CONSUMER HEALTH PERSPECTIVES

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End of the Decade: A Consumer View

The American health care system has evolved into its present form with very little input from the recipients and purchasers of care. In trust or in ignorance, the consumer has allowed health services to be shaped by the needs and values of those who find their intellectual and financial livelihoods in the provision of health services—that is, by doctors, by health administrators, by the various health industries and by professional organizations. As a result, although consumer tax money now pays for more than half of all hospital costs and more than 70 percent of the costs of medical education (not to mention the billions in consumer monies which enter the health system through private insurance premiums), consumers are in the paradoxical position of having very little to say about the health system they so open handedly finance. In fact, the injection of billions of dollars of public money into health has created an anomaly—a mammoth health system which cannot meet the nation's health needs rationally, safely, economically, or equitably.

To bring about a health care system which is responsive to public needs, consumers must—as a first step—abandon their dependence on health "experts" to run the system for them and begin to educate themselves on how decisions are made in this all important sector. In sum, blind trust must be replaced by knowledge and action.

The Myth of Excellence

American medicine has a reputation as the world's finest. Thus, it is often assumed that the American method of organizing and delivering health services has led to the best of all possible medical worlds. Certainly, if excellence in medicine is judged by the length and rigor with which practitioners are trained, by the number of specialists in the medical profession, or by the amount of highly sophisticated diagnostic techniques and treatment technology which can be brought to bear on any individual case, it can probably be said that America offers the best which can be had.

However, the best treatment available within a system is not necessarily an indicator of the quality of the system as a whole. It must be asked whether the health system provides accessible, affordable and comprehensive services and it must be asked whether those services which are provided are delivered in a cost-effective manner. Defenders of the present system hold that the current multiplicity in types of services, the varied reimbursement methods, the different forms of ownership allow for individual freedom of choice and accomodate the needs of all.

Another View

Nonetheless, the facts say otherwise. In terms of the general health status of the population, the availability of services to the general public, the cost of services and the efficiency with which they are delivered, the United States does not necessarily surpass the other developed nations of the world.

Item: America's infant mortality rate, the statistic considered by public health experts as an indicator of a

In This Issue

nation's overall health, is so high that we fall behind 14 other nations in infant deaths per 1,000 live births.

Item: Life expectancy in the U.S. has not been appreciably increased by our medical capabilities. American men will die sooner, on the average, than those in eighteen other countries, including Sweden, East Germany, Bulgaria, Ireland, Italy and Greece. American women rank sixth in the world in terms of life expectancy.

Item: Hospital costs have risen more than any other item on the Consumer Price Index.

Item: The costs of service are highly erratic. A gall bladder removal operation in Ohio costs about $300; the same operation in Manhattan, by a physician of comparable training, is about $1,000.

Item: Serious ethical questions have been associated with our system. It has been estimated that about one of every four surgical operations performed in the United States is unnecessary.

Item: Some reports estimate that as many as 25,000 American workers die on the job each year, with another 20 to 25 million work-related injuries. And these figures do not include the deaths from occupational diseases that may take 20 or more years to manifest themselves. In a similar vein are the increasing number of diseases related to the air we breathe and food we eat.

These irrationalities in the American health care system are not aberrations from an otherwise acceptable norm, but are typical, abiding traits of the system. Their causes can be found in the economic and medical factors which are the hallmarks of American medical philosophy: our method of paying for care (a fee for every service); our deference to private sector providers; the current trend toward specialization and technology and an emphasis on in-hospital treatment. Unfortunately, our present methods of public and private health insurance financing (open-ended third party payments) have tended to reinforce the faults of the status quo. In fact, because so many decisions in the health sphere are made in accomodation to the interests of those who provide care, there has been very little incentive for doctors and hospitals to tailor their services to publicly determined priorities or to keep costs down. As a result, we now have the following system-wide problems:

Shortage of primary care.

Primary care is the routine care provided by general practitioners, pediatricians, internists, and gynecologists. However, in the last two decades general practitioners have all but disappeared. Their places have not been filled, either by those entering the new specialty of "family practice" or by a sufficient number of health centers or outpatient clinics oriented to general health needs. More than 80 percent of physicians now limit their practice to a specialty or subspecialty.

As a result, people seek primary care where they can find it: in hospital emergency rooms, in specialists' offices and (where available) in neighborhood health centers. Often the overcrowded hospital outpatient department, with its notoriously long waits and ever-changing personnel, is the only solution. More recently, we have seen the emergence of the "Medicaid mill," where great numbers of patients may be seen in superficial fashion and where needless prescriptions and drugs may be dispensed. In other words, primary care—the medical attention which is most commonly needed—is sought in inappropriate, expensive, and qualitatively inferior settings.

Unfortunately, public need is usually not a factor in determining how many practitioners should be trained in a given field. This prerogative is reserved by medical educators and the national specialty boards.

From the point of view of the medical practitioners, specialization is attractive intellectually and more lucrative and prestigious than general practive. However, from the point of view of a populace which has difficulty getting primary care, a disproportionate amount of specialists is an expensive burden.

Again, the irony is in the fact that although state, local and federal expenditures subsidize nearly three-quarters of the cost of educating a physician, the public has little say in how this money is used. To date, no public or private program or policy has emerged which addresses this system-wide shortage of basic medical care.

Lack of Preventive Programs.

Another conspicuous flaw in the American health care system is the relative absence of preventive programs. Like the shortage in primary care, this phenomenon is partly related to our emphasis on hospitals, where physicians intervene primarily in the acute stages of disease. Since preventive measures (such as immunization, screening and early detection, sanitation, etc.) have a better historical record than many medical techniques in improving length and quality of life, one would expect major preventive programs to be part of any truly excellent health system.

Instead, however, American medical education and practice are focused on disease treatment at the expense of prevention and public health. Along with emphasis on hospitalization, specialization and technology have contributed to creating a vested interest in disease treatment as opposed to health promotion.

This system-wide focus on acute care is reinforced by health insurance plans, most of which cover in-hospital charges and surgical fees but do not pay for out-patient visits, office visits, screening tests or many other preventive measures. Obviously, this method of "insuring" health financially discourages customers from seeking early and preventive care which must be paid for "out of pocket."

Harmful Side Effects

The increasing mechanization of care is an outgrowth of specialization, high technology and hospital-based treatment. Although these aspects of modern medicine have many stunning benefits, they have also been associated with serious threats to health. Routine use of so-called "invasive" procedures for testing (radiation, arteriograms) or for treatment (surgery and chemotherapy) themselves often involve health risks of great magnitude. Iatrogenic (healer-

induced) and technogenic (technology induced) illnesses and disabilities are fairly common occurrences nowadays. To some extent, the occurrence of these health problems has been associated with the idiosyncrasies of our payment system: the fact that a fee is charged for every service performed creates an incentive for physicians to order a greater number of procedures, exposing patients to needless risks. Likewise, the growing problem of unnecessary surgery can be attributed to the very great (perhaps excessive) number of surgeons now in practice and to the fee-for-service reimbursement system.

Institutionalization and specialization have also contributed to making health care increasingly impersonal. There is less likelihood today that a patient's personal history will be known over a period of time to a single practitioner. Rather, the typical patient may have several encounters with various practitioners over the years or even in seeking treatment for a single illness. Emphasis on scientific specialization means that physicians have less time or inclination for personal interactions with patients. Their interest is in their area of specialization, such as the central nervous system, rather than the patient.

The routine of large hospitals also works to intimidate patients, depriving them of initiative. Under these conditions, people are not easily able to make choices and determinations about their own physical and mental welfare. The alienation which patients sometimes experience in the hospital situation does not promote recovery from illness and is in itself a health problem which must be addressed.

Maldistribution of Physicians

Since physicians tend to cluster in the large population centers (where the major medical centers are located), many rural areas have severe doctor shortages. At the same time, the inner city poor have few community doctors serving them and must rely on hospital clinics or health centers when available. Unfortunately, the experience of the last decade has demonstrated that increasing the total number of doctors has not significantly changed this picture. Apparently, the market is able to absorb an almost endless supply of physicians without forcing some of them to relocate their practices in the areas of greatest need.

At present there is no effective mechanism to bring sufficient medical services to these "under-served" publics in both urban and rural regions.

Maldistribution of Resources.

Competition and lack of coordination among health facilities have at times led to an expensive and wasteful duplication of equipment and services within a single region, while other areas go without the basics. The National Health Planning and Resources Development Act, passed by Congress in 1974, was a first step in acknowledging and attacking this problem, by providing regional planning bodies to oversee the development of health services within certain defined regional service areas. However, the shape of our system is still for the most part determined by a vast array of public, private non-profit, and profit making health institutions each of which are making decisions based on their own individual priorities. In this "pluralistic" and independent system, the survival of the health facility, rather than public needs and health priorities, is uppermost in determining health policy and practices.

To attract affiliating physicians who will bring in patients, each hospital must compete with its neighbors in provision of specialty care and up-to-date technology. The effort to provide comprehensive care within one facility, by attempting to maintain a full complement of equipment and specialty units (regardless of whether such services are available elsewhere in the community) can have serious consequences for both quality and cost of health care. An under-used surgical unit, for instance, may not perform enough procedures per week or per month to maintain the skills of the surgical team. Without generating sufficient revenue, the unit pushes up the total daily operating costs of the hospital which are (usually) the basis for the size of the reimbursement payments coming from third-party insurers. Obviously, lack of regional coordination among institutions, combined withan insurance reimbursement method which covers hospital's costs pushes up the total cost of health care without really meeting service needs.

The Myth of Choice

Often, the presence of multiple, independent providers in the system is defended as being necessary to protect the freedom of consumers to choose their own doctors and facilities. However, in those cases when consumers appear to be making a choice, that choice is often based on little more than chance, or hearsay and is not made on any substantial knowledge of the health system. The issue of freedom of choice is not relevant to patients who are unable to get a doctor, or who are denied the care of their choice because they can't pay for it. People are shocked by ghost surgery in which an unknown resident performs surgery rather than the patient's "chosen" surgeon.

Fragmentation and Episodic Care.

The separate, uncoordinated tasks of the many health facilities and programs in our system means that it is very difficult for the average person to negotiate the system at all. In the course of being diagnosed or treated for a single episode of illness, the patient may find himself or herself traveling to three or four different treatment centers and encountering as many different medical practitioners. Insurance may or may not cover all aspects of care, diagnosis and follow-up visits, hospitalization and surgeons' fees. Whatever the individual situation, the disorganization in the system develops in consumers a tragic reluctance to seek health care until an illness has produced a noticeable discomfort or disability.

In the United States there are about 7,000 hospitals, 22,000 nursing care and nursing-related homes, 14,000 clinical laboratories, thousands of clinics, hundreds of group practices, 345,000 physicians, 274,000 dentists and 4.4 million health workers. In each metropolitan area there are literally dozens, if not hundreds of institu-

tions and thousands of practitioners.

Government has superimposed upon this "pluralistic" and confusing system a set of financial structures which pay for the medical care that specific groups of people (i.e., the elderly, poor, veterans and government employees) receive in the private sector.

Incredible jurisdictional and administrative fragmentation of public programs and agencies make it nearly impossible for people to get comprehensive, coordinated services. Some programs (e.g., mental health) are designated for selected segments of the population and fall under the jurisdiction of the states. Other programs are targeted at people having specific diseases or who live in a specific catchment area or region of the country. Responsibility for financing, planning, construction and regulation of these services is also dispersed among many agencies of government.

In addition, the reliance on multiple sources of financing results in varying amounts of coinsurance, deductibles, and benefit periods—all of which require multiple billing, complex administration and partial payments from people who are often not in a position to pay.

High Costs.

The astronomical costs of the health care system—particularly hospitalization—are well known to everyone. It is also known that a significant portion of the unnecessary expenditures in the system can be attributed to the wastage of resources which comes from the almost complete lack of coordination among the many independent providers of care. Another problem is that hospitals have very little incentive to operate economically. Most third party insurance plans (including Blue Cross, Medicare and many commercial and union plans) base their payments to hospitals on the *fait accompli* of hospital operating costs.

Similarly, physicians' bills (such as surgeon's charges, anesthesiologists' fees, office visits and hospital consultations) are set by doctors, and insurers tend to pay the prevailing fee in the geographical area. Hospitals and doctors, so far, have been given *carte blanche* by the public. In terms of non-hospital care, the fact that most medixal practitioners charge a fee for every service and that most out-of-hospital care is not insured means that the individual consumer is under an enormous financial burden when it comes to getting primary and follow-up care.

Again, in this all-important sphere where public monies are involved, decision-making still resides in the private sector, among the physicians organizations, hospital associations and insurance companies where consumer and public influence is almost nil.

Public Money, Private Decisions

Virtually all of these symptoms—absence of primary and preventive medicine, emphasis on acute care, episodic treatment, uncontrollable costs, unnecessary multiplication of services, and all the sub-symptoms associated with them—can be traced to a common cause. Decisions about how many doctors and what they shall do, how many hospitals and what they shall purchase, as well as what shall be insured, have been the result of random pressures applied by professional and specialty associations, individual hospitals, and organized hospital associations. Third-party financing systems and government funds have supported the whole edifice while taking only a negligible role in checking, monitoring or shaping the services which they purchased. Though there is systemwide financing, there has been negligible systemwide planning, and little public accountability.

The Government Role

Government is responsible for protecting the public by ensuring the quality and quantity of health care purchased with tax dollars. At the time, both the public health and the public purse have been entrusted to an essentially private health care delivery system. In the public interest, the government, standing outside the market system, must be charged by consumers with making necessary adjustments to ensure that the health care system works for everyone ensuring the public interest in this way means taking on the functions of providing care through local public institutions and by regulating the private sector.

What have federal and state governments done to fill these responsibilities? Unfortuntely, state and federal government have, for the most part, failed to provide adequate monitoring and enforcement techniques to ensure efficient delivery of services.

To pass the Medicare Act the federal government had to promise not to interfere with American medicine.

Title XVIII, the Medicare statute, specifically states (in the Prohibition Against Any Federal Interference, Sec. 1801):

> Nothing in this title shall be construed to authorize any Federal officer or employee to exercise any supervision or control over the practice of medicine or the manner in which medical services are provided, or over the selection, tenure, or compensation of any officer or employee or any institution, agency, or person providing health services; or to exercise any supervision or control over the administration or operation of any such institution, agency, or person.

This prohibition negated the federal government's right to set adequate or meaningful review of the services provided or to set strict enforcement mechanisms to correct the failure of providers to meet standards.

Congress established Medicare (and Medicaid and other health care programs) without adequate controls or accountability. The federal government does not directly conduct inspections of health facilities.

Hospital inspections were assigned to a private provider-dominated group (i.e. Joint Commission on the Accreditation of Hospitals). Nor does it directly pay health providers except in a few cases.

Blue Cross and private insurance companies are used as intermediaries and carriers to review and pay most bills. Care provided by a private practitioner is not

Continued on page 7

National Guidelines for Health Planning Summary of Statement of Goals

Part I—Institutional and Personnel Resources and Systems of Care

1. **Primary care**
   a. The supply of primary care health personnel in a community should be no less than the equivalent of one physician per 2,000 population. This ratio can be achieved by fostering the use of nurse practitioners and physicians assistants.
   b. To the extent that shortages of primary care personnel and/or excesses of other medical specialties exist and are documented, these imbalances should be corrected.
   c. The integration of mental health services in general health care delivery programs should be increased through in-service mental health training of primary care providers and placement of mental health professionals in primary care programs.

2. **Regionalization**
   Providers of health services should be organized into regionalized networks which assure that various types and levels of services are linked together to form comprehensive and efficient systems of care. These networks should work to improve access to medical services and to eliminate unnecessary duplication of services.

3. **Prepaid health care**
   Every resident within the health service area should have the option of joining a federally qualified group practice Health Maintenance Organization or other prepaid system of health care, such as a qualified independent physicians' association.

4. **Group practices**
   The number of group practice arrangements for the delivery of medical care should be increased.

5. **Shared services**
   Efficiency and productivity of health care institutions should be furthered through the development of multi-institutional arrangements for the sharing of support services.

6. **Quality of health services**
   Health planning and review decisions should take into account the results of quality assessment and utilization reviews to support efforts to improve the quality of health services.

7. **Management procedures**
   Efficiency and productivity of health care institutions should be furthered through the adoption of uniform cost accounting, equitable reimbursement arrangements, utilization reporting systems, and improved management reporting procedures.

8. **Energy conservation**
   Efforts should be made to promote an effective energy conservation and fuel conservation program for health service institutions to reduce the rate of growth of demand for energy.

9. **Access to care**
   Every person should have access to the full range of health care services.
   a. Equal access to needed health care services for all population subgroups (including racial and ethnic minorities, the elderly, the handicapped, and low income person) should be fostered through the elimination of financial, physical, geographic, organizational and other barriers unrelated to the need for care. Planning and review decisions must take into account the specific health care needs of these groups and give priority to projects which seek to address these needs.
   b. The elderly and others suffering from physical or mental disabilities should have access to a full range of medical and social services including home health care, homemaker services, day care and other services appropriate to their needs while living in the community.

10. **Mental health**
    An increasing proportion of mentally ill persons should be restored to productive living by:
    a. developing community-based services for unserved, underserved, or inappropriately-served populations, especially children and youth, the aged, the chronically mentally ill, racial or ethnic minorities, poor persons, and persons in rural areas.
    b. minimizing unnecessary or inappropriate institutionalization and ensuring that persons requiring long-term residential care due to mental illness or disability receive such care in the least restrictive settings possible, and
    c. providing economical and high quality facilities for chronic mental patients who require prolonged periods of care.

11. **Child mental health**
    Services should be available to improve the level of social and cognitive functioning for children

identified as "most in need" of mental health services.

12. **Dental services**
Dental services should be available and reasonably accessible to all persons who would seek dental care.

13. **Second opinions**
All individuals should be encouraged to seek a second opinion before undergoing elective surgery.

14. **New technology**
When found safe and effective, the introduction of new procedures and equipment should take place in ways that enhance economy, equity and quality.

Part II—Disease Prevention, Health Promotion, and Health Status Outcomes

1. **Disease prevention and health promotion***
   a. Health promotion and disease prevention should be extended through both individual and community actions with emphasis on high risk populations.
   b. People should be better informed as to how, when, and where to get health care of an appropriate kind and quality at a reasonable cost.
   c. Health promotion and preventive health services should be an integral component of care provided by health care and other community institutions.
   d. Programs should be established to assure that all women receive adequate prenatal care.
   e. The rate and adverse consequences of unwanted teenage pregnancy should be reduced.
   f. At least 90 percent of all children under 15 years of age and newborns at the earliest appropriate time, should be immunized against polio, measles, rubella, diptheria, mumps, pertussis and tetanus.
   g. Programs should be undertaken to prevent accidents in the home, at work and on the highway. Particular efforts should be made to reduce accidents involving children.
   h. Community water supplies containing insufficient natural fluoride should be fluoridated to optimal levels for the prevention of dental caries.
   i. People should be informed about what constitutes good nutrition and should be encouraged and aided in obtaining a proper diet.
   j. Communities, working through all available institutions and media, should strive to avoid the initiation of the smoking habit among young people, and to break the habit among those who smoke.

2. **Health status outcomes**
   a. Health status should be improved in all parts of the country and among all population groups, especially among medically underserved populations.
   b. The infant mortality rate should be less than 12 per 1,000 live births.
   c. Child health and development should be improved and death rates for those ages 1-14 reduced to less than 39 per 100,000 persons.
   d. Deaths from preventable communicable diseases should be less than 12 per 100,000 persons. Diseases and deaths preventable by vaccine should approach zero. Measles should be eliminated as an endemic disease in the United States.
   e. The health of adolescents and young adults should be improved and death rates for those ages 15 to 24 reduced to less than 102 per 100,000 persons.
   f. The health of adults should be improved and death rates for those ages 25-64 reduced to less than 500 per 100,000 persons.
   g. The health and quality of life of older adults should be improved and the age-adjusted average number of days of restricted activity due to acute and chronic conditions reduced to less than 30 days per year.
   h. Substance abuse should be reduced by (1) decreasing the prevalence of alcoholism and related disabilities and deaths; (2) interrupting and reversing by at least 15 percent the trend of increased incidence of phencyclidine (PCP) abuse among 12-17 year olds; and (3) decreasing by at least 20 percent the use of barbiturates and other potentially harmful sedatives used for the treatment of insomnia.
   i. Oral health status should be improved so that (1) for persons 17 years of age, at least 85 percent retain all of their permanent teeth; and (2) for persons 55-64 years of age, at least 80 percent retain some natural teeth.
   j. Age-adjusted death rates for heart disease should be reduced to 195 per 100,000 persons; for cancer to 126 per 100,000; and for stroke to 46 per 100,000 persons.

The above guidelines are proposals issued for public comment.

Some Thoughts on the Proposed National Guidelines

The new National Guidelines for Health Planning are out for public comment. The Summary Statement of Goals from the Guidelines is reproduced beginning on page five of this issue. These comprehensive goals were developed by consumers and providers working within the health planning network. They are an amalgamation of local perceived needs that address many of the problems about which we've all been concerned for some time. Nevertheless, how these goals are to be achieved remains a mystery. The Health Resources Administration (HRA) admits "... that limited tools and authorities are currently available to HSAs to make needed change in the health system." It is apparent that these goals cannot be achieved within our current fragmented, for profit health care system. To really be able to improve health status, increase the availability and accessibility of primary care and other medical services, to prevent disease and promote health we need a coordinated, public National Health Service. We must also face the reality that, in contrast to the cost containment expectations which permeate thinking about health planning, achieving these goals may cost more rather than less money.

In a way, the sheer magnitude of the changes needed in the system and the lack of an existing mechanism capable of effecting them, seems to corroborate the point made by those who feel that involvement in the current health care system is an exercise in frustration and wasted energy for consumers.

Consumers involved in health planning are left in a difficult, frustrating position. Not only are they unable to effect the broad changes necessary to achieve the goals they have helped to set, but, even in their day to day HSA activities, their role as spokespeople for community needs often conflicts with the expectation that they will work to contain health system costs.

How does the HRA suggest that the planning goals be attained? "HSAs should work with providers, State and local health departments, other State and local officials, hospitals, health care insurers, community agencies, and others in the area and State to build consensus on desirable goals and to assure their accomplishment." It seems that once again consumers are being asked to depend on the spirit of volunteerism and altruism of health professionals. We are asked to believe that they will band together in an unself-interested way to seek solutions to problems resulting in large measure from the basic systemic forces of profit-making, status seeking and professional rivalry, secrecy and insularity. This comes somewhat as a surprise. We thought that such naive notions had been put to rest with the failure of Comprehensive Health Planning and the professionals' abuse of the Medicare and Medicaid programs.

The Consumer Commission commends all those involved in taking this opportunity to set broad national health goals. Now these goals must be made achievable. The Commission rejects the idea that on a large scale we can depend on people of good will to march forward voluntarily. Rather, we believe that a National Health Service must be created with both the responsibility to create comprehensive plans for the promotion of health and prevention and treatment of disease, and the authority to carry these plans out. Many previous achievements in health and public health services were brought about by the combined efforts of consumers and providers of care. Active health consumers have participated in the development of national health goals. Now, they must use their knowledge and experience to work for the authority to carry out the plans they have so laboriously developed.

• End of the Decade (continued from page 4)

evaluated under either Medicare or Medicaid by the federal government. This task was assigned first to utilization review committees at hospitals and later to Professional Standard Review Organizations (PSROs). No one reviews the quality or need for care delivered in private doctor offices.

The Government and the New Consumers

To effectively counterbalance the influence of providers in defining health care services and to provide a strong back-up constituency for a government role in creating and enforcing high standards for health care delivery, consumers must be strongly involved in the health care system.

A commitment to such involvement has begun, but at the present time, consumer influence is still minimal. Meanwhile, the health care delivery system continues to be run primarily by and for those who find their livelihood in the system.

To bring about needed changes there must be a new

breed of consumer who regard themselves as fully equipped to make decisions about health services. Providers and professionals should not be regarded as gods, but as consultants to the public interest on matters of medicine and health. Because decisions about health care involve very broad social, economic and ethical questions they are the business of the whole society. Thus, consumers, through their own autonomous organizations, through government, and individually should be making health policy as it is broadly defined.

By pressing government to assume its responsibilities, consumers can protect the public interest in respect to the quality and cost of health services purchased with tax monies in the public's name.

Bringing the health consumer into a position of authority and responsibility vis-a-vis the health care delivery system is the most obvious fundamental change required. Consumer responsibility is the foundation for a credo that argues that changes should, can and will take place.

Despite the obstacles to efficient participation, increasing numbers of people are involved in efforts to create a responsive health care system. Through health planning, such as HSAs, and activities on facility boards, consumers and concerned poviders have made meaningful efforts to insure their communities the best available health and medical care. Planning for the long run, there is also significant involvement in local coalitions of the National Health Service movement.

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