HEALTH-CARE REFORM: A HUMAN RIGHTS ISSUE

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PROLOGUE

Whether they realized it or not, those responsible for putting Measure 16 on the Oregon ballot in 1994 underscored the futility of debates over health-care reform which lack an ethical focus.

As Art Caplan, Director of the Center for Biomedical Ethics at the University of Pennsylvania, observed, "Measure 16, or what Oregonians are calling the Death with Dignity Act, permits physicians to prescribe lethal does of medicine to patients who want to end their lives."[i] Although the proposal was well thought-out, had many safeguards, and put the responsibility for ending a life on the individual, it was nevertheless dangerous in a society that has no right to basic health-care. Ultimately, the choice to end a life can only be informed and voluntary if the terminally ill individual has other options from which to choose. For Americans who lack money and insurance, these other options may not be available. This means, in effect, that money becomes the major factor in decisions of life and death.

Caplan went on to insist that people should not have to ingest a fatal dose of pills because of a lack of health insurance or because they could not qualify for home care. In his words, "A society that is not ready to offer a decent package of comprehensive health-care to all its citizens is a society that is not ready to offer them death by prescription."[ii]

Until recently Representative Jim Moran (D-Va) was doubtful about the call for universal health-care. Then, on August 13, 1994, he and his wife learned that their three-year-old daughter, Dorothy, was suffering from a deadly form of brain cancer. Realizing his own health-care coverage was tied to winning re-election (which he did), Moran vowed to fight for universal coverage for children.[iii]

INTRODUCTION

It is clear that debates over health-care reform have become arguments over costs, procedures, and policies, and have lost sight of the single most important issue, namely, the people behind the statistics. Health-care is, in the end, all about people. And any issue that affects human life and development is an ethical issue. There is no such thing as a decision that is simply political or simply economic: all decisions that have impact on human life have an ethical dimension. Health-care reform, therefore, is more than

just a medical and economic challenge; health-care reform is also part of the struggle for universal human rights. A purely technological or economic approach to health-care reform ignores families who lack insurance, the sick who lack options, and children who lack proper care.

Adequate health care is a basic human need; therefore, every person has a right to such care. Yet today, in the United States, more than 35 million people have no guaranteed access to health care. Uninsured Americans are forced to let problems go untreated until routine health-incidents become medical emergencies. In addition to those who are currently uninsured, thousands more are in danger of losing insurance through job-changes or layoffs. By one estimate 45,000 New Jersey residents and 85,000 Pennsylvanians lose their insurance each month.[iv]

Washington's failure to pass a health-care reform package leaves us with a problem that won't go away, a problem which will, in fact, grow only more burdensome and complex. Health-care costs will continue to rise and some 17% of Americans will continue to be denied access to quality care. Is it any wonder that a 17-year old high school senior shared her discouragement with a local journalist? "Everyone should have health-care. It should be one of the basic human rights. It's sad. I'm only 17 years old. My peak of idealism is supposed to be now, and it's over already."[v]

The statistics are readily available: one out of three Hispanics and one out of five African-Americans are uninsured. Some 39 million Americans, or one in five, are now officially poor. Over 22% of American children live in poverty, the highest level since 1964. Some 40% of all people living in poverty are children.[vi] Our infant mortality-rates, especially in inner-city and rural communities, are shockingly high, rivaling those of some Third World countries. The U.S. also has a high percentage of babies born at dangerously low birth-weights. So, while the U.S. spends nearly 50% more per person on health-care than any other country, we don't compare favorably with them in terms of measurable health-outcomes.[vii]

Obviously, then, existing patterns of health-care in the U.S. do not meet the demands of social justice.[viii] Our nation's health-care system serves too few and costs too much.[ix] And, the experts warn, health-care costs are continuing to grow at such a rate that costs by the year 2000 will be more than double those of 1980.

Reform, then, is imperative. Nor only are millions without adequate health-care, but rising costs deplete resources needed in other vital areas, such as housing and education. And, in all of this, it is the poorest who are most adversely affected; health-policies and efforts at health-care reform, then, must be examined in light of their effect on the poor and weak among us.

We must believe, truly believe, that every American, indeed every human being, has the right to quality health-care. "The needs of the frail elderly person, the unborn child, the person living with AIDS, and the undocumented immigrant must be addressed by healthcare reform."[x]

SOME ASSUMPTIONS

Any attempt to address health-care reform in the U. S. must also realistically acknowledge several underlying attitudes or assumptions that affect bioethical thought.[xi] One of the most pervasive of these attitudes is the denial of our mortality. It is a basic fact of human life that death is a certainty, and yet Americans seem determined to prolong life at any cost. "Health-care has much more important things to offer than the false hope of immortality."[xii]

The attempt to deny our own mortality leads to the conviction that no one must die who can be saved, no matter the cost or ultimate futility of the treatment. Intensive care units, which often function more like high-tech hospices, are over-used, while around 30% of Medicare's money goes to patients with less than a year to live.[xiii] It is also widely accepted that doctors are trained to cure diseases, not to address the place of suffering in human life. Curing is, in effect, more highly valued than caring. Medicine has, to a large extent, been divorced from values. Being a physician is becoming increasingly a service-oriented profession, with doctors forced to spend more and more time on the business aspects of medicine, such as utilization-review.

Americans, who tend to consider morality as something purely personal, also fail to see the social dimension of issues like reproductive technology and positive eugenics. Yet, anything that affects an individual's life affects the life of society. In an era of increasingly sophisticated prenatal diagnosis in a culture which considers abortion an acceptable form of health-care, the danger of applying a consumer-mentality to human reproduction is unfortunately quite real. Although no one would deny parents the right to use all means available to assure the healthiest child possible, the leap to discarding children who do not meet certain subjective standards of perfection is not unthinkable.

This eugenic mentality leads further to a denial of the aging process. A good deal of surgery is performed, not because it is medically indicated, but to allow people to conform to their own, or society's notion of acceptability. "Contemporary medicine is increasingly treating the desires of people in a move toward a discomfortless society and in the process medicalizing some basic human problems."[xiv]

Another assumption currently driving developments in health-care is that of patient-autonomy. Although the move away from the "Doctor knows best" (or "Doctor God") paternalism of earlier days was a positive change, reaction to it has become over-reaction: patient-autonomy is now viewed as absolute. "The offshoot of this absolutization is that very little attention is given to the values that ought to guide the use of autonomy. The sheer fact that the choice is the patient's is viewed as the sole right-making characteristic of the choice."[xv] The result of assumptions such as these is an over-emphasis on longevity, which leads to an over-valuing of technology. When a society undervalues the social dimension of medical choices and refuses to acknowledge human mortality, it is difficult to move people to the kind of sacrifice which true health-care reform involves.

SOME BACKGROUND

What has been missing in the health-care reform debates, then, is attention to the deeper issues. Instead of quarreling over policies and procedures, Americans should be called to examine their attitudes toward life and death. We must ask ourselves what we mean by "health" and assess the real goals of medicine.[xvi] Until now much of the public debate has centered on costs, not justice. Since 1968 the percentage of the GDP (gross domestic product) devoted to health-care has nearly doubled, from 7.6% to 14%. Obviously, the increased money targeted for health-care is taken away from programs like drug-control, crime-prevention, and so on.[xvii] Furthermore, as we have already seen, even such a large increase in health-spending has not resulted in a system that works for vast numbers of Americans.

In 1986 the Catholic bishops of the United States made an observation that has even more urgency today: "By bringing healthcare cost inflation down, we could cut the federal deficit, improve economic competitiveness, and help stem the decline in living standards for many working families."[xviii] Resources have to be freed up to address other problems that have impact on health.

Real reform can be jeopardized by special-interest groups and powerful lobbies who have a major stake in maintaining the status quo. Partisan politics likewise works against true reform. Health-care reform has come up in every administration since World War II. In 1948 President Harry S. Truman introduced proposals for national insurance. Under pressure from political opponents Truman cut the proposals, but the plan was never enacted. During the 1950s the impetus for reform waned as much of the middle class gained private health coverage. Federal medical coverage, at least for the elderly, was part of John F. Kennedy's "New Frontier."

President Richard M. Nixon, Senator Edward Kennedy, and Representative Wilbur Mills worked for reform in the early 1970s but a compromise plan fell victim to Watergate, Chappaquidick and special-interest forces. President Jimmy Carter's efforts in the later part of the 1970s met with similar frustration. In every case partisan politics or the wishes of the affluent and those with special interests have blocked attempts at reform. During the Reagan/Bush years there was a definite move toward applying market principles to health-care.[xix]

In the first ten months of 1993 the health-care industry gave $8.4 million to members of Congress, an increase of 27% over 1992. Members of the Senate Finance Committee received an average of $393,000 in donations from the health and insurance industries between 1987 and 1993, as compared to $232,553 for other senators.[xx] It is easy to see why the health-care reform debate has focused on the needs of special-interest groups rather than on the broader ethical issues about government-responsibility in the area of health-care.

Health-care in America, then, is marked by ever-rising costs, increasing gaps in health-insurance coverage, and persistent inequities in access to health-care. The American model of health-care relies on treatment rather than on prevention, and it invests more in high technology than in basic health-care. Policy-making must address these disturbing trends and conceptualize health-care as a human right while reforming the system.[xxi]

A RIGHTS-BASED APPROACH TO HEALTH-CARE REFORM

The U.S. is the only Western democracy that does not recognize a right to health-care. While other countries consider health-care a social, public good, in the U.S. health-care is considered a private good, a commodity. The fundamental basis of a reformed health-care system must, therefore, be a recognition of the right to adequate health-care. Furthermore, this belief in a right to health-care must be rooted in the wider context of a commitment to improve the health of the general public. This commitment in turn must be translated into specific steps, taking into account our society's resources.[xxii]

Ethically, health-care is a basic right. In other words, a basic standard of health-care is a human right for all people.[xxiii] Obviously, it is important to have a clear understanding of the meaning of *rights* and *human rights* as these terms are being used here. After all, too much insistence on *my rights* can make it difficult to establish a framework for reform. Rights-language must be related to the common good and must be balanced by the language of duties and responsibilities.[xxiv]

There does exist a good for a society as a whole which respects but is

ultimately more important than the good of any individual. In the context of health-care reform, health-services must truly foster this common good. Nor are material concerns enough: a holistic notion of the common good considers all facets of who we are as human persons. Such a notion demands that we not limit considerations of health-care reform to questions of cost and number served. Reform must yield a true sense of participation and partnership in health-care; it must enhance the quality of human life and interpersonal relationships; it must foster values; and it must be realistic about the limitations of human life.[xxv]

Ethically, a right is an entitlement to some good or service. If the entitlement is universal, i.e., based solely on one's status as a human being and not tied to gender, race, nationality, or economic and social status, it is referred to as a human right. Human rights generally include the minimum conditions necessary for a person's life, growth, and development. Society recognizes these rights and accepts responsibility for their promotion and protection.[xxvi] A right to health-care implies an entitlement to a basic and adequate standard of health-care consistent with a society's resources. In our country "basic and adequate" health-care must include both preventative and curative services, as well as access to rehabilitation, mental health-care and related supports. Just as crises in health are common to all humans, so too should access to health-care be.[xxvii]

Since health-care is a social good rather than a commodity, health-care reform must be based on the principles of justice, equity, and social obligation. A rights-based approach to health-care reform respects the dignity of each individual and thus satisfies the demands of justice by focusing special attention on the poor, on minorities, and on children.[xxviii] In other words, such an approach rightly emphasizes the ethics of health-care reform over the economics of reform. Quantifiable questions are important, but so is a more complete vision of the meaning of human life. Only in this way can quantifiable issues be approached with justice. An individualist mentality makes real health-care reform virtually impossible.[xxix]

This human rights approach to health-care reform has other advantages. It provides standards and goals which can be useful not just for the immediate process of reform but also for the ongoing evaluation and revision of the system. It goes beyond individual interests and links health-care to our nation's concept of the social covenant binding government and society. (Of course, groups who profit from the expansion and commercialization of health-care will resist such fundamental changes since their income and profits would potentially be affected.)

A human rights approach to reform protects the benefits of the "haves"

while giving priority to improving the health-status of the "have-nots." It does this by going beyond the provision of health-insurance in order to address inadequacies and structural deficiencies in the health-care system as a whole. Such an approach translates human rights into moral norms which are themselves translated into laws, thus institutionalizing the social covenant and creating a framework for a national consensus. Government recognizes the entitlement to basic health-care for all; individuals accept limits on the scope of publicly provided health-care. Here the need for wide public input becomes clear since citizens are expected not to demand a standard of care for themselves that would not also be available to all other members of society and affordable within specified, agreed upon budgetary limits.[xxx]

The goal of a human rights approach to health-care reform is not equality of well-being but a decent minimum level of health. In reality, a second tier of services would be available to those who could afford it, but that second tier must not be permitted to jeopardize the prior right of those not getting the decent minimum, for example, by tying up the best physicians or monopolizing research-facilities.[xxxi]

JUSTICE

Justice demands that we give all persons the goods and services that they rightly expect. Justice is about duties and responsibilities and building a good community. Justice concerns what we must do for others on the basis of our common humanity. Even more central to the health-care debate is the question of distributive justice or allocation.[xxxii] "The litmus test... is the extent to which the rights of the most vulnerable and disadvantaged individuals... are assured.... A human rights standard assumes a special obligation or bias in favor of the needs and rights of the poor, the disadvantaged, the powerless, and those at the periphery of society."[xxxiii] Decisions must be judged in light of what they do to and for the poor, and what they enable the poor to do for themselves.[xxxiv] We must see reasonable access to health-care as a social responsibility. As long as over 35 million Americans are uninsured, we are failing to meet the demands of distributive justice. Cost, the market, tax burdens, these are all necessary issues, but they are not central.

What is central in health-care reform is to discover criteria for reform that satisfy the demands of social justice. Criteria based on consideration of merit, social usefulness, or the ability to pay must be rejected, since judgments in these areas would both be arbitrary and hard to reach, and they would work against children, the elderly, and those of limited means. Level of need is an appropriate criterion, but it is not enough. Perhaps the most

fitting standard to satisfy distributive justice is similar care for similar cases.[xxxv] In other words, we as a society should determine what we consider a minimum standard of health-care and then pledge ourselves to provide that standard to everyone, without regard to merit, social usefulness, and so on.[xxxvi] It should be noted that such a standard requires an acceptance of death as part of life. The extension of life is not always an absolute need, especially if the common good ultimately outranks the individual good.

HEALTH-CARE RATIONING

Once a society has agreed that every person has a right to guaranteed access to health-care, a recognition of the limitations of that society's resources leads naturally to the question of health-care rationing. We have to face head-on the question of what we must do for all people in terms of supplying them with access to health-care. The goal, once a decent minimum standard has been set, is to give everyone whatever health-care it takes to bring them to that level.[xxxvii] We must be honest about the existence of *de facto* rationing caused by variations in income, insurance, geographical location, or even type of disease or condition. No one can deny that under the present system the rich have access to a number of advanced medical procedures which are unlikely to be made available to the poor. There are natural limits, too, to individual life and health; and as we have seen, it is possible to spend money on health-care that might be spent more effectively in some other area, such as education.

So, the question is not whether we should ration health-care, but how we should do it. Covert or secret rationing must be exposed to the light of ethical examination, and criteria governing the morality of its use must be developed and applied. Rationing, defined as the decision not to develop or not to provide people with potentially beneficial medical treatments, should be considered a last resort, used only after all alternatives have been explored. Society must determine what constitutes "futile" measures and apply the same standard universally, so that beneficial treatment is not withheld from some in order to provide others who can afford it with futile treatment. Further, that universal standard must be high enough that most people agree to it, while recognizing that the cost and resources involved in some elaborate medical procedures can take away from the common good.

An honest approach to rationing must also deal with questions of gender-based and age-based discrimination. Some treatments may be specific to one sex and not to the other, and while age-discrimination is generally not acceptable, there may be treatments which are not age-appropriate. Gender and age, then, may be valid factors in rationing decisions, but only in a

holistic examination of all the circumstances involved in a particular case. Finally, while the patient always has the option of refusing treatment, treatment may only be withheld because of factors arising from the treatment itself, such as cost or disproportionate use of resources, and never because of any personal judgment about the patient.[xxxviii]

Furthermore, while some rationing will be unavoidable, our society is actually affluent enough to provide more than a minimum level of care for all its citizens. Government and the private sector must work together so that all Americans, most of whom support universal health care in the abstract, will become convinced of the justice of the concrete measures needed to make such universal care a reality. All of us have a responsibility to be sure that society has the resources it needs to provide a basic set of health-care services to all people. The level of services would be the same for all, but the poor and marginalized may need extra assistance and training to be sure they fully understand their right to access to just health care.[xxxix]

CRITERIA FOR REFORM

The central question is how much inequity in the distribution of health-care we as a society can tolerate. Current levels of disparity are significant, costly, and unjust.[xl] The best health-care system would be one that combines universal access to health-care with cost-control, quality-care for the poor, and respect for human life and dignity. To achieve such a goal, government as the instrument of the common good must work together with all parts of the private sector to develop and promote policies and procedures that satisfy the demands of fundamental human justice. "Linking the healthcare of poor and working class families to the healthcare of those with greater resources is probably the best assurance of comprehensive benefits and quality care."[xli] Health-care is collective in nature: sick and healthy, poor and wealthy, all must participate with equal freedom and access.

Success or failure in the area of health-care reform will have a lot to say about who we are as a nation and about what kind of nation we will be in the 21st century. A single-payer plan (similar to Canada's), in which all citizens have guaranteed access to a comprehensive standard benefits package, is most consistent with a human rights approach, because such a system is best capable of achieving universality, assuring social equity, and holding down health-costs.[xlii]

Since the single-payer system faces stiff opposition from both the health-insurance industry and health-care providers, however, managed competition is likely to provide the framework for reform. How can managed competition be improved from a human rights perspective? Audrey R.

Chapman (Program Director, Science and Human Rights, American Association for the Advancement of Science) suggests the following recommendations.

Recognize the right of all citizens and residents to basic and adequate health-care. Reduce stratification in the present system and limit regional price-differentials. Develop stronger monitoring of regional health-alliances to prevent the exclusion of certain categories of the population. Incorporate older Americans into regional health-alliances at benefits equal to those granted younger citizens to avoid age-discrimination. Place greater emphasis on protection and prevention, including environmental and lifestyle concerns. Facilitate the adoption by states of a single-payer system, to avoid penalizing states for attempting to provide greater equity. Give regional health-alliances both the responsibility and the resources to provide health-care services to under-served populations. Give highest priority in the allocation of resources to low-income persons and those with disabilities and special needs. Utilize taxes on things like cigarettes, alcohol, and guns and ammunition, to finance health-care reform. Control costs by setting funding priorities and imposing price-controls on fees, procedures, and pharmaceuticals. Promote public participation in shaping health-care reform. Develop an effective monitoring system that will be able to assess the impact of health-care reform on an ongoing basis.[xliii]

AN INTERESTING EXPERIMENT

In Buckpoint, Maine, several full-time employees of MacLeod's Restaurant are participating in a unique program called "First Sunday," which allows them to operate one day a month for their own profit and pay health-insurance premiums with pre-tax earnings. George MacLeod, the restaurant's owner, estimates that his outlay (rent, utilities, licenses, and so on) is just 15% of what it would cost to provide insurance for his employees. In other words, MacLeod has made it possible for any employee who is willing to work one eight-hour shift on a day when the restaurant would otherwise be closed to have adequate health-insurance which they could not otherwise afford. This program could serve as one model for providing employee-coverage at minimal cost to the employer.[xliv]

CONCLUSION

"The injustice of the mansion next to the ghetto is dwarfed by the prospect of an uninsured mother with poor prenatal care giving birth to a child four weeks premature while, several floors below in the same hospital, an endocrinologist is evaluating a boy for synthetic growth hormone to improve

his self-esteem."[xlv] We can equalize the system and still allow for individual freedom and technological advances.

The moral force of a right to health-care should sustain continuing efforts to provide equitable health-care for all. Only then will our nation have achieved true health-care reform.

NOTES

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i. A. Caplan, "Let's get universal health care before granting the right to die" in *The Philadelphia Inquirer* (Sept. 27, 1994) A 19.

ii. Ibid.

iii. J. Moran, "Moment of Crisis" in *People* (Oct. 31, 1994) 129-30, 132. Inquiries to Rep. Moran concerning his pursuit of this goal have gone unanswered.

iv. S. Burlind, R. Smith and S. Vedantam, "Lost in the health debate: People who need insurance" in *The Philadelphia Inquirer* (Aug. 21, 1994) E 1-2.

v. M. Dribben, "Politics enough to make you sick" in *The Philadelphia Inquirer* (Sept. 1, 1994) B 1.

vi. R. A. Zaldivan, "Poverty rate rises despite growth in the economy" in *The Philadelphia Inquirer* (Oct. 7, 1994) A 1, 12.

vii. S. FitzGerald, "U.S. is the top spender on health" in *The Philadelphia Inquirer* (Oct. 6, 1994) A 1, 17.

viii. Comments and statistics like these are available in many sources. See, for example, the U. S. Bishops, "A Framework for Comprehensive Healthcare Reform" in *Health Progress* (Sept. 1993) 20-23.

ix. Bishops 20.

x. Bishops 22.

xi. See R. A. McCormick, "Value Variables in the Health-Care Reform Debate" in *America* 168/19 (May 29, 1993) 7-13.

xii. C. F. Koller, "An Open Letter: Four Things to Keep in Mind" in *Commonweal* (April 23, 1993) 5-6.

xiii. McCormick 8 (statistic from *The New England Journal of Medicine*, April 15, 1993).

xiv. McCormick 10.

xv. Ibid.

xvi. W. Gaylin, "Faulty Diagnosis: Why Clinton's health-care plan won't cure what ails us" in *Harper's Magazine* (Oct. 1993) 57-64.

xvii. Ibid. 58.

xviii. U. S. Bishops, *Economic Justice for All* (Washington, D.C.: USCC 1986) 23.

xix. A. Chapman, "Introduction in *Health Care Reform: A Human Rights Approach*, ed., A. R. Chapman (Washington, D.C.: Georgetown Univ. Press 1994) 1-32, here 23-25.

xx. These figures are from a study by Citizen Action and are cited in Chapman 27.

xxi. Chapman 1-4.

xxii. Chapman 1, 11.

xxiii. P. S. Keane, *Health Care Reform: A Catholic View* (New York: Paulist Press 1993) 128.

xxiv. Keane 126-27. See also M. A. Glendon, *Rights Talk: The Impoverishment of Political Discourse* (New York: The Free Press, 1991).

xxv. Keane 130-31.

xxvi. Chapman 4-5, 7.

xxvii. Keane 128.

xxviii. V. A. Leary, "Defining the Right to Health Care" in Chapman 87-105.

xxix. Keane 133.

xxx. Chapman 5, 17.

xxxi. R. M. Veatch, "Egalitarian Justice and the Right to Health Care" in Chapman 106-23, here 112.

xxxii. Keane 133.

xxxiii. Chapman 7.

xxxiv. U. S. Bishops, *Economic Justice for All*, esp. paragraphs 23-24 and 61-95.

xxxv. Keane 139-42.

xxxvi. For an extended treatment of what constitutes a decent minimum standard of health-care, see M. A. Baily, "Defining the Decent Minimum" in Chapman 167-85.

xxxvii. Veatch 112.

xxxviii. Keane 144-47.

xxxix. Keane 143.

xl. Koller 6.

xli. U. S. Bishops, "A Framework" 22.

xlii. A. R. Chapman, "Policy Recommendations for Health Care Reform" in Chapman 308-14, here 308.

xliii. Chapman 309-14.

xliv. N. Matza, "Cooling up an idea for health care" in *The Philadelphia Inquirer* (Dec. 26, 1994) A 1, 4.

xlv. Koller 6.