care is provided where it is needed most.

B. ACCESSIBILITY

Even when health care is *available*, it may not be *accessible*. In the United States, even the insured are frequently subject to large co-payments or pharmaceutical bills that prohibit their access to health care. They also face growing fears of losing their benefits as employer insurance premiums rise.⁶⁷ This lack of economic accessibility (affordability) is compounded by a lack of access to information concerning health services and issues and by a growingly complex health care delivery system that compounds every element of access.

⁶² 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).

⁶³ Miriam Komaromy et al., *The Role of Black and Hispanic Physicians in Providing Health care for Underserved Populations*, 334 (n. 20) *NEW ENG. J. MED.* 1305 (1996).

⁶⁴ GRANT MAKERS IN HEALTH, *supra* note 24 at 2.

⁶⁵ Dorschner, *supra* note 50.

⁶⁶ The Bush Administration’s FY 2005 budget proposal eliminates 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](http://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.”)

⁶⁷ TO ERR IS HUMAN, *supra* note 3 at 24.

Children

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.

(Sources: ONE IN THREE, *infra* n. 69 at 7, LEIGHTON KU AND SASHI NIMALENDRAN, CENTER ON BUDGET AND POLICY PRIORITIES LOSING OUT: STATES ARE CUTTING 1.2 TO 1.6 MILLION LOW-INCOME PEOPLE FROM MEDICAID, SCHIP AND OTHER STATE HEALTH INSURANCE PROGRAMS (2003))

In 2003, 15.6% of the population lacked health insurance for the full year,⁶⁸ and from 2002-2003, approximately one-third of the population lacked health insurance for at least part of the year.⁶⁹ Health insurance is so prohibitively expensive that going without is not confined to the indigent. Indeed, 78.8% of the uninsured work full- or part-time.⁷⁰ For the estimated 45 million Americans who cannot afford medical insurance, there is very limited access to viable health care.

The uninsured receive less preventive care, less appropriate care for chronic illnesses, and fewer hospital services when admitted.⁷¹ They are also more likely to die prematurely.⁷² 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.⁷³ Ironically, people without insurance pick up a large portion of the nation's health care tab. In 2001, the uninsured spent \$80.1 billion on health care.⁷⁴

Overall, the lowest income patients and those with chronic health conditions end up carrying the greatest health care burden as a percentage of their family income.⁷⁵ This directly violates the CESC's guideline that "poorer households should not be disproportionately burdened with health expenses as compared to richer households."⁷⁶ Although the United States offers coverage for the very poorest Americans 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 2004, health insurance premiums paid by employers rose by 11.2%, the fourth consecutive year of double-digit percentage increase

(Source: HENRY J. KAISER FAMILY FOUNDATION AND THE HEALTH RESEARCH AND EDUCATIONAL TRUST, EMPLOYER HEALTH BENEFITS: 2004 SUMMARY OF FINDINGS 1 (2004))

⁶⁸ Genaro C. Armas, *Ranks of Poverty, Uninsured Rose in 2003*, ASSOCIATED PRESS, August 26, 2004. (The U.S. Census Bureau reported that nearly 45 million people were uninsured in 2003. This includes only those who were uninsured for the entire year.)

⁶⁹ FAMILIES USA, ONE IN THREE: NON-ELDERLY AMERICANS WITHOUT HEALTH INSURANCE, 2002-2003 1, 3 (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).

⁷⁰ *Id.* at 5.

⁷¹ INSTITUTE OF MEDICINE, NATIONAL ACADEMIES PRESS, CARE WITHOUT COVERAGE: TOO LITTLE, TOO LATE 1-2 (2002).

⁷² *Id.*

⁷³ *Medical Fees are Often Higher for Patients without Insurance*, NEW YORK TIMES, Apr. 2, 2001. See also Irene Wielawski, *Gouging the Medically Uninsured: A Tale of Two Bills*, HEALTH AFFAIRS (2000).

⁷⁴ 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).

⁷⁵ *Id.*

⁷⁶ *Id.*

In addition, many who are eligible for Medicaid do not join because they are discouraged by the program's administrative burdens and web of complexities.⁷⁷

C. ACCEPTABILITY

The United States has a strong history of requiring its physicians and other medical personnel to adhere to minimum ethical guidelines.⁷⁸ 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. Unfortunately, the U.S. 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."⁷⁹ Ten 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,⁸⁰ less likely to get preventative care and screening,⁸¹ and less likely to receive analgesia in emergency rooms for bone fractures.⁸² 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 make up over one quarter of the population (and are projected to constitute one third by 2010), they still represent less than 10 percent of the health care workforce.⁸³ 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.

⁷⁷ INSTITUTE OF MEDICINE, UNINSURANCE FACTS & FIGURES: INCREMENTAL APPROACHES TO EXTEND COVERAGE ARE INSUFFICIENT, (No date), available at <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").

⁷⁸ See, e.g. the American Medical Association's Principles of Medical Ethics (2001), available at <http://www.ama-assn.org/ama/pub/category/2512.html>.

⁷⁹ 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, U.N. Doc. E/CN.4/1995/78/Add.1 (16 Jan 1995).

⁸⁰ Alice Dembner, *Disparities found in health care for blacks*, BOSTON GLOBE, August 2004.

⁸¹ 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*, 135 ANN. INTERN. MED. 352, 352 (2001) (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.)

⁸² UNEQUAL TREATMENT, *supra* note 26 at 30.

⁸³ GRANT MAKERS IN HEALTH, *supra* note 24 at 8.

The relationship between a patient and a doctor is critical to effective health care delivery, which requires trust between a physician and patient, a certain level of comfort, and uncompromised communication.⁸⁴ Research indicates that minority patients have a higher level of comfort when treated by physicians of their own race,⁸⁵ and that they are more likely to follow through with necessary treatments and seek preventive care when they are satisfied with their physicians.⁸⁶ The reasons vary, and include language barriers and the patient's level of education.⁸⁷ 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."⁸⁸

"Physicians and patients belonging to the same race or ethnic group are more likely to share cultural beliefs, values, and experiences in the society, allowing them to communicate more effectively and to feel more comfortable with one another."

(Source: Cooper-Patrick, *infra* n. 38 at 588.)

According to a 1995 study by the Pew Health Professions Commission, "a substantial body of literature concludes that culturally sensitive care is good care."⁸⁹ 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.⁹⁰ Increasing the number of minority students is also shown to increase access to medical services in under-served communities.⁹¹

Despite increasing concern among medical professionals about issues of diversity,⁹² the problem remains entrenched in the U.S. 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.⁹³ Since then, however, legal attacks on affirmative action policies have taken their toll: over 60% of public medical schools have experienced declines in minority student enrollment since 1994, resulting in a collective decrease of 9.1% in the number of minority students enrolled.⁹⁴ Despite the recent Supreme Court decision allowing continued affirmative action for educational purposes in professional schools at the federal level, state policies against affirmative action

⁸⁴ UNEQUAL TREATMENT, *supra* note 26 at 131.

⁸⁵ *Id.* at 131-132.

⁸⁶ Brief of the Association of American Medical Colleges et al as *Amici Curiae* in support of the Respondents at 12, *Grutter v. Bollinger* (U.S. Supreme Court 2003) (No. 02-241).

⁸⁷ Lisa Cooper-Patrick et al., *Race, Gender, and Partnership in the Patient-Physician Relationship*, 282 J. AM. MEDICAL ASS'N 583 (1999).

⁸⁸ UNEQUAL TREATMENT, *supra* note 26 at 131.

⁸⁹ PEW HEALTH PROFESSIONS COMMISSION, *CRITICAL CHALLENGES: REVITALIZING THE HEALTH PROFESSIONS FOR THE TWENTY-FIRST CENTURY* 31 (1995).

⁹⁰ *Id.*

⁹¹ 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.

⁹² 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 U.S." *See* the AAMC website at www.aamc.org/diversity/initiatives.htm.

⁹³ The project increased minority enrollment to 12.4% of the total between 1990 and 1994—a 34.5% increase. UNEQUAL TREATMENT, *supra* note 26 at 121.

⁹⁴ *Id.*

continue to result in declining minority representation in the medical field.⁹⁵ Furthermore, current budget proposals aim to scale back even further the funding available for programs supporting minority recruitment in the medical profession.⁹⁶

A rights-based reform to the health care system would raise the level of minority representation at medical training facilities so that it reached levels congruent with the minority proportion of the population at large. It would also require all medical institutions to introduce training in cultural sensitivity for all medical personnel.

D. 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.⁹⁷ However, despite these

“Our patients are struggling just to put food on the table, put clothes on their back, and get to and from work... If everyone had to put themselves in their shoes for just one day, we would have health care reform in this country by the end of the year.”

– Claudia Sowell, Director of St. Luke Free Clinic, Hopkinsville, KY.

achievements, the quality of care delivered to patients varies widely, and good quality care is unavailable to vast numbers of Americans.⁹⁸

The Institute of Medicine (IOM)⁹⁹ has called attention to the growing safety flaws and quality problems in the U.S. health care system.¹⁰⁰ The IOM has divided these quality problems into three categories: overuse, under-use, and misuse.¹⁰¹

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.¹⁰² **Under-use** stems from lack of insurance and lack of preventive care, including when those who are insured fail to seek

⁹⁵ *Grutter v. Bollinger* 529 U.S. 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>.

⁹⁶ The Bush Administration FY2005 budget proposal virtually eliminates 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*, 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.”)

⁹⁷ 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/>.

⁹⁸ CROSSING THE QUALITY CHASM, *supra* note 28 at 13.

⁹⁹ The Institute of Medicine was chartered in 1970 as a component of the National Academy of Sciences. For more information, see www.iom.edu.

¹⁰⁰ CROSSING THE QUALITY CHASM, *supra* note 28.

¹⁰¹ *Id.* at 23.

¹⁰² *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.

treatment for which the potential benefits outweigh potential risks.¹⁰³ One example of under-use is that approximately one-quarter of American children have not received appropriate immunizations.¹⁰⁴ Finally, **misuse** includes errors by medical personnel, which can be difficult to document because instances often go unreported.¹⁰⁵ 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.”¹⁰⁶ This is more than the number of people who die in car accidents every year, and more than die from AIDS.¹⁰⁷

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.¹⁰⁸ 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.¹⁰⁹ To improve the quality of care and meet international standards, the United States must change the way it thinks about health care reform.

“[A]lthough the health care workforce is trying hard to deliver the best care, those efforts are doomed to failure with today’s outmoded and poorly designed [health care delivery] systems”

(Source: PRIORITY AREAS FOR NATIONAL ACTION, *infra* note 109 at 2).

IV. RECOMMENDATIONS

The neglect of basic medical services for much of its population 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,¹¹⁰ it is increasingly urgent to rethink the way the U.S. finances health care and the delivery of services, including essential drugs. Changes which are rooted in human rights principles must be made if there is to be lasting improvement in the health care situation for the majority of Americans.

¹⁰³ *Id.* at 227.

¹⁰⁴ *Id.* at 250.

¹⁰⁵ *Id.*

¹⁰⁶ TO ERR IS HUMAN, *supra* note 3 at 26.

¹⁰⁷ *Id.*

¹⁰⁸ CROSSING THE QUALITY CHASM, *supra* note 28 at 182.

¹⁰⁹ INSTITUTE OF MEDICINE, PRIORITY AREAS FOR NATIONAL ACTION: TRANSFORMING HEALTH CARE QUALITY 2 (2003) (“[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”).

¹¹⁰ Paul Krugman, *America’s Failing Health*, 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.”)

A. *HEALTH CARE POLICY NEEDS TO BE ABOUT THE RIGHT TO HEALTH*

All Americans must have full access to basic health care as a matter of right. Although many initiatives have been proposed for health care 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 health care system. The international norms are then able to provide standards by which to evaluate competing proposals. Framing debates about health care 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.

“The fact is that the mainly private U.S. health care system spends far more than the mainly public health care systems of other advanced countries, but gets worse results... Does this mean that the American way is wrong...? Well, yes.”

(Source: Krugman, *supra* note 110)

Human rights standards do not specify whether a country should use a public system, a private system, or some mixture of the two. No matter which system is ultimately chosen, however, it must adhere to the basic requirements of the right to health. Although the experience of other countries implies that systems based on public funding are more successful in meeting human rights requirements¹¹¹ (and certainly it is clear the U.S.’s over-reliance on private financing has resulted in numerous violations of the right to health), the structure chosen is not necessarily related to the human rights outcome. What is more important is that policymakers measure proposed legislation according to its impact on health for all Americans, and not merely on the basis of private-sector profitability.

B. *THE HEALTH CARE SYSTEM NEEDS TO BE SIMPLIFIED*

The myriad issues facing U.S. health care have one element in common: they are exacerbated by the system’s complexity. 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 huge barrier to accessibility. Hospitals and other providers must employ large numbers of staff simply to figure out different insurance schemes for charges, and individuals trying to select an insurance plan face a bewildering array of premiums, co-payments, and services. Every new piece of legislation requires numerous lawsuits to figure out who should pay for what. Wading through all these “choices”—ostensibly created to increase accessibility—is an overwhelming task.¹¹² Ultimately, the costs of administration and litigation, as well

¹¹¹ Tuohy et al., *supra* note 35.

¹¹² UNINSURANCE FACTS & FIGURES, *supra* note 77 (“strict eligibility requirements often make public coverage and some private insurance difficult to obtain, including different eligibility rules for members of

as the difficulty of navigating the system, have reduced the number of people with access to health care.

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 inefficiencies become human rights concerns. A recent popular proposal for health reform is particularly problematic in terms of increasing the system's complexity. The tax credit plan allows those who purchase health insurance plans (whether individuals or employers) to deduct the cost of those plans from the amount they owe in federal income tax. The idea is to maintain the current system, but simply make it more affordable.

Unfortunately, the tax credit plan does nothing to streamline payment systems to help control administrative costs. Worse, it fails to address the underlying problems plaguing the health care system.¹¹³ There is no guarantee of universal coverage, as evidenced by similar voluntary programs that have failed to provide it in the past.¹¹⁴ There is no attempt to address quality concerns, since health care would still be financed by a combination of individual, private industry, and public money. And there is no recognition that the market is not providing adequate service in underserved areas. Meanwhile, the current system would be made more complicated. Those without disposable income to purchase a given health plan would suffer a further disadvantage, since they would either have to wait for the credit, or they would have to figure out the procedure for obtaining the credit immediately. Either way, the tax credit system would do nothing to simplify and streamline the current complexity that creates a barrier for so many.

C. *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.

Universal access to health services requires two fundamental changes in the way the U.S. approaches health care. First, policymakers can no longer depend on assumptions that the "invisible hand" of the marketplace will provide adequate health services for everybody. Millions of uninsured 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.

the same family...complex enrollment and re-enrollment procedures create barriers to participating in public insurance programs.”)

¹¹³ Most tax credit plans suggested are voluntary in nature, and the following comments pertain to those. If a tax credit plan was mandated, it would likely achieve more success in increasing enrollment numbers. However, since it would essentially maintain the current funding structure, the current problems of quality, availability, and cultural acceptability would persist. For more information, *see* INSTITUTE OF MEDICINE, *INSURING AMERICA'S HEALTH: PRINCIPLES AND RECOMMENDATIONS* (2004).

¹¹⁴ *Id.* at 133.

Second, debates over appropriate reform must ask at the outset how well a given plan will work to cover all—not most, or more, but *all*—of the people in this country. Current proposals for how best to expand coverage to the uninsured or how best to control medical costs often rely on assumptions that cost and lack of insurance are the only barriers to access. A human rights approach to health care reform attempts to reframe that debate within a larger societal context.

Proposals for reform that favor universal access include a national health service (where the government is responsible for financing and delivery of services) and a single-payer system (where the government is only responsible for financing services). Both of these plans might be able to provide universal access that meets international criteria. 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.¹¹⁵ 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.

D. 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 sensitivity training and protections for cultural differences. As a state party to the International Covenant on the Elimination of all Forms of Racial Discrimination (ICERD),¹¹⁶ the United States is legally bound to address the systematic racial discrimination within the U.S. health care system. The U.S. has admitted that minorities receive “less adequate access to health insurance and health care,”¹¹⁷ and the governing Committee for ICERD has recommended that the U.S. ensure the right of everyone to access public and private health care.¹¹⁸

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.¹¹⁹ The law is particularly important for victims of sexual and intimate partner violence, whose medical

¹¹⁵ For more information on the French health care system, see <http://www.info-france-usa.org/atoz/health.asp>.

¹¹⁶ International Convention on the Elimination of All Forms of Racial Discrimination, U.N. 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.

¹¹⁷ 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. U.N. Doc. CERD/C/351/Add.1 at 20 (English version).

¹¹⁸ Concluding Observations of the Committee on the Elimination of Racial Discrimination: United States of America, U.N. Doc. A/56/18 (14 Aug 2001) at para 398.

¹¹⁹ 45 CFR 80.3(b)(2) requires all recipients of federal financial assistance to provide meaningful access to persons with limited English language skills.

needs cannot be met without translation that is provided by a non-family member.¹²⁰ A recent 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.¹²¹ Worse, a group of doctors and a group supporting the designation of English as the official national language filed a lawsuit in August 2004 challenging the regulation.¹²² Although it is unlikely they will prevail, the lawsuit represents the importance of expanding medical training to include education about how cultural sensitivity and linguistic skills are fundamental components to providing appropriate health care.

Beyond enforcing the laws that already exist, there must also be a commitment to increasing minority representation within the medical profession. Funding must be provided for medical personnel who are minorities or who wish to practice in underserved minority areas. Cultural sensitivity training must also be made an integrated part of medical training.

The parallel and less adequate health care system encountered by minorities denies them their right to available, accessible, appropriate, and quality care. Further, the parallel system is a direct violation of U.S. 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, but to actually integrate minorities into the U.S. health care system, policymakers must address these problems from a rights-based perspective by looking at why these issues exist, placing them in their larger social context, and using internationally agreed-upon criteria to evaluate proposed solutions.

V. CONCLUSION

Americans pay more per capita on health care than the population of any other country in the world, and receive 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 funding structures—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.

The international right to health sets out clear expectations for providing the best possible health care to all people. Health care must be physically and financially accessible, and no one may be deprived of health services because of income, location, race, or insurance

¹²⁰ LATINA ALLIANCE AGAINST SEXUAL AGGRESSION, *ELIMINATING BARRIERS TO SERVICES FOR LATINA/O SURVIVORS OF SEXUAL AND INTIMATE PARTNER VIOLENCE* (May 2004).

¹²¹ 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 1* (2004).

¹²² Michelle Morgante, *Hospital Translation Rule Challenged*, ASSOCIATED PRESS, August 31, 2004.

status. Services must meet minimum standards of quality, and must be culturally appropriate. These elements of the right to health are already being discussed as problems requiring urgent attention, but they are too often considered in isolation rather than as interrelated and fundamental components of the human right to health.

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 populist language to the cause of health care reform. Momentum is building for a system that recognizes that human dignity requires the protection not only of civil and political rights but also of economic, social, and cultural rights. The time has come for the U.S. to fully recognize the universality of all human rights, and to join others in implementing a health care system that fulfils Franklin D. Roosevelt’s vision.