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During the past years, there has been an intensive involvement of social scientists with the formulation and resolution of public issues. In this volume, the issue has to do with the health and illness of American citizens. Seemingly once far removed from the political arena, except in the agitation of New Dealers for some form of medical insurance, health care issues have become the subject of furious political debate and maneuvering at every level of government. A rising chorus of criticism from within and without the health professions has accompanied the gradual redefinition of health as a right of citizenry rather than a commodity to be purchased on a voluntary basis, when it is not actually a gift from God. Among the loudest complaints one hears are those concerning the rising costs of care and its increasing impersonality. Significantly, these criticisms are voiced mainly by people who can afford to pay for private doctors and hospitalization.
Health Care and Self-Care: The Genetic Fix

AMITAI ETZIONI

Recent developments in biological and medical science have given man new power over his health and life-span—even the possibility of determining the genetic makeup of his children. Technological developments are transforming death from an unavoidable, natural event into a phenomenon demanding our active participation decision-makers. More and more persons can be kept alive, with the help of machines, long after their consciousness has been lost and cannot be retrieved. This newfound knowledge brings with it new questions. Who has the authority to turn off the machine, to decide to end "life" (if existence without awareness can even be defined as life)? the technocrat-doctor? the hospital-institution-bureaucracy? the guilt-ridden family? the ever-obsolescent legal system? economic forces which allow fewer heroic efforts to save the lives of ward patients compared to paying ones?

The unlocking of the genetic code and subsequent related developments allow the breeding out of a rapidly growing list
of illnesses which are partially or completely genetically determined. A test of the fluid surrounding the fetus (amniocentesis) can diagnose a fetus as defective and permit subsequent abortion. Should we allow such selected breeding for therapeutic purposes? promote it? require it? Should we encourage the development of genetic surgery and manipulation? even if it might open the door to the breeding of “superpersons”?

Beyond that are problems of allocation. If a limited number of hearts are available for transplant operations, who should get them? In view of the fact that hundreds of thousands of persons may eventually need replacement hearts, would it be better to focus research on mechanical devices (artificial hearts) rather than on organ transplants? To what extent should we tolerate research on drugs which modify behavior (for example, anti-aggression powders) and affect thoughts (LSD and beyond)? Should we continue research on subliminal communication, in which messages too rapid to be consciously perceived are flashed on TV screens, commanding persons to buy (or vote) as dictated? If we want to curb such research, how can we do so without violating the freedom of scientific inquiry?

In light of these and many other issues raised by the new biomedical technologies, Senator Walter Mondale has championed legislation which calls for setting up a temporary (two-year) commission to study such questions. The commission would be composed of 15 professionals in fields ranging from law to medicine, from theology to technology, and would be budgeted at about one million dollars a year. The bill was endorsed unanimously by the 92nd Congress in December 1971; “died” when the House did not act on it by the time the session ended; was recently resurrected as Senate Resolution 71, and is again pending. Such a commission would be a first step toward developing the sorely needed tools of effective and responsive societal guidance to biomedical ethics and policies. Even though limited in scope, support, funds and staff, temporary commissions can illustrate both the need for a full-fledged, representative, adequately endowed and staffed permanent commission on biomedical ethics and policies, and the virtue of attempting limited action until such a body is constituted.

The Institute of Society, Ethic and Life Sciences, often referred to as the Hastings Institute, issued a report in the New England Journal of Medicine (May 24, 1972) on the ethical and social issues raised by screening large numbers of people for genetic disease. Daniel Callahan, director of the Institute, explained that “the group who formulated the guidelines for mass screening was mostly opposed to the whole idea but favored a cautious and careful approach.

The report’s most basic criterion for assessing the merits of genetic screening programs is that no system be set up before adequate testing procedures are available “to avoid the problems that occurred initially in PKU screening.” (Mandatory screening for PKU [phenylketonuria], an inherited biochemical malady which, untreated, can result in severe mental retardation and shortened life span, was by 1971 required in 43 states, though the test is not 100 percent reliable. Many children were wrongly identified as having the disease, and quite a few who did have it passed the test as healthy.)

A hastily introduced program to test for the sickle cell trait (carried by about one out of every 500 black children) fails by the Hastings criteria. The program tests either schoolchildren, at an age when the illness very often has already struck, or newborns, a stage at which detection is difficult. Tests of couples considering having a child would make much more sense, although such programs are more difficult to administer than school programs, in which all students can be lined up at will.

Besides asking for safe tests, the Hastings group also called attention to a risk of possible psychological or social injury. The question is, How harmful will the “labeling” of persons be? As the result of mass screening tests, people will be labeled as
carriers of sick genes, which may harm their social standing and their view of themselves. Social science data leaves no doubt that at least in some areas, labeling (such as who is branded a criminal and who a law-abiding citizen) has rather serious consequences.

There is little doubt that if children are told that they have an XYY chromosome structure, which occurs in about one of every 1,000 males and which has been repeatedly reported as being associated with a predisposition toward seriously deviant behavior, they could easily begin to assume that a criminal destiny is inevitable. Moreover, parents who are told that their child carries the XYY gene may come to suspect normal assertive moves as being manifestations of their child’s criminal potential; consequently, they may push their child—whatever the influence of his genes—into an aggressive, ultimately criminal, personality and way of life.

Beyond parents, teachers and self-image, such labeling is likely to affect the attitudes of practically everyone who knows about a person’s genetic test scores. This is no longer a hypothetical consideration. The undesirable consequences which the Hastings group warned were possible have already made themselves felt. In 1971 the state of Massachusetts, responding to the demands of black community leaders and their white supporters, passed a law requiring that all school-age children be tested for the sickle cell trait. A dozen states rushed to follow suit. The trait is harmless by itself, but when both parents have it, there is a one in four chance that their child will have sickle cell anemia, a horrible disease which first causes pain, then deterioration of major organs such as the liver and kidneys.

The results of the tests, presumably kept only on school records, have increasingly been used to brand carriers of the disease as poor employment and life insurance risks. Recently, many black people started wondering whether or not the undesirable consequences of the test outweighed its benefits, especially as there is, so far, no known cure for the illness.

Related questions must be asked about other genetic tests that are being increasingly used, promoted or sought. Screening programs for carriers of the gene for Tay-Sachs disease were started among Jews in Baltimore in 1971. A screening test for Cooley’s anemia, most common among people of Mediterranean descent, is being developed, and a new genetic test which will predict people’s susceptibility to emphysema, a degenerative lung disease, is being worked on. Tests for dysautonomia (a disease which affects chiefly Ashkenazi Jews) and cystic fibrosis (which hits one out of every 1,500 Caucasian babies) are being actively sought. Dozens of other tests are likely to follow. If they are to do more good than harm, there must be a mechanism for reviewing the programs before they are enacted.

The Hastings report also points out that it is necessary to accompany such a new program with carefully designed and executed public information programs. Experience shows that the public—even some doctors—confuse the sickle cell trait, quite harmless by itself, with the disease of sickle cell anemia, which is found only when both parents have the trait and then only in approximately one out of four of their offspring.

The Hastings report also suggests other criteria for evaluating or designing mass genetic screening tests, including equal access, absence of compulsion and informed consent. The record shows that these recommendations have not often been followed in the past.

This particular Hastings report (other ones are being formulated) is not comprehensive. For instance, it does not deal with the question, How safe is safe?—an essential issue for new tests—or, How can safety be tested before tests are used en masse? In addition, because the report is based chiefly on deliberations and dialogue, it shows little benefit from empiri-
cal input to back up its points. Nevertheless, it is of immense
value, if only because it provides all those who will listen with a
detailed list of what must be taken into account before such
programs are initiated. If similar efforts were undertaken by a
national health ethics commission, composed of leading au-
thorities in the respective fields, and representative members of
the community backed up by congressional status and a staff,
they would command an even greater following. Of course, even
if such a national body were formed, private groups would still
have to continue their deliberations. These issues must be as
widely discussed as possible, for a continuous dialogue of many
divergent viewpoints is essential if the bases for a new ethic as
well as policy guidelines are to evolve. A national body would
provide a much-needed focus for such private deliberations, but
neither could it nor should it try to replace them.

Patient's Bill of Rights

Another development illustrates how, without benefit of a
review mechanism, the nation tries to cope with its need to
review and form policy in the health and genetic field. The
American Hospital Association first issued a bill of rights for
patients in November 1972 and again in January 1973 to its
7,000 member hospitals. Formulated by a committee ap-
pointed by the trustees of the American Hospital Association,
discussed by its regional advisory boards (which are composed of
hospital administrators) and consumer representatives, the bill's
12-point protocol is summarized below:

1. The patient has the right to considerate and respectful
care.
2. The patient has the right to obtain from his physician
complete current information concerning his diagnosis,
treatment and prognosis in terms the patient can reasonably
be expected to understand.
3. The patient has the right to receive from his physician
information necessary to give informed consent prior to the
start of any procedure and/or treatment.
4. The patient has the right to refuse treatment to the
extent permitted by law, and to be informed of the medical
consequences of his action.
5. The patient has the right to every consideration of his
privacy concerning his own medical care program.
6. The patient has the right to expect that all commu-
nications and records pertaining to his care should be treated as
confidential.
7. The patient has the right to expect that within its
capacity a hospital must make reasonable response to the
request of a patient for services.
8. The patient has the right to obtain information as to
any relationship of his hospital to other health care and
educational institutions insofar as his care is concerned.
9. The patient has the right to be advised if the hospital
proposes to engage in or perform human experimentation
affecting his care or treatment.
10. The patient has the right to expect reasonable con-
tinuity of care.
11. The patient has the right to examine and receive an
explanation of his bill regardless of source of payment.
12. The patient has the right to know what hospital rules
and regulations apply to his conduct as a patient.

Several hospitals adopted the bill, and at least two (Boston's
Beth Israel Hospital and New York's Martin Luther King
Health Center) now provide their patients with their own
version of it, but most hospitals did not embrace it. Yet, the
charter is of great value. Both technological and social developments have rendered the existing hospital structure virtually obsolescent, and there is a particularly great need for a new definition of the relationship between the patient and the institution.

The fact that those who administer hospitals took the initiative in preparing this bill is hardly surprising, since there is no community-based body to assume such duties. However, it must also be noted that the charter, lacking public hearings of the kind a congressional committee would have generated, was not subject to wide discussion or involvement. It is no wonder, then, that the charter is easy to ignore. Moreover, the fact that it was formulated by a board composed chiefly of those in power will hardly reassure the more activist "consumer" groups. (Dr. Willard Gaylin went so far as to indicate that the document "perpetuates the very paternalism that precipitated the abuses." A more widely representative body would have given the bill more authority.

Like most documents formulated chiefly to express a sentiment and to affirm a position the charter is rather long on general statements, and somewhat short on specifics. For example, the statement, "The patient has the right to refuse treatment," is qualified by the phrase "to the extent permitted by law," as though the law provided a clear guideline. Actually, if the patients themselves have the right to insist, for instance, that life-extending machines be turned off, they must be conscious when they so choose, but their action would be tantamount to suicide. On the other hand, if the patient has to be unconscious beyond recall before the machines can be turned off, the right to refuse service is not his. Who, then, exercises the right? one doctor? two? three? with or without consultation of the next of kin? under what medical conditions?

The Medical Society of the State of New York suggested adding the clause, "irrefutable evidence that biological death is inevitable," but such evidence may come long before a person loses consciousness. The society also suggested using the phrase, "is the decision of the patient and/or the immediate family with the approval of the family physician." But what if there is no family physician? Should not at least one other doctor, not as deeply involved, be consulted? Clearly the Patient's Bill of Rights leaves these and many other issues unresolved.

If the authors of the bill had expressed greater concern with procedure they would have been more aware of the need for local health ethics boards to review decisions made to "turn off" lives; the need for national and international boards to formulate guidelines; and the need for a research staff to study the actual results of various procedures in order to apply them in future deliberations. (There are review committees inside hospitals but these, with few exceptions, are limited to physicians associated with that hospital. Such insularity tends to limit their critical power.)

On January 22, 1973 the U.S. Supreme Court over-ruled all state laws that prohibit or restrict a woman's right to obtain an abortion during the first three months of pregnancy. It is now up to the woman and her physician to decide what course to follow. For the last six months of pregnancy, abortion can be "regulated" by the states to secure maternal health (for example, they can limit abortions to qualified facilities). Only in the last ten weeks of pregnancy, when the fetus is judged "viable," that is, capable of surviving if born, may a state prohibit abortion.

This welcome act also turned a matter that was previously controlled by the government over to individual choice. About 1.6 million American women undergo abortions each year. The risks are not trivial. While an abortion performed by a well-trained physician, during the first 12 weeks of pregnancy, is said to be safer than a tonsillectomy or an actual birth (out of 100,000 patients, the death rate for abortion is two; for tonsillectomy, 17; for pregnancy, delivery and postnatal period, 20).
In the second trimester abortion complications are three to four times more likely to arise.

Arranging the public education campaign which must follow the court's ruling—for instance, advising those who either use no contraceptives or use an unreliable method not to rely on abortion for birth control, or cautioning those who need an abortion not to put it off—is the job of the Department of Health, Education and Welfare. But a public authority could go a long way to see to it that matters the Court leaves undone will be picked up by the appropriate executive agency, and with the desired vigor and scope. Such an authority could also develop and implement a systematic procedure through which the relevant medical data and considerations on this or any other matter are regularly brought before the Supreme Court before it makes a ruling.

Another highly relevant development came in October 1972, when Congress enacted a bill widely referred to as “H.R. 1,” a large package of amendments to the Social Security Act. Among the numerous clauses of the bill is Section 249F, barely known to the general public. The amendment calls for setting up “professional standards review organizations” (PSROs) in order to subject hospitals and other health units to outside review, not only of proper use of funds—the typical accountability expected and required of anyone who uses public funds—but also of professional, that is, medical, matters. The main motive seems to be to reduce the number of poor and aged hospitalized charity patients. (The amendment calls for checking non-emergency cases with the PSRO before admission). At the same time, the provision opens the door, in principle, to outside or perhaps even public scrutiny of what doctors are doing.

The law is rather vague as to who is to provide these outside review boards. But the basic assumption is that doctors will oversee doctors. Even this is quite innovative because many doctors feel they need no overseer and that if review is to take place, it should be by their peers. Although peer reviews are often surprisingly strict, the PSROs, which are to be established throughout the United States by January 1, 1976, go one necessary step further, calling for outsiders to review insiders, acting as a kind of medical audit. Above all, it seems desirable that the PSROs should include not only doctors but also community representatives and “specialists” in societal and ethical matters to make sure that consumer, social and moral issues be taken into account, and to counteract any self-serving tendencies of doctors.

The PSROs represent an important spot at which to enter the closed professional system, because, unlike community advisory boards, set up around hospitals or comprehensive health planning agencies, the PSROs will be able to control the main flow of taxpayers' funds to health units.

As the 93rd Congress got underway in early 1973, Senator Mondale reintroduced his 1971 biomedical technology study commission legislation, now numbered “Senate Resolution 71.” The Senate may well approve it again, but no one can make any predictions as to what the House will do.

Early in 1973, Senator Edward Kennedy held extensive hearings on an issue that a health ethics commission, had it existed, would have dealt with: the conditions under which experimentation with human subjects can be tolerated. The press was again filled with gory reports about this or that ethical violation, but paid little attention to the more general questions concerning how such regulations could be implemented. Progress was made during the hearing—two expert witnesses called for the establishment of a more advanced, more potent, health ethics commission than the Mondale bill outlines. Dr. Bernard Barber testified before the Subcommittee on Health of the Senate Committee on Labor and Public Welfare that he favored... the establishment of a National Board of Biomedical Research Ethics. As members of that board I would like to see
not only members of the medical research profession, who are of course indispensable, but also people who are outsiders to the profession and who represent the public. These outsiders cannot be ordinary men-in-the-street or men given to absolute morals; they should be informed outsiders, lawyers or social scientists who have the expertise to deal with the fact that medical research ethics are also social and not just medical matters. The Board could define goals, establish institutions and mechanisms, and provide necessary monitoring for standards and practices that are only what the profession rightly values and the public increasingly and rightly demands.

Jay Katz, adjunct professor of law and psychiatry at Yale University, suggested that a permanent body be established to regulate all federally supported research involving human subjects. Such a board, Katz said, should be independent from the government, since much experimentation that requires supervision is carried out in government-owned laboratories. He wanted the President to appoint the board, and suggested that "its members should come from many disciplines, including representatives from the public at large," and that the board should have "regulatory authority," that is, it should formulate policy and set up the needed regulations and mechanisms to promote them.

Note that the concern in the Kennedy hearings focused on those relatively few persons who are subjects in experiments. My feeling is that we are all "subjects"—the millions who take the Pill, the millions who do not receive genetic counseling, the millions exposed to food additives which may well be cancer-inducing and so forth. We need to develop a more effective review mechanism of all illness-producing and illness-preventing forces in our life. The focus on human subjects in laboratories should be the opening wedge, not just a conciliatory gesture that gives reprieve from much-needed nationwide, not just lab-wide scrutiny.

The reforms must not stop here. The efforts to form effective and responsive overview mechanisms cannot be advanced by a few senators and professors. Their future depends on the informed general public, led by active groups of citizens, taking on this issue, as they took on those for peace in Vietnam, civil rights and pollution control.

On the national level, Congress must be urged to set up a permanent national health ethics commission which includes members of a variety of disciplines, not just medicine, and representatives of the public, backed up by a research staff. Locally, each state, city and town needs a local review health ethics board—to oversee its hospitals and clinics, its medical healers and researchers. Individually, citizens and their leaders need to inform themselves about new medical and genetic developments and the public and private issues raised by their effects on matters of illness and health, life and death.

To reap the full benefits of the developments in genetics and medicine—and to be spared the many dangers—individual citizens must be both knowledgeable and aware of the implications of the new technology. A national health ethics commission plus local review health ethics boards would reveal problems and present possible solutions, furthering not only knowledge but also the physical and emotional well-being of the American people.