



**REGIONAL OFFICE FOR THE WESTERN PACIFIC
BUREAU REGIONAL DU PACIFIQUE OCCIDENTAL**

REGIONAL COMMITTEE

WPR/RC53/INF.DOC./1

**Fifty-third session
Kyoto, Japan
16–20 September 2002**

30 August 2002

ORIGINAL: ENGLISH

Provisional agenda item 16

**ETHICAL ISSUES RELATED TO NEW DEVELOPMENTS
IN THE HEALTH SECTOR**

The document for this agenda item was written by Dr John H. Bryant. Dr Bryant is a key figure in the history of primary health care. He is a former Dean of the School of Public Health of Columbia University and Director of the Office of International Health in the Department of Health and Human Services, United States Government. In the latter capacity, he represented the United States of America at the International Conference on Primary Health Care at Alma-Ata in 1978. He is currently the President of the Council of International Organizations for Medical Sciences (CIOMS), founded by WHO and UNESCO in 1950 and located at WHO Headquarters. CIOMS focuses on health policy, ethics and human values and has recently been involved in formulating International Ethical Guidelines for Research Involving Human Subjects.

This document is presented for the information of the Regional Committee and for discussion at its fifty-third session.

**ETHICAL ISSUES RELATED TO NEW DEVELOPMENTS
IN THE HEALTH SECTOR**

John H. Bryant

**Paper prepared for the fifty-third session of the Regional
Committee for the Western Pacific Kyoto, Japan
16-20 September 2002**

The views expressed in this paper are those of the author and do not necessarily reflect those of the World Health Organization.

SUMMARY

The challenge of this presentation is to bring together various issues, including *new developments* in the health sector, that are critical to providing *effective* and *equitable* health care, as well as *other approaches* to improving the health of populations, particularly in developing countries.

We see *primary health care* as an essential base on which health systems are built, and these new tools and other new developments must include effective and supportive interactions with primary health care and back-up referral arrangements so as to ensure coverage of populations in ways that are *relevant to their needs*, and *consistent with ethical precepts* related to health care and the public's health.

Now, consistent with the above introduction, we will reflect on four sets of materials that we see as having potential for contributing to more effective means of coping with the challenges of ill health of our world, particularly in developing countries.

- First, the exciting history of health care, as launched at Alma-Ata as part of the commitment to Health for All (HFA) and expressed through evolving patterns of primary health care (PHC), including concerns for limitations and potentials for improvement.
- Second, a discussion of *key ethical concepts* used in health care, research and other concerns related to health and development, including: fairness, principles of biomedical ethics, equity, human rights, and social determinants of health.
- Third, the development of new tools that strengthen those patterns of health care:
 - ✓ WHO's approach to *Strengthening Health System Performance*, developed as a key component of the World Health Report, 2000.
 - ✓ *Global Health Equity Initiative*, an approach to ensuring equity, as described in *Challenging Inequities in Health*, an important new book from the Rockefeller Foundation.
 - ✓ *Benchmarks of Fairness for Health Care Reform*, developed by philosopher Norman Daniels (Harvard University) and colleagues, and now being used as a policy tool for strengthening health sector reform in developing countries of Asia, Africa and Latin America.
- Fourth, to consider *other new developments* in terms of challenges for the health sector, some entirely new, others that have been around but received limited attention:
 - ✓ *Genomics and World Health*, described in a new book by WHO, that looks ahead to the importance and complexities of applying the benefits of

interventions involving human genetics to populations in ways that do not increase the disparities between developed and developing countries.

- ✓ *Innovative Care For Chronic Conditions* – a new monograph by WHO that focuses on the serious problem of caring for the increasing number of people with chronic conditions in ways that bridge the current inadequacies of care that tends to focus on acute and episodic care in health facilities instead of family and community-based care and prevention.
- ✓ *Integration of Traditional (Complementary/Alternative) Medicine and Modern Medicine*. WHO, and other international and national organizations, are encouraging increased attention to these traditional forms of medicine that are being used by large proportions of the populations of both developed and developing countries, including particular concern for efficacy and safety.

Further, it is important that these various advances in the health sector do not function independently and in isolation from one another, but evolve toward interactive and complementary components of systems that have an overall integrated nature. Given its leadership or collaborative involvement in each of these activities, *WHO is in an excellent position to advance them collectively in a form of convergence for constructive action.*

ETHICAL ISSUES RELATED TO NEW DEVELOPMENTS IN THE HEALTH SECTOR

Introduction

The challenge of this presentation is to bring together various issues, including new developments in the health sector, that are critical to providing effective and equitable health care as well as other approaches to improving the health of populations, particularly in developing countries. We see primary health care as an essential base on which health systems are built, and these new tools and other new developments must include effective and supportive interactions with primary health care and back-up referral arrangements so as to ensure coverage of populations in ways that are relevant to their needs, and consistent with ethical precepts related to health care and the public's health. Further, it is important that these various advances in the health sector do not function independently and in isolation from one another, but evolve toward interactive and complementary components of systems that have an overall integrated nature. Now, we will reflect on four sets of materials that we see as having potential for contributing to more effective means of coping with the challenges of ill health of our world, particularly in developing countries.

- First, the exciting history of health care, as launched at Alma-Ata as part of the commitment to Health for All (HFA) and expressed through evolving patterns of primary health care (PHC), including concerns for limitations and potentials for improvement.
- Second, a discussion of key ethical concepts used in health care, research and other concerns related to health and development.
- Third, the development of *new tools* that strengthen those patterns of health care:
 - ✓ WHO's approach to Strengthening Health System Performance
 - ✓ Challenging Inequities in Health
 - ✓ Benchmarks of Fairness for Health Care Reform
- Fourth, to consider *other new developments* in terms of challenges for the health sector, some entirely new, others that have been around but received limited attention:
 - ✓ Genomics and World Health
 - ✓ Innovative Care For Chronic Conditions
 - ✓ Integration of Traditional (Complementary/Alternative) Medicine and Modern Medicine

I. The Place of PHC in a Changing World

Here we will focus on a series of issues that guide us toward better understanding of the place of PHC – past, present and future – and how it relates to the larger health system context in which it functions, keeping in mind the global reach. Those issues will include the origins and evolution of PHC beginning with Alma-Ata.

A. PHC – Origins and Evolution. For the moment, let us switch back to the formal origins of PHC – Alma-Ata, 1978. There we put it this way: PHC is *essential health care* based on practical, *scientifically sound* and *socially acceptable* methods and technology, made *universally accessible* to individuals and families in the community through their *full participation*, and at a cost the community and the country can *afford* to maintain at every stage of their development in the spirit of *self-reliance* and *self-determination* (1).

A fine way to reflect on the origins of PHC and its subsequent pathways is to turn to the International Meeting to Celebrate 20 Years After Alma Ata, held in Almaty (same city, different name), Kazakhstan, November, 1998. That meeting included a number of the original participants (Halfdan Mahler, Jo Asvall, Carl Taylor, the author of this paper and others), and the report of the meeting is a fine rendering of the recollections and prospects relating to PHC and Health for All (HFA) (2).

A *consensus statement* of the participants captures important insights and feelings.

We, the participants of the international meeting "Primary Health Care 21", reaffirm our belief in the values of equity, participation and intersectoral development which are expressed in the 1978 Declaration of Alma Ata. They are as valid today as they were twenty years ago. We also believe that the understanding and implementation of PHC needs to be revitalized in view of the changes taking place on the threshold of the 21st Century. The challenge will be to operationalize the values of Alma-Ata by developing, on the one hand, sustainable health systems for managing PHC and by establishing, on the other hand, complementary systems for governance that will ensure equity and intersectoral response to health needs of people, thereby, effectively uniting PHC and HFA.

Dr. Gro Harlem Brundtland, Director-General of WHO, supported the meeting in Almaty with the following statement: *"PHC remains a key strategy in implementing the policy of HFA. We will continue to work with our partners in UNICEF as well as new partners including the World Bank, UNDP and UNFPA in ensuring that the PHC movement continues and builds on the lessons learned and the gains achieved and the leadership and commitment of the many who have tirelessly worked to make PHC a reality."*

The meeting gave rise to a *Contextual Overview*, which can be usefully summarized:

The insights into health problems and societal responses as seen in 1978 were strikingly accurate, and the proposed solutions have proven to be highly appropriate, namely:

- The critical place that human values would play in the pursuit of HFA and PHC, such as equity, fairness and gender sensitivity;
- The importance of having accurate information regarding the nature of the problems and the effectiveness of responses;
- The importance of community participation as essential to health care that would improve the health and well being of those communities;
- Weaknesses in health systems research and the needs for building research capacities, particularly for reaching toward the needs of the poor.

Not surprisingly, however, some problems of the time were less apparent and came more fully to light as the struggles to pursue HFA and PHC moved onward. As examples:

- The limitations of governmental capacity to absorb and carry forward comprehensive approaches to health care;
- The notions of health services being interactive with other sectors, moving onward to advanced concepts of intersectoral action, expressing a key characteristic of PHC as the centrepiece of health development;
- Social and cultural parameters, often locally unique, involved in identifying and responding to health problems of particular societies;
- The ways in which the challenge of incorporating PHC into health systems enlarged to encompass needs for health care reform in virtually every nation, whatever its level of development.

Turning to another dimension in this historic sequence of global change, there ***were other problems in the health sector that were largely beyond the range of predictability***. As examples:

- Emerging and re-emerging diseases, such as HIV/AIDS;
- Dramatic advances in market orientation and information technologies have led to *globalization* of interactions across the world, benefiting some immensely but aggravating inequities for others;
- The shift in political tensions between the larger powers to armed conflicts at local levels with widespread civil disobedience emerging as threats to peace and human well-being;
- In increasingly pluralistic societies, the call is for PHC to be designed to embrace the major components of life styles, environment and health care issues – as through society-wide movements focused on settings-based programs such as schools, workplaces and cities.

It is very much worth while quoting the words of Dr. Jo Asvall (previously Regional Director for WHO - Europe): –“the Alma-Ata concept of PHC in Europe is very much "alive and kicking", steadily growing in comprehension and depth, solidifying its position as the most sensible way forward for the 51 Member States of our Region as they enter the 21st century.”

Attached in the Annex is a description of PHC at the Hospital Albert Schweitzer in Haiti, as a contemporary example of PHC that builds on the principles of Alma Ata, with additional ideas and concepts including concern for equity, fairness and community participation (3).

II. Ethics – fairness, principles, equity, rights, and social determinants of health.

To be sure we are on the same ground with respect to ethics and related moral values, we will discuss four sets of issues: fairness; principles of biomedical ethics; equity; human rights; and social determinants of health.

A. Fairness. For the concept of fairness, let us turn to the work of Norman Daniels and colleagues on Benchmarks of Fairness for Health Care Reform (4). Fairness is a many-sided concept, broader than the concept of equity, including:

- *Equity in health outcomes, in access to all forms of care, and in financing;*
- Fairness also includes *efficiency* in management and allocation, since when resources are constrained their inefficient use means that some needs will not be met that could have been;
- For the public to have influence over health care, fairness must also include *accountability;*
- Finally, fairness also includes appropriate forms of patient and provider *autonomy.*

(We discuss the Benchmarks of Fairness in Section III)

B. Principles of Biomedical Ethics. A framework of moral principles is put forward by Beauchamp and Childress in their well known book: *Principles of Biomedical Ethics* (5). The common morality contains a set of moral norms that includes principles that are basic for biomedical ethics. These principles function as guidelines for professional ethics, and are used widely in relation to physician-patient relationships, in health care more broadly, and in research involving human subjects, among many others. *The four clusters of moral principles are:*

- *Respect for autonomy* – a norm of respecting the decision-making capacities of autonomous persons.
- *Non-maleficence* – a norm of avoiding the causation of harm.
- *Beneficence* – a group of norms for providing benefits and balancing benefits against risks and costs.
- *Justice* – a group of norms for distributing benefits, risks, and costs fairly.

C. Equity. Another ethical concept that is of central importance in health and health care is *equity*. For understanding this concept, we turn to the book: *Challenging Inequities in Health – From Ethics to Action* (6). What is meant by equity in health?

- *Inequalities* in health describe the differences in health between groups independent of any assessment of their fairness.
- *Inequities* refer to a subset of inequalities that are deemed unfair.
- The *unfairness* qualification invokes assessments of whether the inequalities are avoidable as well as more complex ideas of distributive justice as applied to health.

A further notion of importance is that of *equity in health outcomes*. This reflects the premise that disparities in health outcomes are the most important dimensions of health equity. Other dimensions, such as *equity in access to health care*, although important, need to be understood in relation to their impact on *health status*. Indeed, as will be discussed below, health has many determinants beyond those of health care.

D. Rights. Jonathan Mann (sadly departed) has had a particularly important role in directing attention to the human rights aspects of public health (7). His work begins with acknowledgement of the fundamental difference between the population emphasis of public health and the essentially individual focus of medical care. Public health identifies and measures threats to the health of populations, develops governmental policies in response to these concerns, and seeks to assure certain health and related services. In contrast, medical care focuses upon individuals – diagnosis, treatment, relief of suffering and rehabilitation. Promoting and protecting human rights is inextricably linked with promoting and protecting health. This is because human rights offers a societal-level framework for identifying and responding to the underlying – societal – determinants of health. It is important to emphasize that human rights are respected not only for their instrumental value in contributing to public health goals, but for themselves, as societal goods of pre-eminent importance.

E. Social Determinants of Health. Here, we draw on the writings of Dan W. Brock, Professor of Philosophy at Brown University: *Broadening the Bioethics Agenda* (8), to introduce a concept of major importance for health development – *social determinants of health* – of which many in the health sector are unaware. In discussing the history of bioethics, Brock points out how bioethics has focused principally on ethical issues arising in clinical medicine. When it has addressed justice or equity, it has focused on *access to health care* and on defining a *general moral right to health care*. This dual focus on establishing a *right to health care* and on *health care* rather than *health* has left bioethics largely silent on two issues of fundamental importance for a full account of justice and health:

- First, the focus on establishing a right to health care has contributed to a failure to address difficult issues in developing ethical standards for *equitably prioritizing limited resources in health care*.
- Second, the focus on inequalities in access to health care has ignored the much greater impact of *social determinants health*, in particular socioeconomic class and inequality, on health and health inequalities.

Bioethicists, as well as many in the health care field, seem to have assumed that the main causes of *health inequities* are the *inequities in the health care system*. But *health care's* impact on both health and health inequalities are quite limited. For example, medical care

is estimated to have accounted for only about one fifth of life expectancy gains in the 20th century (9). It is widely appreciated that severe poverty is associated with poor health and decreased life expectancy. In some very poor underdeveloped countries life expectancy is little more than half that of many developed countries. The differences are less dramatic within the U.S. but persist there as well. But the health effects of income differences between different countries tend to disappear when per capita income reaches around \$5,000 and countries undergo the transition from communicable to non-communicable diseases. Among the advanced industrialized countries, there is no significant correlation between per capita wealth and life expectancy. *But something beyond differences in wealth is at work.* Within societies, differences in income beyond poverty levels do have substantial effects on health of different socioeconomic classes. *This social gradient in health suggests that relative, not absolute, income levels are what impact health.*

The most important social impact on health and life expectancy appears to be from socioeconomic inequality and class; education, too, is highly correlated with both health and socioeconomic class. As one moves up the socioeconomic scale, there is a consistent increase in life expectancy. But it is not just where one stands in the socioeconomic hierarchy that affects health, but also the degree of socioeconomic inequality in the society. Higher societal income inequality adversely affects citizens' health and life expectancy. The first major, and still classic, study demonstrating this effect – the Whitehall study – found that as one went up each grade in the British civil service there was a consistent increase in life expectancy, all in the absence of material deprivation at any grade. And the differences in life expectancy were not small. Between the highest and lowest grades it was 4.4 years – greater than the effect on mortality of all coronary disease (8). In short, here were differences in life expectancy related to socioeconomic status but *unrelated to poverty.*

So there are at least *two important social determinants* at work:

- where one stands in the socioeconomic hierarchy affects one's health
- the degree of income inequality in a society affects the society's overall level of health and health inequality.

In the U.S., the difference in age-adjusted mortality between metropolitan areas with the combination of high inequality and low per capita income and those with low inequality and high per capita income is greater than the combined loss of life from lung cancer, diabetes, motor vehicle accidents, HIV infection, suicide, and homicide (10).

What are the mechanisms for these impacts? *They are not fully understood.* Because in developed countries it is one's relative rather than one's absolute income that is important, it appears to be *the psychosocial rather than the material effects* of income levels and inequality that are important. The social gradient of health is largely determined by *relative deprivation.* Socioeconomic status is correlated with the degree of social supports and participation in social networks outside the family, which have strong protective effects on health. More egalitarian societies exhibit stronger social cohesion and community life. In a variety of ways, the lower economic classes are subject to

higher chronic psychosocial stress, which has a powerful effect on death and illness rates. *Put generally, the quality of the social life in a society and the social capital of its members are two of the most powerful determinants of health, and they are very closely related to the particular socioeconomic position of individual members of a society.*

I will now go beyond Brock's thoughtful analysis to comment on the applications of these ideas to developing countries. We have seen the evidence that socioeconomic inequalities, with their psychosocial effects, contribute in significant ways to decreased life expectancy in developed countries, and this is seen in the absence of poverty. In developing countries, while poverty contributes in major ways to diminished life expectancy, surely the social determinants described for developed countries are at work in developing countries and to a much greater degree. *The notions of a sense of a lack of self worth, of humiliation, of hopelessness – are rampant in developing countries, and clearly contribute in major ways to diminished life expectancies.*

To ask how to cope with these features opens a very large window to an exceedingly important arena of hope and work.

III. New Tools to Strengthen Health Systems

A. WHO's Framework for Assessing Health System Performance

Here we introduce WHO's Framework for Measuring Health System Performance. A fresh conceptualization of health, it is described in the *Bulletin of the World Health Organization* (11) and elaborated in WHO's World Health Report 2000 (12). It has generated considerable debate on its methodology for international comparisons of health attainment. It also represents an encompassing perspective of the function of health systems at the national level.

World Health Report 2000 presents a conceptual description of the Framework, including the statistical base for national indices, along with detailed descriptions of health system realities. It provides *defining goals* of the health system including:

- Improving the health of the population, both the *average* level and the *distribution* of health.
- Enhancing responsiveness of the health system to the *expectations* of the population – the *average* level of responsiveness and its *distribution*.
- Fairness in financing and financial risk protection for households.

Pursuing these goals gives rise to three critical concepts:

- Quality – the level of goal attainment for health and responsiveness.
- Equity – fair distributions of health, responsiveness and financial burdens.

- Efficiency – achieving the socially desired mix of the goals compared to available resources.

Stewardship is a key factor in defining strategic directions for the entire health system. It focuses on the changing role of the state in health system development, and includes the notion of good governance and policy making that serves the public interest

At a meeting of the American Public Health Association in 1999, Julio Frenk (now Minister of Health of Mexico), one of the authors of the WHO Framework (along with Chris Murray), made the following comments: "We hope this Framework will help in reaching to the future with a constructive perspective. We see the commitment to *health for all* as persisting and permanent, and we see *our understanding of PHC* undergoing positive changes as we advance our capabilities for assessing system performance."

In short, WHO's Framework provides a fresh conceptualization of how health services need to be organized and managed in order to achieve equity, quality and efficiency. We join with Julio Frenk in seeing a place for PHC in the Framework. However, we are willing to be a bit provocative by insisting that – for the Framework to achieve its goals of *health attainment*, with a fair distribution of health improvement; an increased *responsiveness* to the expectations of the population, again with a fair *distribution*; and with *stewardship* defining strategic directions for the entire health system – effective approaches to PHC must be included. *The capacity of PHC to reach out to entire populations with basic services and participatory interactions will have to be seen as fundamental to the WHO Framework.* Having said that, we also see the Framework as providing a place for PHC in a variety of health systems across the spectrum of levels of socioeconomic development.

B. Challenging Inequities in Health

Motivated by a common concern about unacceptable differentials in health, what was a small initial international collaboration in 1996 evolved into the Global Health Equity Initiative (GHEI). This network links over 100 researchers from more than 15 countries who are unified by their interest in finding ways to address inequities in health. The GHEI, funded by the Rockefeller Foundation and Swedish International Development Agency (SIDA), represents a concerted effort to ensure that health equity research is undertaken by researchers within countries most affected by inequities in health. An early phase of this work of the GHEI had five aims:

- To articulate the concepts and values underlying equity in health.
- To develop measures and tools for health research and policy to help analyze equity and inequity in health.
- To encourage empirical research on health inequities within countries in the developing world.
- To establish a scientific foundation for proactive advocacy, policies and programs.

- To stimulate action to reduce inequities in health in all levels of society, by providing decision makers with knowledge and concreateed suggestions for change.

A key product of GHEI is this splendid book – *Challenging Inequities in Health – From Ethics to Action* (6). Other publications are to follow.

There are at least three main features that make the GHEI distinctive over and above the wide range of countries and the large number of international researchers involved:

- The participants in the Initiative share common values and concerns about equity, an interest that drew many to the Initiative in the first place.
- The country studies have been undertaken by study teams within each of the countries rather than by Northern “experts” parachuted in from the outside.
- The participants in the Initiative, through a mutually supportive network, were able to engage in an ongoing dialogue on the multiple complex dimensions of health equity analysis.

The concluding chapter of the book provides a policy-oriented overview of the whole process from ethics to action. Given the global nature of the Initiative, this incorporates an important section on how the international agencies could work together to challenge these unacceptable inequities in health. *This issue deserves to be at the top of the public health agenda for the new millennium.*

C. Benchmarks of Fairness for Health Care Reform

Norman Daniels, philosopher at Harvard University in Boston, has long been concerned with interactions of justice and health. His writings have included *Just Health Care, Am I My Parents' Keeper?*, and *Seeking Fair Treatment*. In 1996, working with the Clinton Task Force on Health Care Reform, he and colleagues published *Benchmarks of Fairness for Health Care Reform, 1996* (13).

While health care reform in the U.S. has (sadly) remained somewhat stagnant, the Benchmarks attracted the interest of a number of persons interested in justice and health in developing countries. Over the past two years, a cluster of colleagues from Asia, Africa and Latin America have been working toward adapting the Benchmarks to the realities and needs for reform in those countries, seeing the *Benchmarks as a new tool for health care reform* (4).

The Benchmarks are seen as promoting change related to fairness at local and national levels through policy change. (For a description of the meanings of fairness, return to Section IIA.) There are nine benchmarks.

- 1. Intersectoral public health
- 2. Financial barriers to equitable access
- 3. Non-financial barriers to access
- 4. Comprehensiveness of benefits and tiering

- 5. Equitable financing
- 6. Efficacy, efficiency and quality of health care
- 7. Administrative efficiency
- 8. Democratic accountability and empowerment
- 9. Patient and provider autonomy

While this is not the place for detailed discussion of the Benchmarks, the point can be made that *the intent is not to provide a blue print of health care reform* calling for insistent action following a fixed pattern. Rather, the Benchmarks are seen as a tool for facilitating deliberation and reflection on reform options.

The following are abbreviated examples of emphases drawn from four of the Benchmarks.

- **1. Intersectoral public health**
 - Basic education and health literacy
 - Information infrastructure for monitoring health status inequalities
 - Improvements in social determinants of health
- **3. Non-financial barriers to access**
 - Reduction in geographical maldistribution
 - Reduction in gender and cultural discrimination
- **6. Efficacy, efficiency, quality of health care**
 - Focus on Primary Health Care with community participation
 - Implementation of evidence-based practice
 - Measures to improve quality
- **8. Democratic accountability and empowerment**
 - Explicit procedures for resource allocation with transparency
 - Strengthening civil society and advocacy groups

Reflecting for a moment on some of the most serious aspects of poverty and despair, it is to be noted that the Benchmarks reach well beyond the health sector as such, calling for assessment of fairness across sectors and with respect to social determinants of health.

A further aspect of using the Benchmark includes *scoring of reform options* in terms of their fairness. Employing a scale of -5.0 to +5.0, reform options can be judged according to the fairness of their assessed intent or impacts. The scoring is applied to national, district and local levels, and it is important that the scoring be evidence-based.

Two examples of applications of the Benchmarks can be given. First, in Thailand and Pakistan, the results of workshops on the Benchmarks were presented to policy makers, who then invited follow-on field projects using the Benchmarks to facilitate consideration of health system change. Those follow-on projects are currently underway.

As a second example, in Kenya graduate students studying Health Policy and Management applied the Benchmarks to Health Sector Reform actions promoted by the

Ministry of Health. After analyzing and scoring the reform options, they then interacted with health system personnel, policy makers and communities in dialogue over the Benchmarks. There were both agreements and disagreements over interpretations of the intention of the reforms, and lively debate over scoring the extent of fairness of the reforms achieved at local, district and national levels. Overall, it was seen as a distinctly constructive process for all parties – policy makers, health system managers, students and their faculty, and communities. Plans are currently underway for applications of the Benchmarks to other countries in Latin America, Africa and Asia. These plans include the building of country and regional capacities to use the Benchmarks as a tool for facilitating health policies deliberation with the goal of enhancing fairness.

IV. New Challenges

A. Genomics and World Health

We are all aware of the emerging place of human genetics in health. We sense the technical complexity of this field, and also appreciate its immense potential for benefiting human kind. And we can sense some of the ethical complexity of its uses, particularly in relation to developing countries. WHO has recently published a comprehensive review of these issues in a book entitled *Genomics and World Health* (14). Here we will consider a series of issues that are of concern in looking ahead, particularly as they relate to developing countries.

1. Justice and Resource Allocation in Relation to Genomics

One major concern is that the advances in genomics will benefit the well-to-do of the world much more than the poor and deprived. Thus, the possibility that genomics will further the existing inequities in health and health care must be addressed. It is important for developing countries to strengthen their research capacities. They cannot rely on the market-driven research agendas of developed countries. Regional partnerships are important where there can be coordination of networks of collaborative research centers.

International Property Rights and Sharing the Benefits of Research The situation of patents in relation to genomics is *nothing less than chaotic*. The patents problem is retarding not stimulating scientific and economic progress. There is a need for strong international leadership to address this problem. HUGO (Human Genome Organization), USNBAC (United States National Bioethics Advisory Commission) and UNESCO are all urging that international research collaboration be based on benefit sharing programs without disadvantaging developing countries.

2. Screening and Testing with Particular Reference to Developing Countries.

Most ethical issues relating to genomics are not new – informed consent, confidentiality, stigmatization, discrimination – but they require special consideration and new approaches, for two reasons. First, genetic information relating to individuals can stigmatize them and serve as a basis for discrimination. Second, appropriate uses of our new genetic knowledge and capacities, including the potential for their misuse or abuse, all depend critically on social, political, economic and cultural contexts. By way of illustration, in countries without strong cultural and legal traditions of respecting individual reproductive freedom, the potential for coercion of women’s reproductive choices for eugenic or other reasons is magnified. In highly patriarchal societies where men traditionally make important decisions for family members, including their wives, women are again especially vulnerable to coercion in making reproductive choices, and it will be more difficult to ensure their free and informed consent for genetic services. In countries with significant private health insurance, there is potential for genetic discrimination by insurers that will not exist in those with a national health service available to all. An important priority for developing countries will be to develop the necessary regulatory structures to address both scientific and ethical issues. In some cases, broad international guidelines should be created to help guide the development of genomics and of country specific guidelines in developing and developed countries.

3. Informed Consent.

The consent process employed when developed country researchers undertake research in developing countries should be sensitive and responsive to local cultural and social beliefs and practices, and it should not violate international standards nor be one that would be ethically unacceptable in their own countries. Respecting patients’ rights to give or withhold consent respects their self determination and their right to bodily integrity. In some cultural contexts that lack any strong tradition or practice of individual consensus, it may be more common for community leaders to give consent for screening or research programs in their community. While it is appropriate to respect such cultural practices, it should not substitute for securing the consent of individual participants.

The consent process should be preceded by pre-test counseling, followed by post-test counseling. As countries introduce genetic testing programs, they should simultaneously build capacities for high-quality genetic counseling. In a number of countries, there is potential for coercive pressure from government, society or family members in genetic screening and testing programs. For example, in some countries it is now mandatory to have a test for thalassemia (an hereditary anemia) before getting married – the potential life long costs of treatment, including repeated transfusions, being so extreme that pressures are exerted for couples to undergo testing and to avoid marriage or terminate pregnancy when necessary.

When genetic testing services are not part of universal health services, but instead are available only to those who can pay, the clearly inequitable result could be concentration of genetically transmitted disease among the poor in a society. When genetic testing and

screening programs are introduced in a country, they should be made part of the universal health care services, available to all and not only in the private health sector where they will worsen health and other inequities.

There are several reasons why informed consent for genetic research, screening and testing has special importance in many developing countries. *First*, genetic tests may be developed before any effective therapeutic interventions exist for those found to have a genetic risk. There is also the potential for social misallocation of health resources if genetic tests come into wide use in the absence of cost-effective therapeutic interventions necessary to produce health gains in the population tested. *Second*, where educational levels are low there is a special obligation to inform the participating subjects. *Third*, those performing genetic research in developing countries are often scientists from developed countries or large multinational pharmaceutical or biotechnology companies, who may have research agendas different than the needs of developing countries.

Substantial consensus has developed that research should not be done in developing countries that does not have potential benefits for their populations. To avoid exploitation, there must be reasonable assurance that the benefits of the research will be available at least to the research participants, and to the broader community in which the research is completed. There is considerable debate about what precisely this “reasonable assurance” responsibility requires; for example, what interventions must be available, from whom, to whom, for how long

The informed consent process should not be the only way of regulating and controlling genetic research or the use of genetic testing and screening, especially in developing countries. Health ministries should develop formal structures for the evaluation of potential genetic screening, research or testing programs to ensure that the programs address local health needs in a cost-effective manner.

4. Confidentiality of Genetic Information to Prevent Discrimination and Stigmatization

One way in which genetic information is different than other health care information is that it is typically not just about a particular individual who has been screened or tested, but also involves other family members of that individual. Another is that genetic information is commonly predictable of an individual’s risk of developing certain diseases in the future, some times with a high degree of certainty, as with thalassemia, and other diseases with less certainty, as with breast cancer susceptibility genes.

There are several ethical grounds for the practice of confidentiality of health information generally. *First*, maintaining confidentiality typically prevents various possible harms to the patient, such as discrimination in employment or insurance. *Second*, since the information is obtained only with the patient’s consent and cooperation, the patient should control who has access to it, including family members. *Third*, patients can have a moral obligation to provide such information to potentially affected family members, and many believe that it should be permissible for health care providers to do so as well, even without the consent of the patient, if necessary. Given the complexity of this matter of

availability of genetic information to the family, it is important that there be an institutionalized process for decisions on this matter.

Being labeled as having “bad genes” can have serious social and psychological consequences for individuals, and this stigmatization may be stronger and more common where levels of education and understanding of genetics is low.

Perhaps the most serious worry about genetic discrimination is in health insurance.

There is a compelling ethical case grounded in equity for *community rating* of either social or private health insurance in order to spread the costs of individuals’ health risks across the larger community. Moreover, genetic risks can be seen as *a paradigm of risks that are morally undeserved* and which should not affect people’s cost of or access to health care. Even if individuals may be responsible for some health risks due to their behavior, which is itself problematic, there is no plausible sense in which they are responsible for their genome and the health risks it generates – that is, for their good or bad luck in the “genetic lottery”. This would generate the perverse effect of making it more difficult for those who need the insurance the most.

Similar ethical concerns apply to the use of genetic testing by employers or potential employers. Genetic conditions that constitute risks for future health problems should not be used to bar otherwise qualified people from employment. As in the case of health insurance, countries should not introduce genetic screening or testing without first having clear and enforceable legal prohibitions of the use of genetic information in employment decisions.

5. Gender Issues.

It is important to ensure that women are not subject to coercive pressure from within the family or community to pursue or not to pursue genetic testing. Publicly funded awareness and counseling programs should be established to support women in making decisions about genetic testing on the basis of their own needs and interests. In some countries problems regarding coercion for sex selection of the fetus have arisen which have often proved difficult to prevent.

Genetic information can also be used to discriminate or stigmatize in the context of other social practices. For example, in the case of arranged marriages families may seek genetic information about potential spouses of their children. This information can make women unmarriageable if they are known to have genes for serious diseases, or it can subject them to physical or other harms if they give birth to children with diseases for which they are deemed responsible.

Governments and other organizations should undertake an assessment of the special risks to women (and ethnic or cultural groups) in their countries from potential disclosure of genetic information before genetic research, or testing goes forward, so as to limit the harms to those taking part in these programs.

6. Eugenics

From the 1870s to the 1940s, eugenics movements existed in many countries which focused on a concern for what was seen as a degeneration of the gene pool, which they sought to reverse by encouraging the “fit” to increase their reproduction, and discouraging the “unfit” from reproducing. But the fit and the unfit were commonly determined by racial, class, and national prejudices and stereotypes that still persist today in much of the developed and developing world, and that must be avoided in our use of the powers of the new genetics.

At the heart of many ethical concerns with eugenics are issues of justice and the sacrifice of some individuals’ interests for the sake of some greater social good. The inequalities of social and political power made these injustices possible. A major task of contemporary genomics is to ensure that the interests and rights of individuals are not unjustly sacrificed for what is seen as the benefit of some greater social good.

7. The Disability Rights Movement.

A serious challenge to genetic screening and testing has been raised by members of *disability rights movements* in many countries. They argue that these programs do not share the traditional medical goal of preventing or treating disease in individuals, but instead seek *to prevent the existence of people with disabilities*. Why do many in the disability rights movement view this form of replacement as unethical? *First*, the disadvantages of most impairments are due mainly to the failure of society to accommodate disabled persons. *Second*, typical views about the lives of disabled people are often based on prejudices, stereotypes and other false beliefs with the result that disabled people themselves rate their own quality of life higher than the non-disabled do. *Third*, only a very few genetic disorders, such as Tay-Sachs disease, are so severe as to make life not worth living. *Fourth*, disabled people have made many positive contributions to the lives of others and to society. *Finally*, some worry that genetic screening and testing are part of broader undesirable pressures toward normalization, conformity, and intolerance of differences. How do defenders of genetic testing and screening respond to the disability rights movement? The programs of genetic testing and screening are not a criticism of those who are disabled, but do intend to prevent serious disabilities through genetic testing and screening.

8. Non-therapeutic Genetic Interventions: Genetic Enhancements.

There are mixed perspectives on the acceptability of *genetic enhancements*. Some have condemned non-therapeutic use of genetics to select and control genetic inheritance of children as eugenic and unethical; they support absolute bans on all such uses. Other have take a more measured position that allows for the possibility of genetic enhancement if done within specified ethical limits.

Societies have moral obligations grounded in equity or justice and human rights to ensure access to health care for their citizens. A fundamental part of the moral importance of health care is its role in maintaining normal function, and in turn helping to secure equality of opportunity for persons that serious disease and disability can undermine. Genetic enhancements of normal functions, on the other hand, do not serve justice in this way, and if and when they become possible will almost certainly not be regarded as part of the social obligation to provide health care to all members of society. This means that enhancements would likely be available to the rich and not to the poor – the rich would be able to confer on their children not just social advantages, as they do now, but genetic advantages as well. The result would be a substantial widening of inequalities between developed and developing countries, as well as of inequalities within societies between the well-off and the worse-off. This is perhaps the greatest ethical concern about possible future capacities to use genetics to significantly enhance important normal human functions – the unfairness of further widening already unjust inequalities of opportunity and well being between the rich and the poor. The non-therapeutic use of genetic technology for enhancement of normal function may not be inherently unethical, but it raises a number of ethical concerns that must be addressed if and when it becomes possible.

9. Gene Therapy, Stem Cell Therapy and Human Cloning.

While there is a considerable degree of agreement about how gene therapy should be handled, the position regarding *stem cell therapy* and its relation to human reproductive cloning is still in a state of flux. *Somatic cell gene therapy* does not raise any fundamentally new ethical issues because, in principle, it is little different from organ transplantation or other therapy. *Germ-cell gene therapy* is different in this respect, principally because it has the potential to alter the genetic makeup of future generations.

The ethical issues regarding *human embryonic stem cell research* directed at cell therapy are more controversial. Human embryonic stem cells are currently the only cell population which has unequivocal potential for developing into the wide range of different adult tissues required for organ repair. This raises important and complex ethical issues relating both to the moral status of human embryos and to the relationship of the different manipulations that might be used in relation to genuine *human reproductive cloning*.

The ethical status of human embryos has been widely debated and is controversial. An important distinction revolves around whether objections to research on embryos rest on *rights-based* or *symbolic* grounds. Those who view the *human pre-implantation embryo as a full person with rights* hold that its intentional destruction is equivalent to murder. This perspective conflicts with other widely held philosophical and moral views which hold that *status as a person requires further development*, such as at least a nervous system capable of sentience or even self consciousness. The first sign of the presence of a nervous system is observed at about 14 days of development with the appearance of what is called the *primitive streak*. Even if lacking rights, the *symbolic* status of the embryo as the early stage of human development may create ethical issues in how it is treated.

Based on these distinctions between rights and a symbolic view of the embryo, some countries, the United Kingdom, for example, have permitted research for specified purposes on embryos of less than 14 days development. Other countries have placed different limits on research on human embryos or banned it completely.

A second set of complex ethical issues in stem cell research arise from the practical problems of its applications for organ therapy and ways in which this approach might be seen as leading to human cloning. A reasonable position taken by international organizations is that the line between therapeutic cloning and reproductive cloning is quite clear and that reproductive cloning can be prohibited without impeding therapeutic cloning. Currently, there is near universal consensus of opinion that the risks inherent in any attempt at human reproductive cloning at the present time would make doing so clearly unethical. Many also believe that human reproductive cloning would be unethical under any circumstances and that there is no ethical and medical basis for pursuing work on it. This view has been stated by WHO, and many countries have made it illegal to pursue work towards this end, or are in the process of doing so.

10. Conclusion:

The ethical issues arising from applications of genome research are extremely complex and constantly changing. But although they present particular problems for different societies depending on their religious beliefs, social structure and cultural practices, they can be based on broad principles which are relevant to every society. Hence there is a major requirement for international leadership in developing a broad framework on which individual countries can develop their own codes of ethical practice as the field evolves in the future.

B. Innovative Care for Chronic Conditions

WHO has just published a monograph – *Innovative Care for Chronic Conditions: Building Blocks for Action, A Global Report* (15) – that calls attention to a problem of great seriousness. It is basically that *the management of chronic conditions* – non-communicable diseases, long-term mental disorders, and certain communicable diseases, such as HIV/AIDS – is one of the greatest challenges facing health care systems throughout the world. Currently, chronic conditions are responsible for 60% of the global disease burden. They are increasing such that *by the year 2020, developing countries can expect 80% of their disease burden to come from chronic problems.*

In developing countries, most persons with chronic conditions seek care at the primary health care level, yet most primary health care is oriented toward acute and episodic care. An evolution of primary health care is imperative. To successfully manage chronic conditions, care must be more strongly oriented toward the care and support that can be provided by families and communities, and by the patients themselves. The WHO monograph is well structured in its recommendations and interest in supporting these directions of change.

There are eight essential elements for taking action:

- **Support a paradigm shift.**
Through innovation, health care systems can maximize their returns from scarce and seemingly non-existent resources by shifting their services to encompass care for chronic conditions.
- **Manage the political environment.**
Policy making and service planning inevitably occur in a political context. For transformation toward care of chronic conditions to be successful, it is crucial to initiate bidirectional information sharing and to build consensus and political commitment among stakeholders at each stage.
- **Build integrated health care**
Health care must guard against fragmentation of services. The outcome of integrated services is improved health, less waste, less inefficiency and a less frustrating experience for patients.
- **Align sectoral policies for health**
In government, diverse authorities create policies and strategies that affect health. The policies of all sectors need to be analyzed and aligned to maximize health outcomes.
- **Use health care personnel more effectively**
Health care providers, public health personnel and those who support health care organizations need new, team care models and evidence-based skills for managing chronic conditions. Advanced communication abilities, behavioral change techniques, patient education, and counseling skills are necessary in helping patients with chronic problems.
- **Centre care on the patient and family**
Because the management of chronic conditions requires lifestyle and daily behavioral change, emphasis must be upon the patient's central role and responsibility in health care. At present, systems relegate the patient to the role of passive recipient of care, missing the opportunity to leverage what he or she can do to promote personal health.
- **Support patients in their communities**
Health care for patients with chronic conditions does not end or begin at the doorway of the clinic. It has to extend beyond clinic walls and permeate patients' living and working environments. Patients and their families need services and support from their communities.
- **Emphasize prevention**
Most chronic conditions are preventable. Additionally, many of the complications of chronic conditions can be prevented. Prevention should be a component of every health care interaction.

Chronic conditions will not go away; they are the health care challenge of this century. Alteration of their course will require determined effort among decision makers and leaders in health care in every country in the world. Fortunately, there are known, effective strategies to curtail their growth and reduce their negative impact.

The solution is to embrace a new way of thinking about and managing chronic conditions. Many countries are making the shift and starting with the development of innovative chronic conditions programs. Small steps are as important as system overhaul. Those who embrace change, large or small, are experiencing benefits today and creating the foundation for success in the future.

C. Integration of Traditional and Modern Medicine, and the Place of Equity

It is increasingly apparent that there is an international movement toward the integration of traditional and complementary/alternative medicine – TM(CAM) – and modern medicine (16). WHO and many governments and NGOs are supporting this transition toward greater respect for TM(CAM), with concrete steps for increasing country capacities, including developing countries, for strengthening their uses of TM(CAM). Special attention is being given to research and development processes for ensuring safety and efficacy of such interventions.

Ethical Principles. There are important ethical issues that come into play in this process of integration. The relationship between practitioners of TM(CAM) and the patients and communities to which they relate raises classical ethical questions. Will those relationships be built on the key principles of ethics in health care – *autonomy, beneficence, non-maleficence and justice?* (see discussion of *Ethical Principles in Section II*) The applications of these principles are well tried in relation to conventional medicine, but with many shortfalls along the way, including physician paternalism, unintended but occasional harmful uses of medications, and failure to achieve just distribution of benefits. Considerable attention is already being given to the functions of TM(CAM) in those interactions.

The Place of Equity. (See discussion of equity in Section II). It is here that *equity* comes into play. Does TM(CAM) have the potential for being responsive in terms of equitable health care? There are several reasons for saying – yes it does! First, we are now told that some 60%-90% of people in developing countries are using TM(CAM), as they can neither afford nor gain access to conventional medicine. If TM(CAM) provides beneficial care, then it will be to their distinct advantage to use it. Second, we are also told that 60% of people in developing countries are suffering from chronic conditions (a figure projected to reach 80% by 2020), which call not only for hospital and clinic based care, but also for home, family and community-centered care, and it is there that TM(CAM) can be at its strongest. The care of patients with HIV/AIDS, malaria and tuberculosis in their home settings would be examples. As a further example of this direction of thinking and action, there have been studies in India and China in which traditional medical practitioners have been incorporated as members of primary health care teams, functioning in partnership with conventional medical practitioners, with very positive results.

As a final reflection on equity and TM(CAM), it is fair to point out that a characteristic of conventional medicine is its tendency to focus its science-based perspectives on organ systems and diseases, and while the patient is also of concern, he

or she as a person may not get the concerned attention that his or her disease receives. In contrast, for TM(CAM) the patient, as a person, is often the primary concern, and several individuals with similar patterns of disease may be treated differently according to their social, cultural and spiritual conditions and needs. *Here, then is an example of a full expression of the requirement of equity that care be according to need.*

Safety and Efficacy. A major concern regarding TM(CAM), has to do with safety and efficacy. Central to the strategies of WHO, concerned governments and NGOs, is the effort to advance the research and regulatory processes for widespread assessment and assurance of the safety and efficacy of TM(CAM). This will be a very long and arduous process, but it is seen as essential and efforts are accelerating.

Global Leadership. With the increasing involvement of organizations such as WHO and the U.S. National Institutes of Health in the strengthening of TM(CAM), the possibilities lie ahead that global leadership will encourage and promote advances in this field and its integration with conventional medicine.

V. Concluding Reflections – Global Convergence?

We have been examining the potential interactions of components of health care systems as well as ethical values that must be seen as relating to them. Let us consider what history has given us. The world converged at Alma-Ata to take insistent steps in the interest of human well-being. The conference emerged with a set of ideas – HFA and PHC – based on fundamental human values, ethical precepts, and the most practical perspectives of the time with respect to advancing community-related health care.

The ideas were not perfect, but they broke new ground, reached out to all nations, and advanced critical dimensions of health care. Complexities emerged that were unforeseen: changing roles of governments; lack of support of higher levels of health systems; increasingly complex and costly health care; and persisting and extensive inequities. There were also strongly positive examples of PHC, one of which has been presented here – the programs of the Hospital Albert Schweitzer in Haiti (see Annex).

Now, the world is moving onward, benefiting from the strengths of Alma-Ata, and recognizing important problems of health and development that call for new dimensions of understanding and action. In that context, we have focused on new developments in the health sector, particularly as they are relevant to developing countries, including an insistent concern for relevant ethical values, principles and methodologies. After reflecting on Alma Ata and the resultant ideas associated with PHC and HFA, we spelled out relevant ethical concepts, and then turned to new developments :

- three new tools –
 - ✓ WHO’s approach to Strengthening Health System Performance
 - ✓ The Global Health Equity Initiative
 - ✓ Benchmarks of Fairness for Health Sector Reform
- three new challenges –
 - ✓ Genomics and World Health
 - ✓ Innovative Care for Chronic Conditions

- ✓ Integration of Traditional (complementary/alternative) Medicine and Modern Medicine.

These health system components now before us are not a final answer, to be sure. But, there is no final answer – there will only be steps toward improved answers, and they represent such steps.

On reflection, it is apparent that none of the components put forward can function in isolation. Each is dependent on interactions with the others – effective and efficient interactions. Step by step, an integrated system can emerge as a real possibility. Given this possibility – at this time in our history of global health that is tinged with such inadequacy and uncertainty – we believe it is reasonable to at least address the challenge of bringing these components together into some form of synergy and interdependence. Yes, it is time to generate an international determination to achieve a convergence of the best of current knowledge to shape the development of health systems and other approaches to improving the health of the world's people. And it is of special importance in terms of seeing such a convergence, that of the six issues presented, WHO is primarily responsible for four of them, and the remaining two – Benchmarks of Fairness and the Global Health Equity Initiative – both see their concepts and actions as being entirely complementary to those of WHO.

References:

1. The Declaration of Alma-Ata, 1978.
2. Primary Health Care 21, "Everybody's Business". An International Meeting to Celebrate 20 Years After Alma-Ata. Almaty, Kazakhstan, 27-28 November 1998. Jointly Organized by WHO Headquarters, Geneva, Switzerland and the WHO Regional Office for Europe, Copenhagen, Denmark.
3. John H. Bryant. Origins, Evolution, and Prospects for Primary Health Care in a Changing World, in: *Community-Based Health Care: Lessons from Bangladesh to Boston*. Edited by Jon Rohde and John Wyon. Management Sciences for Health, Boston, 2002.
4. Norman Daniels, J. Bryant, R.A.Castano, O.G. Dantes, K.S. Khan, and S. Pannarunothai. Benchmarks of fairness for health care reform: a policy tool for developing countries. *Bulletin of the World Health Organization*. 2000 **78** (6) 740-750.
5. Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Sciences*. Oxford University Press, 2001.
6. Timothy Evans, et al, ed. *Challenging Inequities in Health – From Ethics to Action*. Oxford University Press, New York, 2002.

7. Jonathan M. Mann. Medicine and Public Health, Ethics and Human Rights. In: Dan E. Beauchamp and Bonnie Steinbock , eds. *New Ethics for the Public's Health*. Oxford University Press, New York, 1999.
8. Dan W. Brock: Broadening the Bioethics Agenda. *Kennedy Institute of Ethics Journal* 10.1 (2000) 21-38.
9. Richard G. Wilkinson. *Unhealthy Societies*. Routledge, London, 1996.
10. John W. Lynch, et al: Income Inequality and Mortality in Metropolitan Areas of the United States. *American Journal of Public Health*, 1998, 88: 1074-79.
11. Christopher J.L. Murray and Julio Frenk. A framework for assessing the performance of health systems. *Bulletin of the World Health Organization* 2000, **78** (6) 717-731.
12. World Health Report 2000. World Health Organization, Geneva. 2000.
13. Norman Daniels, Donald W. Light, Ronald Kaplan. *Benchmarks of Fairness for Health Care Reform*. Oxford University Press, 1996.
14. *Genomics and World Health – Report of the Advisory Committee on Health Research*. World Health Organization 2002.
15. Innovative Care for Chronic Conditions: Building Blocks for Action. Global Report, Non-communicable Diseases and Mental Health. WHO. World Health Organization, Geneva 2002.
16. WHO Traditional Medicine Strategy 2002-2005 (Forthcoming) – Working Document for Adoption and Implementation. WHO, Geneva, 2002.
17. Henry B. Perry. Health for All in Bangladesh – Lessons in Primary Health Care for the Twenty-First Century. The University Press Limited, Dhaka, Bangladesh, 2000.

ANNEX

Primary health care and the Hospital Albert Schweitzer in Haiti

The Hospital Albert Schweitzer (HAS) was founded by Larimer and Gwen Mellon 50 years ago in rural Haiti, inspired by Albert Schweitzer and his philosophy of *reverence for life*. In the early years, the hospital responded to those who came to the hospital seeking care, but later expanded its vision and mission to include the health and wellbeing of all of the 285,000 people in the Artibonite Valley, most of them living in poverty. The overall commitment was directed toward equity-oriented health and development, with three interactive programs: *hospital, community health, and community development*

The health and development programs are largely funded from gifts and grants from outside Haiti, with communities sharing in the costs in ways that are a modest burden to them, but do not dissuade them from seeking care. The entire program costs \$16 per capita per year with hospital services at \$10; community health at \$5, and community development at \$1. 12% of the costs are recovered through patient fees.

It is useful to see the impact of the HAS programs over the years – health status and service indicators are considerably better in the HAS service area than in rural Haiti more generally (Figure 1).

Figure 1: Health status and health care indicators, comparing HAS service area with rural Haiti

	<u>HAS service area</u>	<u>Rural Haiti</u>
•Infant mortality rate	51.6	88.9
•<5 years mortality rate	68.2	144.3
•Total fertility rate	4.8	5.9
•Immunization rate	78%	26%

The HAS recently undertook an evaluation and visioning process in order to ensure that equity and quality of care were being pursued. Working with the government of Haiti and other partners, careful surveillance of health status and other health related indicators were developed. One of the findings related to the physical structure of the valley. About three fourths of the population lives on the plains of the valley, which is generally flat, reasonably fertile and with roads for transportation. The remainder of the population lives on the mountainside, which is extremely rugged, where, with few exceptions, the only transport is on foot or by donkey. The evaluation process revealed that those living on the mountainside are seriously disadvantaged relative to those on the plains (Figure 2).

Figure 2: Comparison between the health and education indicators of people living on the plains and those of people living on the mountainside of the Artibonite Valley

	<u>Mountains</u>	<u>Plains</u>
▪ <5 years mortality rate	90	50
▪ Malnutrition	48%	23%
▪ Illiteracy	65%	33%
▪ Total fertility rate	6	3.6
▪ >2 hours to care	80%	20%

It will be of some interest to know that the HAS and its community partners have decided that while all of the indicators noted in Figure 2 need to be addressed, *priority will be given to education to reduce illiteracy*. Based on widely accepted understanding that education is a fundamental requirement for health, this decision is consistent *with the principle of justice that calls for protecting the opportunity to be healthy*.

Here, then, is an example of PHC that has matured over the years into a health care system that reaches every person, poor though he or she may be, with care according to need, as called for by the commitment to equity. And there is an openness to new ideas and to discovering oversights – such as the differences between the mountains and the plains, and the place of a principle of justice in shaping decisions for rationing health services. Additionally, the pathway towards *going to scale* (using Carl Taylor's words) for the larger Haiti is constantly respected. Notice, too, that the Director of the HAS is Henry Perry, whose book on PHC in Bangladesh can be an inspiration for all of us (17).
